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Quality of Life

Biopsychosocial Perspectives

Edited by Floriana Irtelli,
Federico Durbano and Simon George Taukeni

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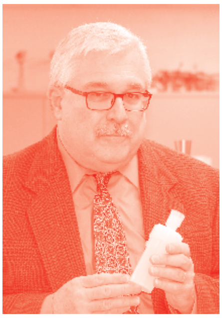

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Meet the editors

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Contents

Preface

This book is a collection of chapters written by scientists from all over the world who provide their insights about quality of life, focusing on a biopsychosocial perspective. The quality-of-life concept was born in the field of social sciences beginning in the 1970s and soon arrived in the field of medicine and health where it is mainly considered as a guiding criterion for health interventions. The World Health Organization (WHO) defines quality of life as the subjective perception that individuals have of their position in life, in the context of the culture and value system in which they live, in relation to their objectives, expectations, reference standards, and worries. It is a complex and articulated concept. It is specified by the perception of one's physical, psychological, and emotional health, by the degree of independence, by social relations, and the type of interaction with one's context. The quality-of-life construct is broader than that of health; it is not a synonym of it. The definition from the WHO connects elements resulting from an enormous amount of studies. In this sense, being healthy is considered a dimension of quality of life, and health-facilitating behaviors are considered the predictors of the quality of life itself. The definition of quality of life always includes a reference to the individual physical state, but is no longer considered only on the basis of the person's functionality quality, detectable with standardized parameters, since they are described in relation to the degree of perceived satisfaction with respect to the functionality level. This definition shifts the emphasis from the scope of objectively definable functionality to that of subjectivity; the detection of both these aspects constitutes a reliable measure of the quality of life.

To focus on the complexity of this notion, this book is divided into six sections. The first section provides a global review with the chapter "Quality of Life and Biopsychosocial Paradigm: A Narrative Review of the Concept and Specific Insights" by Floriana Irtelli and Federico Durbano. The second section on "Health Psychology" contains two chapters: "Health Disparities" by Dr. Bey Ganga, and "Health Sexuality" by Prof. Rao T. S. Sathyanarayana. The third section on "Biological Perspectives" contains two chapters: "Effects of Exercise on Quality of Life of Type 2 Diabetes Patients" by Tomas Carus Pablo and "Quality of Life and Menopause" by Velasco Cesar. The fourth section on "Psychological Perspectives" contains three chapters: "Sport for the Subjective Dimensions of Quality of Life" by Peráčková Janca, "Behavioral and Psychosocial Factors as Mediators of the Oral Health Impact on Adolescents' Quality of Life" by Veronica Kozmhinsky, and "The Impacts of Parental Schizophrenia on the Psychosocial Well-being of Offspring: A Systematic Review" by Sabreena Hussain. The fifth section on "Social Perspectives" contains three chapters: "Quality of Life from the South: Local Knowledge and Socio-ecological Relationships in Times of Global Climate Change" by Rojas Hernández Jorge, "Services for Children with Disabilities and their Families: The Impact on the Family's Life Quality" by Tamara Džamonja Ignjatović, and "Socioeconomic and Demographic Characteristics of Living Conditions of Elderly Quilombolas from Maranhão, Northeast Region, Brazil" by Rafaela Macedo Pires Ferreira, Eriko Bruno Costa Barros, and Bruno Luciano Carneiro Alves de Oliveira. The final section on "Spiritual Perspective" contains one chapter divided into two parts: "Spirituality and Hansen's Disease: Spirituality' Conceptual Structure and Hansen's Disease History - Part One" and "Spirituality and Hansen's Disease: Spirituality' Conceptual Structure and Hansen's Disease History - Part Two" by Makiko Kondo, Mikako Yamabery, Hitomi Yamao, Masato Muguruma, Kayoko Furochi, Shiho Oka, and Aiko Matsushita.

The book adopts a perspective that respects the complexity of human beings, with a focus on biological, psychological, social, and spiritual aspects of the concept of quality of life. All themes in each section of the book are deeply connected, making for a complex and interesting volume.

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Section 1

A Global Overview about Quality of Life

Chapter 1

Quality of Life and Biopsychosocial Paradigm: A Narrative Review of the Concept and Specific Insights

Floriana Irtelli and Federico Durbano

Abstract

The quality of life concept was born in the 1970s within the social sciences and soon it arrived in the field of medicine and health, where this notion has been considered as a criterion to evaluate health interventions. The World Health Organization defines quality of life as the subjective perception individuals have of their life position, in their cultural context and value system, in relation to their objectives, expectations, standards, and worries. It is a very complex and articulated conception, and as a matter of fact in this chapter, we will analyze an overview about this topic, to examine it in depth, and clarify this concept; synthetically, we can note that the quality of life is specified by the perception of one's physical, psychological, and emotional health, by the degree of personal independence, by social relations, and by the type of interaction with one's context. We can note that this construct is broader than that of health, it is not a synonym of it, and it is also important to point out that the definition of the World Health Organization about this topic connects elements resulting from an enormous amount of studies. In this sense, being healthy is considered one of the numerous quality of life dimensions, and health-facilitating behaviors are judged as predictors of the quality of life itself. Moreover, the definition of quality of life always includes a reference to the individual's physical state, but it is not considered only on the basis of a person's bodily functions, detectable with standardized parameters, since it is described in relation to the perceived satisfaction degree regarding this functionality level. This kind of definition shifts the emphasis from the objectively definable functionality to the subjectivity dimension; the detection of both these two aspects can constitute a reliable quality of life measure. Furthermore, we can note that the most common method for measuring quality of life is the administration of questionnaires and, in addition, that there are two questionnaire types: generic and specific for pathology. Finally, this chapter highlights the importance of the biopsychosocial paradigm in relation to the quality of life concept.

Keywords: quality of life, definition, World Health Organization, subjective dimensions, psychosocial factors, biopsychosocial paradigm, questionnaires

1. Introduction

This is a review about the concept of quality of life: today this notion is very important and its definition is really complex; as a matter of fact, it has evolved over the years and become an increasingly articulated idea (i.e., it is specified by the perception of one's physical, psychological, and emotional health, by the degree of independence, by social relations, and by the type of interaction with one's context). We also can note that the quality of life construct is broader than that of health, it is not a synonym of it (as we will analyze). In this sense, being healthy is considered a dimension of quality of life and health-facilitating behaviors are considered the predictors of the quality of life itself [1]. These aspects and many other features are going to be analyzed in depth and clarified in this narrative review.

2. Historical overview: the concept's evolution and scientific assessment

The debate regarding quality of life is quite ancient. Starting from early Greece, Plato had devoted several years of his life in developing a perfect government where quality of life for citizens is a mainstream. The precise term "quality of life" however had not yet been coined at that time; actually, it was introduced later, in the 1970s. We can synthetically define the quality of life as a person's judgment about various aspects of his/her own physical, social, and psychological well-being. The growing importance of personal evaluation of life aspects supported the development of a more precise definition of this concept and the need of a scientific assessment using psychometric standardized tests: thus, an initiative to develop a scientific quality of life assessment was born. The World Health Organization has therefore started a specific research aimed to create a rigorous measurement of this construct. The specific need to develop this research arose for several reasons. First, during recent years, beyond traditional health indicators (such as morbidity and mortality), there has been a broadening focus on the measurement of health outcomes [2], on the inclusion of measures of perceived health, on the impact of disease and impairment about daily activities and behavior [3], and on functional status/disability status measures. Furthermore, it is important to remember that it was also noted that while these questionnaires were beginning to provide a general measure of the impact of the disease, they did not actually assess the specific quality of the disease. This is the reason why, later, some specific questionnaires were developed to measure quality of life in the context of distinguishing diseases. A criticity arose because many measures of health status have been developed in the United Kingdom and in North America, the translation of which for their use in other settings appearing quite unsatisfactory and time-consuming [4]. A third important reason was the need to go beyond the increasingly mechanistic model of medicine that deals only with the eradication of disease and symptoms. The awareness that this model is obsolete reinforced the need for the introduction of a new humanistic perspective into health care. It is widely recognized that health care is essentially a humanistic transaction where the patient's well-being is the primary aim; it no longer stops just at making the symptoms disappear, but it is more inclusive and complete. To deal with these reasons, the World Health Organization created the initiative to develop a quality of life assessment promoting a holistic approach to health and health care, as emphasized in the World Health Organization's definition of health as the "state of physical, mental and social well-being and not merely as the absence of disease and infirmity." Precisely in 1995, this organization defined in an extensive and articulated way the quality of life as the subjective perception that individuals have of their position in life, in their life context, culture and value system, and in relation to the achievement of their goals and their expectations, reference standards, and concerns. The result is a very complex concept in which the quality of life refers to various dimensions: the perception of one's physical, psychological, and emotional health, the degree of independence of the individual, social relations and the type of interaction with their own life context. As we have anticipated, the concept of quality of life therefore appears broader than that of "health," being not synonymous with "health" [5] but at the same time being intertwined with this notion and with the concept of a biopsychosocial paradigm. The definition of quality of life given by the World Health Organization links together a huge amount of studies [6–14], and in this way being in a state of good health is considered only one dimension of quality of life, and behaviors facilitating health are considered predictors of the quality of life itself. An acknowledgement of these aspects is necessary in order to distinguish the notion of quality of life from the notion of health. It is important to point that the definition of quality of life always includes a reference to the physical state of the subject, but it is not enough to describe the quality of a person's functionality. The latter can be detected with standardized parameters, since it is mostly correlated to the degree of satisfaction perceived with respect to these standardized parameters and the level of physical functionality.

In this chapter, we present a definition of quality of life that shifts the emphasis from the scope of objectively definable functionality to the focus on subjectivity. In the field of objectivity, the disease is described as a defined clinical and physical state (the disease) and as the different areas of functionality (work area, psychological area, social area, etc.). It is also important to consider that quality of life refers to a subjective point of view, which is embedded in a cultural, social, and environmental context. In different geographic areas, there can be different concepts and different cultural values that can influence people's perception. It is also important to state that the World Health Organization's quality of life definition focuses on the respondents' "perceived" quality of life; it does not require a measure of any detailed symptoms, conditions, or diseases, nor disability as objectively judged, but rather the perceived effects of disease and health interventions on the person's quality of life. Starting from this point of view, an assessment of this multidimensional concept was developed, incorporating the individual's perception of health status, psychosocial status, and other aspects of life. For several years, the importance of going beyond an observation of the quality of life from an individual point of view was also underlined, and already in 2003 an Italian researcher, Ingrosso, encouraged a collective and social research in this field. In particular, he states that the topic of quality of life can characterize the perspective about a local community and its dynamics. In this broader definition of quality of life, Ingrosso refers to the evaluation that individuals of a population make about the correspondence of certain personal and collective endowments with respect to their own scale of needs and values, based on their own orientations and experiences. He put as example how citizens of a specific local community can express judgments about the adequacy or inadequacy of policies or complexes of interventions that are implemented in a specific geographic territory [15]. He also pointed out that in recent years the debate about the quality of life has partially gotten lost in generalities. The debate was also divided between the extendibility of the objective component and the subjective one, thus losing the perspective about the sense of collective, contextual, relational, and operational evaluation with which the term was originally used as from the 1970s. Scientific research can thus modify the collective knowledge about this topic, to stimulate the citizens, whether directly or indirectly, to think about some aspects regarding the lines of intervention consistent with their own expectations. Therefore, not only quantitative methods like indicators and surveys, but also qualitative surveys and dynamic surveys, such as participatory research-process methods, are useful for the purposes of these surveys. These methodologies are often indicated as the first fundamental step when carrying out interventions in a city or territory [15]. Today the social aspect of quality of life is increasingly present, so the concept of quality of life now is often strictly related to the terms "livable" and "livability," referring to the more or less desirable economic and social environment of a town, a metropolis, or a country: nowadays, these terms have become part of the common language.

3. Specific questionnaires: focusing on the difference between the quality of life concept and the health concept

Often, as before said, the concept of quality of life is confused with the concept of health, but this is wrong because the term health is not enough to explain the quality of life. For example, some individuals can live with a poor functional status or a poor health status but they express a high quality of life, or vice versa; moreover, quality of life cannot also be equated simply with the terms "lifestyle," "life satisfaction," "mental state," or "well-being." As anticipated in the last decades, several scientific studies have tried to define this construct better, outlining the most appropriate areas and tools for the investigations and the observation of this concept; in fact during the past years two classes of complementary health status measures have emerged: objective measures of functional health status and subjective measures of health and well-being. These measures are multilevel and multidimensional, and there are many published quality of life measures. A really important measurement scale is the World Health Organization's Quality of Life scale; this questionnaire measures this specific area by examining the answers that the subject can provide on a Likert scale (from 1 to 5). This questionnaire exists in two versions:

- the World Health Organization's Quality of Life scale-100 (WHOQOL-100);

- the World Health Organization's Quality of Life scale Brief (WHOQOL-Brief).

These scales can also be used to assess variation in quality of life across different cultures or to compare different subgroups. The WHOQOL-Brief is a 26-item version, which summarizes the WHOQOL-100 (i.e, the 100-item version, which is longer); both these questionnaires are useful in clinical settings, medical practices, audits, policy-making, and in the assessment of the effectiveness of different treatments. The brief version of WHOQOL can also be used in a variety of different cultural settings, it is easily administered and does not impose a huge burden on the respondent. The answers are always given on a Likert scale (from 1 to 5); the questions that are addressed in the short version of the test are presented in **Box 1**.

The creation of this questionnaire involved a collaborative approach to international instrument development [16], the aim being to develop a questionnaire that could be individually filled in a collaborative way and in several settings. In order to achieve these results, several culturally different centers were involved in operationalizing the scale's questions about the quality of life, and also in question writing, question selection, and pilot testing. Thanks to this approach, standardization and equivalence between different settings were guaranteed. Many centers in different geographic areas were selected in order to include differences in the levels of industrialization, types of health services, and other elements that were relevant to the measurement of quality of life (e.g., the perception of self, the perception of the dominant religion, and the specific role assigned to the family in a cultural context). This method ensured a real internationality of the collaboration.

1. How would you rate your quality of life?
2. How satisfied are you with your health?
3. To what extent do you feel that physical pain prevents you from doing what you need to do?
4. How much do you need any medical treatment to function in your daily life?
5. How much do you enjoy life?
6. To what extent do you feel your life to be meaningful?
7. How well are you able to concentrate?
8. How safe do you feel in your daily life?
9. How healthy is your physical environment?
10. Do you have enough energy for everyday life?
11. Are you able to accept your bodily appearance?
12. Have you enough money to meet your needs?
13. How available to you is the information that you need in your day-to-day life?
14. To what extent do you have the opportunity for leisure activities?
15. How well are you able to get around?
16. How satisfied are you with your sleep?
17. How satisfied are you with your ability to perform your daily living activities?
18. How satisfied are you with your capacity for work?
19. How satisfied are you with yourself?
20. How satisfied are you with your personal relationships?
21. How satisfied are you with your sex life?
22. How satisfied are you with the support you get from your friends?
23. How satisfied are you with the conditions of your living place?
24. How satisfied are you with your access to health services?
25. How satisfied are you with your transport?
26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?

Box 1.
WHOQOL-26 items.

To summarize, quality of life questionnaires should include different domains:

- physical domain (which refers to physical sensations, health, and pain),
- psychological domain (which refers to emotions, such as anxiety and desperation),
- level of independence domain (which refers to the autonomy of the person in various life areas, from the financial to the physical one),
- social relationships domain (which refers to social interactions with family, friends, and professionals)
- environmental domain (which refers to aspects of the environment that can promote the development of a person) [16].

It is also important to mention that with regard to the measurement of quality of life in illness situations, there are specific questionnaires [17] such as the WHOQOL for people with HIV or diabetes.

In summary, we can state that it is important to note that the definition of quality of life always includes a reference to the physical state of the subject, but is no longer considered only on the basis of the quality of the functionality of a person, detectable with standardized parameters, since they are described in relation to the degree of satisfaction perceived with respect to this level of functionality: this definition shifts the emphasis from the scope of objectively definable functionality to that of subjectivity; the detection of both these two aspects can probably constitute a reliable measure of the quality of life [1]. Finally, we can affirm that within the sphere of objectivity, disease is understood as a defined clinical framework and the different areas of functionality: physical, psychological, social, and work. In the context of subjectivity, the perception of disease and patient satisfaction are placed in the various areas of life, in which it is conceivable that the state of health may influence. Concluding, we can detect that the most common method of measuring quality of life is the administration of questionnaires, and that there are two families of questionnaires: generic and specific for pathology [1].

4. A new perspective: well-being as a promotion of quality of life

Health care professionals are increasingly recognizing that measurements only focused on disease outcomes are an insufficient determinant of health status. Accordingly, nowadays the focus has shifted from the idea of physical/psychological well-being as the elimination of a problem or a disease to a conceptualization of well-being as a promotion of quality of life. This shift of perspective has radically changed not only our concept of health and disease, but also that of the human being, of his/her life process and crises [18]. For a long time, the conditions of well-being have been defined on the basis of normative models that have produced health models consistent with the biomedical model, which was very reductive. Only in relatively recent times, and certainly thanks to the contribution of health psychology, we have begun to implement a new approach that claims the specificity of a discipline connected to the singularity and uniqueness of the subject. This uniqueness, to be grasped, also requires openness to a complex thought, capable of overcoming the reductionist perspective and the dichotomies [18]. Today we accept that to understand a phenomenon we have to take into account the context, the individual perspective and perception of the person that is involved in this context, and the multiple dimensions that contribute to the generation and understanding of the reality that we are studying. All these cognitive shifts have a particularly important impact on care systems and on devices that are designed to intervene in critical situations, which are also the result of the culture and context that can produce them, and consistent with the social representations of illness, health, quality of life, and with the scientific theories that are built on those representations. Today we agree on the need to abandon the medicalist logic of "restitutio ad integrum" adopting a new mentality that redirects our approach to reality [18]: also the concept of quality of life is therefore now detached from the biomedical model, which has been surpassed also thanks to the biopsychosocial model that we will analyze in the next paragraph.

5. The biopsychosocial paradigm

The biopsychosocial paradigm characterizes health psychology [19] and the specific areas regarding quality of life that are analyzed in depth by this discipline. The perspective of the biopsychosocial paradigm was introduced by George Engel who coined the term "Biopsychosocial Approach" as a privileged modality both to decode and understand the processes of health and disease throughout the existential path, and to articulate forms of care [20, 21]. The biopsychosocial model is inspired by the paradigm of complexity, in sharp contrast to biomedical reductionism, as well as to the hierarchization of sciences. It adopts the perspective of the general theory of systems developed by Von Bertalanffy [22], which considers a set of interrelated events as a system that manifests specific functions and properties according to the level to which it is placed compared to a wider system. In fact, this systems theory states that all levels of the organization are connected to each other, so that the change of one affects the change of the other; for example, a biological change affects the psychological level and social level and vice versa [20, 21].
The biopsychosocial model refers to three basic principles: dialogue-connection, relationship, and humility. This paradigm considers the person as a "whole": as a genetic heir, a subject of reflection and decision, as well as a historical-cultural and family subject. The axioms of this model are inclusive (focused on the understanding of diversity) and not exclusive, the perspectives of this approach are conceived as global, always considering biological, psychological, and social facets together [19]. Today we therefore refer to the biopsychosocial model whose fundamental assumption is that every condition of health or disease is a consequence of the interaction between biological, psychological, and social factors and we therefore move beyond the old dualism that separated the body from the mind; it is therefore an attempt to see people in their entirety. It is based on the key concept that the person represents a biological unit made of both body and mind, that is, not only of a biological body but also of psychic and emotional factors, which play a decisive role not only in balancing the life of the individual but also in the genesis and development of organic diseases. Health can therefore be understood as the product of the interaction between a physical-mental-social unit. As a matter of fact anyone who wants to sufficiently understand another person cannot simply observe the individual aspects, which, although important, do not allow to understand his/her overall situation, but must approach him/her on the contrary by seizing his/her entirety and his/her complexity. The centrality of this model has been confirmed and validated by scientific literature. This model marked the shift from a traditional medical model centered only on the body (and on illness as a purely biological event) to a medicine centered on the person [20, 21]. Today there is the awareness that a biopsychosocial

screening, more than a compartmentalized approach of medical and psychosocial models, can help the planning of a more effective treatment in case of illness and can also prevent distress [23]. Human beings tend to grow through the development of complex systems that are intertwined with each other and affect the three main areas explored by the model biopsychosocial paradigm:

- the biological part, consisting of all the systems and subsystems that are part of it;
- the part of the mind and,
- last but not least, the interpersonal/social part.

These three areas are always interacting with each other and are always present in every vital event, so any alteration of the patient's state of health will be recognized by a change in the integration between these three systems that are linked and intertwined [24].

Finally, we can state that in order to approach the concept of quality of life and the knowledge and care of the person in his/her complexity also means to examine the relations between these three systems simultaneously.

6. Conclusions

To summarize, we can affirm that the concept of quality of life (as it is intended in the field of medicine and health psychology) refers mainly to the well-being of the individual from a physical, cultural, social, and psychological point of view, also considering the cultural context and its value and, furthermore, considering the individual's objectives, standards, and life expectancy [25]. Several studies have therefore proposed to develop a quality of life model that would integrate objective and subjective perspectives; some authors also focused on multidimensional nature of this construct by analyzing in depth some key areas: physical well-being, emotional well-being, the material well-being, potential development of the subject and his/her daily activities [26, 27]. Other authors have proposed a holistic model that describes the quality of life as a dynamic process that links the individual reality with the social reality emphasizing the importance of environmental factors and personal factors, and the relationship that the person establishes with the constraints and resources of the environment in which he/she lives [28].

We can conclude by stating that the quality of life construct refers to an indicator of material well-being expressed by money gain and economic resources, of psychophysical well-being of the individual, and the outcome related to the effectiveness of the programs implemented in support of various individuals [29]. The assessment of quality of life can be carried out according to different methodological approaches, but we have to note that making an univocal operationalization of this construct can be sometimes quite difficult for its complexity [30]. Finally, we can also point out that a key distinction between self-report questionnaires can be done according to their targets: they can be generic, or they can refer to the quality of life in relation to a specific disease, such as HIV, as we anticipated. In particular, we can use the first type of generic measurement indifferently on a heterogeneous population, like intelligence tests. We can also divide generic measuring instruments into two macro categories: profile tests, in which the scaffolding represents the evaluation of multiple dimensions of quality of life, which can be observed individually, or we can find tests that offer a single synthetic score. Every approach has its pros and cons, to be considered when choosing them for a specific objective. According to another methodological approach, instead, the subjective dimension of the illness experience is privileged to allow an in-depth analysis of the quality of life understood as a life process capable of facing pathological events. From this point of view, the semi-structured interview may also be useful [31]. In any case, it is always important to integrate the objective observation with the subjective part because (as we stated) the biological, social, and psychological dimensions are always intertwined with each other.

Concluding, we can consider that it makes sense to refer in this context to what was declared by the International Society for Quality of Life Studies [32], which stated overall that the quality of life includes both an objective point of view and a subjective point of view, and involves areas relating to material well-being, health, productivity, affectivity, safety, society, and inner well-being. The objective area includes a sound measure of objective well-being while the subjective sphere includes personal satisfaction. Personal satisfaction has to be linked to the importance assigned by the individual to some subjective and cultural values; however, we can note that the definition of objective could be misleading: social indicators are usually chosen from a theory, or are based on the availability of individual valuation data, influencing researchers' choices. Also the social situation in which the survey is developed has a great influence, but unfortunately these aspects are often ignored or undervalued [19]. On the other hand, it must be specified also that if the perception of quality of life is reduced to a simple psychological survey of consumer satisfaction, it is a really limited perspective because all the relational, social, and cultural facets that the quality of life assessment should contain (referring to the biopsychosocial paradigm) are lost [20, 21]. Certainly all the sets of knowledge obtained through the assessments should be collected with a scientific method that is based on technically reliable and shared hypotheses. It is also necessary to rely on constructive epistemological and methodological interpretations, and it is important that the researchers should not attribute to the data collected an indisputable value of reality, but rather of a map that, because of its characteristics and controllability, allows it to express an orientation. The goal cannot in fact be just abstractly cognitive, but rather that of triggering a process of knowledge, elaboration, and participation in the population concerned, especially if the investigation aimed at finding a shared priority scale [19]. It is also important to note that it is the duty of every mental health professional to work in the direction of maximizing people's well-being and quality of life, but this task cannot be the sole responsibility of the professionals of this discipline. On the contrary, it must be a common goal of all those who, in any capacity, deal with individuals, groups, organizations, and institutions [33]; to do this better, we have to consider human beings in their complexity, and this is possible by using the biopsychosocial paradigm [34] and the articulated concept of quality of life.

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References

[1] Saita E, editor. Psico-Oncologia: Una Prospettiva Relazionale. Milano: Edizioni Unicopli; 2009

[2] World Health Organization World Health Statistics Annual. Geneva: WHO; 1991

[3] Bergner M, Bobbitt RA, Carter WB. The sickness impact profile: Development and final revision of a health status measure. Medical Care. 1981;**19**:787-805

[4] Sartorius N, Kuyken W. Translation of health status instruments. In: Orley J, Kuyken W, editors. Quality of Life Assessment: International Perspectives. Heidelberg: Springer Verlag; 1994

[5] Saita E, Tamanza G. Cure palliative, qualità di vita, passaggi generazionali. In: Saita E, editor. Psico-Oncologia: Una Prospettiva Relazionale. Milano: Edizioni Unicopli; 2009. pp. 40-66

[6] The Whoqol Group Development of the World Health Organization WHOQOL-BREF quality of life assessment. Psychological Medicine. 1998;**28**:551-558

[7] The World Health Organization Quality of Life Group. The World Health Organization Quality of Life Assessment (WHOQOL-BREF): Introduction, Administration, Scoring and Generic Version of the Assessment. Geneva, Switzerland: Programme on Mental Health; 1996

[8] Skevington SM, Lotfy M, O'Connell KA, WHOQOL Group. The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A report from the WHOQOL group. Quality of Life Research. 2004;**13**:299-310

[9] Krägeloh CU, Henning MA, Hawken SJ, et al. Validation of the WHOQOL-BREF quality of life questionnaire for use with medical students. Education for Health. 2011;**24**(2):1-5

[10] Zhang Y, Qu B, Lun S, Wang D, Guo Y, Liu J. Quality of life of medical students in China: A study using the WHOQOL-BREF. PLoS ONE. 2012;**7**(11):1-9

[11] Saqib LF, Raza O, Montazeri A, Nedjat S, Yaseri M, Holakouie-Naieni K. Psychometric properties of the Urdu version of the World Health Organization's quality of life questionnaire (WHOQOL-BREF). Medical Journal of the Islamic Republic of Iran. 2017;**25**:31-129

[12] Al-Shibani N, Al-Kattan R. Evaluation of quality of life among dental students using WHOQOL-BREF questionnaire in Saudi Arabia: A cross sectional study. Pakistan Journal of Medical Sciences. 2019;**35**:668-673

[13] Wei YB, Yin Z, Gao YL, Yan B, Wang Z, Yang JR. Quality of life of Chinese urologists: A cross-sectional study using WHOQOL-BREF. Hong Kong Medical Journal. 2015;**21**:232-236

[14] Izutsu T, Tsutsumi A, Islam A, Matsuo Y, Yamada HS, Kurita H, et al. Validity and reliability of the Bangla version of WHOQOL-BREF on an adolescent population in Bangladesh. Quality of Life Research. 2005;**14**:1783-1789

[15] Ingrosso M. Senza benessere sociale. Nuovi rischi e attese di qualità della vita nell'era planetaria. Franco Angeli: Milano; 2003

[16] The WHOQOL Group. The World Health Organisation Quality of Life Assessment (WHOQOL): Development

and General Psychometric Properties. Geneva: WHO; 1996

[17] Niero M. Qualità della vita e della salute. Franco Angeli: Milano; 2002

[18] Irtelli F. Illuminarsi di Ben-essere. Armando Editore: Roma; 2016

[19] Saita E. Pensare alla salute a alla malattia. Educatt: Milano; 2011

[20] Engel G. The need for a new medical model: A challenge for biomedicine. Science. 1977;**196**:129-136

[21] Engel G. How much longer must medicine's science be bound by a seventeenth century world view? Psychotherapy and Psychosomatics. 1992;**57**:3-16

[22] Bertalanffy V. General System Theory. Foundations, Development, Applications. London: Penguin; 1968

[23] Thomas BC, Bultz BD. The future in psychosocial oncology: Screening for emotional distress—The sixth vital sign. Future Oncology. 2008;**4**:779-784

[24] Scoppola L. Corpo e Psiche: Gruppalità e Integrazione nella Relazione di Cura. In: Cianfarini M, editor. L'Intervento Psicologico in Oncologia: Dai modelli di riferimento alla relazione con il paziente. Carocci Faber: Roma; 2007

[25] The WHOQOL Group. The World Health Organization Quality of Life assessment (WHOQOL): Position paper from the World Health Organization. Social Science & Medicine. 1995;**41**:1403

[26] Felce D, Perry J. Quality of life: Its definition and measurment. Research in Developmental Disabilities. 1995;**16**:51-74

[27] Tempier R, Mercier C, Leouffre P, Caron J. Quality of life and social integration of severely mentally ill patients: A longitudinal study. Journal of Psychiatry and Neuroscience. 1997;**22**:249-255

[28] Dossa PA. Quality of life: Individualism or holism? A critical review of the literature. International Journal of Rehabilitation Research. 1989;**12**:121-136

[29] Lehman A, Possidente S, Hawkner F. The quality of life of chronic patients in a State hospital and in community residences. Hospital and Community Psychiatry. 1986;**37**:901-907

[30] Hays RD, Morales LS. The RAND-36 measure of health-related quality of life. Annals of Medicine. 2001;**33**:350-357

[31] Luoma ML, Hakamies-Blomqvist L. The meaning of quality of life in patients being treated for advanced breast cancer: A qualitative study. Psycho-oncology. 2004;**13**:729-739

[32] Andelman R, Board R, Carman L, Cummins R, Ferriss A, Friedman P. Quality of Life Definition and Terminology: A Discussion Document from the International Society of Quality of Life Studies. International Society of Quality of Life Studies: Blacksburg; 1998

[33] Frati F. Il lato oscuro della mente, premesse per il cambiamento sociale, edizioni la meridiana. 2012

[34] Vincenti E, Irtelli F. Familiar-mente, legami e prospettive che non ti aspetti. Armando Editore: Roma; 2018

Section 2

A Global Overview about Health Psychology

Chapter 2

Health Disparities at the Intersection of Gender and Race: Beyond Intersectionality Theory in Epidemiologic Research

Ganga Bey

Abstract

Racial disparities in health have long been one of the primary foci of health inequity research in the United States, yet the use of theoretical frameworks outside of biological determinism has generally been minimal within this literature. Only recently has epidemiology begun to incorporate Intersectionality and other social theories in the study of racial health inequities. Even still, the majority of this research base neglects to engage deeply the theoretical complexity that such frameworks demand, often leaving unanswered the important question of whether and why any observed race effects vary across other social group categories. The limited body of epidemiologic work grounded in Intersectionality Theory indicates that race can be further divided into meaningfully disparate categories with important implications for accurately assessing health and health disparities. Yet, Intersectionality Theory, as it is frequently applied, is only one lens with which to appraise disparate health outcomes at these social junctures. This chapter provides an overview of current evidence for racial differences in health, which vary across gender, building support for the necessity of wholistic identity approaches that move beyond current understandings of Intersectionality Theory.

Keywords: Intersectionality Theory, health disparities, gender and race, identity pathology, social group identity, social determinants of health

1. Introduction

1.1 Brief overview of health disparities research in the United States

Throughout the history of the United States, disparities in health outcomes between racial groups and individuals of differing ethnic backgrounds have been well documented [1, 2]. Consistently, black and Indigenous persons, and those of Hispanic ethnicity have had poorer overall health, higher rates of both chronic and infectious disease, and increased risk of mortality compared with persons of European ancestry [1–4]. For decades, investigations into the causes of these unequal health outcomes largely operated under an implicit—and at times explicit—biological determinism framework [5]. Because of this narrow theoretical scope, important contributors—the most important contributors, one could argue—to these racial and ethnic gaps in health status were often overlooked in epidemiologic research [5].

Even as epidemiologists increasingly consider the causal role of the social conditions in which individuals live and work [1, 2, 4, 6], a lack of well-developed theoretical context to health disparities research frequently yields data, results, and interpretations that obfuscate the complex mechanisms underlying social group disparities in health [7]. Wide-spread assumptions of racial homogeneity [8, 9], for example, echo biological essentialism, masking important within-race gender or socioeconomic differences in disease risk, pathogenesis, prognosis, and treatment efficacy, even in those studies which acknowledge social determinants of health.

Theory emerging from the social science and social psychological disciplines is often borne of extensive grappling with these complex causal webs. Intersectionality Theory [10] and Multidimensional Identity Theory [11] are among many theoretical frameworks which outline compelling social and psychological explanations for disparate health outcomes along what are frequently conceptualized as "dimensions" of identity—race, gender, socioeconomic status, and other social group designations. From studies of genetic risk, heath service utilization, and health behaviors to the health-impact of identity processes and coping responses, research grounded in these intersectional theories indicates that socially constructed categories such as race can be further divided into meaningfully distinct categories such as "gendered race" with important implications for accurately assessing the causes of, and solutions for, health disparities [12–14].

Despite being one of the most increasingly used social theories in epidemiologic research, much of the theoretical nuance of Intersectionality Theory is often lost in application. The frequent oversimplification of theory manifests, in part, as a growing trend in efforts to decompose the relative contributions of intersecting exposures such as race and socioeconomic status [15]. Aside from the uncertain utility of such findings in addressing social group disparities in health, these methods reflect an interpretation that is in many ways counter to the central claims of Intersectionality Theory—that the effects of such exposures can somehow be separated [16]. The relationship between epidemiologic research and social psychological theory is even more tenuous. Very few studies even consider the population-level health implications of internal identity processes, whose effects on health can in many ways be even more difficult to capture than the consequences of compounded external social processes such as racial, gender, and socioeconomic inequity.

To address the challenge of improving the utility of theory in understanding gender differences in health, I advocate for a conceptualization of social and psychosocial exposures that moves beyond "intersection" toward a "wholistic" identity approach. This approach emphasizes how the external social factors that shape health are experienced by individuals who not separately gendered, raced, or classed, but who each have a wholistic identity developed out of the unique social experience determined by these constructs which influences how external contexts are internally mediated and manifest in health. I argue that such an approach could circumvent the temptation of attempting to quantify the relative contributions of specific dimensions of oppression when far more integral to understanding social group health differences is characterizing the internal and external barriers and resources unique to different social groups. A wholistic identity approach not only aids in elucidating how the lived experience of one's social status as determined by a unique combination of race, gender, etc., affects health, but would also allow for a more ethical and scientifically sound conduct of epidemiologic research if employed with greater frequency.

1.2 Why gender and race?

A question that often arises in epidemiologic research drawing from Intersectionality Theory is how the selection for study of any two identity categories, frequently gender and race, can be justified under the concept of inseparability of identity. In this chapter, I use gender and race as one example to explore the validity of a wholistic identity approach in epidemiologic research. Importantly, of the many designations which demarcate social groups in the U.S., there is strong evidence that gender and race exert a substantial, unique influence on health [14, 17, 18]. Despite the ongoing debate of whether race or socioeconomic status contributes more to poorer health outcomes among black persons in the USA [3], the social categories of gender and race share a number of factors not characteristic of other social constructs.

First, they are arguably two of the most visible and socially reinforced demographic traits. Whether approaching from an external social resource framework or an internal identity framework, the readily recognizable nature of race and gender means that individuals are more frequently subject to interpersonal discrimination based on these characteristics than other types of discrimination [18–22]. Such experiences can have far-reaching consequences for health, from chronic physiological dysregulation associated with toxic stress [22, 23] to receipt of subpar medical care [23] and increased barriers to protective social factors such as stable, safe housing or occupations [24]. With the structurally rooted, pervasive nature of racial and gender discrimination, the visibility of race and gender ultimately yields an overrepresentation of black persons and women among the poor and disadvantaged [3]. In this way, regardless of the magnitude of the effect of socioeconomic status on health, race and gender are determinants of socioeconomic status and therefore can be conceptualized as further upstream on the causal pathway from structural to health inequity.

Secondly, many social psychological and anthropological theories of race, as well as feminist theory, argue that cues for race and gender are more prevalent in the social environment than cues for any other social designation [19, 25, 26]. That is, more cultural elements, whether dress styles or styles of worship, are racialized and gendered than given any other social group categorization. In the context of hierarchical racial and gender structures, the prevalence of these constant reminders of what constitutes blackness and whiteness, or femininity and masculinity, renders race and gender particularly influential on how susceptible individuals are to the health consequences of their groups' perceived inferiority or superiority [17, 18, 27–29].

As will be discussed further in the following section, the majority of theories rejecting biological determinism describe the central, causal role for structural inequity in the poorer health outcomes of racial and ethnic minorities and women [4, 10, 18, 20, 24]. Health outcomes can be neither ethically nor rigorously examined outside of the sociopolitical and sociocultural contexts in which the populations of interest are located. Arguably, in the U.S. as elsewhere, the long history of violence against racial and ethnic minorities and women is unapparelled in its pervasiveness and brutality [26, 30], violence executed with the express purpose of establishing and maintaining white and male supremacy [10, 26, 30, 31]. Given this history and the degree to which racial and gender violence became embedded within the structure of U.S. social institutions [10, 26, 30, 31], it can be reasonably inferred that race and gender will have a more measurable impact on the health outcomes attributed to such inequity than other social designations.

Throughout this chapter, I will use the increasingly popular term "gendered race", therefore, to reinforce the need for a wholistic identity approach in epidemiologic research on health disparities. The term captures the concomitant elements of socially assigned gender and race categories that cannot be decomposed, neither within an individual's self-concept nor in the manner which social inequities operate to structure privilege and marginalization based on these characteristics.

1.3 Chapter goals

Far from being the first to advocate for the increased use of theory in epidemiologic research, the primary objective of this chapter is to argue for a wholistic identity approach that moves beyond concepts of intersecting social forces of oppression as determinants of health. Examining health disparities across gendered race groups through the rich perspectives emerging from the social science and social psychological disciplines, I contribute a novel interdisciplinary interpretation which underscores the need for considering both external social processes and internal identity processes in understanding and addressing the causes of gender differences in health. This chapter provides an overview of current evidence for gender differences in health which vary across race, outlining support for one wholistic identity framework, Identity Pathology theory, and its utility in the optimal execution of ethical epidemiologic research. The chapter concludes with recommendations for the inclusion of a wholistic identity approach in epidemiologic and statistical methods, as well as health intervention development.

It is important to note that the research explored in this chapter is based on cisgender identities (gender identities which are consistent with sex assigned at birth), and do not address how gendered race operates in the lived experiences of trans or gender non-conforming individuals to impact on health.

2. Theoretical frameworks for social group differences in health

2.1 Biologically driven vs. socially constructed differences in health

The distinction between biologically and socially defined categories, while rarely considered theoretically or analytically in epidemiologic research, is integral to understanding how the wholistic effect of gender and race on health extend beyond the individual contributions of either construct. Sex, a biological category, influences physiological processes through the accumulation of hormones, gene expression, and reproduction determined by the presence or absence of the X chromosome. Gender, a sociocultural category, informs identity concepts, exposure to and appraisal of stressors, behaviors, and access to care—all factors whose physiological significance is also dependent on the external contexts in which identity is experienced.

As sex and gender are often conflated in health research [32], it is all the more difficult to tease out the individual contributions of each to specific patterns of health, disease, and mortality, particularly given their interdependent nature. For example, testosterone, a naturally produced hormone is present on average at higher concentrations in males [33], is associated with aggressive behavior. Culturally designated masculinity often reinforces aggression in males [31], leading to increased production of testosterone [33]. In this way, the interplay between sex and gender renders efforts to disentangle their individual effects on population-level health differences particularly challenging.

Despite the difficulty of distinguishing health outcome differences attributable to gender and sex, focusing on eliminating those differences that are unnecessary—and therefore unjust—can serve as a useful target for epidemiologic research. Because gender is a sociocultural construct, gender differences in health are also largely a function of the social meaning assigned to gender. These definitions carry value constructed by structural, institutionalized gender prejudice as well as cultural traditions that are heavily based in binary, hierarchical concepts of gender [19, 25]. The value assigned to gender is also dependent on other social designations such as race. In fact, perhaps contributing to persistent conflicting evidence on the magnitude and causes of gender differences in health is an assumption of consistency in gender effects on health across racial groups. Any efforts to clarify the causes of gender-related differences in health must necessarily engage the historical contexts in which these health-determining social designations are constructed. These analyses may yield additional, accessible intervention targets on gendered health disparities.

2.2 Social, anthropological, and social psychological perspectives on social group differences in health

A vast store of sociological and anthropological literature describes the racial, gender, and economic inequity inherent to the hierarchical social structure of the United States (e.g. [10, 19, 25, 26, 34–36]), as well as the ways in which such social environments are inextricably linked with health [1, 6, 7, 37, 38]. Intersectionality Theory [10], Ecosocial Theory [2], and the Environmental Affordances model [39] specifically emphasize the compound effect of multiple forms of structured inequity intersecting to influence the disproportionate distribution of social, material, and natural resources across dominant status and marginalized populations. Social dominance theory [40] further suggests that structured inequity is supported through “legitimizing myths”, or consensually shared ideologies which position certain groups as beneficiaries of these health-impacting resources while also promoting narratives that influence the political practices which deprive other groups of access.

Social Identity [41] and Multidimensional Identity [11] theories exist in parallel with these frameworks, describing how the construction of social group identity, likewise informed by intersecting axes of structured oppression, designates advantage and disadvantage across social groups. Identity triggers, what the Jedi Public Health framework [42] terms the overt and covert cues embedded within the social environment which reinforce shared social ideologies, connect structural-level identity outputs with individual-level identity inputs. The Social Signal Transduction Theory of Depression [43] proposes specific ways in which these individual-level identity signals are transduced through psychoneuroendocrinological pathways that ultimately lead to disease. In this way, these frameworks each provide important but distinct elements of the larger machination by which structural inequity shapes the external social processes and internal identity processes that yield social group differences in health.

To truly engage these theories in a manner that is meaningful for researchers to understand the health significance of social hierarchies, the historical contexts which have defined concepts such as gender and race, and the ways in which these constructs become biology [38], must be carefully analyzed. Legal sanction of rape, physical assault, and other forms of wide-spread abusive behavior against women has deep historical roots in the U.S. as globally [18, 19, 30]. These practices are only one element of a social environment in which female persons have been subject to gender-based dehumanization so pervasive and persistent as to appear not only unavoidable but a product of nature [18, 19, 30].

Beyond sanctioning violence in ways that left little possibility for reprise or protection, legal disempowerment of women occurred in a variety of other ways. Among them include inheritance and land ownership prohibitions, and denial of voting rights. Historical analyses also reveal the ways in which the practice of medicine has been used to subjugate female persons [44, 45], not in the least by employing psychiatric diagnoses to discredit resistance to oppressive social and cultural norms [44, 46]. Decades of research have accumulated substantial evidence [10, 18, 30, 34] that like black persons, women's exposure to violence, exploitation, and abuse by men while being simultaneously deprived of the physical, political, or legal means to defend themselves or prevent misogynistic violence has resulted in a greater propensity for appraising trauma through a lens of powerlessness.

The structural violence employed to enforce female subordination also conditions females to see violence committed against them as consequences of their own behaviors [19, 30], which can promote the learned helplessness that drives internalization. The widely practiced tradition of female denigration following experiences of gender-based violence increases the likelihood of females' perceptions of their own complicity in traumatic experiences, and likely contributes to the increased vulnerability to internalization observed in this group [18, 19, 30]. The sense of helplessness fostered by a lack of social and legal repercussions for males' physical and sexual aggression toward females, as well as pervasive denigrating responses to female victims of gender-based violence, has promoted internalization in a space where any outward expression of discontent might yield further abuse.

These experiences of gendered dehumanization carry compelling implications for gender differences in health. As has long been argued, there is strong evidence that socially reinforced gender hierarchies directly influence female susceptibility to internalizing psychopathologies like depression and post-traumatic stress disorder (PTSD) [18, 47]. Research highlights a key role for chronic exposure to negative circumstances, or "strain", in women's predisposition toward depressive symptoms [18, 19]. The source of this gender-specific strain is often identified in unique experiences associated with lack of social power as well as societal norms and expectations of women [18, 19]. Accordingly, the IP framework argues that the experience of being a female person in a male-dominated society [rather than solely inherent biological traits of the female sex], increases susceptibility to specific types of psychological and physical disorders associated with the physiological conditioning of subordinate status. Similar to the manner by which race becomes biology [38], so too, does gender become biology.

Growing literature on the role of inflammation in depression [48] supports this argument. The Social Signal Transduction Theory of Depression [43] offers a comprehensive framework for understanding the processes through which chronic stress associated with social identity threat can lead to depression. The framework outlines how inflammatory processes chronically triggered in response to social isolation, rejection, and marginalization stemming from subordinate social status can increase risk for several conditions, including rheumatoid arthritis, asthma, obesity, and depression. As a function of their subordinate social status, those who identify (and are identified) as female are therefore at increased risk for the identity threat which can cause sustained activation of the immune system's inflammatory response. In accordance with this theory, women and black persons are consistently found to have higher levels of inflammation than men and white persons, respectively [49, 50]. These racial and gender disparities in inflammation may underlie the increased risk for conditions such as depression, which has been increasingly linked to chronic inflammation [43, 48, 49, 51], among women (see **Table 1**). In conjunction with increasing psychological susceptibility through socialized helplessness, socially constructed subordinance can thus also act physiologically to increase female vulnerability to disorders that may be better classified as internalizing symptomatology.

While the association between subordinate status and toxic stress is well-documented, less attention is devoted to the impact of higher-status on the

Biomarker	Black women	White women	Black men	White men
Systolic BP	1.2 (0.6, 2.5)	1.1 (0.6, 2.0)	1.7 (1.1, 2.7)[*]	1.4 (0.8, 2.5)
Diastolic BP	1.1 (0.6, 2.1)	1.3 (0.8, 2.2)	1.2 (0.8, 1.9)	1.3 (0.8, 2.1)
Pulse	1.1 (0.7, 1.6)	1.5 (1.1, 2.2)[*]	1.2 (0.6, 2.4)	1.8 (1.1, 2.9)[*]
BMI	0.8 (0.5, 1.2)	1.1 (0.7, 1.7)	1.1 (0.6, 2.0)	0.9 (0.6, 1.3)
Total cholesterol	1.6 (1.0, 2.7)[*]	1.1 (0.8, 1.5)	1.0 (0.5, 2.0)	0.8 (0.4, 1.3)
HDL cholesterol	1.2 (0.6, 2.3)	1.1 (0.7, 1.7)	1.7 (0.9, 3.4)	1.3 (0.8, 1.9)
Glyco-hemoglobin	1.1 (0.8, 1.7)	1.0 (0.6, 1.7)	0.9 (0.5, 1.6)	0.8 (0.5, 1.4)
Serum Albumin	0.9 (0.6, 1.3)	1.0 (0.7, 1.6)	1.7 (1.0, 2.9)[*]	1.3 (0.7, 2.5)
CRP	0.8 (0.6, 1.1)	1.7 (1.1, 2.6)[*]	0.9 (0.5, 1.5)	1.8 (1.1, 2.8)[*]
High-risk AL[d]	1.1 (0.6, 2.0)	2.1 (1.5, 3.0)[*]	1.7 (1.0, 2.9)[*]	1.4 (0.8, 2.5)

Abbreviations: BP, blood pressure; BMI, body mass index; HDL, high-density lipoprotein; CRP, c-reactive protein.
[a] *Models adjusted for PIR (ratio of household income to the US poverty threshold), age, and all biomarkers.*
[b] *PHQ-9 scores of ≥10.*
[c] *Results are from four separate regression models. The reference category for the biomarkers in each model is "low-risk".*
[d] *AL scores of ≥4 were considered "high-risk".*
[*] *$p < 0.05$*

Table 1.
Adjusted[a] odds of depression[b] with high-risk allostatic load and biomarker levels by gendered race in National Health and Nutrition Examination Survey 2005–2010, OR (95% CI)[c].

experience of chronic strain. Still, previous research has identified stress correlates of perceived dominance, showing increased pituitary–adrenal responsiveness to psychological stressors in socially dominant males [52]. This limited evidence suggests that those in dominant positions can also experience higher levels of stress as a function of their status. However, chronic exposure to dominant-status stress likely acts to shape brain physiology and manifestations of identity-based trauma in ways distinct from the chronic stress generated by subordinate social status [53–55].

Where subordinate social status promotes internalizing disorders, dominant status promotes externalizing disorders characterized by antisocial behavior. Social dominance orientation (SDO) measures the degree of preference for inequality among social groups, a personality trait that negatively correlates with empathy, tolerance, and altruism [40], and promotes reduced activity in the brain regions associated with the ability to feel concern for the pain of others [53]. In studies measuring variation in SDO, both male and white persons were found to have significantly higher orientation, suggesting that white males are more likely than either female or black persons to both promote and subscribe to legitimizing myths (rape myths of victim culpability, for example) that enable justification of their dominance-reinforcing behavior [40]. Because high SDO also correlates with low empathy, it is likely that experiences of inequity among those whose race and gender are ranked as superior can yield a proclivity for antisocial behaviors. This propensity is manifest in gendered racial disparities in suicide risk, perpetration of rape, pedophilic child molestation, and mass violence, and risk for Anti-Social Personality disorder.

2.3 Beyond Intersectionality: identity pathology, a wholistic identity approach

Intrinsic to the concept of intersection is the existence of distinction that two distinct elements, at some point, intersect. This is the basis on which Intersectionality Theory is built. As described, the structural institutions that distribute social resources do so along specific axes—inequitably, across races, genders, socioeconomic positions, abilities, sexual orientations, etc. Groups at the junctions of these axes are multiply advantaged or disadvantaged; disparities in health outcomes manifest at social intersections are, according to Intersectionality Theory, testament to the existence of a synergistic effect [10]. Internal identity processes that influence health in myriad ways, from stressor appraisal to behavior, have similarly been conceptualized in intersectional terms. The concept of dimensions outlined in Multidimensional identity theory also conjures an axial formulation of distinct identities. The intersection of these identities shapes how the external environment is experienced internally [11, 41], and subsequently, how social exposures impact on health.

A wholistic identity approach challenges the notion of both intersecting identities and intersecting axes of oppression. Intersectionality Theory calls attention to the locations where the distinct mechanisms of social hierarchies such as racism and patriarchy overlap to dictate social and health outcomes [10]. A wholistic identity approach instead argues that because racism is inherently gendered and sexism is inherently racialized, any effects of racism or sexism on health cannot be decomposed into distinct measurable units. The impact of either on the outcomes of individuals targeted by these systems therefore has less to do with the number of marginalized social group categories under which individuals fall and more so with the sociocultural paradigms unique to specific social groups which shape the internalization of, and response to, adverse social experiences. As such, while acknowledging the influence of social context and experience on the content and salience of specific identities, the argument put forth here is that individuals do not experience oppression in an axial fashion, but rather through a wholistic identity lens. That is, experiences of inequity are filtered simultaneously through each element of self-concept which predominates an individual's identity in a manner with direct implications for how such experiences will impact on health. While perhaps appearing problematically theoretical, this concept of wholistic identity as a determinant of health can be readily applied to improve current understandings of gender differences in health.

One newly emerging wholistic identity approach is the Identity Pathology (IP) model, an infectious disease framework for the effects of structural inequity on health. The triad paradigm of disease causation which sits at the foundation of infectious disease epidemiology describes interactions between an environment, a host, and a pathogenic agent [56]. The IP framework incorporates the three elements of the infectious disease triad to conceptualize the health-impacting interaction between structural inequity, individuals subscribing to socially constructed identities, and pathogenic identity beliefs. Conceptualizing identity beliefs as a pathogen that spreads through social interaction over time in a contagious manner to cause specific disease patterns across socially defined groups is an innovative approach to characterizing the causal pathways from structural inequity to disease. Contagion modeling of social determinants of health has been useful in explaining and predicting the effects of other social exposures, such as gun violence [57]. The IP model goes beyond identifying the contagious nature of socially driven health outcomes to directly characterizing the fundamental infectious elements underlying the spread of pathogenic social exposures.

According to IP theory, structural inequity serves as a breeding ground for the multilevel processes which yield unequal health outcomes. Through the construction and hierarchical organization of race and gender, as well as the disproportionate distribution of social and material resources across these categories, the ubiquitous nature of structural inequity lends itself to the nourishment of belief systems and associated behaviors which produce population-level disease patterns.

Transgenerational effects of trauma [58, 59] ensure that even prior to socialization, individuals are vulnerable to particular kinds of identity imprintation, making identity an ideal vector for pathogenic beliefs. Within an environment of structural inequity, what begins as an involuntary process of gendered racial socialization eventually leads to the development of identity paradigms capable of housing the pathogenic beliefs which infect and predispose individuals to various manifestations of pathology. The IP framework argues that the interconnectedness of social, psychological, neurological, and physiological processes renders every individual susceptible to the disruptive effects of identity on biological homeostasis. Whether through transgenerational epigenetic pathways [59], direct neurological pathways [43], or indirect behavioral pathways [60, 61], identity beliefs can chronically disrupt homeostasis and produce disease, a phenomenon which the framework terms *identity pathology*.

The IP model is distinct from Intersectionality theory in that it hypothesizes the concept of identity pathology, which describes a disease-prone state characterized by certain acquired beliefs about individual or group identity that are inherently pathological. Constructed in the context of structured inequities such as institutional gendered and classed racism, these identity beliefs are informed by unique experiences of individuals defined simultaneously by multiple social group designations and may partially account for the types of chronic diseases prevalent among different socially defined groups. The IP concept applies infectious disease modeling to the integration of the aforementioned theoretical frameworks in situating the adoption of socially constructed identities as a mediator of the disease patterns observed across different socially defined groups.

3. Evidence supporting the necessity of a wholistic approach to health disparities research

3.1 Current evidence supporting both intersectional and wholistic identity approaches

Extant epidemiological literature in accordance with an intersectional framework has identified gendered racial differences among black and white women and men in lung cancer treatment and mortality [12]; in the protective effects of income on depression [62]; in the association of depression with mortality [63]; and in the link between chronic stress and depression [64] among other exposure-health combinations. Yet, the results of these studies may also be viewed as evidence for the need of a wholistic identity approach.

The IP model builds on Intersectionality Theory in asserting that gendered racialization yields identity pathologies distinct to different gendered race groups, even among those not dually marginalized. Social hierarchies act to create unequal access to health-impacting resources, but it the convergence of each element of an individual's wholistic identity that accounts for the unique manifestations of disease caused by identity pathology across different social groups. In this section, I present evidence for the concomitantly protective and harmful effects of these gendered race-specific identity pathologies that can partially explain patterns of disease observed across gendered race groups in the United States.

For the purposes of demonstrating the application of IP theory to the epidemiology of gendered racial health disparities, I use the example of the socially constructed identity which has been the focus of this chapter thus far, gendered race, among four groups who occupy different tiers within a historically grounded social hierarchy: U.S.-born black and white women and men. Taking a snapshot of the pathologies (which fit accepted notions of disease) endemic to each of these groups at middle age (45–55), we see that black women are more likely to be afflicted by cardiometabolic conditions such as obesity and uncontrolled hypertension than the other groups [65]; black men, prostate cancer (compared with white men) and cardiovascular disease [65–67]; white women, prescription opioid abuse and depressive symptomatology (MDD) [17, 68]; and white men, alcoholism and suicide [17, 69, 70]. The IP framework asserts that these disease patterns result directly from the ways in which each of these group experience identity pathology as dictated by their gendered race.

Most individuals are categorized as possessing at least one privileged and one marginalized identity. Queer or poor white men, for example, experience discordant social identities, as heteronormativity and classism rank these statuses as inferior [19, 71] even as their race and gender grant certain privileges. However, as previously noted, the immutable physical attributes assigned to gender and race lend a permanence and identifiability that make social processes particularly susceptible to discrimination based on these characteristics. Gendered racial identities are therefore particularly influential in shaping the manifestation of identity pathology.

As the theories covered in this chapter outline, female and black persons occupy subordinate social positions in the U.S. gendered racial hierarchy. Those who are both female and white, or male and black, however, occupy both subordinate (female and black) and dominant (white and male) positions and therefore can experience a particular kind of dissonance associated with simultaneous disempowerment and privilege. Because of this incongruence between the socially constructed racial and gender identities of white females and black males, these groups likely share underlying identity pathologies distinct from those of black women and white men. However, sociocultural influences as well as the influences of other centralized identities on coping can lead to distinct manifestations of identity pathology even among white women and black men.

Shared identity pathologies in which self-worth is predicated on an unattainable, but desired social status underlies prevalent diseases among white women and black men. The increased cardiovascular disease risk (as well as other chronic inflammatory diseases like prostate cancer) [72] in black men has been shown to correlate with John Henryism, a type of goal-striving stress caused by a refusal to succumb to racial or economic barriers to the practice of a socially defined masculinity among members of this group [73]. Similarly, the IP model asserts that white women's increased risk for inflammatory-based internalizing disorders such as depression are caused by an increased likelihood of self-blame and denial of social inequity. As the social value granted by whiteness is diminished through gender marginalization, opioid addiction becomes a method of avoidant coping consistent with the socialized internalization of female persons.

In this manner, black men and white women can perceive similar barriers to the benefits of their advantaged social positions. For some black men, racism prevents the full practice of socialized concepts of masculinity, leading to social deprivation, identity threat, and the cognitions and health behaviors that increase risk for cardiovascular disease [27, 73]. Likewise, for some white women, gender discrimination impedes access to the full perceived benefits of whiteness, leading to social marginalization, identity threat, and the cognitions and health behaviors that predispose members of this group to inflammatory-based depressive disorders. These hypotheses are supported by emerging evidence of a link between cardiovascular disease and depression [48, 74, 75], making a case for the assertions that (a) black men and white women may share identity pathologies that manifest distinctly based on sociocultural contexts, and (b) ostensibly dissimilar symptoms of illness may stem from shared disease origins [49, 76].

The identity pathologies of white males and black females differ from those of black males and white females, and present with different symptomatology. White males occupy both racially and gender superordinate social positions, and are therefore more likely to be socialized to adopt identity paradigms which rely primarily on socially constructed relational self-worth. Without exposure to the subordinate status that conditions adoption of identity paradigms embedded with increased risk of internalization and chronic inflammation, white males are more likely to exhibit symptoms of recurrent identity stress through externalized control-reinforcing behaviors, which have been discussed at length. Subscribing to socially constructed white male identity paradigms not only increases susceptibility to anti-social tendencies attributable to pathologized whiteness, including lack of empathy, feelings of entitlement, and behaviors to reinforce feelings of control, but also externalizing disorders driven by pathogenic masculinity that manifest through violent or aggressive behavior toward self and others. As the practice of white male identity also requires the perpetuation of the structural violence that enables members of this group access to a disproportionate share of social and material resources, white males subscribing to these identity paradigms are also less susceptible to the physical disorders such as cardiovascular disease promoted by material deprivation.

On the other hand, dominant narratives of white and male identity which distance whiteness from poverty [71] ensure that certain groups of white men are particularly susceptible to the health consequences of identity pathology. With increased dependence on superior status for a sense of self-worth [17, 28], not being afforded the expected privileges of white male membership can exacerbate the negative health effects of poverty. Poor white men, for example, face increased risk of depression, and substance abuse may serve as a form of coping [17, 77] for those white men not succumbing to other self-destructive compulsions of identity pathology such as suicide [17, 77, 78].

In contrast, the dual occupancy of subordinate social positions may reduce the risk of psychopathology among black women, while conferring an increased risk for cardiometabolic disorder. As both female and non-white, their dually marginalized positions might predict that black female identity paradigms manifest a propensity for disorders such as depression as an expression of chronic stress. Identity pathology theory, however, contrasts the external social circumstances in which black women are situated with the internal resources characteristic of this group. The necessity for adapting to multi-faceted forces of structural violence may have enabled the development of psychological durability within black female identity paradigms that is protective against psychological symptoms of toxic stress. So, while occupying both racially and gender subordinate tiers might predict higher risk of psychological manifestations of depression among black women, the greater necessity for the development of effective coping strategies may actually act to confer psychological resilience and reduce risk in this group [64, 79].

Not permitted access to social privilege or higher social status as a result of their race or gender, evidence suggests that black women have been compelled to develop alternative standards of value in order to build self-worth. In this way deprived of access to sources of socially constructed self-esteem, black women subscribing to dominant black female identity paradigms are likely to appraise potential identity threats in a manner distinct from other groups. Specifically, acute, interpersonal experiences of identity threat may be perceived as less threatening. Previous research grounded in IP theory indicates, which will be later examined in more detail, that reported lifetime gender and racial discrimination in certain settings is associated with poorer cardiovascular health among black men, white women, and white men, but not black women (**Table 2**) [80].

Setting[c]	Black women	Black men	White women	White men
In public/on the street	+0.2 (0.0, +0.5)*	0.0 (−0.3, +0.3)	+0.1 (−0.2, +0.5)	−0.5 (−1.0, −0.1)*
Getting a job	0.0 (−0.3, +0.3)	−0.3 (−0.6, 0.0)*	−0.6 (−1.3, +0.1)	−0.5 (−1.1, +0.1)
Getting housing	−0.1 (−0.3, +0.2)	−0.2 (−0.5, +0.1)	−1.5 (−2.5, −0.4)*	−0.4 (−1.5, +0.7)
At work	+0.1 (−0.2, +0.4)	−0.4 (−0.7, −0.1)*	−0.4 (−0.9, +0.1)	−1.0 (−1.6, −0.3)*
At school	+0.3 (0.0, +0.6)*	−0.4 (−0.8, 0.0)*	−0.1 (−0.6, +0.5)	−0.3 (−1.1, +0.4)
Receiving medical care	−0.5 (−0.9, −0.1)*	−0.7 (−0.9, −0.1)*	−1.5 (−3.8, +0.7)	−1.1 (−2.7, +0.5)
By the police or courts	−0.1 (−0.2, +0.4)	−0.1 (−0.4, +0.2)	−1.1 (−2.0, −0.3)*	−0.3 (−0.9, +0.4)
At home	+0.1 (−0.3, +0.4)	−0.1 (−0.6, +0.4)	−0.2 (−0.5, +0.1)	−0.2 (−0.7, +0.3)

[a] *All models are adjusted for age and study center.*

[b] *Health scores are calculated based on data collected in year 30 or the last follow-up after year 7, using six components with a total possible 12 points: body mass index, total cholesterol, systolic blood pressure, fasting glucose, smoking status, and physical activity. Higher scores indicate better health.*

[c] *At year 7, discrimination "at home" was excluded from the race or color scale; "by the police or courts" and "getting housing" were excluded from the gender scale.*

*$p < 0.05$

Table 2.
Adjusted[a] difference in cardiovascular health Score[b] at year 30 of the CARDIA study across settings of simultaneously reported racial and gender discrimination at year 7, ß (95% CI): 1992–2016.

This psychological resilience among black women may be grounded in an ability to redefine standards of value in a manner that challenges the very notion of socially constructed subordinance. Contrary to what many psychological theories once predicted, members of stigmatized groups tend to have comparable levels of self-esteem with non-stigmatized groups [81]. Researchers attributed these surprising findings to the use of self-protecting mechanisms by members of stigmatized groups such as "selectively devaluing, or regarding as less important for their self-definition, those performance dimensions on which they or their group fare(s) poorly, and selectively valuing those dimensions on which they or their group excel (s)" [81]. Dominant sociocultural narratives rank black women at the bottom in most highly regarded social dimensions—physical beauty, intellectually capability, etc. [82], but celebrate their caregiving, selfless, mothering natures [83, 84]. However, rather than devaluing the dimensions in which society ranks them poorly as identity stigma predicts, many black women appear to have developed alternative social rating systems which do not predicate socially valued traits on dominant group standards [79, 82].

Furthermore, their professions, voting patterns, and activism demonstrate that black women have identified a source of self-worth inherent to the practice of caring for and about others [85]. In this way, by enabling a greater sense of self-efficacy in which black women feel capable of determining for themselves standards against which their value will be measured [82], multifaceted forces of disempowerment may confer individuals subscribing to dominant black female identity paradigms a measure of protection against the psychological manifestations of the very chronic identity threat they cause.

In support of this hypothesis, research demonstrates that allostatic load, a measure of cumulative physiological dysregulation stemming from chronic stress that precedes and correlates highly with many chronic diseases [86], is associated with depression among black men and white women, but not black women or white men

(**Table 3**) [64]. Furthermore, there is indication that the underlying neurobiology of depression differs among black women compared with black men, white women, and white men (**Table 1**) [49, 87]. The depressive response to deprivation among black women, rather than being a function of a perceived threat to deeply held self-concepts that promotes sustained inflammation, as IP theory argues is more likely to be the case among black men and white women, may be based more in a situation-appropriate response to the uniquely disadvantaged social conditions in which black women are disproportionately situated. So, while the prevalence of depressive symptoms may be substantial among black women, these symptoms may be indicative of a response that is distinct from the pathology manifest in depressive symptoms among other groups. Evidence that adjusting for socioeconomic status eliminates the gender disparity in depression among black persons but not white [88] further supports this theory.

These potential psychological benefits do not come without physical costs, however. Where black women may be psychologically resilient, they are likely to be physically vulnerable; high rates of obesity, hypertension, and poor maternal/neonatal outcomes in this group reflect a unique adaptation to structural inequity—metabolically, rather than psychologically, exhibiting pathology. In addition to the structural racism and sexism that concentrates economic deprivation and limits the capacity for health-promoting behaviors within black female populations [10, 82, 85], black female identity paradigms demand what could be argued as a pathological minimization of self-care in efforts to be valued as caregiver [84, 89]. As Superwoman Schema theory suggests, in prioritizing the needs of others, black women often bear an extensive familial and community burden without complaint at the cost of their own emotional and physical needs [84]. Adherence to these gendered race-specific identity paradigms predisposes black women to automated coping such as emotional eating [90, 91], other risk-factors for obesity such as postpartum weight retention [92], and other health-impacting behaviors such as low health services utilization [93]. Furthermore, another form of identity pathology characterized by a failure to acknowledge the existence, or negative psychological impacts, of structural inequity can lead to denial and internalization which may lead to premature disease and mortality [29, 94].

	All (*n* = 6431)	**Black women (*n* = 980)**	**White women (*n* = 2147)**	**Black men (*n* = 1028)**	**White men (*n* = 2276)**
Depression, % (SE)	7.3 (0.5)	14.6 (1.3)	8.5 (0.7)	7.1 (0.8)	4.9 (0.6)
Low AL[b] (0–3)	6.1 (0.5)	13.4 (1.4)	6.9 (0.7)	6.1 (0.9)	4.3 (0.6)
High AL (4–9)	11.8 (1.2)	17.1 (3.0)	15.3 (1.9)	10.1 (2.0)	7.4 (1.5)
Crude	2.1 (1.6, 2.7)**	1.3 (0.8, 2.2)	2.4 (1.7, 3.4)**	1.7 (1.0, 3.0)*	1.8 (1.0, 3.0)*
Adjusted[c]	1.7 (1.3, 2.2)**	1.1 (0.6, 2.0)	2.1 (1.5, 3.0)**	1.7 (1.0, 2.9)*	1.4 (0.8, 2.5)

[a] *Results are from five separate logistic regression models; one for the total sample and one for each gendered race group.*
[b] *Allostatic load, calculated as a composite of nine cardiovascular, metabolic, and immune biomarkers.*
[c] *Adjusted for five age groups and five groups of ratio of household income to the US poverty threshold.*
*p < 0.05.
**p < 0.0001.

Table 3.
Depression in relation to Allostatic load by gendered race Group[a] among Black and white US adults: National Health and Nutrition Examination Survey, 2005–2010.

Importantly, the IP framework does not assert that compounded inequities necessarily translates to greater likelihood of a specific disease outcome among multiply marginalized groups. Instead, the framework argues that the lived experience of race and gender in a society which advantages some groups in certain ways while disadvantaging others in different ways [12, 95] based on these identities yields variation in the efficacy of health-protective factors. This variation in turn manifests as a differential vulnerability to disease across gendered race groups.

3.2 Application of IP theory to investigating gendered racial differences in cardiovascular health

Recently published work applies the IP framework to the study of gendered racial variation in the association of discrimination with cardiovascular health (CVH). This emerging body of research makes a compelling case for considering the role of wholistic identity in assessing the manner by which structural inequity contributes to unjust and unnecessary gender differences in health. Persistent gendered racial differences in the prevalence and severity of cardiovascular disease (CVD) in the U.S. highlight the necessity for a stronger theoretical foundation in understanding the role of discrimination in yielding social group disparities in CVD [21, 22, 80].

The age-adjusted likelihood of a CVD diagnosis is approximately equal for black and white men [65, 66], but black women are nearly twice as likely as white women in the same age group to develop CVD [65, 66]. Black women are also more likely than white women or black men to develop cardiometabolic precursors to CVD [96]. Among other risk factors [7, 10], researchers frequently attribute this increased risk among black women to a greater likelihood of experiencing racial and gender discrimination [12, 95]. Unlike the large gender disparity among whites, however, black women and men report comparable exposure to interpersonal gender and racial discrimination [21, 97] even as black men develop CVD at a faster rate than black women [65, 66].

Due to these prominent disparities in cardiovascular outcomes between black and white women and men, researchers have examined social group-specific exposures as potential contributors to these inequities [98]. Consistent with the dominant biomedical, individual-level orientation of epidemiological research [7], the literature has largely focused on interpersonal racial discrimination as a driver of poorer CVH within these groups [7, 22, 98, 99]. Often conceptualized as a proxy for structural discrimination, or, alternatively, as a mechanism through which structural discrimination acts on health, interpersonal discrimination provides an accessible method for investigating social determinants of health [7]. The underlying assumption for the majority of studies examining interpersonal discrimination appears to be that the stress associated with experiencing discriminatory interactions has a detrimental effect on CVH, directly through chronic activation of the stress response system, or indirectly through promoting poor health behaviors, which in turns increases risk for cardiovascular morbidity and mortality [7, 22, 100]. As such, populations more likely to encounter these experiences (e.g. women compared with men in the case of gender discrimination) will exhibit poorer health behaviors, experience higher rates of cardiometabolic dysfunction, and necessarily have a greater burden of disease.

In line with this reasoning, previous studies have linked reported racial discrimination to sedentary behavior, smoking, hypertension, obesity, and incident CVD within black and white populations [21, 100–103]. Because the prevalence of reported interpersonal racial discrimination is substantially higher among black persons than whites [7, 23] these findings have generally been interpreted through the lens of differential exposure rather than vulnerability [16]. That is, a higher prevalence of disease theorized to correspond with a higher prevalence of exposure, rather than with differential vulnerability to the effects of exposure [7, 99]. Consequently, consensus has leaned toward an association of reported racial discrimination with the disproportionate rate of cardiovascular morbidity and mortality among blacks [7, 98, 99].

Admittedly, researchers have emphasized relevant differences in the effects of exposure depending on the basis of discrimination [98, 102] (racial versus weight, for example), the frequency of discrimination [98], demographic characteristics such as the age or gender of the individual to whom the discrimination is directed [103], and how individuals respond to stress [21, 104]. Even still, few have theoretically considered the nature of these differences and whether the reasons for these differences have implications for the exposure-disease relationship; even fewer have taken these potential implications into account during analysis.

Further, while the consequences of structural and interpersonal discrimination are documented more frequently among women [20, 95], recent evidence showing no association of reported gender discrimination with incident CVD [21], along with other recent findings inconsistent with previous evidence [94], calls into question unidimensional conceptualizations of discrimination as a cause of poorer CVH. A focus on differential exposure to interpersonal discrimination as underlying gendered racial disparities in CVH may prevent identification of other relevant group-specific characteristics such as varying *susceptibility* to the health effects of perceiving discrimination [7, 12, 62, 63, 105]. For example, a recent study assessing the effect of cumulative unfair treatment on subclinical CVD among a multi-ethnic sample of women found an association only among white women [106]. Such evidence supports the argument that while women and black persons are more likely to experience both structural and interpersonal gendered racial discrimination, men and white persons may be more susceptible to the health consequences of perceiving interpersonal discrimination as a result of group-specific internal resources [29, 80, 107].

Previous findings also suggest that the magnitude of stress discriminatory experiences cause and whether responses to these experiences exacerbate or reduce the risk of CVD depends on the context in which they occur [100, 104, 106]. Therefore, in addition to the challenge of capturing variation in the subjective identity characteristics that might render interpersonal discrimination detrimental to CVH, as well as the complex psychological processes by which individuals attribute discriminatory experiences, it is also necessary to consider how the setting in which discrimination is reported reflects access to both internal and external psychosocial resources that may independently relate to CVH differently for different gendered race groups. Everyday experiences of discriminatory treatment not only encompass individual acts but also the complex relation of acts that will be specific to specific social contexts, as argued by some critical race theorists [12]. The particular relationship between individual and context bears important implications for the physiological impact of perceived discriminatory interactions.

Further, the context of reported discrimination, such as at school, at work, by the police or courts, or while seeking healthcare, may provide insight into distinct effect pathways operating among different gendered race groups. While discrimination may act directly on CVH through repeated activation of the stress response system for some, others may be more susceptible to the indirect effects of interpersonal discrimination such as barriers to quality health care [98, 100, 108].

The complex relationships of these psychosocial exposures with CVD among black and white women and men connoted in the literature point to a need for further consideration of how and in whom discrimination operates to affect risk for disease [7].

Evidence suggests that the multifaceted nature of the interpersonal discrimination experience operates within distinct social groups to differentially influence CVH in a manner not frequently captured in epidemiologic studies [22, 98, 99, 103]. Inconsistencies in the literature may be attributable, in part, to an inadequate conceptualization, measurement, and analysis of interpersonal discrimination in relation to CVH across demographically diverse populations.

The Identity Pathology framework provides a useful model for investigating these inconsistencies in the relationship of discrimination with CVD (see **Figure 1**). While not solely applicable to CVD, the model is useful for clarifying inconsistencies in the literature on interpersonal discrimination and CVD because it specifies the conditions under which—and in whom—reported experiences of interpersonal discrimination will be measured as damaging to CVH and lead to the development of disease. As applied to CVD disparities and interpersonal discrimination, the model makes three central assertations.

First, that in order to more accurately capture the effects of interpersonal discrimination on cardiovascular health and health disparities, multiple aspects of the discrimination experience must be considered in the design, analysis, and interpretation of health-related studies. Secondly, the IP framework posits that experiences of interpersonal discrimination are fundamentally based in historically structured inequities that impact on each dimension of the discrimination process in health-relevant ways. Finally, the model purports that the precision with which reported experiences map onto perceptions and intentionally or implicitly driven acts of discrimination depend on a variety of psychosocial characteristics, one of the most important of which is an individual's beliefs about their gendered racial identity. In other words, the contribution of discrimination to disparities in CVH may extend beyond gendered racial variation in *exposure* to gendered racial differences in the effect of perceiving interpersonal discrimination.

The IP model argues that this variability in effect across gendered race groups can be attributed to differing manifestations of identity pathology. Due to the relationship between identity pathology and the experience of interpersonal discrimination, the experience being captured in reported discrimination among different gendered race groups must necessarily be different. For men reporting frequent experiences of gender discrimination, these experiences are less likely to reflect objective encounters with discrimination as traditionally conceptualized and are more likely to signify that these men feel they are being deprived of the

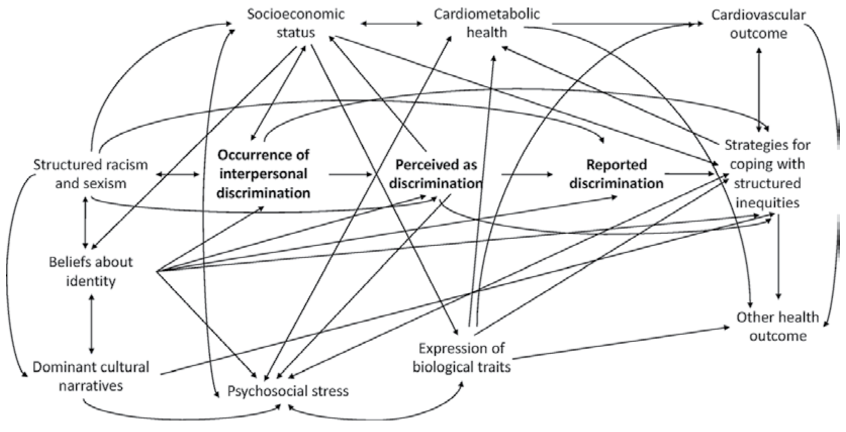

Figure 1.
Application of the emerging identity pathology framework to describe potential pathways from intersecting axes of structured racism and sexism to cardiovascular disease.

entitlements they believe they are due as a result of their manhood. Similarly, reporting of multiple encounters with racial discrimination by white persons likely indicates encounters in which these individuals believe they were deprived of entitlements due to them as white persons. Regardless of the accuracy of their reporting, the perception of what members of dominant status groups consider discrimination can be stressful enough to have a measurable impact on their cardiovascular health. This effect may be exacerbated by their recognizing the inconsistencies of their perceptions with the way that society defines experiences of discrimination.

Moreover, even among those whom the occurrence, perception, and reporting of discrimination overlap with high accuracy, differences in beliefs about the significance of being perceived and treated as inferior by another group will influence the stressfulness of perceiving discrimination. Finally, identity beliefs associated with gendered race also shape how individuals will cope with the reality of being perceived and treated as inferior, thereby creating another source of variability in the effect of reported interpersonal discrimination on CVH. Because increased exposure to social stressors among marginalized groups may yield an array of adaptive coping strategies that are protective against the health consequences of psychosocial adversity, the IP model predicts, perhaps counterintuitively, that the association between reports of racial and gender discrimination and declining CVH to be stronger among members of dominant status groups. The IP framework also posits that the susceptibility to direct versus indirect effects of discrimination on CVH are primarily a function of an individual's cumulative social experiences and will therefore manifest differentially across gendered race groups.

Given these hypotheses, two studies [29, 80] examined the relationship of reported interpersonal discrimination with CVH among black and white women and men using 30 years of longitudinal data from the Coronary Artery Risk Development in Young Adults study. The first study evaluated whether the associations of reported interpersonal experiences of racial and gender discrimination simultaneously compared with racial or gender discrimination alone, or no discrimination, with cardiovascular health 23 years later was stronger among white men than other groups. The second study explored variation in the relationship between simultaneously reported racial and gender discrimination and future CVH across eight social settings.

The studies identified important characteristics of the relationships between reported racial and gender discrimination and cardiovascular health (CVH) in black and white women and men. The first study identified differences in the associations between reported gender and racial discrimination and CVH, suggesting differential vulnerability (**Table 4**). Compared with reporting no discrimination, reporting any racial discrimination predicted higher CVH scores among black women, while no statistically significant associations were found among black men. Among white women, reporting any gender discrimination predicted higher CVH scores than reporting no discrimination. For white men, predicted CVH scores were higher for those reporting any racial discrimination, and lower for those reporting racial and gender discrimination in at least two settings, than in those reporting no discrimination.

These findings contrasted with those describing a link between racial discrimination and poorer cardiovascular health among black persons [7, 99, 101]. Though inconsistent, the literature has demonstrated associations of reported racial discrimination with CVD risk factors including diet, hypertension, smoking, sedentary behavior, obesity, and inflammation [50, 101, 103, 109], as well as social predictors of CVD such as marital status, socioeconomic position, and education, in both black women and men [7, 23]. In this study, we did not find a statistically significant association between racial discrimination and poorer CVH within these groups.

	Black women	**Black men**	**White women**	**White men**
Discrimination (year 7)	ß (95% CI)	ß (95% CI)	ß (95% CI)	ß (95% CI)
None	ref.	ref.	ref.	ref.
Any racial only	0.4 (0.0, 0.8)*	−0.1 (−0.5, 0.4)	−0.3 (−1.2, 0.6)	0.4 (0.1, 0.8)*
Any gender only	−0.3 (−0.8, 0.2)	0.2 (−0.6, 1.0)	0.3 (0.0, 0.6)*	0.0 (−0.4, 0.3)
Any racial or gender, in <2 settings	0.1 (−0.3, 0.5)	0.0 (−0.5, 0.5)	0.2 (−0.2, 0.6)	−0.2 (−0.6, 0.1)*
Both racial and gender, in ≥2 settings	0.2 (−0.1, 0.6)	−0.3 (−0.7, 0.1)	0.0 (−0.4, 0.4)	−0.6 (−1.1, −0.1)

$^{*}p < 0.05$.

[a] *Cardiovascular health scores are calculated based on data collected in year 30 or the last follow-up using six components: body mass index, total cholesterol, systolic blood pressure, fasting glucose, smoking status, and physical activity. Higher scores indicate better health.*

[b] *Models are adjusted for age and geographic location.*

Table 4.
Adjusted difference in cardiovascular health Score[a] for categories of reported racial and/or gender discrimination by gendered Race[b]: CARDIA, 1992–2016.

Other cross-sectional analyses [100, 110] and the only study prospectively examining the relationships of racial discrimination with incident CVD exclusively among black women and men have also failed to find a connection [94]. Taken together, these findings offer evidence that traditionally accepted risk factors may be poorer predictors of CVD among black persons. Accordingly, while interpersonal racial discrimination may increase the likelihood that black women and men develop cardiometabolic risk factors for CVD, other factors integral to the experience of multiply marginalized identities may have a much more substantial impact on the development of CVD in these groups. As these other potential risk factors remain under studied [7, 95], the long history of investigating interpersonal discrimination as a cause of poorer health has done little to expand an understanding of CVD disparities between black and white women and men.

In addition to suggesting alternative causes of higher CVD morbidity and mortality among marginalized groups, the IP model theorizes that discrepancies between the occurrence, perception, and reporting of interpersonal discrimination contribute to the observed variability in the associations of reported racial and gender discrimination with CVH among black and white women and men (see **Figure 1**). The model suggests that for some gendered race groups in certain places and settings, reported discrimination is more likely to reflect interactions that meet objective standards of inequitable treatment. In these cases, acknowledging experiences that actually occur may be beneficial for health, while denying may lead to increased stress and stress-related pathology regardless of one's gendered race group [50, 111]. From building social networks based on shared experiences to enabling the development of healthier coping behaviors [27, 109], recognizing and acknowledging the discrimination one encounters may allow for chronic stress relief that reduces risk for CVD associated with discrimination exposure [50, 111]. Reported experiences of racial and gender discrimination may thus be measured as protective among those against whom such experiences actually occur.

To fully account for the results of this study in the context of IP theory, it is important to note that across the four gendered race groups, reporting or not reporting exposure likely signify different health-relevant psychological and emotional states [27, 112]. The relatively low percentage of black women who reported experiencing no racial or gender discrimination did so despite a considerable body of evidence to the contrary, indicating a measure of denial or "tough it out" mentality in this group [27] distinct from the evidence-based reasons that a much greater proportion of white men would report no exposure. Even within gendered race groups, the meaning of reported exposure to discrimination may vary. As proposed in the IP framework, white men reporting few experiences of racial discrimination may subscribe to identity paradigms distinct from those in their group reporting both racial and gender discrimination in multiple settings. The framework posits that among white persons, reported experiences of racial discrimination in only one setting (e.g. at school) may be more likely to meet objective standards of discriminatory treatment. Accordingly, better CVH scores among white men who reported only racial discrimination would not be inconsistent with a protective effect of reporting interpersonal experiences of discrimination that meet objective measures. That is, white men who reported only exposure to racial discrimination were likely the white men for whom the overlap of the occurrence, perception, and reporting of discrimination was relatively accurate. As the IP model predicts, in such cases, there is likelihood that reported discrimination will be measured as protective of CVH. That the positive effect on CVH among white men reporting only racial discrimination persisted even after adjusting for SES further supports this assertation.

Study 2 revealed that simultaneously reported racial and gender discrimination were differentially associated with CVH depending on gendered race and setting (**Table 2**). Among black women, with one exception, reported instances of interpersonal discrimination were not associated with CVH or were associated with a higher CVH score while the opposite findings were observed among the three other gendered race groups. For black men, simultaneously reported discrimination in four of the eight settings was significantly associated with poorer CVH. Associations across settings also differed between white women and men. For white women, reported racial discrimination by the police or courts or while seeking housing was associated with lower CVH scores, while among white men, self-reports of racial and gender discrimination in public or at work were associated with a lower CVH score. For all groups, reporting discriminatory experiences while receiving medical care had a negative impact on future CVH, although effect estimates did not reach statistical significance among white women and men.

That the settings in which reported racial and gender discrimination were associated with poorer CVH differed among black and white women and men is consistent with disparate effect pathways for these groups that may be linked to gendered race-specific external and internal characteristics. The findings suggest that for black women, interpersonal experiences of discrimination are more likely to act indirectly on CVH by deterring access to health-influencing resources such as medical care, a mechanism that has been demonstrated in previous research [113]. Black women who reported racial and gender discrimination while receiving medical care were the only individuals of their gendered race group to experience a decline in CVH associated with reported discrimination; reported exposure in other settings was measured as either protective or had no influence on CVH. Rather than yielding a greater vulnerability to the negative health consequences of psychosocial stress as might be intuitively concluded, these findings suggest that black women may more readily adapt to hostile social environments such that the effects of recurrent interpersonal discrimination on the stress response system [64], or on certain health-related behaviors that preempt cardiovascular disease [103], are minimized in comparison to other gendered race groups. These results do not suggest that black women are immune to the physiological impacts of the discrimination they report. Rather, these findings indicate that structural barriers, such as reduced access to high-quality medical care, may have a much more compelling effect on the cardiovascular health of black women than stress stemming from encounters with interpersonal discrimination, as has been previously argued [4, 98].

The settings in which reported discrimination impacted CVH among black men in this study indicate that members of this group may be more susceptible to the direct physiological impact of perceived subordinate status than black women. This may be because racism targeted at black men has historically been more ostensibly violent [97], or due to other psychosocial and cultural factors influencing the distinct coping methods of these groups [10, 64, 97]. The observed patterns in the associations of reported discrimination with CVH indicate that reminders of marginalized status may be experienced as more stressful among black men than black women and therefore may be more likely to act on CVH through direct physiological mechanisms in addition to creating barriers to health and social resources in this group.

One explanation for the patterns observed in this study is that interpersonal discrimination may act as an "identity trigger" consistent with claims of the Jedi Public Health framework [42]. The authors suggest that identity triggers, or elements of the social environment that trigger awareness of one's social status, are one mechanism through which structured inequities act to differentially impact on health and lead to health disparities. The unequal social conditions in which black and white women and men are situated influence the type and saturation of identity triggers each of these groups will encounter, as well as available coping resources [39, 111], within and across various social settings [42]. According to this framework, experiences of discrimination pose a setting-specific disease risk for each gendered race group. We suggest further that perceived experiences of interpersonal discrimination can act as identity cues, even in the absence of actual occurrences of discrimination, which might partially explain the associations we found among white women and men. Identity triggers and the perceived coping resources [39] particular to black and white women and men may act to specify conditions under which experiences of interpersonal discrimination will have a measurable impact on CVH.

Hierarchical social conditions create power dynamics between marginalized and dominant status groups which influence how inequity will be experienced on a personal basis by members of both types of groups [7, 10, 97, 114]. Experiences of discrimination based on gendered race that occur in the context of medical care, education, or in interactions with law enforcement, for example, can bring to bear historically structured power imbalances through heightened awareness of one's stigmatized status in the form of race consciousness [99, 115]. Instances of interpersonal discrimination in these specific settings may be uniquely stressful for marginalized persons both because of the likelihood of recurrence and a perceived lack of opportunities for retribution [39, 42, 111].

On the other hand, the settings in which awareness of unequal social status might be triggered among dominant group members—whether or not a discriminatory interaction actually occurred—and the resources they believe are available for coping with the accompanying stress, likely differ. These perceptions of social status triggered by interpersonal discrimination lead to between-group differences in the types of social contexts in which experiencing discrimination will contribute to deteriorated CVH. This interplay is consistent with our findings that although a higher percentage of black men reported encountering discriminatory treatment in public or on the street than in any other setting, this setting was the only one in which exposure was not associated with poorer CVH within this group. In contrast, "in public or on the street" was one of the two settings in which white men who reported experiencing racial and gender discrimination experienced declining CVH. Given the historical contexts in which white men's social status afforded a measure of public and occupational deference, for some white men instances when this deference is absent or challenged in settings such as on the street or at work may be more likely to be perceived as discriminatory and more stressful than encounters perceived as discriminatory in other settings, an explanation that is consistent with the findings of this study.

4. The role of valid theory in ethical and scientifically sound research

Despite the detailed theoretical focus of this chapter, a wholistic identity approach to epidemiologic research, of which the IP framework is one example, has practical application for clarifying gender-related differences in health. One of the most significant assertions of the IP framework is that epidemiologic research should embrace a more nuanced approach to social determinants of health and health disparities research, specifically as related to assumptions of homogeneity in social group differences in health. This paper has presented strong evidence that concepts of gender and race are conceptually far more complex than is often operationalized in many epidemiologic analyses. Furthermore, the health implications of adverse social experiences associated with gender and race are heavily dependent on psychosocial characteristics that are rarely measured in epidemiologic studies.

The inclusion of sound theoretical foundations is necessary to ethically and rigorously address these concerns. The IP framework calls for reconsidering some standard methodologies of epidemiologic research. Because the white male referent presents a number of conceptual problems, using stratified analyses can circumvent many of the biases to which research questions based on multi-gender, multi-racial, or multi-ethnic samples are vulnerable. Stratified analyses can also avoid the pitfall of including variables for complex social constructs such as gender or race in regression models, as recent literature has described notable limitations and conceptual inconsistencies in this approach [15, 16].

In addition to implications for improving the rigor of scientific research, the increased application of well-developed theory to research into the causes of social group differences in health has ethical implications as well. Outside of the academic settings in which health research frequently occurs, epidemiologic findings have significant impact of the health and lives of real people. What we discover about the causes of gender differences in health informs the policies and societal changes intended to alleviate unnecessary and unjust suffering. A failure to fully consider all available evidence is a failure to meet the lofty ideals of epidemiology as a discipline —to identity the causes of disease in order to eradicate.

5. Conclusions

In this chapter, I have addressed the necessity and challenge of incorporating sound theory into epidemiologic research on the causes of gender differences in health. Intersectionality Theory has in many ways served as a springboard for the growing collaboration of epidemiology with social science. Still, although the use of interdisciplinary theory in epidemiologic research has increased substantially within the last decade, there is much room for improving the application of theory to everything from developing research questions to the selection of confounders to the interpretation of results. Moreover, much of the research employing an intersectional approach struggles to deeply engage the health implications of concepts like socially constructed gendered race. While there is acknowledgement of the external social processes which shape the health of groups in different socially defined categories, little attention is given to how internal identity processes also play a pivotal role in determining health. This oversight is largely due to a resistance within the field of epidemiology to grapple with complex social psychological phenomena such as the influence of social group identity on population-level differences in health.

For this reason, I have argued in this chapter for the necessity of moving beyond intersectional approaches to health disparities research. The use of a wholistic identity approach to understanding social group differences in health requires the engagement of wide array theories which each provide important but distinct elements of the larger mechanisms by which structural inequity produces social group differences in health. One wholistic identity theory, the Identity Pathology model, is built on such an interdisciplinary conceptualization of health disparities.

According to Identity Pathology theory, embedded in socially constructed identities are beliefs that moderate whether and how exposure to chronic adverse social conditions, for example experiences of interpersonal discrimination, will generate disease. When individuals are socialized with identities built on pathogenic identity beliefs, they are more susceptible to a number of physical and mental illnesses. Pathologized identities act to foster disease through dictating cognitive and behavioral practices—stressor appraisal, health behaviors, etc.—that yield distinct pathologies in the context of unequal social conditions. The IP framework argues that gendered racial identities constructed in the context of inequitable social conditions create unique manifestations of health and disease among black and white women and men, contributing to gender differences in health that will vary across race in a manner that may not be adequately captured in current interpretations of Intersectionality Theory.

Fundamentally, many theories on social determinants of health, including Intersectionality Theory, predicate the health of the socially marginalized—whether that be on the basis of gendered race, socioeconomic status, etc.—on a set of resources of which they are systematically deprived. In some ways, these theories carry undercurrents of an adversarial tone by situating the “disadvantaged” as those who have everything to gain from social change against the “privileged” who are at risk for a corresponding loss. As such, any improvements in the health of members of marginalized groups are necessarily dependent on the decisions of those who retain power over the distribution of these resources, individuals who have little incentive to relinquish their positions of authority (perceived and actual) or enact more inclusive policies [28].

In *The Health Gap*, Marmot observes: “Being at the wrong end of inequality is disempowering, it deprives people of control over their lives. Their health is damaged as a result. And the effect is graded–the greater the disadvantage the worse the health” [116]. This observation, while not incorrect, seems to suggest, almost tacitly, unintentionally perhaps, that at the “right” end of inequality, individuals are artificially empowered. I consider whether the focus on external resources to the exclusion of internal resources of health is another form of disempowering marginalized persons. To act on the idea that the marginalized many cannot even enjoy health without the permission of the advantaged few feels, at its core, like another practice of structural violence.

If structural inequities and the unequal health outcomes such conditions cause are to be truly deconstructed, intervention must entail more than efforts to change social and economic policies which were intentionally established to ensure that power and resources remain under the control of white men [10, 26, 28, 34].

The persistence of documented health disparities over the last century despite long-standing calls for social, economic, and political reform as well as substantial advances in our understanding of the role of social determinants in health indicates, as the IP framework theorizes, that these policies and the decision-makers behind them are resistant to change. Reservoirs of infection, source populations which stubbornly harbor pathogenic identity beliefs even as changing discourse variably decreases or increases the acceptability of social prejudice, ensure that interventions focusing only on shifting policy will do little to yield lasting social equity.

In light of these observations, the IP framework suggests that because pathogenic identity beliefs perpetuate the pathogenic social environments in which they flourish, interventions must target the environment, agent, and host simultaneously. Eradicating health disparities therefore requires an additional approach that acts in conjunction with efforts to deconstruct problematic institutions and policies, and efforts to create identity-safe cultures. In the case of identity pathology, environmental interventions, which have been well-described in extant theory [1, 37], involve abolishing the policies and practices which maintain and promote inequity within social institutions and the inequitable distribution of health-impacting resources. Agent interventions require shifting the cultural and social norms in which pathogenic beliefs flourish and are transmitted, as proposed by the Jedi Public Health Framework [42]. Host interventions, which the IP framework newly proposes, target the identity beliefs which make individuals particularly susceptible to the effects of inequitable social conditions on the cognitions and behaviors that directly and indirectly influence their own health as well as the health of others.

Although the IP framework uses the example of race and gender hierarchy among black and white women and men, application of the framework extends well beyond these particular groups and examples of structural inequity. As the objective of the framework is to highlight the substantial role of identity processes in health outcomes, the principles of the IP framework can be adapted to describe the effects of any inequitable social contexts on the physical and psychological well-being of any populations exposed to those contexts. The IP framework may be particularly useful for examining the understudied health impacts of structural inequity among groups such as those with varying physical abilities or native populations whose suffering has been systematically made invisible.

The framework is densely theoretical and draws from a number of disciplines in outlining complex mechanisms from structural inequities to health inequities. Despite its ambitious reach, the core concepts of the framework are readily applicable to health research. Through suggesting adjustments to analytic methods, outlining testable causal mechanisms, and proposing an evidence-based intervention, the IP model orients health researchers toward another channel for more ethical and rigorous investigation the causes of and solutions to unjust gender disparities in health.

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References

[1] Adler NE, Stewart J. Health disparities across the lifespan: Meaning, methods, and mechanisms. Annals of the New York Academy of Sciences. 2010;**1186**(1):5-23

[2] Krieger N. Methods for the scientific study of discrimination and health: An ecosocial approach. American Journal of Public Health. 2012;**102**(5):936-944

[3] Kawachi I, Daniels N, Robinson D. Health disparities by race and class: Why both matter. Health Affairs. 2005; **24**(2). DOI: 10.1377/hlthaff.24.2.343

[4] Williams DR, Mohammed SA. Racism and health I: Pathways and scientific evidence. American Behavioral Scientist. 2013;**57**(8). DOI: 10.1177/0002764213487340

[5] Krieger N. Epidemiology and the People's Health. New York, NY: Oxford University Press; 2011

[6] Marmot M, Allen JJ. Social determinants of health equity. American Journal of Public Health. 2014;**104** (Suppl 4):S517-S519

[7] Krieger N. Discrimination and health inequities. International Journal of Health Services Research. 2014;**44**(4): 643-710

[8] Harrell JP, Hall S, Taliaferro J. Physiological responses to racism and discrimination: An assessment of the evidence. American Journal of Public Health. 2003;**93**(2):243-248

[9] Vandiver BJ, Fhagen-Smith P, Cokley KO, Cross WE, Worrell FC. Cross's nigrescence model: From theory to scale to theory. Journal of Multicultural Counseling and Development. 2001;**29**:174-200

[10] Crenshaw K. Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. University of Chicago Legal Forum. 1989;**1989**(1):139-167

[11] Reynolds AL, Pope RL. The complexities of diversity: Exploring multiple oppression. Journal of Couseling and Development. 1991;**70** (1):174-180

[12] Williams DR, Kontos EZ, Viswanath K, Haas JS, Lathan CS, MacConaill LE, et al. Integrating multiple social statuses in health disparities research: The case of lung cancer. Health Services Research. 2012;**47**(3):1255-1277

[13] Robinson WR, Gordon-Larsen P, Kaufman JS, Suchindran CM, Stevens J. The female-male disparity in obesity prevalence among black American young adults: Contributions of sociodemographic characteristics of the childhood family. American Journal of Clinical Nutrition. 2009;**89**(4):1204-1212

[14] Bey GS, Ulbricht CM, Person SD. Theories for race and gender differences in management of social identity-related stressors: A systematic review. Journal of Racial and Ethnic Health Disparities. 2019;**6**(1):117-132. DOI: 10.1007/s40615-018-0507-9

[15] Jackson JW, Williams DR, VanderWeele TJ. Disparities at the intersection of marginalized groups. Social Psychiatry and Psychiatric Epidemiology. 2016;**51**(10):1349-1359

[16] Schwartz S. Commentary: On the application of potential outcomes-based methods to questions in social psychiatry and psychiatric epidemiology. Social Psychiatry and Psychiatric Epidemiology. 2017;**52**(2): 139-142

[17] Metzl JM. Dying of Whiteness. New York, NY: Basic Books; 2019

[18] Nolen-Hoeksema S, Larson J, Grayson C. Explaining the gender difference in depressive symptoms. Journal of Personality and Social Psychology. 1999;**77**(5):1061-1072

[19] Butler J. Gender Trouble. New York, NY: Routledge, Chapman & Hall, Inc.; 1990

[20] Kawachi I, Kennedy BP, Gupta V, Prothrow-Stith D. Women's status and the health of women and men: A view from the states. Social Science and Medicine. 1999;**48**(1):21-32

[21] Udo T, Grilo CM. Cardiovascular disease and percieved weight, racial, and gender discrimnation in U.S. adults. Journal of Psychosomatic Research. 2017;**100**:83-88

[22] Ferdinand KC, Nasser SA. Disparate cardiovascular disease rates in African Americans: The role of stress related to self-reported racial discrimination. Mayo Clinic Proceedings. 2017;**92**(5): 689-692

[23] Williams DR, Yu Y, Jackson JS, Anderson NB. Racial differences in physical and mental health: Socioeconomic status, stress, and discrimination. Journal of Health Psychology. 1997;**2**(3):335-351

[24] Williams DR, Collins C. Racial residential segregation: A fundamental cause of racial disparities in health. Public Health Reports. 2001;**116**(5): 404-416

[25] Bem S. Gender schema theory: A cognitive account of sex typing. Psychological Review. 1981;**88**(4): 354-364

[26] Smedley A. Race in North America: Origins and Evolution of a Worldview. 3rd ed. Boulder, CO: Westview Press; 2007

[27] Chae DH, Lincold KD, Jackson JS. Discrimination, attribution, and racial group identification: Implications for psychological distress among Black Americans in the National Survey of American Life (2001–2003). American Journal of Orthopsychiatry. 2011;**81**(4): 498-506

[28] Jardina A. White Identity Politics. Cambridge, MA: Cambridge University Press; 2019

[29] Bey GS, Jesdale BM, Forrester S, Person SD, Kiefe C. Intersectional effects of racial and gender discrimination vary among black and white women and men in the CARDIA study. Social Science & Medicine-Population Health. 2019;**8**. DOI: 10.1016/j.ssmph.2019.100446

[30] Walker L. The Battered Woman Syndrome. 4th ed. New York, NY: Springer Publishing company; 2017

[31] Bosson JK, Vandello JA, Burnaford RM, Weaver JR, Wasti AS. Precarious manhood and displays of physical aggression. Personality and Social Psychology Bulletin. 2009;**35**(5):623-635

[32] Krieger N. Genders, sexes, and health: What are the connections–and why does it matter? International Journal of Epidemiology. 2003;**32**:652-657

[33] Regitz-Zagrosek V. Sex and gender differences in health. EMBO Reports. 2012;**13**(7):596-603

[34] Kendi I. Stamped from the Beginning: The Definitive History of Racist Ideas in America. New York, NY: Nation Books; 2016

[35] Golash-Boza T. A critical and comprehensive sociological theory of race and racism. Sociology of Race and Ethnicity. 2016;**2**(2):129-141

[36] Blumer H. Race prejudice as a sense of group position. The Pacific Sociological Review. 1958;**1**(1):3-7

[37] Conrad P, Barker KK. The social construction of illness: Key insights and policy implications. Journal of Health and Social Behavior. 2010;**51**(1):S67-S79

[38] Gravelee C. How race becomes biology: Embodiment of social inequity. American Journal of Physical Anthropology. 2009;**139**:47-57

[39] Mezuk B et al. 'White Box' epidemiology and the social neuroscience of health behaviors: The Environmental Affordances model. Society and Mental Health. 2013;**3**(2). DOI: 10.1177/2156869313480892

[40] Pratto F, Jim S, Stallworth LM, Malle BF. Social dominance orientation: A personality variable predicting social and political attitudes. Journal of Personality and Social Psychology. 1994; **67**(4):741-763

[41] Tajfel H, Turner JC. The social identity theory of intergroup behavior. Psychology of Intergroup Relations. 1986;**5**:7-24

[42] Geronimus AT et al. Jedi public health: Co-creating an identity-safe culture to promote health equity. SSM—Population Health. 2016;**2**:105-116

[43] Slavich GM, Irwin MR. From stress to inflammation and major depressive disorder: A social signal transduction theory of depression. Psychological Bulletin. 2014;**140**(3):774-815

[44] Verbrugge MH. Women and medicine in nineteenth century America. Signs. 1976;**1**(4):957-972

[45] Charatz-Litt C. A chronicle of racism: The effects of the white medical community on black health. Journal of the National Medical Association. 1992; **84**(8):717-725

[46] Metzl J. The Protest Psychosis: How Schizophrenia Became a Black Disease. Boston, MA: Beacon Press; 2009

[47] Kessler R, Price R, Wortman C. Social factors in psychopathology: Support, stress, and coping processes. Annual Reviews of Psychology. 1985;**36**: 532-571

[48] Miller AH, Raison CL. The role of inflammation in depression: From evolutionary imperative to modern treatment target. Nature Reviews Immunology. 2016;**16**(1):22-34

[49] Bey GS, Jesdale BM, Ulbricht CM, Mick EO, Person SD. Allostatic load biomarker associations with depressive symptoms vary among U.S. black and white women and men. Healthcare. 2018;**6**(3):105

[50] Cunningham TJ et al. Racial/ethnic and gender differences in the association between self-reported experiences of racial/ethnic discrimina tion and inflammation in the CARDIA cohort of 4 US communities. Social Science & Medicine. 2012;**75**(5):922-931

[51] McEwen B, Gray J, Nasca C. Redefining neuroendocrinology: Stress, sex and cognitive and emotional regulation. Journal of Endocrinology. 2015;**226**(2):T67-T83

[52] Hellhammer D, Buchtal J, Gutberlet I, Krischbaum C. Social hierarchy and adrenocortical stress reactivity in men. Psychoneuroendocrinology. 1997;**22**(8): 643-650

[53] Chiao J, Mathur V, Harada T, Lipke T. Neural basis of preference for human social hierarchy versus egalitarianism. Annals of the New York Academy of Science. 2009;**1167**:174-181

[54] Zink C, Tong Y, Chen Q, Bassett D, Stein J, Meyer-Lindberg A. Know your place: Neural processing of social hierarchy in humans. Neuron. 2008;**58** (2):273-283

[55] van der Kolk B. Developmental trauma disorder. Psychiatric Annals. 2005;**35**(5):401-408

[56] Nelson KE, Williams C, editors. Infectious Disease Epidemiology: Theory and Practice. 3rd ed. Boston, MA: Jones and Bartlett Learning; 2014

[57] Papachristos AV, Wildeman C, Roberto E. Tragic, but not random: The social contagion of nonfatal gunshot injuries. Social Science & Medicine. 2015;**125**:139-150

[58] Kirmayer LJ, Gone JP, Moses J. Rethinking historical trauma. Transcultural Psychiatry. 2014;**5**(3):299-319. DOI: 10.1177/1363461514536358

[59] Szyf M. Nongenetic inheritance and transgenerational epigenetics. Trends in Molecular Medicine. 2015;**21**(2):134-144

[60] Forsyth J, Carter RT. The relationship between racial identity status attitudes, racism-related coping, and mental health among Black Americans. Cultural Diversity and Ethnic Minority Psychology. 2012;**18**(2):128-140

[61] Haeffel GJ, Abramson LY, Brazy PC, Shah JY. Hopelessness theory and the approach system: Cognitive vulnerability predicts decreases in goal-directed behavior. Cognitive Theory Research. 2008;**32**(2):281-290

[62] Assari S. High income protects whites but not African Americans against risk of depression. Healthcare. 2018;**6**(2):37

[63] Assari S. Depressive symptoms increase the risk of mortality for white but not black older adults. Healthcare. 2018;**6**(2):36

[64] Bey GS, Waring ME, Jesdale BM, Person SD. Gendered race modification of the association between chronic stress and depression among black and white U.S. adults. The American Journal of Orthopsychiatry. 2016;**88**(2):151-160

[65] Forum NQ. Disparities in Healthcare and Health Outcomes in Selected Conditions. Washington, DC: National Quality Forum; 2017

[66] Benjamin EJ, Blaha MJ, Chiuve SE, et al. Heart disease and stroke statistics—2017 update: A report from the American Heart Association. Circulation. 2017;**135**:e146-e603

[67] Powell IJ, Bock CH, Ruterbusch JJ, Sakr W. Evidence supports a faster growth rate and/or earlier transformation to clinically significant prostate cancer in black than in white American men, and influences racial progression and mortality disparity. Journal of Urology. 2010;**183**(5):1792-1796

[68] Bailey RK, Mokonogho J, Kumar A. Racial and ethnic differences in depression: Current perspectives. Neuropsychiatric Disease Treatment. 2019;**15**:603-609

[69] Pacek LR, Macolm RJ, Martins SS. Race/ethnicity differences between alcohol, marijuana, and co-occurring alcohol and marijuana use disorders and their association with public health and social problems using a national sample. The American Journal on Addictions. 2012;**12**(5):435-444

[70] Kubrin CE, Wadsworth T. Explaining suicide among blacks and whites: How socioeconomic factors and gun availability affect race-specific suicide rates. Social Science Quarterly. 2009;**90**(5):1203-1227

[71] Kuntsman JW, Plant AE, Deska JC. White ≠ poor: Whites distance, derogate, and deny low-status ingroup members. Personality and Social Psychology Bulletin. 2016;**42**(2):230-243

[72] Sfanos KS, De Marzo AM. Prostate cancer and inflammation: The evidence. Histopathology. 2012;**60**(1):199-215

[73] James S. John Henryism and the health of African Americans. Cultural

Medicine and Psychiatry. 1994;**18**(2): 163-192

[74] Mattina GF, Lieshout V, Ryan J, Steiner M. Inflammation, depression and cardiovascular disease in women: The role of the immune system across critical reproductive events. Therapeutic Advances in Cardiovascular. 2019;**13**. DOI: 10.1177/1753944719851950

[75] Dhar AK, Barton DA. Depression and the link with cardiovascular disease. Frontiers in Psychiatry. 2018;**7**(33). DOI: 10.3389/fpsyt.2016.00033

[76] Wright L, Simpson W, Van Lieshout RJ, Steiner M. Depression and cardiovascular disease in women: Is there a common immunological basis? A theoretical synthesis. Therapeutic Advances in Cardiovascular. 2014;**8**(2): 56-69

[77] Baumeister RF. Escaping the Self: Alcoholism, Spirituality, Masochism, and Other Flights from the Burden of Selfhood. New York: Basic Books; 1991

[78] Oliffe JL et al. Men, masculinities, and murder-suicide. American Journal of Men's Health. 2015;**9**(6):473-485

[79] Neblett EW, Rivas-Drake D, Umana-Taylor AJ. The promise of racial and ethnic protective factors in promoting ethnic minority youth development. Child Development Perspectives. 2012;**6**:295-303

[80] Bey GS et al. Gendered race and setting matter: sources of complexity in the relationships between interpersonal discrimination and cardiovascular health. 2020. DOI: 10.1007/s40615-020-00699-6

[81] Crocker J, Major B. Social stigma and self-esteem: The protective properties of stigma. Psychological Review. 1989;**96**(4):241-255

[82] St. Jean Y, Feagin JR. Double Burden: Black Women and Everyday Racism. New York, NY: Routledge; 2015

[83] Black AR, Peacock N. Pleasing the masses: Messages for daily life management in African American women's popular media sources. American Journal of Public Health. 2011;**101**(1):144-150

[84] Woods-Giscombe C. Superwoman schema: African American women's views on stress, strength, and health. Qualitative Health Research. 2010;**20**(5):668-668

[85] DuMonthiers A, Childers C, Milli J. The Status of Black Women in the United States. Washington, DC: Institute for Women's Policy Research; 2017

[86] McEwen B. Allostasis and allostatic load: Implications for neuropsychopharmacology. Neuropsychopharmacology. 2000;**22**(2):108-124

[87] Morris AA et al. Association between depression and inflammation —Differences by race and sex: The META-health study. Psychosomatic Medicine. 2011;**73**(6):462-468

[88] Dunlop DD, Song J, Lyons JS, Manheim LM, Chang RW. Racial/ethnic differences in rates of depression among preretirement adults. American Journal of Public Health. 2003;**93**(11):1945-1952

[89] Beaubouf-Lafontant T. You have to show strength: An exploration of gender, race, and depression. Gender and Society. 2007;**21**(1):28-51

[90] Hayman LW, McIntyre RB, Abbey A. The bad taste of social ostracism: The effects of exclusion on the eating behaviors of African-American women. Psychology & Health. 2015;**30**(5): 518-533

[91] Thompson B. Food, bodies, and growing up female: Childhood lessons about culture, race, and class. In: Fallon P, Katzman MA, Wooley SC, editors. Feminist Perspectives on Eating Disorders. New York, NY: Guliford; 1994. pp. 355-378

[92] Headen IE, Davis EM, Mujahid MS, Abrams B. Racial-ethnic differences in pregnancy-related weight. Advances in Nutrition. 2012;**3**:83-94

[93] Black AR, Woods-Giscombe C. Applying the stress and 'strength' hypothesis to black women's breast cancer screening delays. Stress & Health. 2012;**28**(5):389-396

[94] Dunlay SM et al. Perceived discrimination and cardiovascular outcomes in older African Americans: Insights from the Jackson Heart Study. Mayo Clinic Proceedings. 2017;**92**(5): 699-709

[95] Krieger N. Living and dying at the crossroads: Racism, embodiment, and why theory is essential for a public health of consequence. American Journal of Public Health. 2016;**106**(5): 832-833

[96] Pool LR, Ning H, Lloyd-Jones DM, Allen NB. Trends in racial/ethnic disparities in cardiovascular health among US adults from 1999–2012. Journal of the American Heart Association. 2017;**6**(9):16-22

[97] Harnois CE, Ifatunji MA. Gendered measures, gendered models: Toward an intersectional analysis of interpersonal racial discrimination. Ethnic and Racial Studies. 2011;**34**(6):1006-1028

[98] Wyatt SB, Williams DR, Calvin R, Henderson FC, Walker ER, Winters K. Racism and cardiovascular disease in African Americans. The American Journal of the Medical Sciences. 2003; **325**(6):315-331

[99] Brewer LC, Cooper LA. Race, discrimination, and cardiovascular disease. Virtual Mentor AMA Journal of Ethics. 2014;**16**(6):455-460

[100] Hunte HER, Willaims DR. The association between perceived discrimination and obesity in a population-based multiracial and multiethnic adult sample. American Journal of Public Health. 2009;**99**: 1285-1292

[101] Borrell LN, Diez-Roux AV, Jacobs DR, Shea S, Jackson SA, Shrager S, et al. Perceived racial/ethnic discrimination, smoking and alcohol consumption in the Multi-Ethnic Study of Atherosclerosis (MESA). Preventive Medicine. 2010;**51** (3–4):307-312

[102] Sims M, Diez-Roux AV, Dudley A, et al. Perceived discrimination and hypertension among African Americans in the Jackson Heart Study. American Journal of Public Health. 2012;**102** (Suppl 2):S258-S265

[103] Womack VY, Ning H, Lewis CE, Loucks EB, Puterman E, Reis J, et al. Relationship between perceived discrimination and sedentary behavior in adults. American Journal of Health Behaviors. 2014;**38**(5):641-649

[104] Brown LL, Mitchell UA, Ailshire J. Disentangling the stress process: Race/ethnic differences in the exposure and appraisal of chronic stressors among older adults. Journals of Gerontology, Series B, Psychological Sciences and Social Sciences. 2020;**75**(3):650-660

[105] Assari S, Lankarani MM. Association between stressful life events and depression: Intersection of race and gender. Journal of Racial and Ethnic Health Disparities. 2016;**3**(2):349-356

[106] Peterson LM, Matthews KA, Derby CA, Bromberger JT, Thurston RC. The relationship between cumulative unfair treatment and intima media thickness

and adventitial diameter: The moderating role of race in the study of women's health across the nation. Health Psychology. 2016;**35**:313-321

[107] Everson-Rose S, Lutsey P, Roetker N, Lewis T, Kershaw K, Alonso A, et al. Perceived discrimination and incident cardiovascular events: The multi-ethnic study of atherosclerosis. American Journal of Epidemiology. 2015;**182**(3): 225-234

[108] Mensah GA, Brown DW. An overview of cardiovascular disease burden in the United States. Health Affairs. 2007;**26**(1):38-48

[109] Borrell LN, Diez-Roux AV, Kiefe CI, Williams DR, Gordon-Larsen P. Racial discrimination, racial/ethnic segregation, and health behaviors in the CARDIA study. Ethnicity and Health. 2013;**18**(3):227-240

[110] wAlbertMA,CozierY,RidkerPM,et al.Perceptionsofrace/ethnic discriminationinrelationtomortality amongblackwomen:ResultsfromtheBlack Women'sHealthStudy.Archivesof InternalMedicine.2010;**17010**:896-904

[111] Brenner AB, Diez-Roux AV, Gabreab SY, Schulz AJ, Sims M. The epidemiology of coping in African American adults in the Jackson Heart Study (JHS). Journal of Racial & Ethnic Health Disparities. 2018;**5**(5):978-994

[112] Chae DH et al. Do experiences of racial discrimination predict cardiovascular disease among African American men? The moderating role of internalized negative racial group attitudes. Social Science & Medicine. 2010;**71**(6):1182-1188

[113] Shariff-Marco S, Klassen AC, Bowie JV. Racial/ethnic differences in self-reported racism and its association with cancer-related health behaviors. American Journal of Public Health. 2010;**100**(2):364-374

[114] Szymanski DM, Lewis JA. Gendered racism, coping, identity centrality, and African American college women’s psychological distress. Psychology of Women Quarterly. 2016; **40**(2). DOI: 10.1177/0361684315616113

[115] Jones CP. Confronting institutionalized racism. Phylon. 2002; **50**:7-22

[116] Marmot M. The Health Gap: The Challenge of an Unequal World. New York, NY: Bloomsbury; 2015

Chapter 3

Healthy Sexuality

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Abstract

Sexuality is one of the basic instincts which determine the behavior of an individual. Though it is one of the basic drives, it is under researched. Sexuality has biological, psychological and social dimensions. Sexuality is a developmental phenomenon; from childhood to old age it has several implications. Exercise, sleep, nutrition, marriage, divorce and diseases have their own impact on sexuality. Sexuality is one of the key components in determining the quality of life. In this article, we have tried to explore various dimensions of sexuality.

Keywords: sexuality, healthy sexuality, psychological, social, fantasy

1. Introduction

The fundamental drive behind every thought, feeling and behavior is Sexuality. The way an individual projects himself psychologically and socially is defined by sexuality. Sexuality is the best example of mind body harmony. The world goes around sex. The basis of babies bonding, teens flirting, and adults having babies is sexuality. Our dressing sense, sense of humor and the way we talk is influenced by sexuality; sex defines who we are. Sexuality has been addressed in holy books of great religions.

Karl Pribram, a Neuropsychologist described four drives which motivates us to accomplish our goals. These drives included fighting, feeding, fleeing and sex. These drives are essential for physical and psychological health. The least understood as well as least studied drive is sex [1].

2. History of scientific research in human sexuality

History of human sexuality is as ancient as human history. Some of the artifacts from ancient cultures are thought to be fertility totems. Kama Sutra (400 BC–200 BC), a Hindu epic describes about love, pleasure and desire; in fact about life in general. It is also a manual for sexual intercourse. Quran, Bible, Torah also have rules, advice and stories about sex.

Scientific research on sexuality started only around 150 years ago. Henry Havelock Ellis, an English physician used case study method to scientifically study sexuality. He published a seven volume book titled Psychology of Sex in which he tried to address different topics of sexuality which included arousal and masturbation. He emphasized that the sexuality of transgender is different from homosexuals. He advocated equal sexual rights for women and sex education at public schools [2].

Father of Psychiatry Sigmund Freud linked sex to health development. He recognized sexuality throughout the life span. Freud gave five stages of psychosexual development which includes oral, anal, phallic, latent and genital. According to Freud, each individual should pass all these stages. If the child's needs are unsatisfied or over-satisfied in these stages, either fixation or regression happens. This means child shows attachment to the previous stage, problems from that stage even persists into the adulthood. By keen observation of the individual behavior, one could recognize the psychosexual stage the adult had fixated or regressed [3, 4].

Alfred Kinsey, commonly referred to as Father of human sexuality research, believed most of the sexuality knowledge is guess work and there is lack of unbiased research. He had set a goal to interview around 100,000 people about sexual histories. Though he fell short of his goal, he could collect 18,000 interviews. Most of the contemporary scientists work on "behind closed door" behaviors were based on Kinsey's seminal work [5].

3. Sexual health

Sex describes means of biological reproduction. Sex also describes sexual organs both external as well as internal which defines individual to be male or female. According to the WHO, sexual health must be considered as "a state of physical, emotional, mental, and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Human sexuality emerges in the body, but, like other human phenomena, it simultaneously unfolds in mental landscapes, social relations, and cultural spheres. Sexuality is closely linked to personal integrity, identity, body image, bonding, and social curiosity. Physiological and psychosocial determinants contribute significantly to sexual health."

Healthy sexuality is a dynamic equilibrium, whereby adversity is balanced by personal agency and available resources. Sexual health is not mere absence of sexual dysfunction, it is individual's ability to navigate through problems. Clinical and research experience indicate there is no correlation between subjective well-being and objective strains. Sexual health like any other health is contextual and multifactorial [6].

4. Gender and orientation

The term gender represents psychological and sociological representation of biological sex, which includes gender identity as well as gender role. Though Gender and sex are important aspects of person's identity, it does not tell anything about orientation. Gender orientation refers to persons' sexual attraction to others. Sexual attraction refers to persons' capacity to arouse interest in others. One must be comfortable with their chosen gender and sex role and accept themselves without shame, guilt or fear. Be able to maintain good relationships with both sexes, regardless of whether they are platonic or intimate [7].

5. Attitude towards sex

Associations between general health and sexuality are diverse and intricate, and the two can interact in both positive and negative ways. Culture significantly determines our attitude towards sex. Culture influences our beliefs about what is normal and what is deviant in sexuality. Based on cultural attitude towards sex;

Cultures can be broadly classified into sex positive and sex negative cultures. Sex negative cultures which include India and Asian subcontinent believe that sex is for procreation while sex positive cultures which include western cultures consider sex beyond procreation. Sexual knowledge is usually acquired from someone in charge which may include parents, siblings, religious authorities, school, rumors from friends and mass media. One significant experience or stimulus that matches our fantasy would have long lasting impact on our attitude towards sexuality. Upbringing, witnessing parental interaction and intimacy shapes our life and beliefs [8].

6. Myths about sexuality

About female sexuality

- People think sex is dirty.
- Sex is sweet only during second decade of women's life.
- Sex during menstruation is harmful
- Bigger the breast-better sexuality
- Orgasm is a must in all sexual encounters
- Only vaginal and clitoral sex leads to orgasm
- A women's "no" convey "yes"
- Women never masturbate
- Sexual desire decrease dramatically after menopause

About Male Sexuality

- Erectile dysfunction is inevitable and incurable
- If a man does not get immediate erection he is not aroused
- If a man does not get aroused by mere site of partner he is not able to perform
- Masturbation leads to impotence
- Semen is a special cargo [9]

7. Sexual response cycle

Sexual response cycle which consists of desire, excitement and orgasm, have been classified by various authors in different ways. One of the simplest classifications is given by Kaplan, which is called DEOR model. D stands for desire, E stands for excitement, O stands for orgasm and R stands for resolution. Desire phase has biological, social and psychological component. Biological component is the drive, sexual motivation is the psychological component and sexual wish is the social component. Excitement phase is characterized by penile tumescence in males and vaginal lubrication in female. Orgasm phase is characterized by heightening of sexual pleasure and resolution phase is characterized by disgorgement of blood from genital organs. Any impairment in any of these stages constitutes dysfunction [10].

8. Childhood sexuality

A strong emotional response is expected socially, whenever this topic is raised. Discussion on sexual behavior in children is obviously going to raise many eyebrows. Sexuality forms part of the personality and is a normal aspect of growing up. On one hand we resist talking to children regarding sexuality and on the other they get exposed to various sexual behaviors through the media. This makes it difficult for children to make right decisions during their adolescence. It is important to understand that the concept of normal sexual behavior in children is likely to vary with change in society's attitude. Research in the area of childhood sexual knowledge and behavior is scarce. Methodical issues are important during research as many of these rely on parental interviews leading to inconsistent results [11]. Sexual behavior is related to the age of the child, maternal education, family sexuality, family stress and violence, and hours spent in day care. For the clinician to understand the relationship between sexual abuse and sexual behaviors, it is important to understand normative childhood sexual behavior [12].

Much important psychosexual development occurs during childhood. Sexual development starts from birth and as the child develops the knowledge of gender identity during the first 2 years of life, genital exploration begins. Sexual knowledge is a child's basic under-standing of sexual acts. It varies with the child's age and the education level of the parents [13]. A child learns labeling of body parts including genitals and experiences genital pleasure during this time. They may use slang labels and touch other children's genitals or take off clothes in public. The physiology related to sexual arousal and orgasm is present in children at birth or even before that. Fetuses suck fingers/toes and penile erection or vaginal lubrication is seen in new born males and females. Sexual arousal is associated with REM (Rapid Eye Movement) sleep in infants and young children similar to adults. However infants and young children lack cognitive capacity to understand this autoerotic behavior which is more of "pleasure seeking" and is a reflex behavior. Sexual development occurs throughout early years but except for during puberty none of these sexual development milestones have been clearly defined [13].

During 3–5 years of sexual development, gender is permanently established and gender differences are clearly understood. The child has only little information regarding pregnancy and delivery. The child may use slangs for sexual parts of the body. During the preschool years (2–6 years) many overt sexual behaviors are seen. The child may masturbate for pleasure and experience orgasm either in public or private. Nudity is enjoyed and removing clothes in public may be noticed. Sex play with peers (mimicking dating behavior, using naughty words even if they do not understand the meaning) self-genital exploration and that of others, attempted intercourse may be noticed. Sitting close to others, touching breasts of mother or other females (in males), trying to view peer or adult nudity may be noticed. Masturbation is likely the most commonly observed sexual behavior in children. It has been noted in infants as young as 7 months, which is initially based on curiosity about one's body but gradually the pleasure obtained becomes a decisive act. Friedrich et al. [15] has reported that some of the behaviors like inserting objects into vagina/ anus, putting mouth on sex parts and masturbating with objects may rarely be seen in children aged 2–12 years. Many parents may react negatively to this and punish their children for this behavior. Caregiving and nurturing provide the first sensual and erotic encounters to the new born and these experiences of physical affection are critical for healthy development of the child [14, 15].

During 6–12 years the child understands genital basis of gender. The child is able to label sex parts but uses slang. The child is able to understand sexual aspects of pregnancy; with increasing knowledge of sexual behavior, children may masturbate in private. Sex games with peers (like girlfriend/ boyfriend, truth or dare, playing family) role plays and sexual fantasy may be seen. Developmentally appropriate behavior includes touching their own genitals, trying to view another person's genitals or breasts and standing too close to other persons. Young children, who are yet to learn culturally appropriate distance, may rub against people, or casually touch their mother's breasts or father's genitals [16]. Sexual behaviors become more covert after 5 years of age [18]. Gundersen reported in 1981 that among preschool children aged 3–7 years sexual play was common including body exploration, genital manipulation and attempts at sexual intercourse. Kissing is part of normal sexual development. Exhibitionistic behavior in children, showing body parts to other children or adults, may be part of "playing doctor" [17]. About 85% of college women recalled engaging in sexual games during childhood in a study done by Lamb and Coakley in 1993. Over 40% reported fantasy sexual play including sexual stimulation, intercourse, rape, prostitution and strip shows. Over one third of the games involved genital fondling. These games are due to curiosity, however some children find them a source of sexual excitement. Coercive childhood sexual games are considered to be "normal" especially as boys and girls usually play together. Children may develop anxiety when parents or adults show affection towards each other. The frequency of childhood sexual behaviors when retrospectively recalled by adults may differ from the frequency reported by parents; recollection bias and personal acceptance of sexual behaviors as normal, differs. Educated mothers are likely to report more sexual behaviors in their children [18].

Sexual encounters between siblings are very similar to those seen with friends in terms of the activities occurring, motivations associated, age and perception of them being positive or negative. Finkelhor in 1981 reported that younger children are more likely to exhibit their genitals whereas older children are more likely to engage in attempted or actual intercourse. Younger children show a broad range of sexual behaviors which decrease with the growing age. Sex between siblings occurs much less frequently than between friends. Sexual encounters in siblings range from 9 to 13%. Lower reported rates of sexual encounters between siblings may be either due to age difference or biased retrospective reporting due to incest taboo. However frequency of coercive sexual encounters is almost similar to that with friends and girls are predominantly the victims. Young children are likely to explore their sexuality more at home than in structured and monitored settings among children. The results reported may not represent full range of sexual behaviors seen in children due to ethnic differences in subjects on which research is conducted. Women who have had sibling sexual experiences (positive or negative) are more likely to be sexually active as adults. Sexual sibling experiences before the age of 9 with large difference of age between siblings led to lower sexual self-esteem. Sexual experiences between friends or siblings suggest that normal sexual contact occurs on a continuum and differentiation between sexual play and abuse is not always clear [19].

The child gains knowledge of physical aspects of puberty by age 10. The child shows modesty and embarrassment and tries to hide sex games as well as masturbation from adults. Masturbation most likely increases before puberty especially among boys. There are few physical changes associated with sexual development before the onset of puberty. Just before the teenage years body changes begin, menstruation starts in females and boys may experience wet dreams; fantasizing about sex, interest in media sex, using sexual language with peers is observed [19].

9. Adolescent sexuality

Adolescent sexuality has received much attention in comparison to childhood sexuality. Teens are sexually active but they are hardly prepared for developing responsible sexual behavior. Adolescents reach physical maturity but they are cognitively immature to handle it. A teenager's primary source of exposure to sexuality related information is his or her peer group. Family dynamics may not be strong enough to guide the teenagers in developing healthy and non-risky sexual behavior [20].

Puberty is the time when sexual development can be much clearly delineated especially the physical changes. There is variation in age at which puberty begins although the onset is typically 18–24 months earlier when compared to boys [21]. The average age of first ejaculation in boys is 14 years (range 14–16 years). However, girls' breast development begins between 8 and 13 years of age; menarche starts at an average age of 13 years (age range 10–16.5 years). Adolescents acquire knowledge about sexual intercourse, contraception and sexually transmitted diseases. Adolescents get fondness for dating, kissing and petting; sexual fantasies are common. The issue of greatest concern for parents has been the age at which teens engage in sexual intercourse. The average age of first sexual contact has decreased rapidly. They may make sexual contacts including mutual masturbation and first sexual intercourse may occur in 75% by the age of 18 years. However in India as per National Family Health Survey (NFHS), males are mostly likely to have their first sexual intercourse between 20 and 24 years, whereas in females, the peak age at first sex is lower between 15 and 19 years [5].

Early onset of sexual intercourse affects the psychosocial development. Early onset sexual activity has been linked to delinquent behavior. Chances of unintended pregnancy are higher in teens who engage in sexual activity earlier. Teenage parents are at an economic disadvantage and are more likely to drop out of school. Authoritarian parents, poor communication regarding sexuality and having older siblings who are sexually active can facilitate early sexual activity. Rutter and Rutter refer to early sexual activity as a "turning point" which can change the course of a teenager's life. Understanding early sexual activity can help in planning intervention programs. Other factors which are associated with adolescents who are sexually active include: (1) less educated mother, (2) lower educational expectation, (3) presence of a boyfriend or girlfriend, and (4) higher age. Adolescents are at cross roads as far as sexuality is concerned. A wrong decision can have strong and negative economic and social consequences for the society at large and for the individual in particular. Sex education is an important area which needs to be taken seriously particularly for the adolescent age group [22, 23].

10. Other factors influencing sexuality

10.1 Nutrition and sexuality

Mediterranean diet which includes fruits, nuts, legumes, monounsaturated fats from olive oils, vegetables and whole grains is gaining popularity in the last few decades. Studies have shown that these groups of foods improve or at least diminish the progression of sexual dysfunctions. Paleolithic diet which is an ancestral diet, before agricultural revolution is gaining more attention in the recent past. Paleo diet which includes lean meat, fruits, legume, plant based foods, restricted consumption of dairy, salt and sugar similar to Mediterranean diet have shown to be beneficial, but well-designed studies are not available. Vegetarian or vegan diet which can be classified as pesco-diet (absence of all animal products except fish), lacto-ovo-vegetarian diet (absence of all animal products except egg and dairy products), ovo-vegetarian diet (absence of all animal products except egg) and vegan-diet (absence of all animal products). Vegetarian diet has shown to reduce morbidity due to vascular causes, which in turn may help in healthy sexual functioning. Vegetarian or vegan diet may cause protein and vitamin B12 deficiency which can be prevented through careful monitoring and supplementation [24].

10.2 Intelligence and sexuality

There is evidence for correlation between intelligence and the age at the first sexual contact. There is inverse correlation between intelligence quotient and the age at first sexual intercourse. Though there is evidence that more intelligent people have more sexual desire, but the frequency of intercourse is less. Emotional intelligence plays a key role in marital relationship. Knowledge, self-competence, secured attachment, emotional processing and self-compassion were few aspects which determined good marital satisfaction [25].

10.3 Job, vocation and sexuality

Job stressors have significant impact on sexuality. It majorly depends upon the role the individual is having in the job. It depends on working ability of individual for that job. Work ability includes physiological and psychological ability of the individual to cope with the specific type of the job. The managerial and organizational support also played important role in job stress. Job stress significantly affected desire, arousal and orgasm phases of sexual response cycle [26].

10.4 Exercise and sexuality

Exercise releases hormones called endorphins, which has a feel good component as well as analgesic effects. Exercise may be acute as well as chronic exercise. Acute exercise increases metabolic rate, causes muscle activation and increases blood flow. Chronic exercise causes long lasting adaptation and improves performance. Acute exercise improves physiological sexual arousal through increasing sympathetic nervous system activity and endocrine factors. Chronic exercise increases sexual satisfaction by maintaining autonomic flexibility. Autonomic flexibility helps in maintaining cardiovascular health as well mood. Chronic exercise also gives positive body image which in turn gives sexual well-being. A couple of small studies have shown the effectiveness of exercise as intervention for dysfunctions [27].

10.5 Sleep

Adequate sleep is essential for normal sexual activity. Quality of sleep has significant impact on various phases of sexual response cycle. Desire is a motivational state which drives the individual to search for sexual activity, while arousal prepares individual physically and psychologically for sexual activity. Rapid eye movement sleep (REM) deprivation increases unstimulated sexual arousal but does not have any effect on desire. Sleep deprivation can also have impact on endocrine factors [28].

10.6 Fantasy

Fantasy both during masturbation as well as sexual intercourse enhances sexual responsiveness dramatically. Sometimes it may be perplexing for some individuals while having sex with someone. Sexual fantasies indicate person's sexual values that may not be overt in their behavior. Source of fantasies is not always obvious, it may be something one has read or seen or may be totally imaginary. Sexual fantasies can arouse sexual excitation and vice versa is also true, sexual excitation arouses sexual fantasy. Women and men who fantasize are more likely to experience orgasm during intercourse. Individuals who report frequent sexual fantasies are less likely to develop sexual dysfunctions. Themes of sexual fantasies are varied, imagining of having sexual intercourse with someone whom you love, having sexual encounters with strangers, having multiple sexual partners simultaneously, forcing someone to have sex or you being forced, being found sexually irresistible by someone, having sex with someone famous and many more. There are gender differences in sexual fantasies, men have more sexual fantasies than women. Even the content also varies, men fantasize an active role in sexual encounter while women more a passive role. Women fantasies' have more of emotional or romantic theme, revolves around current or previous partner, thoughts and feelings about love and devotion. Men usually fantasize impersonal sexual behavior, implicit visual sexual imagery, specific parts of partner's body, group sexual activity and focus on specific sexual activity [29].

10.7 Masturbation

Masturbation is genital self-stimulation with some anticipation of rewarding erotic feelings, though it is not a necessity that to achieve orgasm genital stimulation is required, some women achieve orgasm even with breast stimulation. Autoeroticism conveys a different meaning, it involves self-stimulation which may or may not involve external physical stimulation. It refers to personal sexual perception and feelings.

There are lots of myths and misconceptions about masturbation. Lot of cultural and religious myths surrounds masturbation. There is a misconception that masturbation is a dismal alternative to sexual intercourse. Professor NN Wig, an Indian psychiatrist described a syndrome called "Dhat Syndrome" which is characterized by "undue concern about debilitating effects of passage of semen". It has been included in International classification of disease (ICD 10) both under neurotic disorder and culture specific disorder. There is cultural myth that semen is made up of "Dhat" (Elixir), when individual loses semen either through masturbation or wet dreams, they start feeling apprehensive about loss of vitality. Though this syndrome is prevalent worldwide, it is more common in Indian subcontinent.

There are gender differences in masturbation. The frequency of masturbation is more in men when compared to women. Studies show that individuals who report masturbating more frequently, are more open minded about sexuality and have more satisfactory sexual relationship with the partners.

People who believe masturbation as second best mode of sexual expression, get perplexed finding a place for masturbation in relationship. Age, illness, boredom and interpersonal issues influence frequency and intensity of sexual relationship among couples. Masturbation is not always problematic in relationship. Men and women view masturbation differently in a relationship. Men view it as a supplement to pent up sexual energy, while women view masturbation as a substitutive role.

Vibrators and Dildos are not synonyms. Dildos are erect "penis-like" objects which may or may not vibrate. Though vibrators are not substitutes for nurturance, love and sexual attachment, it helps to explore oneself about their sexual response cycle, remove inhibitions and enhance knowledge about themselves [30].

10.8 Marriage

Religious prohibitions prevalent in the society results in restrictive upbringing. Effect of mass media leads to unrealistic sexual expectations. This leads to a conflict, which in turn causes guilt. Lack of communication, exhaustion and unusual expectation can lead to sexual problems during honeymoon. Interaction patterns among couples play an important role in sexual relationship. Hostility, power struggle and conflicts are few of the destructive interaction patterns. Sex at times can be used as a weapon where one partner may forego sexual pleasure rather than give satisfaction to the other. Emotions like anger, anxiety can act as antierotic stimuli [31].

10.9 Pregnancy

Pregnancy and childbirth are both the part of woman's sexual life. Positive experiences of female sexual functioning (as measured by dimensions including sexual desire, arousal, and satisfaction) were negatively correlated with the experience of stress, anxiety, and depression, and positively correlated with general quality of life during pregnancy. Moreover, experiencing fulfilling sexual experiences during pregnancy has been shown to promote well-being and maintain partner-intimacy, while low sexual functioning during pregnancy has been linked to poor body image [32].

Changes occurring in every trimester of pregnancy have significant influence on the sexual behaviors. A number of physiological and psychological changes occur in pregnancy with surge of hormones like estrogen, progesterone and prolactin that ultimately affect not only the frequency but also the quality and the outcome of sexual intercourse. Duration of coitus decreases over the length of pregnancy due to unfounded fears that intercourse may hurt the health of mother or baby or cause premature labor [33].

Sexual satisfaction correlates with the feeling of happiness resulting from being pregnant. Pregnant women prefer the following types of sexual activity: non-genital fondling, stimulation of the clitoris, vagina and breasts, oral and anal stimulation and masturbation. However females and their partners are under informed on sexual life in pregnancy [34]. Many authors emphasize, that the pregnancy is a stimulus for partners to search for ways to maintain mutual emotional bond, close physical affinity and satisfy sexual needs not necessarily finished with an intercourse. As the pregnancy progresses patients report frequent dyspareunia, decline in orgasm and poor self-image. Anatomical changes during pregnancy compel couples to attempt abnormal uncomfortable positions. For a number of couples, pregnancy becomes a stimulus to search for new ways of pleasing each other in love play, which does not necessarily culminates with intercourse.

Mode of delivery also impacts sexual functioning. Patients who delivered vaginally even after 6 months postpartum may experience dysfunction in all phases of sexual cycle compared to women who deliver by caesarian section. Women who deliver vaginally have weakened pelvic floor muscles and may also have discomfort due to rectocele and cystocele. Kegel exercises are advised early in postpartum period to strengthen pelvic floor muscles. The eventual benefits of cesarean delivery on sexual function do not last longer than a few months after childbirth.

The research makes it evident, that experiencing sexual satisfaction by pregnant women improves their self-esteem, facilitates mutual relationship between partners and tightens the marital bond. There are various factors that may be influencing the lack of dialog initiated by prenatal health-care providers with their pregnant patients and partners regarding sexual activity during pregnancy. For one, our society at large often deemphasizes the sexuality of pregnant women, finding the discussion of sex during pregnancy to be a taboo. Moreover, Hinchcliff et al. noted that prenatal care providers may avoid discussing sexuality proactively as it is a complex issue and requires sensitivity [35].

11. Marriage after living together

After marriage, couple's start taking one another for granted. At times when marriages happen due to social pressure, couple may start taking one another for granted after marriage. When marriage happens after a period of open relationship due to social pressure, they may feel trapped [36].

11.1 Divorce

The rates of divorce have increased in all age groups in the recent times. Life after divorce requires emotional, social and sexual adjustment. Individuals spending most of their lives in wedlock, finds it difficult to adjust to singlehood. Many people are so adjusted to think their adult life as couple, they take time to get used to singlehood. It is confusing and perplexing for people to learn divorced role. Divorce leads to decline in life style in some people while in others it may lead to sexual liberty. Spiritual values and Literacy levels determines the number and frequency of partners [36].

11.2 Remarriage

Multitude of factors influences the likelihood of remarriage. Younger the person, there is more probability of remarriage. About 89% who separate under the age of 25 remarry, it decreases to 31% after 40 years. Shorter the duration of first marriage, there are more chances of remarriage. Other factors are the age at first marriage, younger a person at first marriage, more probability of remarriage [36].

11.3 Families

The attitude of parents about sexuality has a significant impact on sexual well-being. Attitude of parents as well as siblings about nudity, masturbation, willingness to discuss about sex and homosexuality all contributes to the development of sexuality of an individual. Relationship of the parents with the individual as well as the partner also influences sexuality. Distorted intrafamilial relationship, lack of discipline, overcrowding, lack of warmth, unusual helplessness and withdrawal from society may lead to certain deviant sexual behavior [36].

12. Sexuality in geriatric population

Sexuality is an important aspect in Geriatric population. Elderly individuals look sexuality as a means of expression of passion, love, admiration and loyalty.

Furthermore sexuality acts as a means of affirming physical functioning, sense of identity and self-confidence. Though desire may remain the same, there may be alterations in other phases of sexual response cycle [9].

12.1 Sexuality and spirituality

The popular belief is that sexuality and spirituality exists in opposition, but in reality spirituality and sexuality go hand in hand. If we look at different geographical areas, there is lot of literature in Chinese Taoist tradition about practices bringing Yin (Feminine) and Yang (Masculine) in harmony. In Indian literature there is mention about energy generated in the pelvic region moving upwards through chakras to the crown, where one enters the cosmic orgasm generated eternally by union of Shakti and Shiva. In psychotherapeutic perspective, people believe that sexuality is something sin and it should be removed or cured. What spirituality should do is to help these people move from the belief that sexuality is sin to enjoying it as an integrated energy for passionate living [37].

12.2 Medical illness and sexuality

Looking at sexuality from the biological perspective, neurological, vascular and endocrine systems contribute significantly for normal sexual functioning. Neurological disorders like stroke, epilepsy, multiple sclerosis, traumatic brain injury and spinal cord disorders lead to sexual problems. Endocrine disorders like androgen deficiency, hyperprolactinemia, diabetes mellitus can produce sexual dysfunctions. Vascular disorders like hypertension and atherosclerosis, prostatic illness, carcinomas all can lead to sexual dysfunctions. Prevalence of sexual dysfunctions among these psychosomatic disorders is around 20–70%. Sex and intimacy are likely to be powerful providers of salutogenesis in both the chronically and critically ill patients. Sexual encounters can serve as a refuge in an otherwise chaotic and turbulent situation, and intimate relations might constitute engines of meaningfulness and coherence in a context of meaninglessness and incoherence that so often dominate the everyday life of patients with chronic illnesses [38].

12.3 Psychiatric illness and sexuality

Substance use disorders have varying effects on sexual functions. Alcohol at a smaller quantity may have some stimulatory effect, at higher quantity decreases both desire as well arousal through its effect on testosterone. Cannabis causes detrimental effect on initiation as well as maintenance of erection. Cannabis historically has aphrodisiac effect, but current evidence shows mixed results. Long term use of cannabis has detrimental effect on testosterone. Similarly opioids delay ejaculation in men and improve vaginismus in women, but long term use decreases testosterone as well as lutenising hormone.

The rates of sexual dysfunction in people suffering from schizophrenia, mood disorders, personality disorders, anxiety disorders and eating disorders is very high. In these disorders illness itself can have effect various stages of sexual response cycle, and also medication used can have adverse effects on sexuality. One of the major psychiatric disorder schizophrenia has negative symptoms like blunted affect, anhedonia and avolition itself causes impedance in enjoying sexual life. Loss of libido is one of the symptoms in major depressive disorder. Anxiety disorders are usually associated with premature ejaculation. Mania is associated with increased libido during the episode, at times disinhibited sexual behavior leads to high risk sexual behavior [39].

13. Conclusion

Sexuality is one of the key factors for wellbeing. There are more myths than adequate knowledge about sexuality. It plays an important role in molding the personality during childhood and adolescence, while it contributes to self-esteem throughout life. Various bio psychosocial factors may influence sexuality. It is one area where research is lacking. In this chapter we have tried to explore some of the key areas influencing sexuality. More research and evidence based data is needed in this area.

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References

[1] Malacane M, Beckmeyer J. A review of parent-based barriers to parent–adolescent communication about sex and sexuality: Implications for sex and family educators. American Journal of Sexuality Education. 2016;**11**:27-40

[2] Antón SC, Swisher CC III. Early dispersals of homo from Africa. Annual Review of Anthropology. 2004;**33**:271-296

[3] Freud S. The Ego and the Id. New York: WW Norton & Co.; 1923

[4] Freud S. Three Essays on the Theory of Sexuality. New York: Basic Books; 1905

[5] Kinsey AC, Pomeroy WB, Martin CE. Sexual Behavior in the Human Male. Philadelphia: Saunders; 1948

[6] Marshall DS, Suggs RC. Human Sexual Behavior: Variations in the Ethnographic Spectrum. New York: Basic Books; 1971

[7] Avasthi A, Rao TSS, Grover S, Biswas P, Kumar S. Clinical practice guidelines for management of sexual dysfuntions. In: Gautham S, Avasthi A, editors. Clinical Practice Guidelines for Management of Substance Abuse Disorders, Sexual Dysfunctions and Sleep Disorders. New Delhi: Indian Psychiatric Society; 2006. p. 144

[8] Bhugra D, DeSilva P. Sexual dysfunction across cultures. International Review of Psychiatry. 1993;**5**(2-3):243-252

[9] Sathyanarayana Rao TS, Tandon A, Manohar S, Mathur S. Clinical practice guidelines for management of sexual disorders in elderly. Indian Journal of Psychiatry. 2018;**60**(Suppl 3):S397-S409

[10] Shivanand MJ, Hrishikesh Solunke K, Reddy S, Rajesh R. Sexual disorders in Asians. Journal of Psychosexual Health. 2019;**1**(3):222-226

[11] Gordon BN, Schroeder CS. Normal sexual development. In: Sexuality: A Developmental Approach to Problems. USA: Springer; 1995. pp. 162-384

[12] Friedrich WN, Fisher J, Broughton D, Houston M, Shafran CR. Normative sexual behavior in children: A contemporary sample. Pediatrics. 1998;**101**(4):E9

[13] Gordon BN, Schroeder CS, Abrams JM. Age differences in children's knowledge of sexuality. Journal of Clinical Child Psychology. 1991;**19**:33-43

[14] Finkelhor D. Sex between siblings: Sex play, incest, and aggression. In: Constantine LL, Martinson FM, editors. Children and Sex: New Findings, New Perspectives. Boston: Little, Brown; 1981. pp. 129-149

[15] Friedrich WN, Grambsch P, Broughton D, Kuiper J, Beilke RL. Normative sexual behavior in children. Pediatrics. 1991;**88**(3):456-464

[16] Kellogg ND. Sexual behaviors in children: Evaluation and management. American Family Physician. 2010;**82**(10):1233-1238

[17] Gundersen BH, Melas PS, Skar JE. Sexual behavior of preschool children. In: Constantine LL, Martinson FM, editors. Children and Sex: New Findings, New Perspectives. Boston: Little, Brown; 1981. pp. 45-72

[18] Lamb S, Coakley M. "Normal" childhood sexual play and games: Differentiating play from abuse. Child Abuse & Neglect. 1993;**17**:515-526

[19] Miragoli S, Camisasca E, Di Blasio P. Child sexual behaviors in school context: Age and gender

differences. Journal of Child Sexual Abuse. 2017;**26**(2):213-231. DOI: 10.1080/10538712.2017.1280866

[20] Grant LM, Demetriou E. Adolescent sexuality. Pediatric Clinics of North America. 1988;**35**(6):1271-1289

[21] Rutter M. Normal psychosexual development. Journal of Child Psychology and Psychiatry. 1970;**11**:259-283

[22] Donovan C. Adolescent sexuality. BMJ. 1990;**300**(6731):1026-1027

[23] Rutter M, Rutter M. Developing Minds: Challenge and Continuity across the Life Span. New York: Basic Books; 1993

[24] La J, Roberts NH, Yafi FA. Diet and men's sexual health. Sexual Medicine Reviews. 2018;**6**:54-68

[25] Garrison M, Rodgers JL. Casting doubt on the causal link between intelligence and age at first intercourse: A cross-generational sibling comparison design using the NLSY. Intelligence. 2016;**59**:139-156

[26] Mokarami H, Toderi S, Pordanjani TR, Taban E. Role of psychosocial job stressors on sexual function of male nurses: The mediator role of work ability. American Journal of Men's Health. 2018;**12**(6):1908-1915

[27] Stanton AM, Handy AB, Meston CM. The effects of exercise on sexual function in women. Sexual Medicine Reviews. 2018;**6**(4):548-557

[28] Costa R, Costa D, Pestana J. Subjective sleep quality, unstimulated sexual arousal, and sexual frequency. Sleep Science. 2017;**10**(4):147-153

[29] Comfort A. The Joy of Sex. New York: Crown; 1971

[30] Westheimer R k, Lopater S. Human Sexuality: A Psychosocial Perspective. 2nd ed. New York: Lippincot, Williams and Wilkins; 2004. pp. 254-281

[31] Kinsey AC, Pomeroy WB, Martin CE. Sexual Behavior in Human Female. Philladelphia: Saunders; 1953

[32] Antonini G, Busetto GM, De Berardinis E, Giovannone R, Vicini P, Del Giudice F, et al. Minimally invasive infrapubic inflatable penile prosthesis implant for erectile dysfunction: Evaluation of efficacy, satisfaction profile and complications. International Journal of Impotence Research. 2016;**28**(1):4-8

[33] Carteiro DM, Sousa LM, Caldeira SM. Clinical indicators of sexual dysfunction in pregnant women: Integrative literature review. Revista Brasileira de Enfermagem. 2016;**69**(1):165-173

[34] Abouzari-Gazafroodi K, Najafi F, Kazemnejad E, Rahnama P, Montazeri A. Demographic and obstetric factors affecting women's sexual functioning during pregnancy. Reproductive Health. 2015;**12**:72

[35] Faisal-Cury A, Huang H, Chan Y-F, Menezes PR. The relationship between depressive/anxiety symptoms during pregnancy/postpartum and sexual life decline after delivery. The Journal of Sexual Medicine. 2013;**10**(5):1343-1349

[36] Bumpass L, Sweet J, Martin TC. Changing patterns of remarriage. Journal of Marriage and the Family. 1990;**52**:747-756

[37] Paloutzian RF, Park CL. Handbook of the Psychology of Religion and Spirituality. New York/London: The Guilford Press; 2005

[38] Shivananda MJ, Rao TS. Sexual dysfunction in medical practice.

Current Opinion in Psychiatry. 2016;**29**(6):331-335

[39] Sathyanarayana Rao TS, Manohar S, Spurthi TN. Psychiatric disorders and treatment emergent sexual dysfunctions. Indian Journal of Psychiatry. 2018;**60**(Suppl S1):46

Section 3

Biological Perspectives

Chapter 4

Effects of Physical Exercise on the Quality of Life of Type 2 Diabetes Patients

Pablo Tomas-Carus, Nilton Leite and Armando Raimundo

Abstract

Diabetes is one of the most important chronic diseases that impact human health, and the total number of diabetes patients worldwide may rise to about 370 million in 2030 (170 million in 2000). Type 2 diabetes patients account for 90% of all diabetes worldwide. Previous literature reported that type 2 diabetes patients have lower quality of life (QoL) than those healthy persons and that a sedentary lifestyle is a modifiable risk factor for type 2 diabetes and an independent predictor of poor quality of life. When the physical activity is planned, structured, and repetitive bodily movement performed to improve or maintain one or more components of physical fitness, it is a denominated physical exercise. Physical exercise has been effective by altering the body composition, glycemic control, blood pressure, insulin resistance, and mental and physical components of QoL. In this chapter, we also focus our attention on mental disorders. Depression and anxiety are the most common in those patients, which can lead to unfavorable influences on metabolic control and micro- and macrovascular complications compared to those with diabetes alone.

Keywords: type 2 diabetes, quality of life, physical exercise, anxiety, depression

1. Type 2 diabetes and quality of life

Since type 2 diabetes (T2D) is a chronic disease, patients will live with it for the rest of their lives, and the treatment is performed through a healthy diet plan, physical activity, and medication [1]. When not treated properly, patients may suffer various complications over time, affecting the overall health and quality of life, failing with the goals for the treatment of the disease [2, 3]. Quality of life is an individual's perception of overall well-being that comprises of a physical, mental, and social component [4]. The term health-related quality of life (HRQoL), which does not approach the concept of satisfaction or happiness and satisfaction life, that is, related with some specifics of life, is frequently employed [5]. Many psychometric tools were developed to determine the impact of diabetes and other chronic diseases and also the effect of some intervention on quality of life. For those patient, the most used are the Diabetes Quality of Life Measure (DQOL), the Diabetes-Specific Quality of Life Scale (DSQOLS), the Diabetes Quality of Life Clinical Trial Questionnaire-Revised, the Appraisal of Diabetes Scale, the ATT-39, and the revised ATT19; the Questionnaire on Stress in Patients with Diabetes-Revised, the

Type 2 Diabetes Symptom Checklist, the Problem Areas in Diabetes Scale (PAID-1), and the revised (PAID-2); and the Audit of Diabetes-Dependent Quality of Life (ADDQoL), SF36, and the EuroQol-5D [4, 6].

The daily routine of medication to control the disease, fear of injections of insulin, episodes of hypoglycemia, as well as severe dietary restriction are factors that alter the psychological state of this population [7]. Cognitive behavioral therapy and pharmacological treatment are used to manage mental health, but data of some studies indicate that 19–34% and 14–43% of depressed and anxiety disorder patients, respectively, do not respond to treatments. On the other hand, the treatment is scarce accessible and costly [8].

Physical exercise is recognized as an effective non-pharmacological therapeutic strategy to improve insulin action and glycemic control and reduce risk factors for cardiovascular disease [9]. Furthermore, it seems to be an efficient tool to promote brain health in normal and pathological conditions, protecting against cognitive impairment and/or degenerative diseases [10]. The mechanisms underlying the psychologic benefits of exercise are sustained on six theories: (i) sympathetic arousal, based on the rest physiologic adaptations by repeated exercise, mainly lower sympathetic and arousal activity, where the participant experiences a sensation of mental well-being; (ii) cognitive appraisal, where the exercise can help relief of the daily psychological hardship; (iii) affect regulation, characterized by a prolonged improvement on general mood state; (iv) thermogenic regulation, exercise increases body temperature, and this induces a relaxing state and improvement of symptoms of anxiety; (v) synthesis of catecholamines, exercise induces catecholamines production, and it is involved on regulation mood and protect mental dysfunctions; and (vi) endorphin synthesis, exercise induces endorphin production on brain (psychoactive agent of euphoria) that can act such a drug addiction [11].

A recent study that analyze the effect of four meta-analyses of physical exercise on mental and physical in depression shows that in mild to moderate depression the effect of exercise may be comparable with antidepressant medication and psychotherapy, and on the other hand, for severe depression, exercise seems to be a complementary strategic to the habitual treatments [12]. Two systematic reviews with meta-analysis show that exercise was associated with significant lower depression severity in older people [13] and can decrease anxiety symptoms among healthy adults [14]. Besides that, in patients with T2D, it was found that active adults are associated with fewer symptoms of depression [15], better physical, and mental quality of life than the less active [16]. Before the prescription of physical exercise or physical activity, health professional should be aware for both physical and psychological health problems that could interfere the participant in exercise. However, strategies should incorporate a motivation program that enhance adherence.

2. Exercise benefits on patients with type 2 diabetes

The increase in the incidence of T2D has been increasing in parallel with the incidence of overweight and obesity; it suggests a possible causal relationship, particularly when obesity is of the central type [17]. There are several components of health-related physical fitness that are positively affected by regular physical activity [18]: (i) cardiorespiratory resistance, (ii) body composition, (iii) muscle strength, (iv) muscular resistance, and (v) flexibility. Although it is always recommended to practice physical activity during a significant period of time (30–60 min/session), in the last years, it has been alerted to the benefits of physical activities beyond those that are conventionally prescribed (e.g., moderate sessions of less than 20 min duration) [18].

Sedentary lifestyle, or at least reduced levels of physical activity, is often associated with the presence of diabetes. This strong and reliable association between sedentary time and diabetes was largely independent of physical activity levels, adding an additional importance to the concept of sedentary behavior being a distinct behavior in itself [19]. The same study highlights the importance of this fact, since it suggests that the deleterious effects of higher levels of sedentary comportment are not mediated by lower amounts of moderate or vigorous physical activity (MVPA). An explanation for the relation between sedentary activity and diabetes as described in literature is the increase in peripheral insulin resistance that occur in consequence of immobility [20], increasing the blood glucose levels. Recent studies comparing different times of sedentary activities in a day (e.g., in a day with 10 h of sedentary behavior could be a result of thirty 20-min bouts or in ten 60-min bouts) have shown evidence that longer periods of sedentary lifestyle have acute deleterious effects on glucose control and other cardiometabolic risk factors [21]. In line with this explanation, the authors of another study have shown that breaking up periods of prolonged sitting with 2-min bouts of light-intensity activity every 20 min in overweight and obese adults result in a 24% reduction in postprandial glucose and a 23% reduction in insulin, both improving glucose regulation [22]. Recently, the American Diabetes Association (ADA) recognized the potential health benefits of reducing and interrupting sedentary time in adults with type 2 diabetes [9]. In fact, some studies found that patients with type 2 diabetes perform less physical activity and comply with the recommendations for the practice of physical activity less than subjects without diabetes [23]. Same authors referred that about 2/3 of the patients with type 2 diabetes performed a certain frequency of physical activity; however, only 40–43% complied with the recommendations. The recommendations of the ACSM and the American Diabetes Association for adult patients with T2D point to the need to perform moderate physical activity during 150 min per week (60 min per week in 5 days) or 60 min per week (20 min in 3 days) of vigorous physical activity (which can be achieved by adding several 10-min periods), interspersed with 2 nonconsecutive days of moderate-to-vigorous strength training [24, 25]. Planned exercise training of more than 150 min/week is associated with higher hemoglobinA1c (HbA1c) declines than that of 150 min or less per week [26].

A recent study has characterized many individual impairments in key cardiac and vascular measures that are associated with CRF impairment in T2D, such as insulin resistance, endothelial dysfunction, decreased myocardial perfusion with exercise, abnormally increased pulmonary capillary wedge pressure (PCWP), decreased limb blood flow, and skeletal muscle mitochondrial dysfunction [27]. Some researchers highlight that being the reasons for which these abnormalities arise, caused by several factors, makes it unlikely that a single therapeutic approach will resolve the entire problem.

An important and recent article which evidences the benefits of physical exercise as therapy for the treatment of 26 different pathologies stresses that increased physical exercise produces a significant improvement in glucose control in people with type 2 diabetes, yielding an average improvement in hemoglobinA1c of between −0.4 and −0.6% [28]. Indeed, as mentioned in a recently published meta-analysis, a simple walk on a regular basis can provide substantial benefits with little or no impairment to the patient, promoting a reduction of HbA1c [29]. Another meta-analysis, even more recent, highlights that our body’s response to HbA1c reduction is more effective when we perform more than 150/min of moderate-to-vigorous physical activity per week [26]. Several meta-analyses indicate that strength training, aerobic training, or a combination of both can induce reductions in the order of 0.4–0.6% in the amount of HbA1c [28]. It seems that there is no evidence that resistance exercise could differ from aerobic exercise in influencing glucose control, cardiovascular risk markers, or safety [30]. Same authors referred that the use of one type or another of physical exercise for T2D patients may be less important than doing some form of physical activity. Recently, in view of the fact that there is no great difference in results when comparing the effects of a strength program with an aerobic program [30], the adoption of a mixed program has been mentioned as preferential for these patients [31]. In another meta-analyses, with a total of 37 studies with 2208 patients with T2DM, it is also suggested that a mixed program is also preferable to be applied. In this study, both supervised aerobic and supervised resistance exercises showed a significant reduction in HbA1c compared to no exercise (0.30% lower and 0.30% lower, respectively). Nevertheless, when compared supervised aerobic and supervised resistance exercises with combined exercise, there was a greater reduction in the latter type of exercise program (a reduction of 0.17% higher than supervised aerobic and a reduction of 0.23% higher than supervised resistance exercises) [32].

Likewise, strength training has been suggested as beneficial for these patients, using moderate loads (50–74%) to vigorous ones (75–85%), so that as long as there are no contraindications, it is recommended to practice with a frequency of three sessions per week, involving the large muscle groups, progressing until achieving three series of 8–10 RM [33].

Diabetes patient usually has physiologic exercise limitations and decreased cardiorespiratory fitness (CRF). More exactly, when compared with people with and without diabetes, the first ones can present 20% lower maximal oxygen uptake (VO_2 max) [27]. This can be a problem for those patients once a reduced VO_2 max is linked to increased cardiovascular mortality [34]. As suggested recently, practitioners should take into consideration in the preparation of exercise programs that the addition of vigorous exercise may be essential to produce substantial changes in cardiovascular function, as it seems that vigorous, but not low-moderate exercise decreases cardiovascular disease [35]. In terms of type of training, it is suggested that interval training may be more successful than continuous training, as well as there is an evidence that suggests that high-intensity exercise improves glycemic control more than low-intensity exercise [28]. In a 4-month RCT with T2D patients, a group of participants of interval walking ($n = 12$) were compared to a group of continuous walking ($n = 12$) and to a non-exercise control group ($n = 8$). Both exercise groups performed 60-min, 5 days/week respective protocols. Values of VO_2 max, body fat, and glycemic control recorded improvements in interval walking group only, compared to continuous walking and control [36].

To determine which variable influences more the reduction of HbA1c, of the intensity and of the quantity of the exercise, a meta-analysis was performed [37]. They found a relation between relatively high-intensity physical training and a reduction in HbA1c ($r = -0.91$, $P = 0.002$), while no significant association between quantity of physical activity and a reduction in HbA1c ($r = -0.46$, $P = 0.26$) was found.

Comorbidities and complications such as dyslipidemia, hypertension, and hyperinsulinemia are common in patients with T2D [32]. The use of different types of exercise can induce different benefits in the variables associated with these pathologies. Thus, supervised aerobic presented more significant improvement than no exercise in fasting plasma glucose (9.38 mg/dl lower), total cholesterol (20.24 mg/dl lower), triacylglycerol (19.34 mg/dl lower), and low-density lipoprotein cholesterol (11.88 mg/dl lower). On the other hand, supervised resistance showed a higher gain than no exercise in improving systolic blood pressure (3.90 mmHg lower) and total cholesterol (22.08 mg/dl lower) [32].

Another study compared the metabolic and hemodynamic response to high-intensity interval exercise (HIIE) and to a continuous moderate-intensity exercise (MICE). A total of 11 participants (age = 52.3 ± 3 year) underwent with the protocols suggested by the researchers. They found that capillary glycemia reduction was greater ($P < 0.05$) after HIIE than MICE as well as a reduction ($P < 0.05$) in 24 h and tendency toward reduction ($P = 0.06$) in daytime systolic ambulatory BP only after HIIE. These results recommend that HIIE is superior to MICE for reducing glycemia and ambulatory BP in T2D [38]. Recently, a HIIT protocol allows to increase protein synthesis in the skeletal muscle of older adults as well as shows an effect linked to ameliorate insulin sensitivity [39]. HIIT was also the type of program used to verify the cardiovascular benefits of exercise training and postexercise nutrition [40]. A total of 53 adults with T2D were randomized to 12 weeks of cardio- and resistance-based HIIT (4–10 × 1 min at 90% maximal heart rate) with postexercise milk, milk-protein, or placebo supplementation, thrice weekly. They evaluated carotid and femoral artery intima media thickness (IMT) and femoral flow profiles using high-resolution ultrasound. At the end of the exercise program, subjects showed a significant reduction on femoral IMT (pre 0.84 ± 0.21 mm vs. post 0.81 ± 0.16 mm, $p = 0.03$), carotid-femoral PWV (pre 10.1 ± 3.2 m/s vs. post 8.6 ± 1.8 m/s, $p < 0.01$), and resting heart rate (pre 70.4 ± 10.8 bpm vs. post 67.8 ± 8.6 bpm, $p = 0.01$) regardless of postexercise nutrition. Those improvements in vascular function could counteract the high cardiovascular mortality in individuals with T2D caused by largely owing to the progress of atherosclerosis, accelerated by arterial stiffening, reduced perfusion, and vascular inflammation [41]. A recent research did find that HIIT with or without postexercise nutrition improves endothelial function, glucose control, and cardiorespiratory fitness in people with T2D. More precisely, after 12 weeks of HIIT, the 53 adults with T2D reduced the continuous glucose monitoring (−0.5 ± 1.1 mmol/L), HbA1c (−0.2 ± 0.4%), percent body fat (−0.8 ± 1.6%), and increased lean mass (+1.1 ± 2.8 kg). Besides these variables, there were still improvements in the VO_2 peak (+2.5 ± 1.6 mL/kg/min) and %FMD (+1.4 ± 1.9%), as well as on arterial blood pressure (−6 ± 7 mmHg) [42]. Interestingly, those adaptations resulting from interventions of some duration (12 or more weeks) are also present as an acute adaptation to the exercise [43].

To verify what type of training may be more effective for the improvement of some health indicators in patients with T2D, 41 participants were assigned to the non-exercise control group, 73 to resistance training 3 days a week, 72 to aerobic exercise in which they expended 12 kcal/kg per week, and 76 to combined aerobic and resistance training in which they expended 10 kcal/kg per week and engaged in resistance training twice a week [31]. After the 9-month program, a reduction in the waist circumference was recorded in all groups. The fat mass was reduced in the resistance training group and in the combination training group (lost in mean 1.4 kg and 1.7 kg, respectively). Only the combination training exercise group decreased hemoglobinA1c and improved maximum oxygen consumption, compared with the control group. It is important to highlight the reduction on HbA1c, once that has been associated with a 15–20% decrease in major cardiovascular disease events. On the other hand, the increase on 1 MET in fitness compared with control obtained in the aerobic and combination groups will not be less important, because of the public health significance given that each increase of 1 MET is associated with 15–20% lower cardiovascular disease mortality risk [44]. A total of 266 patients with T2D training 3.4 sessions/week, each lasting 49 min with an intensity of 50–75% of maximum pulse, for 20 weeks, showed also an increased VO_2 max (+11.8%) [37].

Another interest result was that just the combination training group lost weight, and although both the combination and resistance training groups lost fat mass compared with the control group, the aerobic group did not. The authors suggest firstly that the resistance training group did not lost weight because they increased their lean mass. The inexistence of a reduction on weight and fat mass on aerobic group may be due to an increase in energy intake, to an expenditure compensation, or to both. This was also the same conclusion from another study where it was found that the weight of the patients was not reduced at the end of the intervention [45]. The possible explanations for this was that the training period was relatively short (8–20 weeks), and also the patients overcompensated for their loss of energy by increasing consumption, or patients lost fat mass; however, their volume of muscle mass increased.

Similar results were published in 2007 study [46]. Although the various groups achieved a reduction in HbA1c compared with control, it was again the combination group, the one that registered a more significant reduction (−1 vs. −0.4% with resistance training vs. 0.5 with aerobic group). The practice of physical exercise also allows to increase fat-free mass (in particular muscle mass) and reduce visceral fat in these patients, which has a positive implication in this pathology [47]. This is the reason for the lack of significant effects on weight reduction. Even they could lose some fat mass, they also increased the muscle mass [28].

Physical exercise increases insulin sensitivity in the trained muscle and muscle contraction-induced glucose uptake in the muscle. This increase in insulin sensitivity leads to an increase in glucose uptake by insulin-sensitive tissues, with lower insulin consumption, leading to a reduction in glycemic levels. The mechanisms that underlie this adaptation include increased postreceptor insulin signaling and increased transport of glucose into the muscles by greater dispersion of the muscle capillary network and blood flow [28]. The decrease in insulin resistance in response to increased insulin sensitivity, as well as the reduction of triglyceride (TG) values as a relevant effect for these patients [47].

It is known that older adults with T2D present an increased risk for cognitive decline reported in verbal memory, information-processing speed, and executive functions [48]. The use of exercise programs has also been used in patients with T2D in order to achieve improvements at the cognitive level. Recent literature has shown benefits with either the application of aerobic exercise, resistance training, or a multicomponent exercise program. A 24-week period of square-stepping exercise (SSE) program was used to mitigate this increased risk for dementia present in this pathology [49]. SSE is a low-intensity program that is convenient to older adults for the improvement of cognitive function. Those 24-week SSE program shows promise in improving cognitive function, specifically executive control, in older adults with type 2 diabetes and sCCs. There remains some question regarding the feasibility of the SSE program in this population that has a high chronic disease burden. In an RCT with 155 community-dwelling women aged 65–75 years living in Vancouver that were randomly allocated to once weekly (n = 54) or twice weekly (n = 52) resistance training or twice weekly balance and tone training (control group) (n = 49), both resistance training groups achieved improvements on their performance on the Stroop test compared to control. They concluded that the 12 months of resistance training improve the executive cognitive function of selective attention and conflict resolution [50]. A total of 33 adults (17 women) with amnestic mild cognitive impairment ranging in age from 55 to 85 years participated in an RCT, which used aerobic exercise. After the 6-month program, the women of the aerobic exercise group presented several benefits in different variables such as a higher executive function, increased glucose disposal during the metabolic clamp, and reduced fasting plasma levels of insulin, cortisol, and brain-derived neurotrophic factor. The men who participated in the aerobic exercise group, they increased plasma levels of insulin-like growth factor I and had a favorable effect in one of the executive function tests [51]. A total of 100 older adults with T2D presenting mild cognitive impairment were randomized into a multicomponent exercise or an education control group. The exercise group exercised for 90 min/d, 2 days/week, 40 times for 6 months, and the multicomponent exercise program consisted of biweekly 90-min sessions involving aerobic exercise, muscle strength training, postural balance retraining, and dual-task training. The results of the study demonstrated the effectiveness of the program in improving the performance on mental state examination and logical memory scores and reducing whole brain cortical atrophy, compared with control group [52].

The benefits that patients with type 2 diabetes can acquire when they undergo an exercise program are numerous, as we have pointed out here. If there are several modes of exercise, it is necessary to break the barriers that impede the regular participation of these patients in these programs and to provide the practice in the programs that most motivate each one.

3. Type 2 diabetes mellitus and mental disorder

Beyond the physical and social well-being implications, patients with T2D are more likely to experience mental health problem. Among the mental disorders, depression and anxiety are the most common in those patients, which can lead to unfavorable influences on metabolic control and micro- and macrovascular complications compared to those with diabetes alone [53].

Depression is a medical condition in which the affected patient experience a feeling of sadness, lack of motivation, and change in thinking which lasts for more than 2 consecutive weeks, and it can lead to a decrease in the performance of the activities of daily living [54].

Individuals with T2D have a doubled risk to be diagnosed with depression than in the general population. The concurrent presence of both these disorders has a negative effect on the quality of life, loss of productivity, and absence at work, a higher risk for mortality and to develop the long-term micro- and macrovascular complication of diabetes compared with those patients without depression [55]. Besides that, those patients are associated with a poor glycemic control and poor adherence to healthy lifestyles [56].

Although it is well documented that patients with T2D are more likely to experience depression, the mechanisms underlying this association is poorly understood. It is pointed out that psychological factors such as the burden of life and related-events of the disease predispose the patient to depression. On the other side, there is a potential biological evidence that is emphasized in three aspects: (i) hyperglycemia, due to the high intracellular glucose level on the brain, it can activate polyol pathway that induces an oxidative stress and formation of advanced glycation end products, and both of them can lead to a neuronal damage; (ii) microvascular dysfunction, involved in an increased cerebrovascular damage, those injury can affect the frontal and subcortical regions of the brain that regulate mood state; and (iii) low-grade inflammation, with less evidence linked to depressive symptoms but is associated with chronic disease and predispose to cardiovascular complications [55]. On the other side, diabetes duration is viewed as a mediator for depressive symptoms. These symptoms tend to elevate immediately following diagnosis and decrease and increases again after several years. The duration of diabetes less than 10 years and bigger than 30 years is associated with increased depressive symptoms, while that between 10 and 30 years is remaining low [56].

It can be classified on (i) major depression, when the presence of depressive mood and anhedonia (reduced positive affect) for 2 weeks is accompanied by at last five symptoms such as depressed mood, uncontrolled weight for no apparent reason, lack of motivation, psychomotor disorder, loss of energy or increased fatigue, alteration in sleep, difficulty thinking and thoughts of dead or suicide; (ii) minor depression, which is similar to major depression, but the patient has few than five symptoms; and (iii) dysthymia, when the patient experiences an acute depressive mood for most of the day which persists for at least 2 years. However, at least two of the following symptoms should be present: changes in appetite, low self-esteem, sleep alteration, difficulty thinking, discouragement, and loss of energy or increased fatigue [57].

The nine-item patient health questionnaire is a valid and reliable screaming tool frequently used for the diagnosis of depression. It is an easy and brief self-report questionnaire and can be used in patient with T2D. It consists of nine questions based in the depressive symptoms with score of "0" (not at all) to "3" (nearly every day). It calculated a total score, and it ranges from 0 to 27. A cutoff score of 10–14, 15–19, and 20–27 indicates moderate, moderately severe, and severe depression, respectively [58].

Referring to anxiety, it is defined as a subjective feeling of fear, worry, and discomfort, for no reason at all or derived from anticipation of something [59]. Results from a recent meta-analysis support scientifically evidence that people with T2DM exhibit an increased likelihood of having anxiety disorder and anxiety symptoms than people without diabetes, and on the other side, it is associated with poor glycemic control and increased diabetes complications [53]. Those patients can experience physiologic sensation such as tachycardia, dizziness, sweating, headaches, and gastrointestinal disorder and also avoid places, people, and events. The diagnosis of the disease may induce anxiety because the patient has to adopt a severe lifestyle change in function of the disease treatment with a daily management of diabetes and worry of the long-term micro- and macrovascular complication [53]. It is common to diagnose anxiety using self-report symptom scales, mainly the Spielberger Trait Anxiety Questionnaire, the general health questionnaire for anxiety subscale, Hospital Anxiety and Depression Scale for anxiety (HADS), and Hopkins symptom checklist [59].

It is important to note that the idea that physical exercise has positive effects on depression and anxiety of patients with T2D in some cases is not unanimous. For instance, results from a systematic review of intervention studies [60] concluded that the evidences of physical exercise on psychological outcomes are conflicting. In this review, aerobic exercise shows to improve symptoms of anxiety. Significant difference in depression was found only in resistance training. For quality of life, among 6 studies (478 participants examined), only 2 reported significant effect of aerobic training compared to control group. Previous studies examined (361 participants), a mixed effect of resistance training on the mental domain of the SF-36 and SF-12 questionnaire was found. The authors stand out that heterogeneity of the studies was reflected on the mixed results found [60]. On the other side, a randomized controlled trial of 218 inactive patients with T2D found that no exercise was superior to resistance or combined exercise of 22 weeks, three times per week for improving mental health status [61]. Against the mixed evidence of physical exercise to improve mental health in T2D, it is necessary for future studies to confirm some findings. The literature showed that physical activity can mitigate mental disorder in active patient with T2D [15], and in this sense, an important benefit of physical activity or physical exercise for mental health on those patients could be speculated.

For these patients, it is expressly recommended to perform at least 150 min of aerobic exercise of moderate-to-vigorous intensity and at least 2 sessions of resistance exercise. The compliance with these recommendations may have a positive impact on the physical functioning and may improve or maintain their health status [62]. In addition to the specific benefits, aerobic and resistance training seems to be synergic, and available evidence recommends combining both form of trainings to confer great improvements for people with T2D. In this sense, the effects of combined physical exercise program in those patients (aerobic-resistance exercise performed 60-min, 3 days/week for 12 weeks) was examined and reported significant effects in several domains of quality of life in the exercise group (mental health, +40%). The authors emphasize the importance of combining aerobic exercise with strength training in the clinical care of people with T2D [63]. In another study, the effect of three types of treatments in people with T2DM for 24 months was evaluated: (PE) physical exercise with a combined program, n = 59; (M) medication with metformin, n = 30; (PE + M) combination of physical exercise and medication, n = 195. The "PE" group trained three times a week, the "M" used 850 mg of metformin twice a week, and in "PE + M" they combined the two treatments. The physical exercise program consisted in a combination of aerobic, resistance, flexibility, and balance trainings which is performed for 60 min. After the study period, the "PE" and "PE + M" groups improved mood states and better perceived of physical and mental domains of quality of life in comparison with the "M" group [64].

This scientific evidence presented above reinforces the preponderant role that physical exercise plays as medicine in treatment of different pathologies, especially T2D. However, faced with the growing interest in using physical exercise as a non-pharmacological treatment for psychological changes, further research is needed to determine the type and dose response in this population.

Conflict of interest

Authors have no conflict of interest to disclose.

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References

[1] Nyenwe EA, Jerkins TW, Umpierrez GE, Kitabchi AE. Management of type 2 diabetes: Evolving strategies for the treatment of patients with type 2 diabetes. Metabolism. 2011;**60**(1):1-23. DOI: 10.1016/j.metabol.2010.09.01

[2] Huang ES, Brown SE, Ewigman BG, Foley EC, Meltzer DO. Patient perceptions of quality of life with diabetes-related complications and treatments. Diabetes Care. 2007;**30**(10):2478-2483

[3] Oguntibeju OO, Odunaiya N, Oladipo B, Truter EJ. Health behaviour and quality of life of patients with type 2 diabetes attending selected hospitals in south western Nigeria. The West Indian Medical Journal. 2012;**61**(6):619-626

[4] Trikkalinou A, Papazafiropoulou AK, Melidonis A. Type 2 diabetes and quality of life. World Journal of Diabetes. 2017;**8**(4):120-129. DOI: 10.4239/wjd.v8.i4.120

[5] Imayama I, Plotnikoff RC, Courneya KS, Johnson JA. Determinants of quality of life in type 2 diabetes population: The inclusion of personality. Quality of Life Research. 2011;**20**(4):551-558. DOI: 10.1007/s11136-010-9772-8

[6] Janssen MF, Lubetkin EI, Sekhobo JP, Pickard AS. The use of the EQ-5D preference-based health status measure in adults with type 2 diabetes mellitus. Diabetic Medicine. 2011;**28**(4):395-413. DOI: 10.1111/j.1464-5491.2010.03136.x

[7] Lu Y, Wang N, Chen Y, Nie X, Li Q, Han B, et al. Health-related quality of life in type-2 diabetes patients: A cross-sectional study in East China. BMC Endocrine Disorders. 2017;**17**(1):38. DOI: 10.1186/s12902-017-0187-1

[8] Kristin LS, Jasper AJS, Gordon JGA, Michael WO. Exercise for Mood and Anxiety Disorders: A Review of Efficacy, Mechanisms, and Barriers. Oxford University Press; 2014

[9] Colberg SR, Sigal RJ, Yardley JE, Riddell MC, Dunstan DW, Dempsey PC, et al. Physical activity/exercise and diabetes: A position statement of the American Diabetes Association. Diabetes Care. 2016;**39**(11):2065-2079. DOI: 10.2337/dc16-1728

[10] Cassilhas RC, Tufik S, de Mello MT. Physical exercise, neuroplasticity, spatial learning and memory. Cellular and Molecular Life Sciences. 2016;**73**(5):975-983. DOI: 10.1007/s00018-015-2102-0

[11] Szabo A, Griffiths MD, Demetrovics Z. Psychology and exercise. In: Bagchi D, Nair S, Sen CK, editors. Nutrition and Enhanced Sports Performance. 2nd ed. Academic Press; 2019. pp. 63-72

[12] Knapen J, Vancampfort D, Moriën Y, Marchal Y. Exercise therapy improves both mental and physical health in patients with major depression. Disability and Rehabilitation. 2015;**37**(16):1490-1495. DOI: 10.3109/09638288.2014.972579

[13] Bridle C, Spanjers K, Patel S, Atherton NM, Lamb SE. Effect of exercise on depression severity in older people: Systematic review and meta-analysis of randomised controlled trials. The British Journal of Psychiatry. 2012;**201**(3):180-185. DOI: 10.1192/bjp.bp.111.095174

[14] Conn VS. Anxiety outcomes after physical activity interventions: Meta-analysis findings. Nursing Research. 2010;**59**(3):224-231. DOI: 10.1097/NNR.0b013e3181dbb2f8

[15] Lysy Z, Da Costa D, Dasgupta K. The association of physical

activity and depression in type 2 diabetes. Diabetic Medicine. 2008;**25**(10):1133-1141. DOI: 10.1111/j.1464-5491.2008.02545.x

[16] Green AJ, Fox KM, Grandy S. Impact of regular exercise and attempted weight loss on quality of life among adults with and without type 2 diabetes mellitus. Journal of Obesity. 2011;**2011**:pii: 172073. DOI: 10.1155/2011/172073

[17] Alberti G, Zimmet P, Shaw J, Bloomgarden Z, Kaufman F, Silink M. Type 2 diabetes in the young: The evolving epidemic the international diabetes federation consensus workshop. Diabetes Care. 2004;**27**(7):1798-1811. DOI: 10.2337/diacare.27.7.1798

[18] American College of Sports Medicine. ACSM's Guidelines for Exercise Testing and Prescription. 9th ed. Baltimore: Lippincott Williams & Wilkins; 2013. pp. 5-8

[19] Wilmot EG, Edwardson CL, Achana FA, Davies MJ, Gorely T, Gray LJ, et al. Sedentary time in adults and the association with diabetes, cardiovascular disease and death: Systematic review and meta-analysis. Diabetologia. 2012;**55**:2895-2905. DOI: 10.1007/s00125-012-2677-z

[20] Bey L, Hamilton MT. Suppression of skeletal muscle lipoprotein lipase activity during physical inactivity: A molecular reason to maintain daily low-intensity activity. The Journal of Physiology. 2003;**551**:673-682. DOI: 10.1113/jphysiol.2003.045591

[21] Brocklebank LA, Falconer CL, Page AS, Perry R, Cooper AR. Accelerometer-measured sedentary time and cardiometabolic biomarkers: A systematic review. Preventive Medicine. 2015;**76**:92-102. DOI: 10.1016/j.ypmed.2015.04.013

[22] Dunstan DW, Kingwell BA, Larsen R, Healy GN, Cerin E, Hamilton MT, et al. Breaking up prolonged sitting reduces postprandial glucose and insulin responses. Diabetes Care. 2012;**35**(5):976-983. DOI: 10.2337/dc11-1931

[23] Zhao G, Ford E, Li C, Mokdad A. Compliance with physical activity recommendations in US adults with diabetes. Diabetic Medicine. 2008;**25**(2):221-227. DOI: 10.1111/j.1464-5491.2007.02332.x

[24] Haskell W, Lee I, Pate R, Powell K, Blair S, Franklin B, et al. Physical activity and public health: Updated recommendation for adults from the American College of Sports Medicine and the American Heart Association. Medicine and Science in Sports and Exercise. 2007;**39**(8):1423-1434. DOI: 10.1161/CIRCULATION.107.185649

[25] Nelson ME, Rejeski WJ, Blair SN. Physical activity and public health in older adults: Recommendation from the American College of Sports Medicine and the American Heart Association. Medicine & Science in Sports & Exercise: Official Journal of the American College of Sports Medicine. 2007;**39**(8):1435-1445. DOI: 10.1161/CIRCULATIONAHA.107.185650

[26] Umpierre D, Ribeiro PA, Kramer CK, Leitao CB, Zucatti AT, Azevedo MJ, et al. Physical activity advice only or structured exercise training and association with HbA1c levels in type 2 diabetes: A systematic review and meta-analysis. Journal of the American Medical Association. 2011;**305**:1790-1799. DOI: 10.1001/jama.2011.576

[27] Wahl MP, Reusch JE, Regensteiner J, Scalzo RL. Mechanisms of aerobic exercise impairment in diabetes: A narrative review. Frontiers in Endocrinology. 2018;**9**:181. DOI: 10.3389/fendo.2018.00181

[28] Pedersen B, Saltin B. Exercise as medicine-evidence for prescribing exercise as therapy in 26 different chronic diseases. Scandinavian Journal of Medicine & Science in Sports. 2015;**25**(S3):1-72. DOI: 10.1111/sms.12581

[29] Qiu S, Cai X, Schumann U, Velders M, Sun Z, Steinacker JM. Impact of walking on glycemic control and other cardiovascular risk factors in type 2 diabetes: A meta-analysis. PLoS One. 2014;**9**(10):e109767. DOI: 10.1371/journal.pone.0109767

[30] Yang Z, Scott CA, Mao C, Tang J, Farmer AJ. Resistance exercise versus aerobic exercise for type 2 diabetes: A systematic review and meta-analysis. Sports Medicine. 2014;**44**:487-499. DOI: 10.1007/s40279-013-0128-8

[31] Church TS, Blair SN, Cocreham S, Johannsen N, Johnson W, Kramer K, et al. Effects of aerobic and resistance training on hemoglobin A1c levels in patients with type 2 diabetes: A randomized controlled trial. JAMA: The Journal of the American Medical Association. 2010;**304**(20):2253-2262. DOI: 10.1001/jama.2010.1710

[32] Pan B, Ge L, Xun YQ, Chen YJ, Gao CY, Han X. Exercise training modalities in patients with type 2 diabetes mellitus: A systematic review and network meta-analysis. International Journal of Behavioral Nutrition and Physical Activity. 2018;**15**(1):72. DOI: 10.1186/s12966-018-0703-3

[33] Sigal RJ, Kenny GP, Wasserman DH, Castaneda-Sceppa C. Physical activity/exercise and type 2 diabetes. Diabetes Care. 2004;**27**(10):2518-2539. DOI: 10.2337/diacare.27.10.2518

[34] Weintraub WS, Daniels SR, Burke LE, Franklin BA, Goff DC Jr, Hayman LL, et al. Value of primordial and primary prevention for cardiovascular disease: A policy statement from the American Heart Association. Circulation. 2011;**124**(8):967-990. DOI: 10.1161/CIR.0b013e3182285a81

[35] Baldi JC, Wilson GA, Wilson LC, Wilkins GT, Lamberts RR. The type 2 diabetic heart: Its role in exercise intolerance and the challenge to find effective exercise interventions. Sports Medicine. 2016;**46**:1-13. DOI: 10.1007/s40279-016-0542-9

[36] Karstoft K, Winding K, Knudsen SH, Nielsen JS, Thomsen C, Pedersen BK, et al. The effects of free-living interval-walking training on glycemic control, body composition, and physical fitness in type 2 diabetic patients a randomized, controlled trial. Diabetes Care. 2013;**36**:228-236. DOI: 10.2337/dc12-0658

[37] Boulé NG, Kenny GP, Haddad E, Wells GA, Sigal RJ. Meta-analysis of the effect of structured exercise training on cardiorespiratory fitness in type 2 diabetes mellitus. Diabetologia. 2003;**46**:1071-1081. DOI: 10.1007/s00125-003-1160-2

[38] Viana AA, Fernandes B, Alvarez C, Guimarães GV, Ciolac EG. Prescribing high-intensity interval exercise by RPE in individuals with type 2 diabetes: Metabolic and hemodynamic responses. Applied Physiology, Nutrition, and Metabolism. 2019;**44**(4):348-356. DOI: 10.1139/apnm-2018-0371

[39] Robinson MM, Dasari S, Konopka AR, Johnson ML, Manjunatha S, Esponda RR, et al. Enhanced protein translation underlies improved metabolic and physical adaptations to different exercise training modes in young and old humans. Cell Metabolism. 2017;**25**:581-592. DOI: 10.1016/j.cmet.2017.02.009

[40] Francois ME, Pistawka KJ, Halperin FA, Little JP. Cardiovascular benefits of combined interval training and post-exercise nutrition in type 2

diabetes. Journal of Diabetes and its Complications. 2018;**32**(2):226-233. DOI: 10.1016/j.jdiacomp.2017.10.002

[41] Mazzone T, Chait A, Plutzky J. Cardiovascular disease risk in type 2 diabetes mellitus: Insights from mechanistic studies. Lancet. 2008;**371**(9626):1800-1809. DOI: 10.1016/S0140-6736(08)60768-0

[42] Francois ME, Durrer C, Pistawka KJ, Halperin FA, Chang C, Little JP. Combined interval training and post-exercise nutrition in type 2 diabetes: A randomized control trial. Frontiers in Physiology. 2017;**8**:528. DOI: 10.3389/fphys.2017.00528

[43] Francois ME, Durrer C, Pistawka KJ, Halperin FA, Little JP. Resistance-based interval exercise acutely improves endothelial function in type 2 diabetes. American Journal of Physiology. Heart and Circulatory Physiology. 2016;**311**(5):H1258-H1267. DOI: 10.1152/ajpheart.00398.2016

[44] Kodama S, Saito K, Tanaka S, Maki M, Yachi Y, Asumi M, et al. Cardiorespiratory fitness as a quantitative predictor of all cause mortality and cardiovascular events in healthy men and women: A meta-analysis. Journal of the American Medical Association. 2009;**301**(19):2024-2035. DOI: 10.1001/jama.2009.681

[45] Boulé NG, Haddad E, Kenny GP, Wells GA, Sigal RJ. Effects of exercise on glycemic control and body mass in type 2 diabetes mellitus: A meta-analysis of controlled clinical trials. Journal of the American Medical Association. 2001;**286**:1218-1227. DOI: 10.1001/jama.286.10.1218

[46] Sigal RJ, Kenny GP, Boulé NG, Wells GA, Prud'homme D, Fortier M, et al. Effects of aerobic training, resistance training, or both on glycemic control in type 2 diabetes: A randomized trial. Annals of Internal Medicine. 2007;**147**(6):357-369. DOI: 10.7326/0003-4819-147-6-200709180-00005

[47] Thomas D, Elliott E, Naughton G. Exercise for type 2 diabetes mellitus. The Cochrane Database of Systematic Reviews. 2006;**3**:CD002968. DOI: 10.1002/14651858.CD002968.pub2

[48] Sadanand S, Balachandar R, Bharath S. Memory and executive functions in persons with type 2 diabetes: A meta-analysis. Diabetes/Metabolism Research and Reviews. 2016;**32**(2):132-142. DOI: 10.1002/dmrr.2664

[49] Shellington EM, Reichert SM, Heath M, Gill DP, Shigematsu R, Petrella RJ. Results from a feasibility study of square-stepping exercise in older adults with type 2 diabetes and self-reported cognitive complaints to improve global cognitive functioning. Canadian Journal of Diabetes. 2018;**42**(6):603-612. DOI: 10.1016/j.jcjd.2018.02.003

[50] Liu-Ambrose T, Nagamatsu LS, Graf P, Beattie BL, Ashe MC, Handy TC. Resistance training and executive functions: A 12-month randomized controlled trial. Archives of Internal Medicine. 2010;**170**(2):170-178. DOI: 10.1001/archinternmed.2009.494

[51] Baker LD, Frank LL, Foster-Schubert K, Green PS, Wilkinson CW, McTiernan A, et al. Effects of aerobic exercise on mild cognitive impairment: A controlled trial. Archives of Neurology. 2010;**67**(1):71-79. DOI: 10.1001/archneurol.2009.307

[52] Suzuki T, Shimada H, Makizako H, Doi T, Yoshida D, Ito K, et al. A randomized controlled trial of multicomponent exercise in older adults with mild cognitive impairment. PLoS One. 2013;**8**(4):e61483. DOI: 10.1371/journal.pone.0061483

[53] Bickett A, Tapp H. Anxiety and diabetes: Innovative approaches

to management in primary care. Experimental Biology and Medicine. 2016;**241**(15):1724-1731. DOI: 10.1177/1535370216657613

[54] American Psychiatric Association. What Is Depression? [Internet]. 2017. Available from: https://www.psychiatry.org/patients-families/depression/what-is-depression [Accessed: 13 March 2019]

[55] van Sloten T, Schram M. Understanding depression in type 2 diabetes: A biological approach in observational studies. F1000Res. 2018;**7**:pii: F1000 Faculty Rev-1283. DOI: 10.12688/f1000research.13898.1

[56] Darwish L, Beroncal E, Sison MV, Swardfager W. Depression in people with type 2 diabetes: Current perspectives. Diabetes, Metabolic Syndrome and Obesity: Targets and Therapy. 2018;**11**:333-343. DOI: 10.2147/DMSO.S106797

[57] Egede LE, Ellis C. Diabetes and depression: Global perspectives. Diabetes Research and Clinical Practice. 2010;**87**(3):302-312. DOI: 10.1016/j.diabres.2010.01.024

[58] Janssen EP, Köhler S, Stehouwer CD, Schaper NC, Dagnelie PC, Sep SJ, et al. The patient health Questionnaire-9 as a screening tool for depression in individuals with type 2 diabetes mellitus: The Maastricht study. Journal of the American Geriatrics Society. 2016;**64**(11):e201-e206. DOI: 10.1111/jgs.14388

[59] Tang F, Wang G, Lian Y. Association between anxiety and metabolic syndrome: A systematic review and meta-analysis of epidemiological studies. Psychoneuroendocrinology. 2017;**77**:112-121. DOI: 10.1016/j.psyneuen.2016.11.025

[60] van der Heijden MM, van Dooren FE, Pop VJ, Pouwer F. Effects of exercise training on quality of life, symptoms of depression, symptoms of anxiety and emotional well-being in type 2 diabetes mellitus: A systematic review. Diabetologia. 2013;**56**(6):1210-1225. DOI: 10.1007/s00125-013-2871-7

[61] Reid RD, Tulloch HE, Sigal RJ, Kenny GP, Fortier M, McDonnell L, et al. Effects of aerobic exercise, resistance exercise or both, on patient-reported health status and well-being in type 2 diabetes mellitus: A randomised trial. Diabetologia. 2010;**53**(4):632-640. DOI: 10.1007/s00125-009-1631-1

[62] Thiel DM, Al Sayah F, Vallance JK, Johnson ST, Johnson JA. Association between physical activity and health-related quality of life in adults with type 2 diabetes. Canadian Journal of Diabetes. 2017;**41**(1):58-63. DOI: 10.1016/j.jcjd.2016.07.004

[63] Tomas-Carus P, Ortega-Alonso A, Pietilainen KH, Santos V, Goncalves H, Ramos J, et al. A randomized controlled trial on the effects of combined aerobic-resistance exercise on muscle strength and fatigue, glycemic control and health-related quality of life of type 2 diabetes patients. The Journal of Sports Medicine and Physical Fitness. 2016;**56**(5):572-578

[64] Baptista LC, Machado-Rodrigues AM, Martins RA. Exercise but not metformin improves health-related quality of life and mood states in older adults with type 2 diabetes. European Journal of Sport Science. 2017;**17**(6):794-804. DOI: 10.1080/17461391.2017.1310933

Chapter 5

Quality of Life and Menopause

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Abstract

Since the middle of twentieth century, the concept of Quality of Life (QoL) has been a point of interest for many investigators and clinicians for different health and physiological issues. Menopause has not been an exemption of this, due to the increase of the life expectation, the importance of Women's Health and the view of this period of life as important as the reproductive one. Many of us work, trying to offer these women with treatments, health solutions, and psychological tools to embrace and enjoy this new chapter in her life. In this chapter, we present a review of the QoL studies on this period and the new trends on treatments and help for these women on health problems, their mental and sexual well-being.

Keywords: menopause, quality of life, HRQoL, depression, sexuality, estrogen, ovarian, Climateric, GSM, vasomotor symptoms, MHT

1. Introduction

According to the World Health Organization, menopause is the permanent termination of menstruation as a result of the cessation of ovarian activity. The climacteric phase is characterized by a decrease in ovarian activity, a decay in probable fertility, and the manifestation of various symptoms along with irregular intervals of menstruation. The period covers a fragment of premenopause and the parts of peri- and post-menopause, up until ancient age [1]. The transition into menopause is related to different physical and mental changes that may affect women's health. Studies show that the physical, psychological, social, and sexual changes in menopause have an adverse effect on women's quality of life. It has been expressed that 96% of women have menopausal complaints and their quality of life is affected not only physically and psychologically but also socially. It is reported that the quality of life of women is especially adversely affected in the perimenopausal and early postmenopausal periods [1].

Health-related quality of life (HRQoL) states to the effects of an individual's physical condition on all phases of psychosocial functioning. For climacteric women, HRQoL is the particular universal standard that is critical for their daily well-being. Symptoms suffered throughout menopause and sociodemographic particularities have an influence in quality of life in postmenopausal women. In younger, symptomatic, postmenopausal women, HRQoL could be meaningfully reduced influenced by many supplementary, non-menopausal factors. However, quality of life after menopause is influenced by many additional, non-menopausal factors [2]. Therapeutic methodologies that treat climacteric symptoms and all measures improving adverse non-hormonal factors could improve HRQoL among climacteric women. This includes marital and sexual therapy as well as psychosocial actions. Menopausal hormone therapy (MHT) may inverse this decline of HRQoL if it is due to postmenopausal estrogen deficiency [2].

2. Menopause

Menopause is a transitional period marked for many women by fluctuating physiological changes, which affect short-term quality of life such as vasomotor symptoms, sleep, and mood disorders; as well as for long-term changes such as genitourinary symptoms and decreased bone mineral density [3].

Four of five women experience physical and psychological symptoms around menopause with different degrees of severity and impact on quality of life [4]. Clinicians and women usually identify the transition to menopause by the onset of menstrual irregularities [5, 6]. This period called perimenopause is variable, but can range from 5 to 10 years before menopause.

Natural menopause is defined as the absence of menses for 12 months without a pathological cause. The average age of menopause is 51.4 years, but can vary according to race, socioeconomic status, smoking habit, etc. [3]. During the menopausal transition, women experience: irregular menses, vasomotor symptoms, fluctuating fertility, sleep disturbances, depression and anxiety, genitourinary symptoms (including vaginal dryness), and sexual dysfunction.

Some studies show that 87% of women who report hot flashes experience daily symptoms, and a third of them experience more than 10 days [7, 8]. Its prevalence is approximately 40% in the early menopausal transition and 60–80% in the first 2 years after menopause [9, 10]. African-American women have more vasomotor symptoms, while white women have more psychosomatic symptoms. Asian women have the least number of symptoms compared to the other races. In the Penn Ovarian Again Study (POAS), African-American women had more physiological symptoms (hot flashes, dizziness, urinary incontinence, and vaginal dryness) compared to white women [8, 9]. In the Study of Women's Health Across the Nation (SWAN) and PSOAS, obese women had greater vasomotor symptoms [6, 11] and highly active smokers had a more than 60% greater likelihood of reporting severe hot flashes [12, 13]. Changes in menstrual bleeding patterns often signal the beginning of the menopausal transition. The acronym PALM-COEIN is useful to recall the main causes in each category [14].

Cutoffs for the endometrial thickness measured by ultrasound vary by guidelines. The American College of Obstetricians and Gynecologists (ACOG) establishes normal endometrial thickness of 4 mm or less in postmenopausal women, while the American College of Radiology (ACR) suggests 5 mm or less; and in premenopausal women, it proposes a value of 16 mm or less as a cutoff [15]. Endometrial sampling using Pipelle has a sensitivity of 90% for endometrial cancer and 82% for atypical hyperplasia. Studies show regression of hyperplasia over 6 months when treated with levonorgestrel-releasing intrauterine device (LNG-IUD) or oral progesterone, 10 mg, 10–14 days per month [3].

Management of acute bleeding, which is appropriate for medical treatment, options include: LNG-IUD, combined hormonal contraceptives, progestin therapy, tranexamic acid, and non-steroidal anti-inflammatory drugs. The surgical options are also varied, being able to perform dilatation and curettage, endometrial ablation, uterine artery embolization, polypectomy, myomectomy, or hysterectomy, depending on the cause [3]. The North American Menopause Society (NAMS) recommends contraception for 12 months after the last menstrual period [3]. For women above 50-years old utilizing progestin-only contraceptives, follicle-stimulating hormone (FSH) is able to measure to help identify menopause. The National Institute for Excellence in Health and Care (NICE) guidelines suggest measuring FSH 6 weeks apart, and if the amounts are greater than 30, then the contraceptive scheme might be discontinued after a year [16].

The Faculty of Sexual and Reproductive Healthcare (FSRH) recommends stopping most methods at age 55, except for combined hormonal contraceptives and depot medroxyprogesterone acetate, which should be suspended at the age of 50 to avoid the increased risk of cardiovascular disease. FSRH also recommends women with a copper IUD placed after age 40 can remain use until menopause, and women with a 52 mg levonorgestrel-releasing IUD located after 45, can continue use until 55. If the LNG-IUD is being used for endometrial protection instead of contraception, it should be replaced every 5 years [17].

Vulvovaginal symptoms affect up to 45% of postmenopausal women. Since 2014, the International Society for the Study of Sexual Health of Women (ISSWSH) and the American Menopause Society (NAMS) have approved a new terminology for menopausal genitourinary and sexual symptoms, previously called vulvovaginal atrophy or atrophic vaginitis. This condition now labeled as genitourinary syndrome of menopause (GSM) as a result of the deficiency of estrogen effect not only on the vaginal mucosa but also on the urethra and sexual functioning [3]. The GSM usually become apparent 2 or 3 years after menopause and continues to worsen as the years go by, having an intense influence on the postmenopausal women's quality of life, disturbing intimacy, satisfaction of sexual intercourse, sleep, and relationships. Physical examination findings include pale and thin vaginal epithelium, a pH greater than 5 (normal pH is 3.5–4.5), and augmented parabasal cells on the maturation index [3]. Prasterone, an intravaginal dehydroepiandrosterone preparation, was approved by the FDA in November 2016 and has also recognized efficacy in treatment of symptomatic GSM and dyspareunia [3]. Intravaginal estrogen therapy continues as the leader option for GSM. Local estrogen is marginally absorbed systemically and does not stimulate endometrial growth, so associated progesterone supplementation is not necessary. The recommended dosing using pills or cream normally starts with daily application until the symptoms improve and then weans down to anywhere between one and three times a week [3].

Women with an intact uterus on estrogen therapy should also receive adequate progesterone treatment to prevent endometrial hyperplasia and cancer. Micronized progesterone has a more favorable safety profile than synthetic progestins, but its twice daily dosing may be an obstacle in therapeutic compliance. Women who cannot tolerate the side effects of progesterone (fatigue, dysphoria, and fluid retention), an alternative agent for endometrial protection, is the selective estrogen receptor modulator, bazedoxifene. The LNG-IUD has also been used for this purpose and has been shown to be equal to or superior to other progesterone formulations in providing endometrial protection [3].

To minimize the risks of hormone therapy, the prescription should be with the lowest effective dose and the shortest duration necessary to improve the symptoms. There is no consensus on the recommended duration of hormone therapy or about its withdrawal, either with gradual dose reduction or abruptly. Approximately, half of the women will experience the return of vasomotor symptoms when they discontinue hormone therapy. The decision to discontinue hormone therapy should be individualized based on the patient's symptoms and medical history [3].

3. Quality of life and menopause

The common conception of QoL was originally believed a useful assistant to conventional conceptions of health and functional status. An ideal health evaluation, therefore, would take account of an assessment of the patient's physical health, a measure of physical, social, and psychological functioning, and a measure of QoL. Such an assessment would include main physical, psychological, social, and spiritual dominions of life. QoL is defined as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a wide-ranging concept influenced in a multifaceted way by the persons' physical health, psychological status, degree of independence, social interactions, and their connexion to relevant features of their environment [18].

Transition into menopause is related to different physical and mental changes that may affect women's health. Studies show that the physical, psychological, social, and sexual changes in menopause have an adverse effect on women's quality of life. It has been expressed that 96% of women have menopausal complaints and their quality of life is affected not only physically and psychologically but also socially. It is reported that the QoL of women is especially unfavorably marked in the perimenopausal and early postmenopausal periods. Simultaneously with the growing extension of the expected life span, the time that is spent in the climacteric period is also growing. Warranting that women having an elevated QoL in this phase may be made likely by showing the complications they suffer, along with associated aspects and defining the status of their QoL [19].

Apparent QoL is difficult to determine and there is no global conformity on how it should be measured. Objective dimensions of health condition (HRQoL) may not obtain the patient's judgment of overall life satisfaction. QoL can be expressed as an indication of an individual's belief about functioning and achievement. HRQoL may be seen as the individual's perception about her physical, cognitive, and mental health as well as social status. Valuations of overall QoL for climacteric patients require taking in count physical symptoms (hot flushes, night sweats, and urogenital atrophy), psychological symptoms (depression, mood swings, irritability, and anxiety), and life conditions (functioning at work and other social scenarios). Thus, overall QoL may include four main factors: occupational, health-related, sexual, and emotional. Consideration of HRQOL is also influenced by women's augmented risk of multiple chronic diseases related to menopause, including osteopenia, osteoporosis and associated fractures, and cardiovascular disease [20].

Symptoms experienced during menopause and sociodemographic characteristics affect the quality of life in postmenopausal women. In younger, symptomatic, postmenopausal women, health-related quality of life (HRQoL) may be significantly diminished. However, quality of life after menopause is influenced by many additional, non-menopausal factors. Management alternatives to manage climacteric symptoms and all measures amending adverse non-hormonal aspects could increase HRQoL among climacteric women. This includes marital and sexual therapy as well as psychosocial actions. Menopausal hormone therapy (MHT) may reverse this decline of HRQoL if it is due to postmenopausal-estrogen insufficiency. In contrast, when MHT is recommended to asymptomatic younger and older climacteric women, no progress in HRQoL can be obtained. Health status and QoL are not linearly related. Recently, there has been a rising alertness of the features of QoL and aging. QoL is a subjective factor. Therefore, open enquiring is the most easy and proper way of adding data about how patients feel and function.

Existing measures of QoL try to quantify the effect of health deficiency through several physical, psychological, and social factors [1].

Symptoms experienced during menopause and sociodemographic characteristics affect quality of life in postmenopausal women. Hot flushes impact the daily activities of most postmenopausal women, especially those with more frequent/severe symptoms. The impact in daily life of menopause symptoms (hot flushes, vaginal dryness, cognitive function, anxiety and depression, urinary complaints, uterine bleeding, low sexual desire, among others) can be seen in work, social and leisure activities, mood, concentration, sleep quality, marital and sexual satisfaction, and the level of daily energy [1]. Vasomotor and sexual complaints have a major impact in the first 5 years after menopause and psychological, and physical symptoms have more effect on QoL in women with more than 5 years of menopause [19]. Quality of partnership, physical activity, weight changes, and education are particularly important for HRQoL during the menopausal transition. Women who decreased their physical activity had deterioration in HRQoL compared with women, whose physical activity remained stable. Inversely, women who increased their physical activity improved their HRQoL. These improvements are likely mediated through greater thermoregulatory control in response to increases in core temperature and enhanced vascular function in the cutaneous and cerebral circulations. Mechanisms involved include a decreased hypothalamic endorphin concentration and declining estrogen production, whereby the release of norepinephrine and serotonin is facilitated. Most likely, improvement of HRQoL by exercise is secondary to the reduction of hot flushes. Exercise may ameliorate vasomotor symptoms by increasing the presence of hypothalamic and peripheral b-endorphin production [1].

The decrease of HRQoL in women suffering from any severe acute or chronic disease may be superimposed on the decrease of HRQoL induced by menopause itself. The impact of coronary heart disease, a frequent disease in postmenopausal women, will serve as an example. Coronary risk factors are highly prevalent among older women and the main cause of death. About one-third of middle-aged women have hypertension. Over one-quarter of these are cigarette smokers, over one-quarter are also overweight. Modifiable coronary risk factors tend to predominate in populations of lower socioeconomic status as well as lower educational levels. Other long-standing metabolic consequences of the climacteric include osteoporosis and osteoporotic fractures skin changes, the general aspects of weight gain and obesity as well as degenerative disease of the central nervous system (CNS). Investigation on the effect of estrogen and other sex hormones on the vascular system, immunity, CNS performance, or musculoskeletal disease is constant, with particular allusion to the cellular level. Awareness of symptoms, nevertheless, and their effect on the everyday life of women, will support the care-giver in given women with proficient care and enduring specialized aid throughout the aging process. It will indeed be appropriately supportive to offer objective evidence about an individual's symptoms of the climacteric woman that might affect her QoL [1].

The effect of menopause on body fat distribution is uncertain, but some studies suggest that menopause is associated with an accumulation of central fat and intra-abdominal fat. Although weight gain during menopause is a normal phenomenon, few studies have proved the relationship between menopausal status and weight gain. The relationship between obesity and health-related quality of life (HRQoL) has been widely investigated that obesity has been associated with compromised HRQoL and psychological well-being. The prevalence of obesity and obesity-linked illnesses is increasing, particularly in the urban environment. Therefore, poor physical functioning and reduced QoL attributable to being overweight are important in terms of public health and should be addressed by preventive measures and interventions to promote healthy living. Most general population studies conclude that QoL in many persons with obesity is suboptimal. The association between obesity and HRQoL is stronger in women than in men, in both physical and mental or psychosocial dimensions [21].

Many tools have been developed for the assessment of the HRQoL in aging and climacteric women. Myra Hunter developed her Women's Health Questionnaire (WHQ) as a self-reported measure of physical and emotional experience and functioning of women aged 45–65 years. The WHQ was used both in epidemiological and intervention studies. A revised WHQ comprises six domains with 23 items. The MENQOL was developed by a group of researchers from Canada during the mid-1990s. The final 32-item menopause-specific HRQoL instrument encompasses four subscales (physical, vasomotor, psychosocial, and sexual) plus one overall HRQoL item. As with the WHQ, no overall score can be obtained, because the relative contribution of each domain to such an overall score is unknown. The Menopause Rating Scale (MRS) was initially developed to provide the physician with a tool to document specific climacteric symptoms and their changes during treatment. The original physician-based scale was revised concerning the layout and some adjustments regarding the number, structure, and wording of items; these were made to support applicability as a self-administered questionnaire.

The MRS finally went through factor analysis of 11 standardized items encompassing 3 domains: psychological, somato-vegetative, and urogenital dimensions. The scoring is based on a five-point Likert scale, ranging from no symptoms to mild, moderate, marked, or severe complaints. It should be regarded as a brief and compact instrument, easy to complete and to score, and suitable for routine controls. It covers the key complaints of women during and after menopause. It is, however, not tailored to detail specific therapies to the needs of each individual woman. A large variety of linguistic validations of the MRS has created an excellent international response and acceptance [1]. Menopause-specific quality of life (MENQOL) talk about perceptions of women living with the menopausal change or premature postmenopause, employing methods to measure, bother and interference with aspects of daily living related to symptoms presented throughout the menopausal transition. The MENQOL questionnaire and the Women's Health Questionnaire (WHQ) clarify the menopause-detailed valuation of QoL [22].

Menopausal Hormone Therapy (MHT) for menopausal symptoms includes use of estrogens, alone or in combination with aprogestogen, tibolone or a blend of estrogens, and selective estrogen-receptor modulators (SERMs). Although MHT is the best effective treatment for menopausal vasomotor symptoms, it has no indication for all women, such as those with a personal history of breast cancer [23]. Despite the negative impact that the results of the WHI study had over patients' and clinicians' attitudes toward menopausal hormone therapy (MHT) [24]; to date, it is still the most effective option for the management of hot flushes and other symptoms related to the menopause. In fact, there is a current consensus to recommend the use of lower dosages and the non-oral route. Emerging data associated to effects of hormone therapy for MENQOL have continued to progress during this period, as well as a growth of novel investigations. Some search complementing evidence for MHT and QoL measure are the menopause strategies: finding lasting answers to symptoms and health (MS-FLASH) trials, the selective estrogens, menopause, and response to therapy (SMART) trials assessing results of combinations of conjugated estrogen therapy (CET) with bazedoxifene, a selective ET receptor modulator (SERM), and Kronos Early Estrogen Prevention Study trial. Besides, researchers have conducted search analyzing use of MHT that contain a diversity of progestins (drospirenone) [22].

New and innovated technologies for hormonal delivery may have a better impact on MHT compliance shortly. Providing a combination of E/P in a parenteral monthly formulation with the presently suggested lower dosages and using a new technology that offers persistent plasmatic levels over time, will have a positive long-term outcome on compliance. It has just reported an optimistic pilot experience in taking care of vasomotor and urogenital atrophy symptoms with three low-dose continuous sequential monthly parenteral formulations of 17b-estradiol (E)/progesterone (P) employing innovative non-polymeric microsphere technology [25]. Later was presented the short-term effect of the same proposed schemes over secondary endpoints (menopausal symptoms and QoL). After 6 months, there was an improvement of menopausal symptoms for all groups [26].

The non-hormonal treatment of menopausal symptoms possibilities includes daily life modifications, régime and food supplements, non-hormonal drugs, and behavioral, alternative, or complementary therapies. While various are effective, for others the data are doubtful. Though, for women who cannot or do not desire to take estrogens, non-hormonal managing is now a real option. For instance, soy isoflavones, coumestans, and lignans are all phytoestrogen supplements that have been suggested as substitutes to MHT for vasomotor symptoms. Phytoestrogens are present in soybeans, hops, flaxseed, fruits, vegetables, whole grains, and legumes. These options have been proposed to have estrogenic or anti-estrogenic effects in human beings. Extracted or synthesized soybean isoflavones have been discovered to diminish hot flush occurrence and seriousness. Nevertheless, a latest meta-analysis establishes that there is no convinced evidence that phytoestrogen supplements successfully reduced the frequency or severity of vasomotor symptoms in perimenopausal or climacteric women. A non-hormonal pharmacological possibility is selective serotonin-reuptake inhibitors (SSRIs) and serotonin-norepinephrine-reuptake inhibitors (SNRIs), which have been suggested as an option to MHT for treatment of hot flushes. SSRIs, (paroxetine, escitalopram, citalopram, and sertraline) have been proven and are helpful in falling both frequency and severity of hot flushes. Paroxetine appears to have the best evidence base of efficacy and was approved by FDA for the treatment of menopausal hot flushes. SNRIs (venlafaxine, desvenlafaxine) have been tried to treat menopausal symptoms, mainly in women in whom MHT is not indicated, and desvenlafaxine is approved for vasomotor symptoms associated to menopause in Mexico [23].

4. Menopause and hormones

Menopause is a period of life when the ovaries are depleted of oocytes and the cyclical action of gonadotrophins, peptides, and steroids is disappeared. Age at menopause reveals the complex networks of health and socioeconomic aspects involving ethnicity, diet, education, oral contraceptive use, weight, occupation, exposure to endocrine disturbing substances, alcohol consumption, smoking, and physical activity [27]. Menopause is an indicator event in a woman's life that marks the end of reproductive capability. Although the age-related loss of vaginal bleeding in women has been described throughout history has been recognized the dramatic reduction in the amount of follicles within the ovary as a function of age, determining that the loss of both germ cells and the hormone-producing cells that help them is critical to the disappearing of menstrual function in women. Menopause is identified by the final menstrual period (FMP), but this diagnosis can only be made retrospectively after a year of amenorrhea and happens at an average age of 51 [28]. In Mexico, the average age is 47.6 [29].

The development of reproductive aging, though, is slow, starts before the FMP, and can be defined as limiting (1) an early phase in which compensatory modifications in the hypothalamus, hypophysis, and ovary facilitate the preservation of both reproductive capability and gonadal hormone secretion; (2) an interval categorized by clear irregularity in follicle progress, ovarian secretion, and resulting symptoms precede to the FMP; and (3) constant and low ovarian hormone secretion [28]. The menopause has important effects on the functions of endocrine, cardiovascular, skeletal, immune, and genitourinary systems. Gonadal hormones affect much of the processes mainly by their effects on steroid binding proteins and receptors, but the changes in lifestyle with aging are also influential [27]. Detailed ultrasonographic show the changes in ovulatory function with reproductive aging largely define the hormonal changes, menstrual cycle patterns, and symptomatology that occur as the FMP approach [30].

Reproductive aging in women is mainly produced by the continuing, and finally quickening deficit of ovarian follicles. The related decay in inhibin B secretion from the ovaries ends in the disappearing of negative feedback on FSH. Inside the ovary, FSH stimulated follicle growth and estrogen synthesis and secretion. With additional follicle loss, these compensatory hormonal processes are no longer enough and follicle development come to be irregular in advance to additional loss of ovarian function results in the stable but very low estradiol levels that exemplify the postmenopause [28].

Several of the biochemical variations at climacteric period are due to estrogen and or progesterone diminution. Both steroids act through cytoplasmic receptors and two receptors for respectively steroid, alpha, and beta (ER-α and ER-β; PR-α and PR-β) are now recognized, occasionally antagonize each other. Isoforms of every receptor be present that have dissimilar tissue expression conformations and purpose which marks gene expression in normal and tumor tissue, therefore ligand treatment. ER-α is largely expressed in reproductive tissues, breast, kidney, bone, adipose tissue, and liver. ER-β is existent in ovary, CNS, lung, colon, kidney, and immune system. PR-α and PR-β are almost equal in configuration with the exception of PR-β having a supplementary 164 amino acids at the N terminus. PR-α and PR-β are expressed similarly in human tissues [27].

The 2001 Stages of Reproductive Aging Workshop (STRAW) and the 2011 STRAW + 10 proposed nomenclature and a staging system for ovarian aging including menstrual and qualitative hormonal criteria to define each stage. The STRAW staging system is extensively considered in the gold standard for describing reproductive aging through menopause. The menopausal shift signs a stage of physiologic changes as patients get close to reproductive senescence. Proof endorses the clinical significance of the transition for many patients as a phase of progressive fluctuations in health and QoL (i.e., vasomotor symptoms, insomnia, and MDD) and longer-term variations in numerous physical consequences (i.e., urogenital symptoms, bone, and lipids) that might impact women's QoL and the probability of healthy aging. As a standardized staging scheme for reproductive aging, STRAW is a huge influence to patient's health investigation by giving trustworthy categorization of menopause status for investigations of midlife patients. Significantly, STRAW helped investigation that proposed to differentiate the health effects of ovarian versus somatic aging. The STRAW staging system also helps as a clinical instrument for women and their healthcare providers to monitor the valuation of fertility, contraceptive needs, and healthcare decision making [31].

STRAW distributed the adult female life into three extensive phases: reproductive, the menopausal transition, and postmenopause. The late reproductive phase indicates the time when fecundability starts to decay and during which a woman might observe variations in her menstrual cycles. Given that significant endocrine factors start to change before obvious variations in menstrual cyclicity and that these endocrine fluctuations are crucial to fertility assessment. Early menopausal evolution is discernible by amplified inconsistency in menstrual cycle extent, conceptualized as a persistent difference of 7 days or more in the length of consecutive cycles. Persistence is defined as recurrence within 10 cycles of the first variable length cycle [31].

Cycles in the initial menopausal transition are also defined by high but varying early follicular phase FSH levels and low antimüllerian hormone (AMH) levels and antral follicle count (AFC). The late menopausal transition is apparent by the manifestation of amenorrhea of 60 days or longer. Menstrual cycles in the late menopausal transition are exemplified by augmented inconsistency in cycle length, severe changes in hormonal amounts, and elevated frequency of anovulation. In this stage, FSH levels are occasionally raised into the menopausal range and sporadically within the span typical of the initial reproductive years, mainly in relationship with elevated estradiol levels. The elaboration of international criteria and the accessibility to fundamental population-based information now allow the definition of quantitative FSH criteria, with levels greater than 25 IU/L in a random blood draw typical of being in late transition, founded on actual international pituitary criteria that approximate more than 40 IU/L in the earlier used urine-based gonadotropin standards. First-hand analyses should be initiated to verify this reference, and investigators and clinicians should prudently estimate the proper FSH value, subject on the test they employ. Founded on investigations of menstrual calendars and on changes in FSH and estradiol, this phase is expected to persist, on average, 1–3 years. Vasomotor symptoms are probable to be present during this phase. Novel data on the routes of change in mean levels of FSH and estradiol indicate that FSH continues to rise and that estradiol continues to decline until around 2 years after the FMP, after which the levels of each of these hormones stabilize. The late postmenopause characterizes the interval in which supplementary variations in reproductive endocrine function are more delimited and processes of somatic aging become of principal worry. Symptoms of vaginal dryness and urogenital atrophy become progressively more prevalent at this time. Nevertheless, several years after menopause, it has been perceived that there may be an added drop in levels of FSH in very old women; forthcoming investigations will be required to define whether a supplementary stage is necessary close to the end of life [31].

Investigations in younger and older climacteric patients insinuate that consequences of aging on the hypothalamus and pituitary are present and those are autonomous of the disappearance of steroid feedback. Following menopause there is a 30–40% reduction in LH and FSH between the ages of 50 and 75. Lie beneath these gonadotropin differences are intricate consequences of aging on GnRH secretion, with a 22% reduction in GnRH pulse frequency that is slightly balanced by a 14% rise in the total quantity of GnRH secreted over that owing to the deficit of ovarian function only. There are also age-related outcomes at the pituitary, with a 30% lessening in both LH and FSH responses to GnRH in older in comparison with younger climacteric patients. Estrogen-negative feedback at the hypothalamic point continues complete in older contrasted with younger postmenopausal patients; low-dose estrogen prescription is related with a substantial descent in circulating levels of LH, FSH, and free alpha-subunit and a parallel reduction in the total concentration of GnRH, with no effect on pulse frequency. Adding of progesterone diminished pulse frequency in younger and older climacteric patients with an associated reduction in total quantity of GnRH.

The outcome of estrogen-negative feedback on the LH response to GnRH is not predisposed by aging even though the FSH response to GnRH is weakened with aging. Numerous reports have proposed that sensitivity to estrogen-positive feedback may be absent with aging in women [28]. Hormone measurements other than FSH during the perimenopause are usually considered to be of little diagnostic value. The transition may take four or more years [27].

In the late perimenopause, where extended cycles (≥60 days) predominate, 60–70% cycles are anovulatory. Regarding the steroid hormone secretion patterns, when ovulatory cycles do happen, the cycle may seem normal, overlaid on one another or have a prolonged follicular phase named as a lag phase. While the initial perimenopause is considered by instabilities in the timing and regulation of ovulation, the advanced perimenopause is distinguished by rareness of ovulation derived to the original ovarian follicle reduction. In the late perimenopause, although AMH has decreased to imperceptible levels, inhibin B frequently persists measureable, particularly if there is still residual follicle function. Both gonadotropins are considerably high and show substantial cyclical differences. FSH amounts can be at their most irregular throughout the late perimenopause. The function that very low AMH amounts to participate in the interference of ovulatory function in the perimenopause continues indeterminate but given its close link with the total non-growing follicle (NGF) pool and primordial follicle recruitment and the intricacy of underlying follicle wave action, it is likely to be crucial [30]. In the initial 1–2 years after the FMP, intermittent follicle growth is obvious in single women. Harmonious with these studies, epidemiologic reports employing sensitive estradiol assays prove a farthest decrease from the FMP to the estradiol lowest point 2 years ahead. Subsequently, estradiol levels persist low and stable. FSH levels also continue steady between 2 and 8 years after the FMP but decay over time such that FSH drops by 30% by around age 75, as does LH. Nevertheless women are no longer concerned by irregular bleeding or breast tenderness, hot flashes may continue for up to 7 years after the FMP, and with lengthy hypoestrogenism, the genitourinary syndrome (GSM) of menopause may appear as a novel clinical symptom [28].

5. Menopause and associated health problems

The transition to menopause is characterized mainly by elevated levels of follicle-stimulating hormone (FSH) and low serum levels of estradiol, which gives rise to the presence of the characteristic symptoms (hot flashes, menstrual irregularities, sleep disruption, mood swings, headache, and genitourinary syndrome) [32]. 80% of women suffer physical and psychological symptoms throughout menopause with different degrees of seriousness and influence on QoL [4]. Clinicians and women usually identify the transition to menopause by the onset of menstrual irregularities [5, 6]. This period called perimenopause is variable but can range from 5 to 10 years before menopause.

The Study of Women's Health Across the Nation (SWAN) is a longitudinal, epidemiologic study designed to examine the physical, biological, psychological, and social changes during their intermediate years when they are suffering from menopausal transition that evaluated a total of 3302 women from different ethnic among 42 and 52 years old with a follow up for 15 years. The scientific areas of study assessed: bone mineral density and body composition, cardiovascular measures/risk factors, ovarian markers, vaginal, urogenital and sexual health, physical functioning, sleep quality, psychosocial factors, and epidemiologic factors. The results of this study contributed to define The Stages of Reproductive Aging Workshop (STRAW), a staging system that categories reproductive life stages of adult women en three main categories: reproductive, menopausal transition, and postmenopause [33].

During the late reproductive year's, progesterone levels in the luteal phase decrease and the follicular phase is shortened from 14 to 10 days, including the decrease in inhibin B and a slight increase in FSH levels with preserved levels of estradiol, which gives rise to menstrual irregularities. The levels of antimüllerian hormone (AMH) and the count of antral ovarian follicles diminish too [32]. As time goes (around 2 years since last menstrual period), the FSH levels continue to rise and estradiol levels start falling and for the next 3–6 years estradiol, AMH and inhibin B levels are even lower, at this time is when the symptoms of genitourinary syndrome (GSM) could be more severe [32, 34, 35]. Contraception should be a part of any counseling during the menopausal transition due to the presence ovulatory cycles that can still occur until 12 months of amenorrhea have occurred [32].

The body mass index (BMI), lifestyle factor like tobacco use could influence the timing of the physiologic changes, but not in the path of change in bleeding patterns or hormonal levels with reproductive aging [31]. Some situations like the surgical menopause caused after a hysterectomy may not let us know when is the patient is in transition to menopause, the only way we could evaluate objectively this stage of life is by endocrine markers of ovarian aging, it is necessary to mention that 3 months after surgery high levels of transient FSH may occur, so for an accurate diagnosis, a new measurement of estradiol or serum FSH is required [36].

The bleeding patterns may not be a reliable parameter for evaluating reproductive aging owing to different endocrine disorders like polycystic ovarian syndrome or any other chronic illness or medications like cancer treatment among other situations that can also affect menstrual patterns or even cause amenorrhea [32]. It is well known that alkylating agents used as chemotherapeutic medication may lead to temporary elevated levels FSH and a decline of AMH and ovarian antral follicle count (AFC), but with time menstruation may resume [37–39]. Women in treatment with tamoxifen may also have altered hormone levels and abnormal bleeding patterns [40].

During this life stage period, serum cortisol levels also increases as well as adrenal androgen levels (androstenediol, dehydroepiandrosterone sulfate). In thyroid function for the moment, there is no information about disorders related to menopause so far [32]. After the cessation of ovarian function, the production of estrogen comes from the aromatization of androgens in the ovarian stroma and, in less quantity, from extragonadal sites mainly the adipose tissue. Hence, it is expected that obese women present vasomotor symptoms more frequently and/or intensively.

Hot flashes, which may be accompanied with some other symptoms like flushing of the face, neck, and upper chest; palpitations; chills; and/or anxiety are some of the vasomotor symptoms [32] that occurs in up to 80% of women, frequently associated with diminished sleep quality [41, 42] irritability, difficulty concentrating, reduced quality of life (QoL) [43], and poorer health status [35]. Some researchers are looking for the relationship with the presence of hot flashes with markers of cardiovascular risk, in order to identify a vulnerable vascular phenotype [44].

Of all possible etiologies of headache, tensional headache is the most common. Migraine-type headache can increase during menopause due to hormonal changes. Tensional-type headache usually shows a favorable response to non-steroidal therapy and can be prevented altogether with tricyclic antidepressants instead of hormonal therapy alone. Non-cyclical hormonal therapies are recommended to minimize headache due to hormonal treatment. Women who suffer migraine headache with aura or other risk factors of CVD can benefit from progesterone-only therapy, like the levonorgestrel intrauterine system, etonogestrel subdermal implant, depo-medroxyprogesterone acetate, or progestin-only contraceptives [32].

The symptoms of genitourinary syndrome (GUS), which may comprise signs and symptoms associated to the hypoestrogenism of the menopause involving changes to the labia, vagina, urethra, and bladder and includes vulvovaginal atrophy [45]. Symptoms are genital dryness, burning, and/or irritation; sexual symptoms of diminished lubrication and pain; and urinary symptoms of urgency, dysuria, and recurrent urinary tract infections (UTIs) [35]. Signs include changes in the skin consequently of the reduction blood flow to the vagina and vulva, the external genitalia reveals less pubic hair and less elasticity of the vulvar skin with introital narrowing and possible changes in the architecture, such as the loss of the labia minora, usually we could appreciate this changes about 3 years after menopause, although approximately 20% of women may report some symptoms in the early or late transition of menopause [46]. Topical estrogen is the best treatment for the relief of vulvovaginal symptoms and current therapeutic therapy, among the options for topical administration include creams, gel, vaginal tablets, or even vaginal ring [34]; other therapeutic options are vaginal lubricants and moisturizers. It is necessary to mention that also systemic estrogen preparations with or without progesterone provide excellent vaginal therapy [32].

Low-dose vaginal estrogen preparations are effective and generally safe treatments in women with actual diagnosis or history of breast cancer and treatment with tamoxifen, that with the non-hormonal treatments did not present relief of the symptomatology, there is lees information about treatment with aromatase inhibitors, taking into account that vaginal estrogen preparations can be absorbed systemically in a minimal amount. Less data are available on the creams containing conjugated estrogens than on those containing 17B-estradiol [47].

Menopause is associated with an increase in skeletal, joint, and muscle symptoms [43]. Estrogen binds on estrogenic receptor on joint tissues, protecting their biomechanical structure and function and maintaining overall joint health, but the exact effect of estrogen on osteoarthritis remains controversial [48–50]. Arthralgias increase with age, also rheumatic disorders incidence has an augment. Women who are obese or depressed may have marked symptoms, nevertheless it seems to be an association with joint pain or stiffness and menopausal transition, these symptoms could be alleviated with estrogen therapy alone or with combination therapy of estrogen and progestin, women in the WHI and some other studies have shown less joint pain or stiffness compared with those on placebo [32, 51].

In 2010, it was estimated that 21% of women in the European Union between 50 and 84 years old have osteoporosis. Osteoporosis, along with osteoarthritis, sarcopenia, and frailty, is considered a part of the so-called musculoskeletal aging phenotype. Adverse outcomes such as falls, fractures, functional deterioration, and increased morbidity can impact quality of life. The clinical complications of osteoporosis are fractures of the hip, wrist, and vertebral bodies. Worldwide, 8.9 million fractures occur annually due to osteoporosis, resulting in a fragility fracture every 3 seconds, which is associated with pain and decreased physical and social function in menopausal women [52].

Cardiovascular disease (CVD) is main etiology responsible of mortality in postmenopausal population. Menopause, itself, increases the risk of CVD no matter the age [53]. There is evidence that the use of estrogenic therapy has beneficial effects in cardiovascular mortality in many ways, some of them includes the reduction diminish of low-density lipoproteins levels and increased levels of high-density lipoprotein as well as the improved endothelial function in the coronary vasculature [32].

The reanalysis of older studies such as the WHI study and the recent studies suggest that in case of no contraindication, the benefits of hormone therapy outweigh its risks, with fewer CVD events in younger versus older women [54].

Venous thromboembolism (VTE) has an augmented incidence when is related to the usage of hormonal therapies for menopause, it is supposed to increase twofold or threefold the risk, presenting a higher risk with oral formulations. Transdermal preparations of estrogen or estrogen and progestins combined and vaginal estrogen preparations did not appear to increase the risks of VTE [55]. In a meta-analysis of women who started HRT less than 10 years following menopause beginning or who were younger than 60 years, robust sign of augmented jeopardy of VTE was seen in the horn therapy group related to placebo (RR 1.74; 95% CI, 1.11–2.73) [56]. Minor doses of oral ET may give reduced VTE risk than higher doses [57], but related RCT evidence is requiring.

Talking about hormone therapy and breast cancer may result controversial, the effect of hormone therapy on breast cancer risk may depend on the type of the formulation, dose, and duration regimen, route of administration, prior exposure, and individual characteristics [35]. In the WHI study, the incidence of breast cancer increased in the estrogen-progestogen cohort and decreased in the estrogen-only and placebo groups. Contrarily, hormone therapy users had more localized tumors and improved survival rates [32]. The NAMS do not recommended the prescription of systemic hormone therapy for survivors of breast cancer, although selected cases may be discussed in conjunction with an oncologist after non-hormone options have been unsuccessful. If the patient refers moderate to severe GSM symptoms, low-dose vaginal estrogens, may be considered after a failed trial of non-hormone therapies and with consultation of the oncologist in charge of the case [35]. Options for symptom management include non-hormonal moisturizers, vaginal estrogens, androgens, selective modulators of the estrogen receptor (SERM).

The skin is another target where the hypoestrogenism may have manifestations after menopause, it is altered by epidermal and dermal thickness, decreased collagen and elastin content, consequently more laxity and wrinkles, many women could also experience hair loss. Estrogen therapy may benefit wound healing through modifying inflammation, stimulating granulation tissue formation, and accelerating re-epithelialization. In studies, ET increased epidermal and dermal thickness, increased collagen and elastin content, and improved skin moisture, with fewer wrinkles [58]. It may be relevant to perform scrutiny studies to those women with hair loss like thyroid function, serum iron, and androgens in order to exclude other pathologies [32].

Cholelithiasis, cholecystitis, and cholecystectomy occur more frequently in women who take oral estrogen, presumably because of the first-pass hepatic effect after oral ingestion, so systemic hormone therapy should be prescribed with caution in women with known gallbladder disease [32, 35]. Estrogens increase biliary cholesterol secretion and saturation, promote precipitation of cholesterol in the bile, and reduce gallbladder motility, with increased bile crystallization [59, 60]. The transdermal route of administration could be the best option for this kind of patients [61].

In epileptic patients, menopause can present at earlier age. The cause of this could be related to the number of crisis the woman presents during her life and the anticonvulsants she uses as treatment, specifically the ones that are metabolized by the hepatic enzyme cytochrome p450, which also affects estrogen levels. It is common that women with epilepsy present seizures during the menopausal transition due to the hormonal fluctuations. It is important to note that some anticonvulsants agents may accelerate the metabolism of vitamin D, which possibly increasing the risks of osteopenia [32].

6. Menopause and psychiatric disorders

One of the most consistent findings in psychiatry and psychology is that from menarche onwards females are at higher risk than males of developing both depressive and anxiety disorders. This sex difference remains robust throughout the lifespan, including old age, in the years beyond the reproductive period. The extensively reported link between puberty, the perinatal period, and menopause and excessive amounts of anxiety and depressive symptoms has directed several researchers to suggest the concept of reproductive-related disorders (RRDs). These psychiatric conditions are said to include a collection of disorders categorized by their connection to reproductive processes and a maladaptive response by patients defined as being "genetically vulnerable" to normal hormonal variations. Other authors have examined not only the validity of such a construct, but also with respect to menopause, whether the marked cross-cultural changes in menopausal symptoms support this hypothesis [62]. While most women do not suffer negative mood consequences during menopausal transition, the risk to develop a major depression disorder (MDD) or depressive symptoms throughout perimenopause is greater than in the premenopausal stage. Nevertheless, estimates from individual studies are diverse and hence the true risk estimate is unknown [63].

Depression (at both the symptom and the disease level) was related with poorer QoL, and that this link appeared to be stable over time. Getting better from MDD after treatment resulted in higher QoL, and the QoL improved even in patients who did not fully recover from the depressive episode. Since MDD affects QoL negatively irrespective of medical health, it is imperative to identify MDD and treat MDD patients. Consequently, it is importantly suggested that the health personnel in specialist and primary healthcare settings have a dual treatment perspective, including both psychological and physical health [64].

MDD is an incapacitating disorder, which frequently directs to substantial personal, societal, and economic costs. It affects 20% of adults in the US, and women are known for being overly more affected than men. The roots of such increased risk (2-fold on average) have been the subject of discussion and research from diverse perspectives—from epidemiology to genetics, from copying strategies to hormone variations. Windows of risk for MDD—also known as reproductive-related depressive episodes—are probable linked with an augmented sensitivity suffered by several women to variations in the hormonal situation that happen throughout the luteal phase of their cycles, in the course of the postpartum phase, and/or throughout the menopause transition [65]. The odds-on depressive symptoms in perimenopause are doubled when associated to the premenopause and similar when compared to the postmenopause. Furthermore, throughout the perimenopausal phase, women describe a higher level of depressive symptoms severity when compared to the premenopause but not to the postmenopause. Moreover, there are signs for a positive connexion between vasomotor complaints and MDD during the perimenopause [63]. The presence of a menopause-associated depression, though, has been a more discussed issue. While it is irrefutable that variations in sex hormones and metabolism may affect QoL and overall functioning among certain women throughout midlife years, supplementary aspects—not connected to the menopause transition—may also influence MDD at this stage in life, involving comorbid medical illnesses, cardiovascular complications, vasomotor symptoms (VMS), sleep disorders, and stressful life events [65].

It is suggested that declines in estrogen around menopause are associated with declines in cognitive functioning as well as increased risk of depressive symptoms and depressive disorders. Estrogen promotes neuronal growth and survival and acts on the cholinergic system, which is closely linked to cognitive functioning, particularly memory. Several studies suggest that cognitive function supported by the prefrontal cortex may be particularly sensitive to estrogen. Estrogen also has a role in neurotransmitter systems involved in depression. For instance, estrogen acts as a serotonergic agonist/modulator by increasing receptor binding sites, synthesis, and uptake in animal models and postmenopausal women and numerous longitudinal studies have demonstrated an increased risk of depressed mood in the menopausal transition compared to the premenopausal stage. The peri- and post-menopausal phases are linked with declines in delayed verbal memory compared to premenopause. Moreover, the postmenopausal stage is linked with reductions in phonemic verbal fluency contrasted to perimenopause. Evidences propose that women are at a meaningfully augmented risk of getting MDD, as determined either by symptom inventory or by structured clinical interviews, in the peri- and post-menopausal stages than in premenopause [66].

The strengthened burden related with depression, at any point in time, is undisputable. Thus far, the existence and perseverance of symptoms of depression over time—symptoms that do not reunite criteria for MDD—may furthermore trigger anyway psychosocial difficulties and negatively impact total health. It is, consequently, significant that physicians maintain a tighter surveillance and regularly re-evaluate the necessity for treatments to resolve depressive symptoms (e.g., low mood, reduced psychological energy and pleasure with habitual activities, and sleep problems), whether by employing pharmacologic options, behavioral/lifestyle modifications, or supplementary alternatives. An important amount of both cross-sectional and prospective reports have discovered a possible relationship between different menopause staging and the risks for depressive symptoms or MDD (new onset or recurrent). In general, information from cross-sectional trials show that symptoms of depression can be found by up to 70% of patients throughout perimenopause contrasted with almost 30% in premenopausal period. Longitudinal studies can describe the ideal approach for evaluating the link between reproductive staging and MDD, have also proposed an augmented risk (1.5- to 3.0-fold) for symptoms of depression during the menopause transition. This augmented risk was documented even between women with no preceding episodes [65].

Longitudinal trials have acknowledged possibility reasons for the presence of midlife MDD that appear persistent during the lifetime; they establish a continuum of risk for MDD and very likely function as regulating aspects. These aspects can be considered as: (1) demographic or socioeconomic (i.e., unemployment, low education, and being black or Hispanic); (2) health-related (e.g., greater body mass index, being a smoker, reporting poor health, and decreased functioning due to chronic medical diseases); and (3) psychosocial (e.g., reduced social care, record of anxiety, and one or more stressful life events). A prior MDD episode signifies the robust prognosticator for MDD throughout midlife years, while antecedents of mood symptoms with a hormone-related background (i.e., history of premenstrual syndrome/PMDD or postpartum depression) have been discreetly related to MDD during the menopause phase and initial postmenopausal years [65].

Investigators also explored the causative role of timing-related, context-related influences. Once more, results from cross-sectional and longitudinal investigation were valued foundations and helped to recognize in facilitating or triggering elements linked to menopause-related MDD. These elements include: (1) hormone changes (i.e., the occurrence of wider variations in follicle-stimulating hormone [FSH] and estradiol [E2] levels over time); (2) menopause-related symptoms (e.g., existence and seriousness of VMS and insomnia); and (3) global health (current poor health and low functioning because long-lasting diseases). Psychosocial stressors (including poor social help and stressful life events—the latter not only considered by the severity and number of episodes but also founded on the timing of their manifestation linked to the menopause transition per se) [65].

Nevertheless, symptoms of MDD such as insomnia and low energy in midlife women may be challenging to differentiate from menopausal symptoms and may not often reveal an MDD. They might also be associated to symptoms of the menopause such as VMS. This is reliable with the results of investigations of depressive symptoms, which demonstrate that they are more frequent throughout the menopausal transition in comparison with both pre and postmenopausal stages. It is too reliable with the remark that depressive symptoms could growth around the postmenopausal phase as somatic symptoms progressively become less frequent and/or severe, and that they can improve with the management of central menopausal symptoms such as VMS [67]. Also, psychological aspects as inter-personal relations, role, and sociocultural factors are defined as predictors for MDD during menopause [63].

Antidepressants are the first-line management of MDD around midlife years, mainly for women who had suffered numerous MDD episodes before (not always hormone-related) and women describing serious symptoms, important functional harm, and/or communicating suicidal thoughts. For recurrent episodes, a prior response to a particular antidepressant (agent or class) must lead the main resolution on what to use initially. For women facing MDD for the first time, women who never received treatment before, or women with antecedents of partial/no response to antidepressants before, current evidence confirmed the efficacy and tolerability of numerous SSRIs and SNRIs at typical doses; there are trials on fluoxetine, sertraline, venlafaxine, citalopram, escitalopram, duloxetine, and desvenlafaxine [65]. In a recent published paper, data support further study of vortioxetine for treating menopausal depression and associated symptoms (VMS) and was generally well-tolerated [68].

The association between depression and menopause has been extensively explored, but the study of anxiety remains largely neglected. This is surprising, since symptoms of anxiety in the community are more common than those of depression, and generalized anxiety disorder (GAD) is the second most prevalent psychiatric disorder in the primary care setting [62]. Peri- and post-menopausal phases represent a window of risk for emergence of anxiety symptoms and disorders in the life cycle of adult women. Compared to MDD, anxiety symptoms and disorders remain mainly unknown throughout this period of a woman's life, regardless of major impact on QoL if not identified and treated [69]. 'Anxiety' is a general term that can opaque the important difference between anxiety symptoms and anxiety disorders. Anxiety includes various symptoms such as feeling on edge, worrying, specific fears, and physiological arousal, and these may be distressing to the patient. Anxiety disorders, however, are defined by reference to specific criteria, and have much lower prevalence than anxiety symptoms. Most of the investigations reviewed measured anxiety symptoms, rather than anxiety disorders. There are physical correspondences between anxiety symptoms, particularly panic attacks and VMS. These include increasing sensations of heat through the chest and head, palpitations, and sweating connected with increased metabolic rate and noradrenergic dysregulation. It is not clear, however, whether body sensations of anxiety come first VMS or vice versa. The up-to-date data based on large community-based investigations proposes that psychological symptoms during the menopause transition are related with known risk factors for anxiety and MDD, including stressful life events. An additional cognitive aspect that could be significant for comprehending the link between anxiety and VMS is that of catastrophic thinking. It is well-known that catastrophic thinking has a negative effect on perceived symptom seriousness in chronic health diseases. Those who report increased catastrophic thoughts also be likely to register poorer perceived control over their hot flashes [62].

Investigation has showed that sleep problems are frequent in middle-aged women, among whom the frequency of sleep problems has been observed to elevate in the period between pre- to peri- and post-menopause. While the precise process causing the connexion between elevated sleep troubles and the development of menopause is not completely recognized, it is probably linked to establish relationship between sleep disturbances. It has been found that VMS and depressed mood at this period in a woman's life are closely related, women who suffer from VMS and sleep troubles, 30% of them were severely depressed. The results of one study were that the findings of this study show that difficulty in initiating sleep (DIS) is meaningfully connected with anxiety and non-restorative sleep (NRS) is meaningfully related with MDD in peri- and post-menopausal women in a clinical scenery. Those who describe suffering DIS or NRS may be highly probable to likewise be experiencing anxiety or MDD, correspondingly, signifying that management of these problems might increase the related insomnia symptoms in this group [70].

Multiple randomized controlled trials (RCTs) support the efficacy of SSRIs and serotonin-norepinephrine reuptake inhibitors (SNRIs) as first-line treatments for anxiety disorders. An analysis of 12 RCTs in panic disorder found a mean effect size for SSRIs relative to placebo of 0.55. In the case of GAD, response rates for SSRIs of between 60 and 75% are generally reported in RCTs, compared to response rates between 40 and 60% for placebo. Data suggest that post-traumatic stress disorder (PTSD) may be less amenable to current pharmacotherapy compared to other anxiety disorders. A Cochrane review of pharmacotherapy for PTSD including 35 RCTs and 4597 participants did support the use of SSRIs as first-line medication treatment. The benzodiazepines (BZD) play a significant position in the management of several anxiety disorders; but, these drugs are commonly kept for second-line or accessory utilization because of their tolerability and abuse danger issues. BZD possess the benefit of a fast onset of action, tempting their employment premature in the process of management preceding to the onset of action of a co-administered SSRI/SNRI. Information backing the longer-term efficacy of BZD is more inadequate [71]. BZD inappropriate use (i.e., misuse and overuse) is a global public health concern. Regardless of existing information about augmented sensitivity to adverse effects in the elderly that should guide to additional carefulness. Only 30% of BZD prescriptions in these women are believed correct. The largely prevalent deficient conditions are disproportionate length and/or dosage of a medical prescription or self-medication, particularly in a situation where it would be contraindicated, for example, long-acting BZD in the elderly. Polypharmacy and comorbidities are the main risk factors. Results of benzodiazepines incorrect employment are falls, delirium and other cognitive dysfunction, acute respiratory failure, traffic accidents, abuse, addiction, and withdrawal symptoms. A developing apprehension is a possibly elevated risk of dementia. Opposing many physicians' idea, discontinuation of long time BZD use in elderly patients is achievable, with acceptable psychotherapeutic or pharmacological options, and can direct to long-term abstinence [72]. Anticonvulsants, including gabapentin and pregabalin, have mixed data to support efficacy in certain anxiety disorders. The data for second-generation antipsychotics (SGAs) in anxiety disorders are likewise mixed [71].

7. Menopause and sexual disorders

Female sexual dysfunction (FSD) and QoL are both multidimensional and have a bidirectional relationship across the reproductive life span and beyond. Methodological difficulties exist in assessing the actual prevalence of FSD because it is difficult to define the level of distress related to sexual symptoms. Around 40–50% of women present at least one sexual symptom, and various disorders related with hormonal variations at menopause, such as vulvovaginal atrophy (VVA) and hypoactive sexual desire disorder (HSDD), have an important influence on sexual function and QoL. Sexual troubles reach a highest point at midlife, decay with age, and are importantly partner-associated [73].

Although in human's sexual drive and performance are to some degree untied from sex hormones, menopause is the most studied medical condition in the framework of FSD from a biological perspective since there is a strong state of hormonal deficiency. Both the substantial descent in blood estrogen levels with natural menopause and the androgen reduction with age and, ultimately, with surgical menopause, have been exposed to back, to a distinct degree, to sexual complains such as low desire, reduced excitement, dyspareunia, orgasm difficulties, and diminished sexual gratification. In contrast, menopause impacts psychologic and cognitive characteristics of sexuality throughout the variation in blood sex hormones, but this could be partially related on the particular antecedents of the specific patient. The mainly important factors are age, global and mental health, and attainment of reproductive objectives, education, body image, self-esteem, values and experiences. Even length and quality of relationship, and global and sexual health of the sexual partner, are significant [73].

Sexual health and function are important goals in the management of menopausal women. The majority of these women wants their sexuality to be a significant part of their life and intensely desire to maintain a healthy and satisfactory sexual life. Nevertheless, the risk of having a disease that negatively affects sexual satisfaction and function as well as the risk for using prescription drugs that have an adverse impact in sexual function increases as women age. Although sexual dissatisfaction and dysfunction are highly predominant in peri- and post-menopausal women, few reveal their concerns to the health care provider. Age-related declines in sexual function may meaningfully reduce QoL [74].

Sexual function decays throughout midlife. The Study of Women's Health Across the Nation and other related observed that this drop links with the menopausal period, including in women who experience hysterectomy. Though symptoms such as vaginal dryness rise during the same interval, variations in sexual functioning are unrelated of other symptoms linked to the menopausal period. Decrease in sexual frequency throughout this period of life is multifactorial. One main factor that women do not participate in sexual activity is absence of a sexual partner. Women who are more sexually active previously menopause appear to remain to participate in sexual behaviors during midlife, even with reduced "functional sex." Lifestyle situations, including enough sleep and exercise, contribute to better sexual functioning during midlife [75, 76].

Vulvovaginal atrophy (VVA) is an important factor of genitourinary syndrome of menopause (GSM) and can end in postcoital vaginal bleeding, vaginal burning, irritation, and pain and distress with sexual behavior. Symptomatic GSM is frequently associated by reduced secretions from vulvar sebaceous glands and decreased vaginal lubrication during sexual arousal. Hypo-estrogenic climacteric patients frequently face a change of the vaginal microbiome from lactic acid-producing lactobacilli to gram-negative and -positive bacteria. This change in the vaginal microbiome causes raising of the vaginal pH, local immune changes, and increased cytokine synthesis, which exacerbates symptoms of vaginal dryness and burning and raise the risk of sexual dysfunctions.

Pelvic organ prolapses (POP) consist of descent of one or more woman reproductive organs (anterior and/or posterior vaginal wall, the uterus or the apex of the vagina). The occurrence of pelvic floor relaxation rises with elderly and is theorized to appear from a mixture of connective tissue degradation, pelvic denervation, and devascularization, all of which prompt to prolapse. Dyspareunia, chronic pelvic pain, and poor self-image are related with POP. All of these undesirable physical alterations can destroy sexual desire and performance. Many medical problems, like diabetes, hypertension, and breast cancer, and their treatments, have been related with female sexual dysfunction. These conditions become more common as women move through midlife. Other medications have been associated with FSD. Among the most common responsible factors is the use of antidepressants. Although MDD itself is associated with sexual dysfunction, odds of sexual dysfunction are 4–6 times higher for women taking an antidepressant. Sexual side effects are less common with bupropion and mirtazapine [75].

The presence of MDD and anxiety symptoms during the menopausal period is frequent. Mood disorders and sexual dysfunction are significantly comorbid, with 25–75% of depressed women reporting sexual symptoms even when treating for other problems. It is important for health personnel to screen women with sexual complaints for MDD and anxiety disorders and be aware of that not all women with FSD have a MDD or an anxiety disorder. Common life stressors also have an undesirable influence. Midlife women may be look after for children of their own, may have adult offspring at home, and/or may attend to aging parents. Job-associated stress and economic worries are also frequent. Health personnel must be familiar to the costs of life stressors and convince patients to cultivate stress diminution approaches, like mindfulness meditation or exercise.

Patients who suffered or are victims of violence and abuse are at augmented risk for FSD, with those who suffered sexual abuse, up to 44% of women over their lifetime, at predominantly elevated jeopardy. The link between abuse antecedent and FSD is not totally explicated by psychiatric disorders, such as MDD, anxiety, and post-traumatic stress disorder (PTSD). It is significant to utilize evidence-based, trauma-informed management tools to ask for these experiences when treating patients with FSD. Helping women preserve healthy sexual function with aging is a crucial element of preserving QoL into older adulthood [75].

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References

[1] Schneider HPG, Birkhäuser M. Quality of life in climacteric women. Climacteric. 2017;**20**:1-8. DOI: 10.1080/13697137.2017.1279599

[2] Ceylan B, Özerdoğan N. Menopausal symptoms and quality of life in Turkish women in the climacteric period. Climateric. 2014:1-8. DOI: 10.3109/13697137.2014.929108

[3] Potter B, Schrager S, Dalby J, Torell E, Hampton A. Menopause. Primary Care; Clinics in Office Practice. 2018;**45**: 625-641. DOI: 10.1016/j.pop.2018.08.001

[4] McKinlay SM, Jefferys M. The menopausal syndrome. British Journal of Preventive & Social Medicine. 1974;**28**:108-115

[5] Freeman EW, Sammel MD, Lin H, Gracia CR, Pien GW, Nelson DB, et al. Symptoms associated with menopausal transition and reproductive hormones in midlife women. Obstetrics & Gynecology. 2007;**110**(2 Pt 1):230-240

[6] Freeman EW, Sammel MD, Grisso JA, Battistini M, Garcia-Espagna B, Hollander L. Hot flashes in the late reproductive years: Risk factors for african american and caucasian women. Journal of Women's Health & Gender-Based Medicine. 2001;**10**:67-76. DOI: 10.1089/152460901750067133

[7] Freedman RR. Physiology of hot flashes. American Journal of Human Biology. 2001;**13**:453-464

[8] Kronenberg F. Hot flashes: Epidemiology and physiology. Annals of the New York Academy of Sciences. 1990;**592**:52-86. Discussion 123-33

[9] Freeman EW, Sammel MD, Lin H, Liu Z, Gracia CR. Duration of menopausal hot flashes and associated risk factors. Obstetrics and Gynecology. 2011;**117**(5):1095-1104. DOI: 10.1097/AOG.0b013e318214f0de

[10] Avis NE, Crawford SL, Greendale G, BrombergerJT,Everson-RoseSA,GoldEB, et al. Study ofWomen's Health Across the Nation (SWAN). Duration of menopausal vasomotor symptoms over the menopause transition. JAMA Internal Medicine. 2015;**175**(4):531-539. DOI: 10.1001/jamainternmed.2014.8063

[11] Gracia CR, Sammel MD, Freeman EW, Lin H, Langan E, Kapoor S, et al. Defining menopause status: Creation of a new definition to identify the early changes of the menopausal transition. Menopause. 2005;**12**(2):128-135. DOI: 10.1097/01.GME.0000141980.81159.B2

[12] Nelson DB, Sammel MD, Freeman EW, Lin H, Gracia CR, Schmitz KH. Effect of physical activity on menopausal symptoms among urban women. Medicine and Science in Sports and Exercise. 2008;**40**(1):50-58

[13] Greendale GA, Gold EB. Lifestyle factors: Are they related to vasomotor symptoms and do they modify the effectiveness or side effects of hormone therapy? The American Journal of Medicine. 2005;**118**(Suppl. 12B):148-154

[14] Munro MG, Critchley HO, Broder MS, Fraser IS; FIGO Working Group on Menstrual Disorders (2011) FIGO classification system (PALM-COEIN) for causes of abnormal uterine bleeding in non gravid women of reproductive age. International Journal of Gynecology and Obstetrics. 2011;**113**:3-13

[15] American College of Obstetricians and Gynecologists. ACOG committee opinion No. 440: The role of Transvaginal ultrasonography in the evaluation of postmenopausal bleeding. Obstetrics and Gynecology. 2009;**114**(2 Pt 1):409-411

[16] Lumsden MA. The NICE guideline menopause: Diagnosis and management. Climacteric. 2016;**19**(5):426-429. DOI: 10.1080/13697137.2016.1222483

[17] FSRH Clinical Effectiveness Unit. FSRH Guideline Contraception for Women Aged Over 40 Years. August 2017 (Updated October 2017)

[18] Power M, Kuyken W. The World Health Organization quality of life assessment (WHOQOL): Development and general psychometric properties. Social Science & Medicine. 1998;**46**(12):1569-1585

[19] Ceylan B, Özerdoğan N. Menopausal symptoms and quality of life in Turkish women in the climacteric period. Climacteric. 2014;**17**(6):705-712. DOI: 10.3109/13697137.2014.929108

[20] Utian WH. Psychosocial and socioeconomic burden of vasomotor symptoms in menopause: A comprehensive review. Health and Quality of Life Outcomes. 2005;**3**:47. DOI: 10.1186/1477-7525-3-47

[21] Ghazanfarpour M, Abdolahian S, Zare M, Shahsavari S. Association between anthropometric indices and quality of life in menopausal women. Gynecological Endocrinology. 2013;**29**(10):917-920. DOI: 10.3109/09513590.2013.819078

[22] Woods NF. Quality of life, menopause, and hormone therapy: An update and recommendations for future research. Menopause. 2018;**25**(7):713-720. DOI: 10.1097/GME.0000000000001114

[23] Mintziori G, Lambrinoudaki I, Goulis DG, Ceausu I, Depypere H, Erel CT, et al. EMAS position statement: Non-hormonal managementof menopausal vasomotor symptoms. Maturitas. 2015;**81**(3):410-413. DOI: 10.1016/j.maturitas.2015.04.009

[24] Blümel JE, Castelo-Branco C, Chedraui PA, Binfa L, Dowlani B, Gómez MS, et al. Patients' and clinicians' attitudes after the women's health initiative study. Menopause. 2004;**11**(1):57-61. DOI: 10.1097/01.GME.0000075503.60230.61

[25] Cortés-BonillaM,Bernardo-EscuderoR, Alonso-Campero R, Francisco-Doce MT, Hernández-ValenciaM,Celis-GonzálezC, et al. Treatment of menopausal symptoms with three low-dose continuous sequential 17β-estradiol/progesterone parenteral monthly formulations using novel non-polymeric microsphere technology. Gynecological Endocrinology. 2015;**31**(7):552-559. DOI: 10.3109/09513590.2015.1019853

[26] Cortés-Bonilla M, Alonso-Campero R, Bernardo-Escudero R, Francisco-DoceMT,Chavarín-GonzálezJ, Pérez-Cuevas R, et al. Improvement of quality of life and menopausal symptoms in climacteric women treated with low-dose monthly parenteral formulations of non-polymeric microspheres of 17β-estradiol/progesterone. Gynecological Endocrinology. 2016;**32**(10):831-834. DOI: 10.1080/09513590.2016.1183628

[27] Honour JW. Biochemistry of the menopause. Annals of Clinical Biochemistry. 2018;**55**(1):18-33. DOI: 10.1177/0004563217739930

[28] Hall JE. Endocrinology of the menopause. Endocrinology and Metabolism Clinics of North America. 2015;**44**(2015):485-496. DOI: 10.1016/j.ecl.2015.05.010

[29] Blümel JE, Chedraui P, Calle A, Bocanera R, Depiano E, Figueroa-Casas P, et al. Age at menopause in Latin America. Menopause. 2006;**13**(4):706-712. DOI: 10.1097/01.gme.0000227338.73738.2d

[30] Hale GE, Robertson DM, Burger HG. The perimenopausal woman: Endocrinology and management. The Journal of Steroid Biochemistry and Molecular Biology. 2014;**142**:121-131. DOI: 10.1016/j.jsbmb.2013.08.015

[31] Harlow SD, Gass M, Hall JE, Lobo R, Maki P, Rebar RW, et al. STRAW + 10

Collaborative Group Executive summary of the stages of reproductive aging workshop + 10: Addressing the unfinished agenda of staging reproductive aging. The Journal of Clinical Endocrinology and Metabolism. 2012;**97**(4):1159-1168. DOI: 10.1210/jc.2011-3362

[32] Bacon JL. The menopausal transition. Obstetrics and Gynecology Clinics of North America. 2017;**44**(2):285-296. DOI: 10.1016/j.ogc.2017.02.008

[33] Sowers M, Crawford S, Sternfeld B, Morganstein D, Gold E, Greendale G, et al. SWAN: A multi-center, multi-ethnic, community-based cohort study of women and the menopausal transition. In: Lobo RA, Kelsey J, Marcus R, editors. Menopause: Biology and Pathobiology. San Diego: Academic Press; 2000. pp. 175-188. ISBN 0124537901, 9780124537903

[34] Lethaby A, Ayeleke RO, Roberts H. Local oestrogen for vaginal atrophy in postmenopausal women. Cochrane Database of Systematic Reviews. 2016;(8):CD001500. DOI: 10.1002/14651858.CD001500.pub3

[35] The NAMS 2017 Hormone Therapy Position Statement Advisory Panel. The 2017 hormone therapy position statement of the North American Menopause Society. Menopause. 2017;**24**(7):728-753. DOI: 10.1097/GME.0000000000000921

[36] Qu X, Cheng Z, Yang W, Xu L, Dai H, Hu L. Controlled clinical trial assessing the effect of laparoscopic uterine arterial occlusion on ovarian reserve. Journal of Minimally Invasive Gynecology. 2010;**17**(1):47-52. DOI: 10.1016/j.jmig.2009.10.001

[37] Broekmans FJ, Soules MR, Fauser BC. Ovarian aging: Mechanisms and clinical consequences. Endocrine Reviews. 2009;**30**(5):465-493. DOI: 10.1210/er.2009-0006

[38] Irene Su H, Sammel MD, Green J, Velders L, Stankiewicz C, Matro J, et al. Antimullerian hormone and Inhibin B are hormone measures of ovarian function in late reproductive-aged breast cancer survivors. Cancer. 2010;**116**(3):592-599. DOI: 10.1002/cncr.24746

[39] Sukumvanich P, Case LD, Zee KV, Singletary SE, Paskett ED, Petrek JA, et al. Incidence and time course of bleeding after long-term amenorrhea after breast cancer treatment. Cancer. 2010;**116**(13):3102-3111. DOI: 10.1002/cncr.25106

[40] Welt CK, Pagan YL, Smith PC, Rado KB, Hall JE. Control of follicle-stimulating hormone by estradiol and the Inhibins: Critical role of estradiol at the hypothalamus during the luteal-follicular transition. The Journal of Clinical Endocrinology and Metabolism. 2003;**88**(4):1766-1771. DOI: 10.1210/jc.2002-021516

[41] Randolph JF Jr, Sowers M, Bondarenko I, Gold EB, Greendale GA, Bromberger JT, et al. The relationship of longitudinal change in reproductive hormones and vasomotor symptoms during the menopausal transition. The Journal of Clinical Endocrinology and Metabolism. 2005;**90**(11):6106-6112. DOI: 10.1210/jc.2005-1374

[42] Thurston RC, Joffe H. Vasomotor symptoms and menopause: Findings from the study of women's health across the nation. Obstetrics and Gynecology Clinics of North America. 2011;**38**(3):489-501. DOI: 10.1016/j.ogc.2011.05.006

[43] Nelson HD. Menopause. Lancet. 2008;**371**(9614):760-770. DOI: 10.1016/S0140-6736(08)60346-3

[44] Thurston RC, Chang Y, Barinas-Mitchell E, Jennings JR, Landsittel DP, Santoro N, et al. Menopausal hot flashes and

carotid intima media thickness among midlife women. Stroke. 2016;**47**(12):2910-2915. DOI: 10.1161/STROKEAHA.116.014674

[45] Portman DJ, Gass ML, Vulvovaginal Atrophy Terminology Consensus Conference Panel. Genitourinary syndrome of menopause: New terminology for vulvovaginal atrophy from the International Society for the Study of Women's sexual health and the north American menopause society. Menopause. 2014;**21**(10):1063-1068. DOI: 10.1097/GME.0000000000000329

[46] Tang MX, Jacobs D, Stern Y, Marder K, Schofield P, Gurland B, et al. Effect of oestrogen during menopause on risk and age at onset of Alzheimer's disease. Lancet. 1996;**348**(9025):429-432

[47] ACOG committee opinion No. 659: The use of vaginal oestrogen in women with a history of oestrogen dependent breast cancer. Obstetrics and Gynecology. 2016;**127**:e93-e96

[48] Xiao Y-P, Tian F-M, Dai M-W, Wang W-Y, Shao L-T, Zhang L. Are oestrogen-related drugs new alternatives for the management of osteoarthritis? Arthritis Research & Therapy. 2016;**18**:151. DOI: 10.1186/s13075-016-1045-7

[49] de Klerk BM, Schiphof D, Groeneveld FP, Koes BW, van Osch GJ, van Meurs JB, et al. Limited evidence for a protective effect of unopposed oestrogen therapy for osteoarthritis of the hip: A systematic review. Rheumatology. 2009;**48**(2):104-112. DOI: 10.1093/rheumatology/ken390

[50] Watt FE. Hand osteoarthritis, menopause and menopausal hormone therapy. Maturitas. 2015;**83**:13-18. DOI: 10.1016/j.maturitas.2015.09.007

[51] Barnabei VM, Cochrane BB, Aragaki AK, Nygaard I, Williams RS, McGovern PG, et al. Women's Health Initiative Investigators. Menopausal symptoms and treatment related effects of oestrogen and progestin in the women's health initiative. Obstetrics and Gynecology. 2005;**105**(5 Pt 1): 1063-1073. DOI: 10.1097/01.AOG.0000158120.47542.18

[52] Ciubean AD, Ungur RA, Irsay L, Ciortea VM, Borda IM, Onac I, et al. Health related quality of life in Romanian postmenopausal women with osteoporosis and fragility fractures. Clinical Interventions in Aging. 2018;**13**:2465-2472. DOI: 10.2147/CIA.S190440

[53] LaCroix AZ, Chlebowski RT, Manson JE, Aragaki AK, Johnson KC, Martin L, et al. WHI Investigators. Health outcomes after stopping conjugated equine oestrogens among postmenopausal women with prior hysterectomy: A randomized controlled trial. Journal of the American Medical Association. 2011;**305**(13):1305-1314. DOI: 10.1001/jama.2011.382

[54] Manson JE, Chlebowski RT, Stefanick ML, Aragaki AK, Rossouw JE, Prentice RL, et al. Menopausal hormone therapy and health outcomes during the intervention and extended poststopping phases of the women's health initiative randomized trials. JAMA. 2013;**310**(13):1353-1368. DOI: 10.1001/jama.2013.278040

[55] Bergendal A, Kieler H, Sundström A, Hirschberg AL, Kocoska-Maras L. Risk of venous thromboembolism associated with local and systemic use of hormone therapy in peri-and postmenopausal women and in relation to type and route of administration. Menopause. 2016;**23**(6):593-599. DOI: 10.1097/GME.0000000000000611

[56] Boardman HMP, Hartley L, Eisinga A, Main C, Roqué i Figuls M, Bonfill Cosp X, et al. Hormone therapy for preventing cardiovascular disease in post-menopausal women.

Cochrane Database of Systematic Reviews. 2015;(3):CD002229. DOI: 10.1002/14651858.CD002229.pub4

[57] Speroff L. Transdermal hormone therapy and the risk of stroke and venous thrombosis. Climacteric. 2010;**13**(5):429-432. DOI: 10.3109/13697137.2010.507111

[58] Emmerson E, Hardman MJ. The role of estrogen deficiency in skin ageing and wound healing. Biogerontology. 2012;**13**:3-20. DOI: 10.1007/s10522-011-9322-y

[59] Everson GT, McKinley C, Kern F Jr. Mechanisms of gallstone formation in women. Effects of exogenous estrogen (Premarin) and dietary cholesterol on hepatic lipid metabolism. The Journal of Clinical Investigation. 1991;**87**(1):237-246. DOI: 10.1172/JCI114977

[60] Cirillo DJ, Wallace RB, Rodabough RJ, Greenland P, LaCroix AZ, Limacher MC, et al. Effect of estrogen therapy on Gallblader disease. Journal of the American Medical Association. 2005;**293**(3):330-339

[61] Marjoribanks J, Farquhar C, Roberts H, Lethaby A, Lee J. Long-term hormone therapy for perimenopausal and postmenopausal women. Cochrane Database of Systematic Reviews. 2017;(1):CD004143. DOI: 10.1002/14651858.CD004143.pub5

[62] Bryant C, Judd FK, Hickey M. Anxiety during the menopausal transition: A systematic review. Journal of Affective Disorders. 2012;**139**(2):141-148. DOI: 10.1016/j.jad.2011.06.055

[63] de Kruif M, Spijker AT, Molendijk ML. Depression during the perimenopause: A meta-analysis. Journal of Affective Disorders. 2016;**206**:174-180. DOI: 10.1016/j.jad.2016.07.040

[64] Sivertsen H, Bjørkløf GH, Engedal K, Selbæk G, Helvik AS. Depression and quality of life in older persons: A review. Dementia and Geriatric Cognitive Disorders. 2015;**40**(5-6):311-339. DOI: 10.1159/000437299

[65] Soares CN. Depression and menopause: Current knowledge and clinical recommendations for a critical window. The Psychiatric Clinics of North America. 2017;**40**(2):239-254. DOI: 10.1016/j.psc.2017.01.007

[66] Weber MT, Maki PM, McDermott MP. Cognition and mood in perimenopause: A systematic review and meta-analysis. The Journal of Steroid Biochemistry and Molecular Biology. 2014;**142**:90-98. DOI: 10.1016/j.jsbmb.2013.06.001

[67] Judd FK, Hickey M, Bryant C. Depression and midlife: Are we overpathologising the menopause? Journal of Affective Disorders. 2012;**136**(3):199-211. DOI: 10.1016/j.jad.2010.12.010

[68] Freeman MP, Cheng LJ, Moustafa D, Davies A, Sosinsky AZ, Wang B, et al. Vortioxetine for major depressive disorder, vasomotor, and cognitive symptoms associated with the menopausal transition. Annals of Clinical Psychiatry. 2017;**29**(4):249-257

[69] Siegel AM, Mathews SB. Diagnosis and treatment of anxiety in the aging woman. Current Psychiatry Reports. 2015;**17**:93. DOI: 10.1007/s11920-015-0636-3

[70] Terauchi M, Hiramitsu S, Akiyoshi M, Owa Y, Kato K, Obayashi S, et al. Associations between anxiety, depression and insomnia in peri- and postmenopausal women. Maturitas. 2012;**72**(1):61-65. DOI: 10.1016/j.maturitas.2012.01.014

[71] Murrough JW, Yaqubi S, Sayed S, Charney DS. Emerging drugs for the treatment of anxiety. Expert Opinion on

Emerging Drugs. 2015;**20**(3):393-406. DOI: 10.1517/14728214.2015.1049996

[72] Airagnes G, Pelissolo A, Lavallée M, Flament M, Limosin F. Benzodiazepine misuse in the elderly: Risk factors, consequences, and management. Current Psychiatry Reports. 2016;**18**(10):89. DOI: 10.1007/s11920-016-0727-9

[73] Nappi RE, Cucinella L, Martella S, Rossi M, Tiranini L, Martini E. Female sexual dysfunction (FSD): Prevalence and impact on quality of life (QoL). Maturitas. 2016;**94**:87-91. DOI: 10.1016/j.maturitas.2016.09.013

[74] Thornton K, Chervenak J, Neal-Perry G. Menopause and sexuality. Endocrinology and Metabolism Clinics of North America. 2015;**44**(3):649-661. DOI: 10.1016/j.ecl.2015.05.009

[75] Thomas HN, Neal-Perry GS, Hess R. Female sexual function at midlife and beyond. Obstetrics and Gynecology Clinics of North America. 2018;**45**(4):709-722. DOI: 10.1016/j.ogc.2018.07.013

[76] Avis NE, Colvin A, Karlamangla AS, Crawford S, Hess R, Waetjen LE, et al. Change in sexual functioning over the menopausal transition: Results from the study of women's health across the nation. Menopause. 2017;**24**(4):379-390. DOI: 10.1097/GME.0000000000000770

Section 4

Psychological Perspectives

Chapter 6

Sport for the Subjective Dimensions of Quality of Life

Janka Peráčková and Pavol Peráček

Abstract

Sport is a social phenomenon. The positive influence of sport helps improve the quality of life of a person. Subjective dimensions of quality of life can be perceived as person's individual perception of his/her life experience with all the influences he/she encounters and how they affect him or her. The aim of this chapter will be to broaden the knowledge with regards to effects of sport on subjective dimensions of quality of life. 196 (sport active) and 149 (sport inactive) adolescents were the research sample for questionnaire research (Q-LES-Q, SWLS). Two subjective dimensions of quality of life gave evidence that sporting activity positively influenced the perception of dimension of quality of life enjoyment and satisfaction and the dimension of global satisfaction with life among adolescents. Sport active boys are statistically significantly more satisfied with the domain quality of life enjoyment and satisfaction in comparison to sport inactive boys ($p = 0.027$). No statistical difference was found in domain quality of life enjoyment and satisfaction between sport active girls and sport inactive girls. In the global satisfaction with life we found out the statistical difference between sport active boys and sport inactive boys ($p < 0.001$) and sport active girls and sport inactive girls ($p = 0.026$).

Keywords: sporting activity, boys, girls, adolescents, quality of life enjoyment, satisfaction with life

1. Introduction

Sociology of sport focuses on the research in the regularity of human social behavior, and sport is such a regular behavior, when applied. Sporting activities and exercising are significant factors for a person's development and his/her integration in the society. Sport, in this way of meaning, is the phenomenon that influences the society. The positive effects of sport improve the quality of life of an individual and fulfill all the human needs on the five-stage pyramid of needs. When sport behavior will convert into practicing sport activities, then the sport will benefit the physical and psychological health, as it is known. We were interested in the topic of how sport can benefit the subjective dimensions of the quality of life. We focus on the dimension of the quality of life enjoyment and satisfaction and the dimension of the global satisfaction with life. We present a general subject area, quality of life, and we lead the context of the research to the topic of the research—subjective dimensions of the quality of life in dependence of gender and activity in sport and exercising. With the help of selected research papers from this field of study, we summarize the background knowledge about the research topic (subjective dimensions of the quality of life) and topic areas, which was created within the quality of life enjoyment and satisfaction (physical health and physical activities, leisure time activities, school environment and school duties, emotions and feelings, taking care of yourself) and global satisfaction with life (satisfaction with life and subjective well-being), for understanding the research problem and offering the readers the introduction to this topic. We know about the lack and insufficient amount of the research papers upon this topic, and we want that our study widens the existing knowledge and brings the results from the small country in the middle of the Europe—the Slovak Republic. We used the quality of life enjoyment and satisfaction questionnaire not for psychiatric patients, as it used to be common, but for the intact school sport active and sport inactive adolescent boys and girls.

The purpose of this chapter was to broaden the knowledge in this area of research. And the following research questions arose:

What effect do sporting activity and exercising have on the perception of the selected areas of quality of life enjoyment and satisfaction (physical health and physical activity, leisure time activities, school environment and school duties, feelings) as part of the subjective dimension of the quality of life in adolescent girls and boys?

What effect do sporting activity and exercising have on the perception of the global satisfaction with life in adolescent girls and boys?

The beginning of adolescence is associated with the first signs of sexual maturity until complete maturation. Adolescence is a period of transition from childhood to adulthood. Adolescence is also associated with complete mental and physical development, which varies for everyone. An adolescent can recognize and can decide if he/she wants to participate in some kinds of sports. Adolescents possess well-developed physical and motor capabilities. The movements of the adolescents are well coordinated, harmonious, and graceful, and they are at the top of their physical performance. They are in a developed cognitive, social, and emotional state. With adolescence increasing the levels of independence, adolescents are capable of taking responsibility for themselves and presenting the solution of ideas as the results of critical thinking. Some may finish their maturation before 18 years of age, but others may not. The statutory maturity is in 18 years of age, but this does not mean that the individual has reached maturity even mentally.

The research about the organization of the adolescents in some forms of sporting activity in the Slovak Republic [1] presented the sample, which consists of 5300 secondary school students of which 2154 were boys and 3146 were girls. A total of 597 male students are said to be organized in some form of exercising or sporting activity (27.7%), and the rest of 1557 male students were not organized in any form of exercising or sporting activity (72.3%) except the school subject physical and sport education. Among female students there were 459 (14.6%) organized, and 2687 (85.4%) were not organized in any extracurricular form of exercising or sporting activity. This research of [1] shows that the organization of male students in some form of exercising activity in Bratislava reached 38%, and 62% male students (n = 1990) were not organized. Among female secondary school students from Bratislava (n = 2646), 21% were organized in some form of exercising or sporting activity, and 79% were not organized.

In this research, which we write on these pages, we realized the questionnaire research in Slovak secondary school, mostly from the capital city Bratislava. The questionnaire for this research content consists of several sample introduction questions (4) and then 50 items from quality of life enjoyment and satisfaction questionnaire (Q-LES-Q) and 5 items from satisfaction with life scale (SWLS). The findings revealed that making and playing sports, realizing sporting activities, and exercising bring benefits to the subjective dimensions of quality of life—the dimension of the global satisfaction with life and the dimension of the quality of life enjoyment and satisfaction, where physical health and physical activities, leisure time activities, social relations, feelings, school environment and school duties, and taking care of yourself were considered. In the introduction part, we present the background of the selected areas of quality of life from the literature review, and then we described the school system in Slovak Republic that concerns physical and sport education, which is for somebody only one possible sporting activity or exercising in a week.

The importance of this research is that we present our research ideas and opinions and we find out new information about life enjoyment and satisfaction and global satisfaction with life among sport active and sport inactive male and female high school students. We feel the shortage of such kind of research, and we present the findings from Slovakia, which can be useful for future scholarly works.

1.1 Quality of life

Quality of life is a social indicator, which affects the whole life of a man. The importance of this field of study is given with the establishment of the global organization International Society for Quality of Life Studies in 1995, with the mission to promote and encourage research in the field of quality of life (QOL), happiness, and well-being studies. Quality of life is the field of study of sociology, and how sport can influence the quality of life is part of the study for sport sociology. Quality of life is a valued societal outcome, and its growing recognition is for the subjective dimensions of the quality of life. An intensive progress of research on quality of life can be observed, not only in health-related issues but in other very specific areas of the research, and sport involvement and participation can be those issues.

There are many definitions and conceptualization of the quality of life (QOL). "Quality of life is multidimensional and influenced by personal and environmental factors and their interaction, and has the same components for all people, and is enhanced by self-determination, resources, purpose in life and a sense of belonging" [2]. The quality of life of an individual depends on many factors. In several explanations of quality of life, we found the emphasis on satisfaction with life [3–8]. According to this understanding, one who is satisfied with his/her life lives better quality of life. The higher the quality of life, the higher is the life satisfaction of the person. The study of [9] has given a theory, which suggests that happiness is primarily a product of the positive assessments of life situations and favorable comparisons of these life situations with those of others and in the past. The concept of quality of life is used in all areas of human existence and all fields of knowledge, including the sport sciences. The quality of life is an open concept, and it changes with the society development.

Three rounds of proposals, comments, and drafts were conducted, to adopt 14 criteria for evaluating quality of life by the policy makers. The criteria for evaluating quality of life indexes for use in public policy are presented [10]. It is worth mentioning the seventh index, which talks that "the domains in aggregate must encompass the totality of life experience." The ninth index presents the requirement that "each domain must have the potential to be measured in both objective and subjective dimension." And the 14th index presents that "the subjective dimension of each domains has both a cognitive and affective component and are measured by the question concerning satisfaction."

Main debates at the core of quality of life definitions are presented [11]. Definitions varied a lot, but they found some consensus within the literature reviews. There are two main approaches to quality of life: objective and subjective. Both subjective and objective information [12] are necessary to assess when considering the quality of life (QOL) even if subjective and objective data are distinct types of information. The authors [13] reported correlation coefficients ranging from 0.04 to 0.57 between objective and subjective indicators suggesting to, although associated, measure different aspects of quality of life. It depends on researchers which perspective (domains, dimensions, aspects, indicators) he/she considers in his/her research and from which point of view he/she looks at the investigated problem. When he/she writes a study only from one side of the problem, it does not mean that he/she does not accept the other side of the problem. The question is also on how many domains can the quality of life concept be divided. The [14] produces a multidimensional profile of scores across 6 domains and 24 sub-domains of quality of life. The main six domains can be listed as physical domain, environmental domain, domain of social relationships, psychological domain, domain for level of independence, and spiritual domain. Based on 16 reviewed publications [15], 19 domains are presented, with the most referenced domain, interpersonal relations (15 times), and the least referenced domain, civic responsibility (once). In the same study [15], core quality of life domains are presented: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. And accordingly, among all core quality of life domains, indicators and descriptors are presented too. The Eurostat quality of life framework focuses on quality of life and [16] presented the following dimensions: material living conditions (income, wealth, and consumption), education, natural and living environment, productive and valued activities (including work), health, leisure and social interactions (inclusion, exclusion), overall experience of life, governance and basic rights, and economic and physical insecurity. All supposed domains are very close each to other and may be the same, because they are presented with synonyms.

The authors [17] subsequently propose a new definition in which quality of life is defined as "the gap between what a person is capable of doing and being, and what they would like to do and be; in essence it is the gap between capability reality and expectations." Quality of life is enhanced when the distance between the individual's attained and desired goals is less [18]. For [19], a person's well-being can be assessed in terms of his/her capability to achieve personally and socially valued functioning. Quality of life has become the crucial determination of the life cycle [11]. The quality of life is perceived differently in a different life stage of age. The quality of life is taken as the degree of satisfaction in life. The term quality of life [20] is a manifestation of self-realization within the framework of contemporary civilizational development. Quality of life from the psychological side is, according to [21], "an expression of the feeling of life happiness."

The concept of quality of life records the growing interest in the recent time. It questions what quality of life is. For some scholars it is the measure of subjective well-being; for some others, it is the indicator of physical health. The statement of [7] is that quality of life takes under the umbrella a variety of concepts such as life conditions, health status, lifestyle, happiness, or behavior. The quality of life, as [4] said, reflects the harmonious satisfaction of personal goals and desires. The subjective side of quality of life has important dimensions of happiness and life satisfaction. Someone gives the equal mark between quality of life and life satisfaction.

The quality of life should be measured in physical function, mental status, and ability to engage in normative social interaction, wrote [22].

The quality of life presents several dimensions of physical, psychological, social, and cultural identifications. Quality of life is a complex, multifaceted construct that requires multiple approaches from different theoretical angles [23]. The attributes of quality of life acquired increased importance in research of psychologists, sociologists, educators, physicians, mental coaches, architects, environmentalists, and many others. Authors [24] integrated the multidisciplinary fields of quality of life and viewed quality of life as a multidimensional rather than unidimensional concept. The model of quality of life integrates objective and subjective indicators of several life domains and individual values of that [25]. An overall understanding of subjective well-being requires knowledge of how objective conditions can influence the individual's evaluation of the people's lives, values, experience, and wisdom. The consideration of [7] thought about the quality of life as a subjective evaluation of one's personal life and satisfaction with life. Quality of life seems to be subjective and that it can only be understood from an individual perspective. It would have been easier if researchers could have agreed that the quality of life is taken into consideration and refers only to subjective well-being, said [8]. Strong formulation of [26] is the request of a comprehensive definition with the acknowledgement of the strengths of each position and the agreement that any general definition must include both dimensions.

If quality of life had to comprehend whole human life, then both objective and subjective dimensions must surely be included. Objective dimension refers to resources of included objective external life conditions, and subjective dimension refers to individual's subjective assessment of life. The significance of objective or subjective evaluation of life domain is in relationship to the value that an individual gives to it. The individual with relatively the same objective domains of quality of life can report the different subjective perceptions of quality of life.

A team of authors [6] suggest their own definition of quality of life. "Quality of life is the extent to which objective human needs are fulfilled in relation to personal or group perceptions of subjective well-being. Subjective well-being is assessed by responses to questions about happiness, life satisfaction, utility, or welfare, and the relation between specific human needs and perceived satisfaction is influenced by mental capacity, cultural context, information, education, temperament. In addition, the relation between the fulfilment of human needs and overall subjective well-being is affected by the weights that individuals, groups, and cultures give to fulfilling each of the human needs relative to the others."

The definition stated by the World Health Organization [14] said that the "quality of life is an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, level of independence, social relationships, and their relationship to salient features of their environment." In the social area of researching the quality of life, the quality of life takes the increasingly acknowledged place for measurement as a valid and appropriate indicator of social needs and possible interventions for the individuals and the groups when needed.

Although the quality of life is the socioeconomic concept, it has been given increasing importance to the individual subjective side of quality of life. Authors [27] present evidence suggesting that subjective dimension of quality of life is a cherished societal goal worthy of attention and has utility as a predictor of important life outcomes such as health and longevity, social relationships, and positive work outcomes. Quality of life is the term, which is analyzed in the literature as two major dimensions—objective and subjective dimension [28]. Objective dimension of quality of life focuses on external, quantifiable conditions of life, such as housing, economic situation of a person or a family, access to medical resources, family income level, living environment, climate and subjective approaches, and focus on individual internal evaluations of life conditions (degree of problems, satisfaction, and happiness) [29].

We agree with this statement, and these will be the content of our research in this chapter, in which we focus how sport can affect the subjective dimensions of quality of life.

1.2 Sport for the quality of life

We have recorded that there is a lack of the research unifying people involved in sport, physical activity, exercise with the measurements of their enjoyment, life satisfaction, and the quality of life.

The [30] defines sport as "a game, competition, or activity needing physical effort and skill that is played or done according to the rules, for enjoyment and/or as a job, or all types of physical activity that people do to keep healthy or for enjoyment. Reasons for engagement in sport differ by participants in it. It should to be health, pleasure, competition, challenge, weight management, motor performance, skills acquiring, motor ability and capability and some societal motives, and/or financial reward."

Movement determines life, develops physical fitness, but also has a positive impact on the psychological well-being of a man and hence the quality of his/her life. Sport as an important part of quality of life can bring people the feeling of self-fulfillment. There are few social influences in the world that can equal sports. Sport can be a unifying or sharing power, which reflects development of society, and, in the case where there will be changes in society development, there will be changes in sport too. Sport is an indispensable and universal element of life improvement. The growth of leisure time will offer the occasions for spending time with exercise and sport to secure the positive health.

Sport and exercise are important contributors to the quality of life for everyone. Exercise can be associated with a wide variety of benefits related to the quality of life [31]. In another research of [32], they set the idea that the exercise can influence the participants' quality of life in desirable and undesirable ways: enhanced physical functioning, subjective well-being, exercise enjoyment and peak moments, exercise taxonomy, diverse personal meaning, stress management, opportunities for socialization, delaying the aging process, and enhancement of self-esteem and self-efficacy.

Sporting activities play a crucial role in subjective well-being. Sporting activities provide occasion to meet values and needs of an individual. The thoughts of [11] noted that, if they accept that exercise is a key part of sport and that psychological well-being is a key part of quality of life, then it can be argued that sport has a role to play in the concept of quality of life, and they highlight the lack of research on the benefits of sport and exercise to the quality of life and well-being.

Physical functioning is a main component of the quality of life. Physical functioning is the essence of all daily human activities. Movement is the life. Sport can be performed collectively or individually. Sport can be performed regularly or irregularly. Sport can be performed with or without club membership (professionally or recreationally). Performance and top elite sports are rule-defined activities that are acquired and learned in the training process led by a trainer, coach, or instructor (an authorized person), conducted in competitions and organized on a voluntary basis. Sport for all—recreational or amateur sport—is a recreational activity carried out by various forms of physical exercise, and other movement activities of interest can be sometimes be also as a competition. Sport is the phenomenon of sociocultural life. Sport affects all the social areas, and sport has grown into a phenomenon in the business too, and that is why we can say that it creates the sport sector [33].

In various parts of the world, the authors have shown significantly higher life satisfaction in people participating in physical and sporting activities than in people who did not practice physical and sporting activities [in Turkey and in Germany [34]; in Turkey [35]; in Slovakia [36, 37]; in Sweden [38]; in Taiwan [39]; in America [40, 41]; in Poland [42]; in Spain [43]].

In the research of [44], the quality of life of sporting individuals was investigated. They investigated quantitative and qualitative analysis of overall quality of life according to gender and sport practiced (individual or team sport) for the 16 life domains. The intrinsic value of exercising and sporting activities presents the relation to quality of life and good health.

1.3 Sport for the subjective dimensions of quality of life

The importance of subjectivity in the definition of what quality of life is emerges as a key aspect [45]. The personal and subjective dimension of quality of life could be the basis for a more understanding of person's evaluation of quality of life. For the person it is related to the extent of which the life aims are reached.

For us, each person is individuality and each is different in what he/she considers important and what he/she considers to be an influence on its subjective quality of life. In our opinion the subjective quality of life is the individual's perception followed by the assessment of things, situations, relations, and all the positive, neutral, and negative matters that affect a person's life. Subjective well-being is an appreciation of these matters in a positive way when expectations are fulfilled or achievements are better than expectations. The measurable domains of subjective quality of life are directly proportional to life satisfaction, and when the level of satisfaction is in a positive manner, then it is presented in the happiness of a person. Bear in the mind is needed when thinking about the weight of the importance of life domains in accordance with the person's own values and standards. The personal perception of life values differs a lot among people. Some positive subjective experiences of well-being could be assessed as neutral or even negative for another one person. It depends mainly on personality dispositions, recognition of the inner state of emotions, self-perception of emotions, and then their display in the external world. The aspects of the model of emotion continuance are perception, regulation, and expression of emotions. The emotions play a crucial role in the life of all of us. It is how people feel and how they can function in the family and society; in terms of emotions, a man evaluates his/her life and transforms them into living through subjective well-being.

The subjective meaning of good living is a person's own experience of his/her positive feelings, and [46] spoke about perceptual aspects of quality of life. The report of [47] presents the subjective well-being as a broad category of phenomena that includes people's emotional responses, domain satisfactions, global judgment of life satisfaction, and the personality considered as one of the strongest and most consistent predictors of subjective well-being.

Given the concern for improving subjective dimension of quality of life, many researchers turn the attention to the benefits of physical activity. The research of quality of life with the physical activity are evident in many investigations [48, 49, 32, 36, 37, 50–53]. Sports are the happiest experience of active leisure category reported in the research of [54], where 828 students were participating. Relative declines in physical activity were found to be associated with low life satisfaction among 4025 persons in the study of [40].

Our opinion is that satisfaction in individual areas of life is also closely related to overall person's satisfaction. The quality of life is the result of the interaction of social, health, economic, and environmental conditions relating to personal and social development. Although quality of life (life satisfaction) may be satisfactory in one area, it may be insufficient in other areas. The components of quality of life change over time. The quality of life is also influenced by subjective well-being, which is strongly dependent on the actual emotional state and can fluctuate rapidly.

Sport has positive effects on psychological and physical characteristics of a man. Sport, exercise, and physical activity are central to health and serve as the prevention to illness. Over the past 40–50 years, the young people have become increasingly less physically active, and this behavior can cause some irreversible outcomes. The evidences brought with the Institute of Medicine [55] show that regular physical activity promotes growth and development and has multiple benefits for physical, mental, and psychosocial health. Motion is a valuable activity for all people not only for young people. Everyone has the opportunity to take chances and face the challenges to move and perform some kinds of exercising and sporting activities. Exercising and making and playing sports will guarantee the lifelong benefits, which will be given to their lives and will be converted to higher quality of life and life satisfaction.

1.3.1 The dimension: quality of life enjoyment and satisfaction

Enjoyment is defined as an optimal psychological state that leads to performing an activity for its own sake and is associated with a positive feeling state [56]. Participation in sporting activity depends also from the feelings of enjoyment. A man lives for emotions and, we can say, for positive emotions, which a man searches more. A man exists to be happy, and the purpose of life, for somebody, is to find this happiness with the means of life enjoyment and satisfaction.

By presenting happiness a man considers various factors of his/her life situations and conditions and the feelings from these situations and conditions in comparison and accordance with prior expectations. Happiness according to the consideration of [57] is defined as the moment-to-moment people's feelings and does not always tell how people evaluate their lives or how they function in the world. However, they admit the positive feelings like happiness can lead to better overall well-being. Finding the opportunities to be happy is also one kind of way of increasing people's potential in finding well-being. The author [58] explains the term life enjoyment as a mental happiness from life and the success in it. We support the concept of [54] that enjoyment is pleasure, affect, attitude, intrinsic motivation, and flow. The author [59] considers the quality of life satisfaction as an evaluation of the life with individuals. The parts of life satisfaction are the satisfaction in these areas, for example, family, peers, friends, and mental and physical health.

People who are happy also tend to be satisfied with their lives [26]. If a person experiences his/her life as good and desirable [60], it is assumed to be so. In this approach, factors such as feelings of joy, pleasure, and life satisfaction are paramount. Such measures, while subjective, are a useful complement to objective data to compare the quality of life.

The quality of life satisfaction can be defined by the assessment of the life by individuals or by a one-sided, extensive human satisfaction ratio. Life satisfaction is related to the parts of the life. Parts of the life satisfaction compound the global life satisfaction. Everyone has their own criteria, and they create the quality of life enjoyment for themselves, but everyone looks at the standards of others, which can also affect oneself. For adolescents the quality of life is joined with solving and mastering the problems that life brings.

1.3.1.1 Physical activity and physical health

Physical activity and physical health are hand in hand to better one's life. Health is one of the most important factors affecting an individual's quality of life. In good health, one feels comfortable and well, and at the same time, nothing restrains him/her from doing what he/she wants and what is important for him/her. But health cannot be understood only from a physical point of view but also from a mental and social point of view. For a healthy life, the World Health Organization (WHO) recommended 30 min of moderate physical activity each day [61]. When people highlight the good physical and mental health, they are more likely to highlight also their overall well-being. Improvement in health has an immediate influence on an individual's quality of life. Young people are mostly satisfied with their health.

Regular physical activity boosts the health. In the article of [62], the literature review of the benefits of physical activity is evaluated. In the summary of studies, there is compelling evidence that regular physical activity and a high fitness level are associated with reduced risk of premature death from any cause and from cardiovascular disease among asymptomatic men and women. The people who have the highest level of physical activity and fitness are at lowest risk of premature death. The health-related quality of life (HRQOL) was developed by the Center for Disease Control, Health Care, and Aging Branch [63].

The importance of physical activity is for the primary prevention of type 2 diabetes. Exercise interventions for patients with diabetes are beneficial in improving glucose homeostasis. Physical activity can be helping in the fight with the cancer and osteoporosis. Physical activity need not to be vigorously intense. Every increase in activity adds some benefit to physical health. People of both genders and of all ages benefited from regular physical activity. Most people do not engage in regular sporting activities and exercising despite the indisputable effect of these activities on physical and psychological health. Exercising and making and playing sports for every stage of life are the important strategies for preventing diseases.

To make exercising and sporting activities as a habit, it is needed to build the knowledge and the practices of exercising and sporting activities in the school environment, because these activities can bring positive attitude to school-aged population. This habit can last for an entire life, and exercising and sporting activities will be the activities on a daily basis, because physical activity is recognized as a very important factor in a person's health.

1.3.1.2 Leisure time activities

In order to devote our time to own physical activities, exercise, and sport, it is necessary to have time for these, unless in the case that someone has sport, exercising, and physical activities as a regular job. Time that is devoted to the activities based solely on somebody's own interest decision (I want to do it now) is the leisure time. The leisure time is the time when a person does not perform activities under the pressure of obligations. It is the time that is understood to be the time range that remains for relatively free use after the fulfillment of obligations. The concept of leisure time is to be understood also as a space for self-improvement of the individual and its possibility to fulfill own interests and needs, which can reflect the individual's value system. Sometimes it is defined as a time that remains after school duties and work and nonwork duties; household duties, which must be fulfilled as a member of the family; and satisfaction of the basic biological needs (sleeping, eating). The leisure time should be fulfilled with the leisure time activities, which bring to a person pleasant experience and satisfaction. We can see the leisure time as a time space, with which we can freely dispose of and for an individual it could mean the freedom of decision. It is also a time in which one can freely realize whatever he/she wants, independently of any duty and without subconscious pressure of doing some work and duties. Having the free choices for engagement in leisure time activities, the happiness comes and rises. The research on this matter presented [64] and confirmed that perceived freedom of choice has a major impact on happiness.

Leisure time is a very valuable asset of the nation, and therefore it is important to pay attention to it and create conditions for its active and meaningful fulfillment. To know how to spend the leisure time matters to the families, the school management and the teachers, the social service sector, and the policy makers. Nowadays, it is important that one develops harmoniously, both physically and mentally. Parents, teachers, coaches, and other educators play an important role in this. They all are responsible for leading young people how to spend the leisure time and give the examples. They can provide the time to experience the opportunities and possibilities of spending leisure time with positive activities, which enrich the person. Many times, a child is raised in a family where sport and movement are strongly supported. This is also the reason why the child is more willing to devote the time to exercising and sporting activities.

Leisure time activities are different, as evidenced by the list of more than 250 different forms of leisure time activities published by the World Leisure and Recreation Association (WLRA). A very good idea is when a man decides that his/her leisure time activities will be fulfilled with the sporting activities and exercising, but the most often excuse of not doing these activities is that a man has not enough time.

1.3.1.3 School environment and school duties

Attending the school is compulsory for all children who reached 6 years of age and lasts for 10 long years. Children in this age period spend more time in the school environment than in any other places and must fulfill some school requirements, beginning with the homework and then learning knowledge and preparing all for the next day school duties. In the school and after the school time, there are duties that pupils must manage. Someone is excited when going to school, but not all. School activities are rates below average scores in happiness, while social, active, and passive leisure activities are rated above average of personal happiness [54]. The school helps the students improve academically, socially, and individually. Students are happy in school [65] when they are as a team member to the classroom and school activities, when they are appreciated, and when they succeed and had good social relations. They are unhappy when there are exams in school, homework and home projects, syllabi, teachers, pressure, violence, and punishment [ibid]. School is a place, where school climate, with all the staff and pupils, has a considerable mutual influence on the physical and psychological well-being and the quality of life of children, adolescents, and teachers too.

1.3.1.4 Emotions and feelings

Emotions and feelings influence the behavior. Emotions and feelings should be oriented in a useful manner of behavior. Emotions are important aspects of sporting activities. The emotions occur before, during, or after sporting activities. When these emotions are positive, a man can be keener to realize the activities. Rather than the intensity, the frequency of positive feelings is more important for happiness. It can be said that what a man likes can be made with greater engagement, enjoyment, and satisfaction. If we assume that experience of joy and happiness can improve life, then we can say that sporting activity improves life, because sport brings joy, happiness, and life satisfaction and brings positive feelings to a man. Emotions are also a possible factor of exercising and sporting activities. Exercise reduces stress and increases the feeling of happiness. Measuring feelings is a very subjective matter, which provides an individual evaluation of one's own feelings, education, income, personal fulfillment, family, and other social conditions.

1.3.1.5 Taking care of yourself

It is important to take care of yourself, because it can make the social life easier and can ensure confidence, social relationships, and happier and healthier life. Taking care of yourself means also the interest of your own physical appearance and personal hygiene, to have better life feelings; to manage the needed matters outside of the home, without the help of somebody else; to be able to cope with the occurring problems in your life; and to have good feelings because you can manage it all. Taking care of yourself means also regular exercising, whether it can be a daily walk, jogging, home exercising or going to a gym, or regular participation in organized kinds of sports as an athlete. The time of taking care of yourself covers also the time for relaxing (maybe even time to be lazy for a while), time for sleeping, and time with family and friends, because taking care of yourself is important for your own satisfaction of life and well-being.

1.3.2 The dimension: global satisfaction with life

Global satisfaction with life has its part in subjective well-being and subjective quality of life of people. Measurement of the life satisfaction among adolescents is needed. The comparison with adults can bring some new information to social research.

1.3.2.1 Satisfaction with life and subjective well-being

What is subjective well-being? For one it is only the feeling of positive evaluation of life. For another there are many areas, which influence the life. Areas, which most influence well-being, are in accordance of [66] as follows: physical well-being, economic well-being, social well-being, personal development and development of activities, emotional well-being, psychological well-being, satisfaction with life, specific areas in life and satisfaction within, participation in activities, and participation at work. How man perceives own well-being or lack of well-being accordingly to this he/she evaluates his/her quality of life.

The findings of [48] supported the statement that physical activity can have long-term effects on well-being. Satisfaction with life represents the cognitive dimension of subjective well-being and captures a global sense of well-being from the perspective of the respondent [3, 5]. Subjective well-being is popularly often called happiness. Happiness or subjective well-being is often measured as a part of life satisfaction. In evaluating happiness, it is important to remember that the appreciation and assessment depend on the time of evaluation. If it is evaluated immediately after the experienced situation or after a longer time only as a recall from the memory, there can be some differences in evaluations. The subjective well-being is composed of several separable although somewhat related variables [5]. Measuring national well-being and quality of life [67] in the United Kingdom provides results that younger people (mainly aged 16–24 years) were more likely to report higher ratings of satisfaction with their health and higher ratings of physical activity engagement. Especially the young people in the age range 16–19 years (adolescents) reported a higher level of life satisfaction (9–10 out of 10) than those aged 20–24.

In accordance to [68], well-being is divided into two aspects; these are life satisfaction and personal development. In the year 2015, [69] presented the comparison about the overall quality of life around the world and found out that Northern European nations are at the top of many well-being indicators and many African nations are near the bottom. Life satisfaction is the result of a judgmental process of an individual who assesses the quality of his/her life according to his/her own criteria. In the ideas of [7], the overall satisfaction with life is an indicator of quality of life, because one indicates how satisfied one is with one's life. Subjective well-being comprises people's longer-term levels of pleasant affect, lack of unpleasant affect, and life satisfaction [4]. The report of [70] noticed that satisfaction is an area of psychic phenomena that is classified into the subjective experience sphere of a man. An individual is satisfied when he/she can achieve predetermined goals. The relation between life domain satisfaction and overall life satisfaction, values, and internal/external perceived control has been explored by [71] at the sample of

Spanish adolescents. Individuals having internal perceived control are more likely to report they are satisfied with their overall life.

A large sample of individuals in 21 nations was studied with authors [72] who found that high life satisfaction was associated with not smoking, physical exercise, a healthier diet, and using sun protection, fruit intake, and fat avoidance. The revision of several types of reviewed evidence indicates that higher subjective well-being (such as life satisfaction, absence of negative emotions, optimism, and positive emotions) [73] causes better health and longevity. The study of [74] revealed that participants who were more physically active, than those who were less active, experienced higher levels of mental well-being and were generally more satisfied with their lives. Their findings indicated that participants with a healthy body mass index enjoyed higher levels of life satisfaction than those classified as overweight or obese and showed no significant differences between the gender and age groups. They presented that physical activity strengthens the association with life satisfaction and mental well-being [ibid].

The satisfaction with life is evaluated higher also in physically active disabled people [75, 76] than physically inactive disabled people.

Sport participation may be associated with improved life satisfaction and self-rated health for male and female students from the middle school [41], and the females may view exercise and physical activity as more important contributors to health and well-being as compared to males in the same age of 7 and 8 grades of middle school. Sport, exercise, and physical activity can improve mental health and psychosocial competences and improve mood, happiness, social relations, and other aspects of well-being.

"Global satisfaction with life can be considered to be an indicator of quality of life, because one indicates how satisfied one is with one's life as a whole" [7]. When one manages to realize his/her own plans [36], a person is satisfied. This means that the level of satisfaction is closely related to the personal understanding of quality of life. Global satisfaction with life measures how people evaluate their life as a whole rather than their current feelings. Life satisfaction is in the article of [77] characterized as the cognitive component of subjective well-being, and the author stated that it plays an important role in a healthy successful youth development as an indicator, a predictor, a mediator/moderator, and an outcome. Whereas high life satisfaction is related to good adaptation and optimal mental health, low life satisfaction is associated with psychological, social, and behavioral problems among youth [ibid].

1.4 Sport as a physical activity in the school system

Sport as a physical activity has its place in the life of school pupils, pupils in the child and adolescent age. Adolescence is a transitional period between childhood and adulthood. The body changes are rapid and surprising. To adapt to these changes, the body needs movement. Along with the rapid changes that occur in body proportions, especially the increase in body height and body weight, the physical performance and fitness capability are the issues that increase too.

Sport as an exercising activity is provided by the school in a compulsory subject physical education in kindergarten and from the primary school as a subject physical and sport education, in which its most important mission is to create a relationship to regular physical activity as an essential foundation of a healthy lifestyle. In the year 2008 when the curricular transformation was made, the subject physical education was given the new name, physical and sport education, because sport as a social phenomenon should be a part of educational systems. Theoretical knowledge and practical experience from an amount of traditional and nontraditional sporting activities should be presented and learned in school; then the members of our society should know about them and can use and transfer them to leisure time activities while strengthening the health, compensating the workload, and enjoying the life with the social required and accepted activities. There are more than 55 traditional and nontraditional sporting activities written in curriculum for secondary school that can be selected by the qualified teachers and learned from them during the schooling. The pupils are involved in a year-round sporting competition between classes in the same year of study and classes between different years of study and between local schools in the town, and they can go forward to the school's European championship or school's world championship.

Physical education is a compulsory subject within the educational area "health and movement" from the beginning in the kindergarten International Standard Classification of Education 0 (ISCED 0). The goal of the health and movement educational area is to provide basic health-related information and through appropriate physical exercises lead the child to acquire and improve motor skills and develop motor abilities. The educational area is focused on movement as a means of strengthening health and promoting proper psychosomatic and psychomotor development of preschool children. The child should be motivated to exercise and use it in everyday life without feeling tired or exhausted. An important part of this area is also basic hygiene habits and self-care activities. Physical activities are involved in everyday activities of schooling the kindergarten children.

From the school year 1960/1961 until the end of the school year 1983/1984 had been the schooling at the primary school nine years. From the school year 1984/1985 until the end of school year 1996/1997 had been the schooling at the primary school eight years. Since the school year 1997/1998, primary schools once again have comprised nine grades. These schools consist of two levels, the first level (first–fourth grade) and the second level (fifth–ninth grade), which are usually differentiated according to the interests and skills of students. Students are accepted in the first grade after reaching the sixth year of age. The compulsory education lasts for 10 years. After their graduation from primary schools, students must apply to a secondary school and finish the 10 year compulsory schooling. This means that at least one year must be completed at the selected secondary school.

In the primary education (ISCED 1 and ISCED 2) [78], the educational area health and movement provides pupils with the opportunity to express themselves and acquire basic movement skills that can be used in leisure time activities. The area focuses on basic information related to a healthy way of living, caring for own health, and physical activity. The focus of physical and sport education in primary education is predominantly on physical, functional, and movement enhancement, thus contributing to the strengthening of health, fitness orientation, and motor performance in two 45 min compulsory lessons weekly. Physical and sport education provides elementary theoretical and practical education in the field of movement, exercise, and sport. Physical and sport education significantly contributes to the psychological, social, and moral development of pupils, contributes to the formation of a positive relationship to physical activities, and fulfills a significant compensatory function in the educational process at school.

Physical and sport education uses a wide range of physical means that contribute to the psychological, social and moral development of pupils, with the emphasis on the development of both gross and fine motor skills, and contribute to the formation of a positive relationship to physical activity too, and fulfils a significant compensation function in the process of education. Through movement—movement exercises, games, and competitions—it positively affects the pupils' motor development. Emphasis is placed on the pupils' individual dispositions, which should be considered in content planning and pupil assessment. It is important to motivate pupils to achieve individual improvements in their motor performance while respecting their own individual preconditions. With its focus, physical education has an exceptional and specific position within the education of pupils of the younger school age.

A characteristic feature of the educational area health and movement is the knowledge and practical experience leading to the development of motor skills, improving the pupil's motor performance and acquiring the basics of sports and their use with the prospect of their application in the structure of their own movement regime.

The most important mission is to establish a relationship to regular physical activity as an essential foundation for a healthy lifestyle. The educational area combines knowledge, habits, and skills related to health, healthy lifestyle, and physical and sporting activities not only during schooling but also their use in adulthood. The basic knowledge of the importance of physical and sporting activities for health, disease prevention, proper diet, and sport activities and its evaluation and physical activity means are divided into four modules of education in school: health and its disorders, healthy lifestyle, fitness and motor performance, and sporting activities of movement regime. Pupils finishing study at primary school should have a clear concept of the importance of physical and sport education in strengthening active health; they should know the effect of exercising on the body. They should express their interest in physical activities independently, have a corresponding level of motor abilities in accordance with their motor preconditions, and have acquired physical activities from which they can create movement programs for their own needs.

The secondary education is currently offered within these educational groups: in grammar schools and secondary specialized schools. After the Velvet Revolution in 1989, grammar schools were transformed into a modern type of secondary schools offering general education, which prepares students especially to study at universities and higher forms of education. Subject to the current School Act, the mission of secondary specialized schools is to prepare industrial and technical employees at a secondary educational level for the needs of the labor market and practical life and at the same time, also for their subsequent university or further education. Secondary specialized schools educate specialists for individual industries, such as the construction, transportation, agriculture, food industry, services, economics, financial sector, culture, state administration, and other areas of social life. Secondary specialized schools thus provide education at the third educational level (ISCED 3) for the school-leaving examination but also at the fourth educational level (ISCED 4)—higher vocational education received during further studies leading to a certificate or diploma.

In the secondary education (ISCED 3) [78], the educational area health and movement creates a space of realization and awareness of the need for lifelong care of pupils for their health. The pupils recognize the quality of movement as an important part of his/her general development, and they can choose the movement in terms of occurrence of the needs (for enjoyment, for improving physical fitness, for compensation to work or school duties load). The complex subject and key competences obtained in schooling, with acquired sport skills, should ultimately become part of his/her lifestyle and attitude to life philosophy. Pupils should understand health as a subjective and objective value category; take responsibility for their health; acquire knowledge and skills related to care for their body, active movement regime, movement literacy, personal sport performance, and healthy lifestyle; and learn that prevention is a major tool for health protection.

Physical and sport education is a compulsory subject in both primary and secondary schools. There are two physical and sport education lessons each week. Swimming courses, skiing, snowboard courses, and courses for protecting the life and health are also the basic parts of physical and sport education. One aspect of the school physical education and sport delivery system in Slovakia, which has been in the past years envied by some other countries, is the comprehensive program of extracurricular activity, traditionally serviced by physical and sport education teacher on a voluntary basis. In addition to the compulsory physical and sport education lessons, pupils may attend non-compulsory lessons after school—extracurricular sporting activity.

2. Methods

2.1 Study design and data collection

2.1.1 Participants

A total of 345 adolescents (151 boys and 194 girls) in the decimal age ranging from 15.38 to 19.60 years (whole sample age mean was 17.13 ± 0.92; boys 17.14 ± 0.98; girls 17.12 ± 0.87) were included in the research sample. A total of 196 were labeled as sport active (sample age was 17.10 ± 0.95) and 149 as sport inactive (sample age was 17.16 ± 0.87). Sport active boys were 105 (with age 17.13 ± 1.00); sport inactive boys were 46 (with age 17.16 ± 0.92); sport active girls were 91 (with age 17.07 ± 0.88); and sport inactive girls were 103 (with age 17.16 ± 0.86). Sport active respondents were those who exercised regularly, at least twice a week (at least 120 min) of extracurricular physical activity, and sport inactive respondents were those who exercised less than 2 extracurricular hours in a week. They all attended two compulsory physical and sport education lessons in school weekly. Four main items were included in the questionnaire to gain the additional data about the research sample.

A questionnaire survey was conducted during the physical and sport education lessons. We used questionnaires quality of life enjoyment and satisfaction questionnaire and satisfaction with life scale. The procedures of the research were in accordance with the ethical standards of the ethics committee and with the Helsinki Declaration of 1975, as revised in 2000.

Student's t-test, Mann-Whitney U Test, and Kruskal-Wallis H test were taken into consideration in finding statistical differences according to test of normality. Pearson's correlation was run, and we calculated Hedges' g and Cohen's d for calculating effect size.

We used the statistical program IBM SPSS Statistics (Version 17 for Windows; SPSS, Chicago, IL, USA). Significance was considered at $p < 0.05$.

The importance of preselected domains of subjective quality of life (quality of life enjoyment and satisfaction and global satisfaction with life) was investigated individually. The levels of satisfaction with each of these domains were assessed. We hypothesized that the mean values of the domains would differ as a function of gender (boys and girls) and gender and sporting activity (sport active boys, sport inactive boys, sport active girls, and sport inactive girls).

2.1.2 Q-LES-Q

The quality of life enjoyment and satisfaction questionnaire (Q-LES-Q) is a self-reported measure designed by [79] to obtain sensitive measures of the degree of enjoyment and satisfaction in various areas of daily functioning. The Q-LES-Q is a multidimensional measure of life satisfaction also for healthy people [80].

From the original questionnaire, we selected 50 items from 93-item self-reported measure asking about satisfaction on items over the past week from the areas physical health and physical activity, leisure time activities, social relations, feelings, taking care of yourself, and school environment and school duties, and we put them into one domain—quality of life enjoyment and satisfaction. That is why we present the mean of the scores from selected areas rather than the total scores for each area as a summary score. The higher the score is, the greater the satisfaction indicated for these selected areas.

Respondents indicate on a five-point scale how much of the time they have agreed or disagreed with regard to the statement presented in questionnaire during the past week. The five-point scale ranges from 1 not at all or never, 2 rarely, 3 sometimes, 4 often or most of the time to 5 frequently or all of the time.

2.1.3 SWLS

To measure the global life satisfaction, [81] developed and validated the satisfaction with life scale (SWLS). This scale is used worldwide and has shown to have favorable psychometric properties, including high internal consistency and high temporal reliability. The SWLS is suitable for use with different age groups. The SWLS can assess the respondent's life and the positive side of the individual's experience rather than focusing on unpleasant emotions. The SWLS has potential as a cross-cultural index of life satisfaction. SWLS is a five-item scale designed to measure global cognitive judgements of one's life satisfaction (not a measure of either positive or negative effect). Respondents indicate how much they agree or disagree with each of the five items using a 7-point scale that ranges from 1 strongly disagree, 2 disagree, 3 slightly disagree, 4 neither agree nor disagree, 5 slightly agree, 6 agree to 7 strongly agree, with higher scores representing greater life satisfaction. The highest amount of points in global satisfaction with life is 35 (**Table 1**).

The satisfaction with life scale (SWLS) was developed to assess satisfaction with the respondent's life. It assesses an individual's conscious evaluative judgment of his or her life by using his/her own criteria [82]. Reviews of research using the SWLS suggest that it is sensitive enough to detect changes in life satisfaction over time.

The five items are:

1. In most ways my life is close to my ideal.

2. The conditions of my life are excellent.

3. I am satisfied with my life.

4. So far, I have gotten the important things I want in life.

5. If I could live my life over, I would change almost nothing.

By measuring the different aspects of people's lives differentiated according to sport, exercise and physical activity participation, we can gather and find information as the evidences, which can be used to improve the circumstances of living active and valuable life, when they need it. Then we can tailor suitable leisure time sporting activities for those who want it and most need it, because of the desire to have a better life. Because we know that the sporting activities bring indisputable benefits to the life of people.

In this study that we are presenting here, we examined some important issues.

Summed score	The mean score	Statement	SWLS category
31–35	6.00–7.00	Extremely satisfied	Satisfied
26–30	5.00–5.99	Satisfied	
21–25	4.01–4.99	Slightly satisfied	
20	4.00	Neutral	Neutral attitude
15–19	3.00–3.99	Slightly dissatisfied	Dissatisfied
10–14	2.00–2.99	Dissatisfied	
5–9	1.00–1.99	Extremely dissatisfied	

Table 1.
The points of global satisfaction with life, which constitute seven benchmark statements and three SWLS categories in satisfaction.

The aim of the research was to extend the knowledge about the quality of life enjoyment and satisfaction and about global satisfaction with life of secondary school pupils in terms of their level of extracurricular physical activity, to compare the results among different areas of the domain of quality of life enjoyment and satisfaction and the items of global satisfaction with life, and to find out the differences between the areas and items of the domains among sport active and sport inactive boys and girls.

3. Results

3.1 The dimension quality of life enjoyment and satisfaction

Investigation of quality of life enjoyment and satisfaction in selected areas (**Table 2**)—physical health and activity, leisure time activities, social relations, emotions and feelings, taking care of yourself, and school environment and school duties between girls and boys—revealed more areas where the boys indicated higher scores, which means they have more often been or felt in positive statements (physical health and activities, leisure activities, emotions and feelings, taking care of yourself) than girls have been or felt in.

The girls more often felt better in the statements from the school area and social relation area.

We found statistical significance $p < 0.001$ for boys in comparison of the responses between boys and girls in the areas: physical health and activity, leisure time activities, and feelings. We found statistical significance $p = 0.002$ in the area taking care of yourself (in favor of boys). And we found statistical significance $p = 0.040$ for girls in the area school environment and school duties. There was no statistical significance in the area social relations in comparison between girls and boys.

The domain quality of life enjoyment and satisfaction is valued statistically and significantly better in boys than in girls ($p < 0.001$). The mean 3.51 for the whole sample of adolescents presented 70.2% quality of life enjoyment and satisfaction from all the possible time of life enjoyment and satisfaction.

Table 3 shows the highest score attributed to some statements (items) from the domain quality of life enjoyment and satisfaction in boys and girls. Neither the score nor the order is the same to each other between boys and girls.

	Gender					
	Boys (n = 151)		**Girls (n = 194)**		**Total (n = 345)**	
	Mean	**Std. deviation**	**Mean**	**Std. deviation**	**Mean**	**Std. deviation**
Physical health and activity	3.57	0.59	3.23	0.64	3.38	0.64
Leisure time activities	3.98	0.57	3.60	0.76	3.77	0.71
Social relations	3.78	0.55	3.79	0.57	3.79	0.56
Emotions and feelings	3.71	0.74	3.14	0.77	3.40	0.81
Taking care of yourself	4.02	0.67	3.72	0.68	3.85	0.69
School	2.79	0.54	2.97	0.47	2.89	0.51
Quality of life enjoyment and satisfaction	3.64	0.49	3.41	0.48	3.51	0.50

Table 2.
Quality of life enjoyment and satisfaction and its areas of research in adolescent boys and girls.

The statement that reached the lowest score in both girls (2.23) and boys (1.98) was the frequency of joy when being in the school.

Kruskal-Wallis H test was used to compare four groups of research sample: sport active and sport inactive boys and sport active and sport inactive girls. We found statistical significance $p < 0.001$ in the areas physical health and activity, leisure time activities, emotions and feelings, taking care of yourself, and the domain quality of life enjoyment and satisfaction. The significance $p = 0.018$ was detected in the area school environment and school duties. No statistical significance was found in the area social relations. Sport active boys have the highest score in all areas except school environment and school duties and social relations. In comparison of the area social relations, sport active boys are at the same level as the sport inactive girls (both 3.82) (**Table 4**). The highest score in the area school (school environment and school duties) have the sport inactive girls and the sport inactive boys (both 3.04) (**Table 4**). The area taking care of yourself is valued at most in three groups, sport active boys, sport inactive boys, and sport active girls, in comparison to other investigated areas.

When we compared results of the sport active boys to the results of the sport inactive boys from the **Table 4** we found statistical significance for sport active boys in the areas: leisure time activities $U = 1623.50$, $p = 0.001$, taking care of yourself $U = 548.50$, $p = 0.004$, and emotions and feelings $U = 562.00$, $p = 0.005$. The area school environment and school duties was significant for sport inactive boys in comparison to sport active boys ($U = 237.50$, $p = 0.027$). No statistical differences were in the areas physical health and activity and social relations. Sport active boys are statistically and significantly more satisfied with the domain quality of life enjoyment and satisfaction than sport inactive boys ($U = 1868.50$, $p = 0.027$).

When we compared sport active girls and sport inactive girls, the statistical significance was found only in the area leisure time activities ($U = 3279.00$, $p < 0.001$). No statistical difference was found in domain quality of life enjoyment and satisfaction.

In comparison of sport active boys and sport active girls, statistical significances were found for boys in the areas physical health and activity ($U = 3387.00$, $p < 0.001$), emotions and feelings ($U = 783.50$, $p < 0.001$), taking care of yourself ($U = 982.50$, $p < 0.001$), and leisure time activities ($U = 3706$, $p = 0.007$). No statistical significances were found in the areas social relations and school environment and school duties. The domain quality of life enjoyment and satisfaction reached statistical significance for sport active boys ($U = 3604.50$, $p = 0.003$).

Significant differences between sport inactive boys and sport inactive girls were found in the areas of physical health and activity ($U = 1864.00$, $p = 0.038$) and leisure time activities ($U = 1747.50$, $p = 0.010$), and the statistical significance is in favor of sport inactive boys. The domain quality of life enjoyment did not reach statistical significance in comparison of sport inactive boys and sport inactive girls.

Boys' score	Statements	Girls' score	Statements
4.37	Joking, laughing with other people	4.40	Be interested about own appearance and hygiene
4.30	Frequency of hobby's joy	4.38	Looking forward to getting together
4.27	Looking forward to getting together	4.30	Joking, laughing with other people
4.26	Ability to take care of yourself	4.26	Enjoyed talking with friends
4.23	Keeping interest in hobbies	4.08	Looking forward in advance for hobbies

Table 3.
The highest score attributed to some statements (items) from the domain quality of life enjoyment and satisfaction in boys and girls.

Table 5 shows the highest score attributed to some statements from the domain quality of life enjoyment and satisfaction in sport active boys and sport inactive boys. Neither the score nor the order is the same to each other between sport active boys and sport inactive boys.

Table 6 shows the highest score attributed to some statements (items) from the domain quality of life enjoyment and satisfaction in sport active girls and sport inactive girls. Neither the score nor the order is the same to each other between sport active girls and sport inactive girls.

The statement that reached the lowest score in all four compared groups—sport active boys (1.89), sport inactive boys (2.24), sport active girls (2.03), and sport inactive girls (2.39)—was the frequency of joy when being in the school.

Pearson's correlation was run to assess the relationship between domain quality of life enjoyment and satisfaction and the selected areas of the domain in 345 adolescents.

	Sport active boys (n = 105)		**Sport inactive boys (n = 46)**		**Sport active girls (n = 91)**		**Sport inactive girls (n = 103)**	
	Mean	**Std. dev.**	**Mean**	**Std. dev.**	**Mean**	**Std. dev.**	**Mean**	**Std. dev.**
Physical health and activity	3.61	0.59	3.42	0.58	3.30	0.65	3.17	0.63
Leisure time activities	4.09	0.52	3.74	0.60	3.77	0.79	3.45	0.70
Social relations	3.82	0.54	3.69	0.58	3.75	0.64	3.82	0.51
Emotions and feelings	3.84	0.74	3.42	0.67	3.15	0.75	3.13	0.78
Taking care of yourself	4.14	0.67	3.77	0.61	3.79	0.54	3.65	0.79
School	2.69	0.57	3.04	0.37	2.88	0.44	3.04	0.48
Quality of life enjoyment and satisfaction	3.69	0.51	3.51	0.42	3.45	0.48	3.37	0.48

Table 4.
Quality of life enjoyment and satisfaction and its areas of research among adolescent sport active and sport inactive boys and girls.

Sport active boys' score	**Statement**	**Sport inactive boys' score**	**Statement**
4.43	Enjoying the leisure activities	4.39	Joking, laughing with other people
4.36	Joking, laughing with other people	4.22	Looking forward to getting together
4.33	Keeping interest in hobbies	4.21	Ability to take care of yourself
4.29	Looking forward to getting together	4.12	Satisfaction with the schoolmate's communication
4.28	Ability to take care of yourself	4.09	Enjoying talking with friends

Table 5.
The highest score attributed to some statements from the domain quality of life enjoyment and satisfaction in sport active boys and sport inactive boys.

Sport active girls' score	Statement	Sport inactive girls' score	Statement
4.41	Looking forward to getting together	4.45	Joking, laughing with other people
4.36	Be interested about own appearance and hygiene	4.44	Be interested about own appearance and hygiene
4.23	Enjoying talking with friends	4.35	Looking forward to getting together
4.20	Enjoying the leisure activities	4.29	Enjoying talking with friends
4.20	Looking forward in advance for hobbies	3.98	Ability to take care of yourself

Table 6.
The highest score attributed to some statements from the domain quality of life enjoyment and satisfaction in sport active girls and sport inactive girls.

There was a strong positive correlation between:
Emotions and feelings and quality of life enjoyment and satisfaction, r= 0.902, p < 0.001, with the emotions and feelings explaining 81% of the variation in quality of life enjoyment and satisfaction.
Taking care of yourself and quality of life enjoyment and satisfaction, r = 0.808, p < 0.001, with taking care of yourself explaining 65% of the variation in quality of life enjoyment and satisfaction.
Physical health and activity and quality of life enjoyment and satisfaction, r = 0.766, p < 0.001, with the physical health and activity explaining 59% of the variation in quality of life enjoyment and satisfaction.
Social relations and quality of life enjoyment and satisfaction, r = 0.721, p < 0.001, with the social relations explaining 52% of the variation in quality of life enjoyment and satisfaction.
Leisure time activities and quality of life enjoyment and satisfaction, r = 0.690, p < 0.001, with the leisure time activities explaining 48% of the variation in quality of life enjoyment and satisfaction.

School environment and school duties and quality of life enjoyment and satisfaction, r = 0.541, p < 0.001, with the school environment and school duties explaining 29% of the variation in quality of life enjoyment and satisfaction.

3.2 The dimension global satisfaction with life

Investigation of the domain of satisfaction with life in the five given questions in boys and girls revealed that the most scored item was "The conditions of my life are excellent" (for both girls 5.41 and boys 5.51) with no statistical significance in comparison.

The next items (**Table 7**) with significant differences between boys and girls were:
"I am satisfied with my life" (for both girls 4.49 and boys 4.88) with statistical significance in comparison t(2.276) = 326.96, p = 0.023. Boys, from the research sample, were significantly more satisfied with their life than girls.
"In most ways my life is close to my ideal" (for both girls 4.23 and boys 4.71) with statistical significance in comparison t(3.109) = 327.21, p = 0.002. Boys, from the research sample, had in most ways their life significantly closer to their ideal life than girls.

	Gender					
	Boys (n = 151)		**Girls (n = 194)**		**Total (n = 345)**	
	Mean	**Std. deviation**	**Mean**	**Std. deviation**	**Mean**	**Std. deviation**
In most ways my life is close to my ideal	4.71	1.42	4.23	1.45	4.44	1.45
The conditions of my life are excellent	5.51	1.29	5.41	1.44	5.46	1.38
I am satisfied with my life	4.88	1.56	4.49	1.61	4.66	1.60
So far, I have gotten the important things I want in life	4.56	1.46	4.09	1.55	4.29	1.53
If I could live my life over I would change almost nothing in my life	3.82	1.99	3.44	1.94	3.61	1.97
SWLS mean of five items	4.70	1.21	4.33	1.18	4.49	1.21

Table 7.
Satisfaction with life and its items of research in adolescent boys and girls.

"So far, I have gotten the important things I want in life" (for both girls 4.09 and boys 4.56) with statistical significance in comparison t(2.877) = 331.10, p = 0.004. Boys, from the research sample, significantly have gotten more important things they wanted in their life than girls.
There was no significant difference in the item "If I could live my life over, I would change almost nothing in my life" between the score for the item in boys (3.82) and girls (3.44).
Comparing the mean of the domain satisfaction with life among the boys and the girls, we found out that boys were significantly more satisfied with their life than girls (t(2.801) = 319.71, p = 0.005). The boys are satisfied with their life at 67.14%, girls at 61.86%, and adolescents (both girls and boys together) at 64.14% from the possible highest measured score of satisfaction with life (7 points are 100%).
Pearson's correlation was used to assess the relationship between domain global satisfaction with life and the selected items of the domain in 345 adolescents.

There was a strong positive correlation between:
I am satisfied with my life and global satisfaction with life, r = 0.839, p < 0.001, with the statement "I am satisfied with my life" explaining 70% of the variation in global satisfaction with life.
In most ways my life is close to my ideal and global satisfaction with life, r = 0.818, p < 0.001, with the statement "In most ways my life is close to my ideal" explaining 67% of the variation in global satisfaction with life.
If I could live my life over, I would change almost nothing in my life and global satisfaction with life, r = 0.751, p < 0.001, with the statement "If I could live my life over, I would change almost nothing in my life" explaining 56% of the variation in global satisfaction with life.
So far, I have gotten the important things I want in life and global satisfaction with life, r = 0.730, p < 0.001, with the statement "So far, I have gotten the important things I want in life" explaining 53% of the variation in global satisfaction with life.
The conditions of my life are excellent and global satisfaction with life, r = 0.656, p < 0.001, with the statement "The conditions of my life are excellent" explaining 43% of the variation in global satisfaction with life.

The global satisfaction with life (**Table 8**) presented that boys, girls, and adolescents are in the category as slightly satisfied within the domain satisfaction with the life.

Table 9 shows the mean and standard deviation of the items of global satisfaction with life and SWLS mean of the five items in sport active boys and sport active and sport inactive girls.

Kruskal-Wallis H test was used to find out the statistical significance of differences in comparison of four selected groups from the sample (sport active boys, sport inactive boys, sport active girls, and sport inactive girls). We found out in all items the significant differences in comparison of these groups ($p < 0.001$) except one "The conditions of my life are excellent." All compared groups perceived this item at a very similar level of strength of agreement (5.22–5.64 from the seven-point scale), and we did not find out statistical differences in crisscross comparison.

We search for the answer how much one group differs from another, so we used the calculation of effect size. The Hedges' *g* for calculating effect size with the different sample sizes (sport active boys and sport inactive boys) when comparing SWLS mean of the five items (from **Table 9**) revealed the number 0.63, and it means medium effect. Cohen's *d* was calculated for the girls' groups (sport active and sport inactive for comparison), because the sample size is more than 50 girls. And we found out the effect size 0.35, and this is a small effect. Sport active boys differ more to sport inactive boys than sport active girls differ to sport inactive girls in global satisfaction with life.

No statistical significance was found out in comparison of two independent groups (**Table 9**):

1. Between sport active boys and sport inactive boys in the item: "The conditions of my life are excellent"

2. Between sport active girls and sport inactive girls in the items: "The conditions of my life are excellent"; "In most ways my life is close to my ideal"; and "I am satisfied with my life"

3. Between sport active boys and sport active girls in the items: "The conditions of my life are excellent"; "So far, I have gotten the important things I want in life"; and "If I could live my life over, I would change almost nothing in my life"

4. Between sport inactive boys and sport inactive girls in all five items and the global satisfaction with life presented as SWLS mean of five items

Statistical significance was found out in comparison of two independent groups (**Table 9**):

1. Between sport active boys and sport inactive boys in the items: "In most ways my life is close to my ideal" ($U = 1849.00$, $p = 0.018$); "I am satisfied with my life" ($U = 1596.00$, $p = 0.001$); "So far, I have gotten the important things I want in life" ($U = 1806.00$, $p = 0.012$); and "If I could live my life over, I would change almost nothing in my life" ($U = 1601.50$, $p = 0.001$). And in the global satisfaction with life presented in **Table 9** as SWLS mean of five items ($U = 1536.00$, $p < 0.001$)

2. Between sport active girls and sport inactive girls in the items: "So far, I have gotten the important things I want in life" ($U = 3767.50$, $p = 0.016$) and "If I could live my life over, I would change almost nothing in my life" $U = 3806.50$,

p = 0.022). And in the global satisfaction with life presented in **Table 9** as SWLS mean of five items (U = 3818.50, p = 0.026)

3. Between sport active boys and sport active girls in the items: "In most ways my life is close to my ideal" (U = 3839.50, p = 0.015) and "I am satisfied with my life" (U = 3948.00, p = 0.032). And in the global satisfaction with life presented in **Table 9** as SWLS mean of five items (U = 3851.50, p = 0.019)

	Gender					
	Boys (n = 151)		**Girls (n = 194)**		**Total (n = 345)**	
	Mean	**Std. deviation**	**Mean**	**Std. deviation**	**Mean**	**Std. deviation**
Global satisfaction with life	23.48	6.03	21.66	5.92	22.46	6.02
Category of global satisfaction with life	Slightly satisfied		Slightly satisfied		Slightly satisfied	

Table 8.
Global satisfaction with life in adolescent boys and girls.

	Sport active boys (n = 105)		**Sport inactive boys (n = 46)**		**Sport active girls (n = 91)**		**Sport inactive girls (n = 103)**	
	Mean	**Std. dev.**	**Mean**	**Std. dev.**	**Mean**	**Std. dev.**	**Mean**	**Std. dev.**
In most ways my life is close to my ideal	4.89	1.34	4.30	1.49	4.41	1.48	4.07	1.42
The conditions of my life are excellent	5.64	1.24	5.22	1.37	5.53	1.43	5.31	1.45
I am satisfied with my life	5.16	1.49	4.24	1.54	4.67	1.63	4.33	1.59
So far, I have gotten the important things I want in life	4.73	1.51	4.15	1.26	4.35	1.64	3.85	1.44
If I could live my life over I would change almost nothing in my life	4.17	1.96	3.03	1.83	3.78	1.97	3.15	1.87
SWLS mean of five items	4.92	1.18	4.19	1.12	4.55	1.18	4.14	1.16

Table 9.
Satisfaction with life and its items of research in adolescent sport active and sport inactive boys and girls.

Sport active boys	**The order of the items of satisfaction with life in sport active boys and girls in dependence on the score**	**Sport active girls**
5.64	1. The conditions of my life are excellent	5.53
5.16	2. I am satisfied with my life	4.67
4.89	3. In most ways my life is close to my ideal	4.41
4.73	4. So far, I have gotten the important things I want in life	4.35
4.17	5. If I could live my life over I would change almost nothing in my life	3.78

Table 10.
The order of the items of satisfaction with life in sport active boys and girls in dependence on the score.

The order of the items of satisfaction with life in sport active boys and girls in dependence on the score is the same for sport active boys and sport active girls (**Table 10**).

The order of the items of satisfaction with life in sport inactive boys and girls in dependence on the score is the same for sport inactive boys and sport inactive girls (**Table 11**).

All selected groups evaluated the domain global satisfaction with their life (from the mean of the total sum) as slightly satisfied (**Table 12**).

Table 13 presents the detailed percentage of sport active and sport inactive boys and girls classified according to the statements of satisfaction degree (from extremely satisfied to extremely dissatisfied). Sport active boys scored the highest percentage of extreme satisfaction, followed by sport active girls, sport inactive girls, and sport inactive boys.

Sport inactive girls scored the highest percentage of extreme dissatisfaction followed by sport active boys and sport active girls, and no one among the sport inactive boys scored the points from 5 to 9, which mean extreme dissatisfaction in the global satisfaction with life.

The sample of sport active boys consists of 79.05% sport active boys who were satisfied, 15.24% who were dissatisfied, and 5.71% who presented neutral attitude to global satisfaction with life.

The sample of sport inactive boys consists of 52.17% sport inactive boys who were satisfied, 34.78% who were dissatisfied, and 13.04% who presented neutral attitude to global satisfaction with life.

The sample of sport active girls consists of 64.83% sport active girls who were satisfied, 29.67% who were dissatisfied, and 5.49% who presented neutral attitude to global satisfaction with life.

Sport inactive boys	The order of the items of satisfaction with life in sport inactive boys and girls in dependence on the score	Sport inactive girls
5.22	1. The conditions of my life are excellent	5.31
4.30	2. In most ways my life is close to my ideal	4.33
4.24	3. I am satisfied with my life	4.07
4.15	4. So far, I have gotten the important things I want in life	3.85
3.03	5. If I could live my life over I would change almost nothing in my life	3.15

Table 11.
The order of the items of satisfaction with life in sport inactive boys and girls in dependence on the score.

	Sport active boys (n = 105)		Sport inactive boys (n = 46)		Sport active girls (n = 91)		Sport inactive girl (n = 103)	
	Mean	Std. dev.	Mean	Std. dev.	Mean	Std. dev.	Mean	Std. dev.
Global satisfaction with life	24.59	5.88	20.94	5.61	22.74	5.89	20.71	5.81
Category of global satisfaction with life	Slightly satisfied		Slightly satisfied		Slightly satisfied		Slightly satisfied	

Table 12.
Global satisfaction with life in adolescent sport active and sport inactive boys and girls.

The sample of sport inactive girls consists of 57.28% sport inactive girls who were satisfied, 37.87% who were dissatisfied, and 4.85% who presented neutral attitude to global satisfaction with life.

We created three SWLS category (satisfied, neutral, and dissatisfied) from the seven benchmarks of statements (see in methods of **Table 1**). We put together all the statements with word satisfied (extremely satisfied, satisfied, slightly satisfied – statements with the points 21–35) in one criterion and all the boys and girls, who reached the points in this range, we classified as satisfied. Neutral statement (with the points 20) remains neutral. All the statements with the word dissatisfied (extremely dissatisfied, dissatisfied, slightly dissatisfied – statements with the points 5–19) we put together in one criterion and all the boys and girls who reached the points in this range, we classified as dissatisfied.

In **Table 14**, we present how many sport active boys and sport inactive boys from the entire sample of boys (n = 151) answered dissatisfied, neutral attitude, and satisfied. In **Table 15**, we present the same for sport active girls and sport inactive girls (n = 194).

Summed score	Statement	Sport active boys (n = 105) (%)	Sport inactive boys (n = 46) (%)	Sport active girls (n = 91) (%)	Sport inactive girls (n = 103) (%)	Total (n = 345) (%)
31–35	Extremely satisfied	17.15	2.17	8.79	2.91	8.70
26–30	Satisfied	28.57	21.74	28.57	19.41	24.93
21–25	Slightly satisfied	33.33	28.26	27.47	34.96	31.59
20	Neutral	5.71	13.04	5.49	4.85	6.38
15–19	Slightly dissatisfied	9.52	17.39	20.88	23.30	17.68
10–14	Dissatisfied	3.81	17.39	7.69	11.66	8.99
5–9	Extremely dissatisfied	1.91	0	1.10	2.91	1.74

Table 13.
The percentage (%) of sport active and sport inactive boys and girls in seven SWLS benchmarks of statements.

Sport active and sport inactive boys (n = 151) and the SWLS category: satisfied, neutral attitude, dissatisfied	Frequency (n)	Percent (%)
Sport active boy satisfied	84	55.63
Sport inactive boy satisfied	24	15.89
Sport inactive boy dissatisfied	16	10.60
Sport active boy dissatisfied	15	9.94
Sport active boy neutral attitude	6	3.97
Sport inactive boy neutral attitude	6	3.97
Total	151	100

Table 14.
The frequency (n) and the percentage (%) of sport active and sport inactive boys in SWLS categories.

Sport active and sport inactive girls and the SWLS category: satisfied, neutral attitude, dissatisfied	Frequency (n)	Percent (%)
Sport inactive girl satisfied	60	30.93
Sport active girl satisfied	59	30.41
Sport inactive girl dissatisfied	38	19.58
Sport active girl dissatisfied	27	13.92
Sport active girl neutral attitude	5	2.58
Sport inactive girl neutral attitude	5	2.58
Total	194	100

Table 15.
The frequency (n) and the percentage (%) of sport active and sport inactive girls in SWLS categories.

The largest number of satisfied boys was sport active boys. They were 39.74% more satisfied than sport inactive boys. Slightly more dissatisfied (0.66%) were sport inactive boys than sport active boys. Sport active and sport inactive boys had the same number in terms of neutral attitude to global satisfaction with life.

Sport inactive girls took the first place in satisfaction with life (**Table 15**). They were slightly more satisfied than sport active girls (0.52%). More dissatisfied were sport inactive girls (5.66%) than sport active girls. Sport active and sport inactive girls had the same number in terms of neutral attitude to global satisfaction with life.

Pearson's correlation was run to assess the relationship between domain global satisfaction with life and the domain quality of life enjoyment and satisfaction and its areas in 345 adolescents.

There was a strong positive correlation between:

Emotions and feelings and the domain global satisfaction with life, $r = 0.739$, $p < 0.001$, with emotions and feelings—explaining 55% of the variation in the domain global satisfaction with life.

The domain quality of life enjoyment and satisfaction and the domain global satisfaction with life, $r = 0.657$, $p < 0.001$, with the domain quality of life enjoyment and satisfaction explaining 43% of the variation in the domain global satisfaction with life.

Taking care of yourself and the domain global satisfaction with life, $r = 0.680$, $p < 0.001$, with taking care of yourself—explaining 46% of the variation in the domain global satisfaction with life.

Physical health and activity and the domain global satisfaction with life, $r = 0.543$, $p < 0.001$, with the physical health and activity explaining 30% of the variation in the domain global satisfaction with life.

Social relations and the domain global satisfaction with life, $r = 0.463$, $p < 0.001$, with the social relations explaining 21% of the variation in the domain global satisfaction with life.

Leisure time activities and the domain global satisfaction with life, $r = 0.423$, $p < 0.001$, with the leisure time activities explaining 18% of the variation in the domain global satisfaction with life.

School environment and school duties and the domain global satisfaction with life, $r = 0.259$, $p < 0.001$, with the school environment and school duties explaining 7% of the variation in the domain global satisfaction with life.

4. Discussion

This study examined the domain quality of life enjoyment and satisfaction with its areas and the domain global satisfaction with life with its items in sport active and sport inactive adolescent boys and girls. It is very important to measure the subjective dimensions of the quality of children's lives. Children and youth are the future of all nations. There are more than 3.2 billion of the world population under 24 years of age (about 42%; 26% children in the age 0–14 and 16% children and youth in the age 15–24) [83].

Emotional well-being in [57] publication shows the overall balance between frequency of experienced positive and negative emotions, with higher scores presented for positive emotions. Positive emotions are felt more often than negative ones. Exercising brings positive emotions, provides serious benefits in mental health, and leads to a happier life. Exercise releases endorphins, and because of them the feelings of happiness occur. There is growing recognition in society presented by [27] that measures of subjective well-being directly index evaluations and feelings associated with the quality of life, and we have confirmed this in our research with the correlation coefficient, which shows that the emotions and feelings explained 81% of the variation in quality of life enjoyment and satisfaction.

The specific aspects of adolescents' health-related quality of life were acknowledged by [84], such as physical maturation and body image, peer relationships, intimacy and sexuality, and autonomy. We considered health as a universal value, independent of the sociocultural context. Health is one of the most important aspects of the quality of life and to some extent affects other aspects. Slovakia, according to the United Nations, is one of the advanced countries of the world, but the overall health of the Slovak population has hardly improved in the last decades. The health of the Slovak population is not only a reflection of the level and quality of national health services but also, and above all, the responsibility of citizens for their health. Health is one of the most important manifested values, but it is surprising how little attendance devotes man to both prevention and treatment of diseases.

Young people in Slovakia presented the main motives for being active with sport—the positive health. It is very encouraging information for the researchers in the field of sport sciences. We found out in our research that the physical health and activity explained 59% of the variation in quality of life enjoyment and satisfaction, and taking care of yourself explained 65% of the variation in quality of life enjoyment and satisfaction. A total of 160 high school students (80 of them were sport active and 80 were sport inactive) were the research sample for the investigation of subjective quality of life (SQUALA) [85] in the research of [37]. This research has confirmed that health clearly dominates all high school students, whether they are sport active or not. The mean for the valued score for sport active was 4.72 of the five-point scale and for sport inactive was 4.61. People in Singapore attached great importance to being healthy and having a happy family life, and they were very satisfied with the various domains of life [86]. The former study of 175,850 adults [87] was based on the recommended guideline of 30 min of moderate exercise daily on most days of the week, or 20 min of intense exercise on at least 3 days of the week revealed that if somebody exercises, according to the recommended guidelines, he/she will have twice as many days when he/she feels physically and mentally healthy compared to a person who does not exercise.

If there are good social relations in the framework of participating in sporting activities, then it is easier for the individuals to stay with some regular sporting activity if supported by their families and other acquaintances. Our research concluded that with the social relations, 52% of the variation in quality of life enjoyment and satisfaction are explained.

The results of [88] investigation is increased level of life satisfaction in the group with higher level of leisure participation. The results of [39] also showed that significant differences existed between college rank and leisure participation, as well as between gender and leisure participation. Results of [54] showed that those participants who reported higher leisure time physical activity levels also reported a significantly higher life satisfaction ($M = 41.9$, $SD = 35.0$) relative to participants with lower levels ($M = 37.6$, $SD = 34.2$, $t(1532) = -2.36$, $p < 0.01$). There were no statistical differences in the perception of health-related quality of life (HRQOL) and leisure time physical activity ($t(1532) = -1.03$, $p = 0.30$), although active people had higher scores. Both HRQOL and life satisfaction scores were higher in individuals who were participating in Recreovía ($p < 0.001$). Higher life satisfaction scores were found in the group with higher leisure time physical activities, while HRQOL showed no differences. Better psychological well-being indices were found in the Recreovía group. The results of this study supported other research on the relationship of leisure participation and leisure satisfaction to other facets of life. In our research we found out that with the leisure time activities, we can explain 48% of the variation in quality of life enjoyment and satisfaction.

School activities rated below average scores in happiness in the research of [54]. In our research there was a statement that reached the lowest score in all four compared groups—sport active boys (1.89), sport inactive boys (2.24), sport active girls (2.03), and sport inactive girls (2.39); and it was the frequency of joy when being in the school. With the school environment and school duties, we can explain 29% of the variation in quality of life enjoyment and satisfaction.

The results of [52] did not show differences between groups of adolescents with various sporting levels of sport performance in the level of quality of life, respectively, its individual areas. The research of [36] found out that significantly reduced life satisfaction was detected for the university students who reported not participating in physical activity. The previous findings [36] suggest physical activity participation is associated with improved life satisfaction for university students. Those students who were more active in physical activity reported higher levels ($p < 0.05$) of satisfaction with life as a whole. In the next research of [37], statistically significant differences were not found in the evaluation of selected quality of life factors (health, leisure time, family, and standard of living) between sport active and sport inactive high school students. Health was evaluated as the most important factor of quality of life. Very important was the factor family, and the factors standard of living and leisure time were evaluated at the middle high of importance. The conclusions of the research [89] present that the group of judo participants ($n = 90$) had significantly higher well-being and life satisfaction scores than normative sample. The investigation of the relationship between involvement in physical activity (sports) and satisfaction with life among 100 ball game participants [90] indicated that there was a significant influence ($p < 0.05$) on satisfaction with life in ball game participants. The findings from the study of [91] showed that the participants in football sample, in particular girls, reported a higher level of moderate-to-vigorous leisure time physical activity than those in the reference sample and they also rated their life satisfaction and subjective health more favorable than reference sample.

The participation in sporting activity as a variable of higher level of psychological well-being is consistent with the authors [92, 93]. High school learners from the South Africa perceived that increasing exercising and sporting activities in sport participation resulted in significantly positive responses of physical health, mental health, happiness, and well-being [94].

The implication of the study [77] is that life satisfaction and positive affect mitigate the negative effects of stressful life events and work against the development of psychological and behavioral problems among youth. And we gave evidence to this; on these pages research presented that exercising and sporting activities should be such a positive affect for positive youth development. The article of [94] talks about the factors, including individual differences in physical and psychosocial development, which can contribute to the way in which adolescents experience the impact of sport participation. Participation in exercising or sporting activities on any level can be enjoyed by all adolescents and can bring the results as in [95, 96].

A total of 1671 Danish adolescents were taken in investigation on physical activity and several psychosocial questions [97]. The most important motives for physical activity for them were improvement of health, to get in good shape, to have fun, and to make new friends. High intensity of physical activity was associated with high social class, strong social interaction in peer group, easy contact with parents and friends, physical exercise among parents and best friends, good health, and high degree of life satisfaction.

Preliminary findings suggest physical activity and sport participation are associated with improved life satisfaction and self-rated health for middle school students [40]. In addition, although some gender differences were observed, consistent findings for sport participation suggest sport participation may carry multiple social, mental, and physical benefits for youth [ibid].

It was found in the investigation of [86] that there were no significant relationships found between life satisfaction and demographic characteristics. The subjective quality of life domain measures correlated most strongly with general life satisfaction—correlation ranged from 0.16 to 0.65 in the study of [98]. Generally speaking, the findings of [35] study indicated that physical activity has an effect on positive physical self-concept and life satisfaction. The study of [99] revealed relationships between perceived life dissatisfaction and noninvolvement in physical activity. Little research of [41] with 245 students was surveyed about physical activity and life satisfaction. Analysis documented significantly reduced life satisfaction for females who reported not engaging in vigorous physical activity during the past 7 days and for both males and females who reported not playing team sports. Of the demographic variables examined [100], only age was significantly associated with the quality of life scores. Satisfaction with life in Portuguese adolescents was 18 points, and this score is less than the findings in our research for Slovak adolescents (22.46). Life satisfaction acts as a protective factor against risky behavior and mood disorders [101]. The researchers, teachers, and parents should understand the adolescents' view of quality of life, where the adolescents emphasize the importance of social relations and psychosocial health to promote and sustain their quality of life [102]. The data obtained in the research [103] indicate that those who engage in physical sporting activity always have higher psychological well-being levels ($p < 0.001$), experience more positive emotions ($p < 0.001$) and fewer negative ones ($p < 0.001$), and feel more satisfied with their lives ($p < 0.001$), than those who do not. Linear relationship between greater sport participation and happiness were observed in the results of [104]. The results of the [95] study presented an overall prediction of higher health-related quality of life with greater physical activity.

Good thoughts are expressed by [105] that when the professional sport is no longer the future of male and female secondary school students, then organized exercising or sporting activity provides them the benefits that can last for the rest of their lives and hopes that such organized activities will lead to adoption of an active lifestyle in the adulthood. Participation in organized sports provides an opportunity for young people to increase their physical activity and develop physical and social skills. And the study of [103] presented the data, which identified that physical activity can be taken as a variable associated with higher well-being scores and the recommended regular basis for exercising should be at least four times a week.

Positive associations between happiness and engagement in sporting activities are indicated in [5, 9, 27, 54, 104, 106]. Happiness as an equal to subjective well-being can be measured in terms of life satisfaction. It can be concerned with the presence of positive experience and feelings and the absence of negative experience and feelings. Slovak people rank in happiness in 38th place among 156 world countries [107, 108] with 6.192 points from a 10-point scale and with the loss of 1.577 points in comparison to the first country, which was Finland, in World Happiness Report 2019, and rank lower than the OECD average of 6.5. In comparison to the year 2008, 0.933 points of improvement can be found. The Slovak Republic ranks 32nd place among 148 nations and 1 special administrative region of China, Hong Kong, in the overall Prosperity Index rankings [109]. In the Prosperity Pillar rankings, Slovakia performs best on education (access to education, quality of education, and human capital) and safety and security (national security and personal security), where it took 26th place. The Quality of Life Index by Country [110] revealed that the Slovak Republic with 153.10 points is on the 31st place in quality of life when concerning purchasing power index, safety index, healthcare index, cost of living index, property price to income ratio (which is the worse rated from selected factors in Slovakia), traffic commute time index, pollution index, and climate index (which is best rated from selected factors in Slovakia). The model of [9] proposes that "happiness is a concept relative to individuals, their unique needs and resources and to the culture and environment in which they function as social beings," and we agree with them.

5. Conclusion

A new strategy should take place in the life of all people—creating a physical activity, exercise and sporting habits as a need for life (like needs of eating and sleeping), because the technologies and the current way of working do not secure enough movement for work of human body organs for healthy life and for the subjective quality of life. Starting and continuing with the appropriate compulsory and extracurricular physical and sporting activities during the whole school system should to use physical and sporting activities to become the habits of exercising and should last for the whole life long because of the premise: when you are used to exercise and adapted for doing it as a young person, it is easier to continue with it during adulthood. Or even when there was a break by doing sporting activities, it is easier to start with them again, when you have been used to do it in a previous time. The body can remember the movement and can be prepared to start again. The members of the human race only speak about healthy lifestyle but have to take the initiative steps for doing something for it.

The research was focused on two main dimensions of the quality of life—the life enjoyment and satisfaction and global satisfaction with life.

The researched areas of the dimension of the quality of life enjoyment and satisfaction presented statistical differences between boys and girls (p_1), sport active and sport inactive adolescents (p_2), and sport active and sport inactive boys and girls (p_3) (physical health and activities $p_1 < 0.001$, $p_2 = 0.001$, $p_3 < 0.001$; leisure time activities $p_1 < 0.001$, $p_2 < 0.001$, $p_3 < 0.001$; emotions and feelings $p_1 < 0.001$, $p_2 = 0.011$, $p_3 < 0.001$; taking care of yourself $p_1 = 0.002$, $p_2 = 0.004$, $p_3 < 0.001$). The only one negative statistical difference was found in the area of school environment and school duties, where sport inactive adolescents ($p = 0.004$) and sport inactive boys and girls ($p = 0.018$) valued higher the feelings of the domain life enjoyment and satisfaction from seven items of this area (school environment and school duties). No statistical differences were found in the area of school environment and school duties in comparison between boys and girls ($p = 0.086$) although the girls reached higher values. No statistical differences were found in the area of social relations in comparison between boys and girls ($p = 0.726$), sport active and sport inactive adolescents ($p = 0.470$), and among sport active and sport inactive boys and girls ($p = 0.58$). The dimension quality of life enjoyment and satisfaction was statistically and significantly better valued by the boys than girls ($p < 0.001$) and by sport active boys than sport inactive boys ($p = 0.027$). No statistical difference was found between sport active girls and sport inactive girls ($p = 0.200$).

In the dimension of global satisfaction with life, we found statistical differences in all compared samples—boys were more satisfied than girls ($p = 0.004$), and sport active adolescents were more satisfied than sport inactive adolescents ($p < 0.001$)—and comparison among sport active and sport inactive boys and girls results in the statistical difference $p < 0.001$.

The dimension of quality of life enjoyment and satisfaction (in the area of physical health and activities, leisure time activities, feelings, taking care of yourself, school enjoyment and school environment, social relations) was statistically significantly better valued by sport active adolescents than sport inactive adolescents ($p = 0.002$).

These findings serve to extend the knowledge in sport sociology. The research included 55 items differentiated in 7 areas, which were taken in 2 subjective dimensions of quality of life and gave evidence that sport activity positively influenced the perception of dimension of quality of life enjoyment and satisfaction and the dimension of global satisfaction with life among adolescents. Sport as a social phenomenon examines and discusses the positive impact on individuals or social group, and here we discussed the positive impact of sport, exercise, and physical activities on subjective dimensions of the quality of life in sport active and sport inactive adolescent girls and boys, which can serve as an important precondition for making and playing sports and for exercising in general. Exercising and sporting activities serve a positive experience for all, children, adolescents, adults, and seniors too, and should encourage all.

6. Limitations of the study

For the limitation of the study, we considered the sample size, because we did not calculate the expected sample size before beginning the study. We worked only with the sample with which we could realize interview. If we have had the access to a representative sample, then maybe we would have more precise results and we could generalize the results to a larger population. We will continue with this research, and we try to gain more respondents also from other parts of the Slovak Republic, not only from the capital city. The second limitation of the study is the selection of 50 items from the entire 93-item self-reported measure. Maybe for the school practice, also a short form with the 16 items would be appropriate. The third limitation of the study is self-reported data, because we gather the responses at the momentary time, when the person, in any mood, perceives the question and answers the question in a subjective manner. To overcome this, some introductory and motivational parts should be provided by the research leader before respondents start fulfilling the questionnaire. The fourth limitation could be that we did not determine the kind of sport. Maybe we would find several new information and which kind of sport has the greatest effect on the subjective dimensions of the quality of life. This approach would require the larger sample size. The fifth limitation could be the selection of the research papers in the introduction and in the discussion because of our individual interest in some papers and not in others paper. We will try to make the larger scope of the next research, because this research is also limited in pages for publishing.

7. Practical implications

Our results provide the evidence that sport and exercising positively affect the subjective dimensions of the quality of life more in boys than in girls. The motivation for sport participation should be gender-focused, and the promotion of the higher volume of time should girls devote to sporting activity to acquire better experiencing of subjective dimensions of the quality of life.

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Conflict of interest

There were no conflicts of interest.

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References

[1] Peráčková J. Prieskum stavu organizovanosti slovenskej stredoškolskej populácie v telovýchovných alebo športových aktivitách [The survey of the organization of Slovak secondary school population in exercising or sporting activities]. In: Zborník z Konferencie—Prvé Kroky kurikulárnej transformácie v Predmete telesná a športová výchova [Proceedings of the Conference—The First Steps of Curricular Transformation in the Subject of Physical and Sports Education]; 11 November 2009. Univerzita Komenského: Bratislava; 2010. pp. 27-37

[2] Bramston P, Chipuer H, Pretty G. Conceptual principles of quality of life: An empirical exploration. Journal of Intellectual Disability Research. 2005;**49**(10):728-733. DOI: 10.1111/j.1365-2788.2005.00741.x

[3] Diener E. Subjective well-being. Psychological Bulletin. 1984;**95**(3):542-575. DOI: 10.1037/0033-2909.95.3.542

[4] Diener E. Assessing subjective well-being: Progress and opportunities. Social Indicators Research: An International and Interdisciplinary Journal for Quality-of-Life Measurement. 1994;**31**(2):103-157. DOI: 10.1007/BF01207052

[5] Diener E, Scollon CN, Lucas RE. The evolving concept of subjective well-being: The multi-faceted nature of happiness. In: Costa PT, Siegler IC, editors. Advances in Cell Aging and Gerontology. Vol. 15. Amsterdam: Elsevier; 2004. pp. 187-220. DOI: 10.1016/S1566-3124(03)15007-9

[6] Costanza R, Fisher B, Ali S, Beer C. Quality of life: An approach integrating opportunities, human needs, and subjective well-being. Ecological Economics. 2007;**61**(2-3):267-276. DOI: 10.1016/j.ecolecon.2006.02.023

[7] Moons P, Budts W, De Geest S. Critique on the conceptualisation of quality of life: A review and evaluation of different conceptual approaches. International Journal of Nursing Studies. 2006;**43**:891-901. DOI: 10.1016/j.ijnurstu.2006.03.015

[8] Post MWM. Definitions of quality of Life: What has happened and how to move on. Topics in Spinal Cord Injury Rehabilitation. 2014;**20**(3):167-180. DOI: 10.1310/sci2003-167

[9] Shin DC, Johnson DM. Avowed happiness as an overall assessment of the quality of life. Social Indicators Research. 1978;**5**(1-4):475-492

[10] Hagerty MR, Cummins RA, Ferris AL, Land K, Michalos AC, Peterson M, et al. Quality of life indexes for national policy: Review and agenda for research. Social Indicators Research. 2001;**55**(1): 1-96. DOI: 10.1023/A:1010811312332

[11] Galloway S, Bell D, Hamilton C, Scullion AC. Quality of Life and Well-being: Measuring the Benefits of Culture and Sport: Literature Review and Thinkpiece (Scottish Executive Social Research) [Internet]. 2006. Available from: http://www.artshealthresources.org.uk/docs/quality-of-life-and-well-being-measuring-the-benefits-of-culture-and-sport/ [Accessed: 13 May 2019]

[12] Ruggeri M, Warner R, Bisoffi G, Fontecedro L. Subjective and objective dimensions of quality of life in psychiatric patients: A factor analytical approach: The South Verona Outcome Project 4. The British Journal of Psychiatry. 2001;**178**(3):268-275. DOI: 10.1192/bjp.178.3.268

[13] Walid K, Fakhoury H, Priebe S. Subjective quality of life: It's association with other constructs. International Review of Psychiatry.

2002;**14**(3):2019-2224. DOI: 10.1080/09540260220144957

[14] WHOQOL Group. The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. Social Science & Medicine. 1995;**41**(10):101403-101409. DOI: 10.1016/0277-9536(95)00112-K

[15] Schalock RL. The concept of quality of life: What we know and do not know. Journal of Intellectual Disability Research. 2004;**48**(3):203-216. DOI: 10.1111/j.1365-2788.2003.00558.x

[16] Eiffe F, Ponocny I, Gärtner K, Till M. Analytical Report on Subjective Well-Being. 2016 Edition. Luxembourg: Publications Office of the European Union; 2016. 38 p

[17] Ruta D, Camfield L, Donaldson C. Sen and the art of quality of life maintenance: Towards a general theory of quality of life and its causation. The Journal of Socio-Economics. 2007;**36**(3):397-423. DOI: 10.1016/jsocec.2006.12.004

[18] Bergner M. Quality of life, health status, and clinical research. Medical Care. 1989;**27**(3):S148-S156

[19] Sen A. Capability and well-being. In: Nussbaum M, Sen A, editors. The Quality of Life. Oxford: Clarendon Press; 1993. pp. 30-53. DOI: 10.1093/0198287976.001.0001

[20] Wohl A. Sport and the quality of life. International Review for the Sociology of Sport. 1997;**12**(2):35-48. DOI: 10.1177/101269027701200202

[21] Hartl P, Hartlová H. Psychologický slovník [Psychological Dictionary]. Praha: Portál; 2000. 776 p

[22] Spitzer WO. State of science 1986. Quality of life and functional status as target variables for research. Journal of Chronic Diseases. 1987;**40**(6):465-471

[23] Theofilou P. Quality of life: Definition and measurement. Europe's Journal of Psychology. 2013;**9**(1):150-162. DOI: 10.5964/ejop.v9i1.337

[24] Camfield L, Skevington SM. On subjective well-being and quality of life. Journal of Health Psychology. 2008;**13**(6):764-775. DOI: 10.1177/1359105308093860

[25] Felce D, Perry J. Quality of life: Its definition and measurement. Research in Developmental Disabilities. 1995;**16**(1):51-74. DOI: 10.1016/0891-4222(94)00028-8

[26] Cummins RA. Objective and subjective quality of life: An interactive model. Social Indicators Research. 2000;**52**(1):55-72. DOI: 10.1023/A:1007027822521

[27] Tay L, Kuykendall L, Diener E. Satisfaction and happiness—The bright side of quality of life. In: Glatzer et al., editors. Global Handbook of Quality of Life. Exploration of Well-being of Nations and Continents. Dordrecht: Springer Science + Business Media; 2015. pp. 839-853. DOI: 10.1007/978-94-017-9178-6_39

[28] Campbell A, Converse PE, Rodgers WL. The perceived quality of life and its implications. In: Campbell A, Converse PE, Rodgers WL, editors. The Quality of American Life. Perceptions, Evaluations, and Satisfactions. New York: Russell Sage Foundation; 1976. pp. 471-508

[29] Wallander JI, Koot HM. Quality of life in children: A critical examination of concepts, approaches, issues, and future directions. Clinical Psychology Review. 2016;**45**:131-143. DOI: 10.1016/j.cpr.2015.11.007

[30] Cambridge dictionary [Internet]. 2019. Available from: https://dictionary.cambridge.org/dictionary/english/sport [Accessed: 10 May 2019]

[31] Berger BG. Keynote presentation—Roles of exercise in quality of life: Exploring integral relationships. Sport and Exercise Psychology Review. 2009;**5**:60-63

[32] Berger BG, Tobar DA. Exercise and quality of life. In: Morris T, Terry PC, editors. The New Sport and Exercise Psychology Companion. Morgantown, WV: Fitness Information Technology; 2011. pp. 483-505

[33] Peráčková J. The Slovak Republic and its Sport Sector. Vol. 112. Bratislava: Peter Mačura—PEEM; 2006

[34] Baştuğ G, Duman S. Examining life satisfaction level depending on physical activity in Turkish and German societies. Procedia—Social and Behavioral Sciences. 2010;**2**(2):492-4895. DOI: 10.1016/j.sbspro.2010.03.790

[35] Mehdinezhad V, Golsanamlou M. Influence of physical activity on students' physical self-concept and satisfaction with life: Physical and non-physical education students' perspective. Turkish Journal of Sport and Exercise. 2014;**16**(2):77-83. DOI: 10.15314/TJSE.201428109

[36] Peráčková J, Matúšek D. Vzťah pohybovej activity a životnej spokojnosti vysokoškolákov [Relationship of physical activity and life satisfaction of university students]. In: Pedagogická Kinatropologie. Soubor referátů z medzinárodního semináře konaného 14.4.-16.4.2010 [Pedagogical Kinantropology. Proceedings from International Conference 14-16 April 2010]. Ostrava: Tribun EU; 2010. pp. 107-112

[37] Peráčková J, Matúšek D. Faktory kvality života športujúcej a nešportujúcej stredoškolskej mládeže [Quality of life factors for sport active and sport inactive high school youth]. In: Športové a pohybové Aktivity a životný štýl (vybrané problémy) [Sports and Physical Activities and the Lifestyle (Selected Issues)]. Bratislava: Slovenská vedecká spoločnosť pre telesnú výchovu a šport v spolupráci s Univerzitou Komenského v Bratislave, Fakultou telesnej výchovy a športu; 2013. pp. 68-81

[38] Melin R, Fugl-Meyer KS, Fugl-Meyer AR. Life satisfaction in 18- to 64-year-old Swedes: In relation to education, employment situation, health and physical activity. Journal of Rehabilitation Medicine. 2003;**35**(2):84-90

[39] Huang CY, Carleton B. The relationships among leisure participation, leisure satisfaction, and life satisfaction of college students in Taiwan. Journal of Exercise Science and Fitness. 2003;**10**(2):129-132

[40] Kaplan GA, Lazarus NB, Cohen RD, Leu DJ. Psychosocial factors in the natural history of physical activity. American Journal of Preventive Medicine. 1991;**7**(1):12-17. DOI: 10.1016/S0749-3797(18)30959-0

[41] Zullig KJ, White RJ. Physical activity, life satisfaction, and self-rated health of middle school students. Applied Research in Quality of Life. 2011;**6**(3):277-289. DOI: 10.1007/s11482-010-9129-z

[42] Kleszczewska D, Dzielska A, Salonna F, Mazur J. The association between physical activity and general life satisfaction in lower secondary school students: The role of individual and family factors. Community Mental Halth Journal. 2018;**54**(8):1245-1252. DOI: 10.1007/s10597-018-0309-x

[43] Gomez-Baya D, Mendoza R, Tomico A. The prospective relationship of sport and physical activity with life satisfaction after a one-year follow-up: An examination of gender differences during mid-adolescence.

Caudernos de Psicologia del. Deporte. 2018;**18**(2):169-186

[44] Păunescu M, Grigore V, Mitrache G, Predoiu A, Predoiu R. Quantitative and qualitative in measuring quality of life in sport. Revista Românească pentru Educatie Multidimensională. 2018;**10**(1):95-108. DOI: 10.18662/rrem/21

[45] Barcaccia B, Esposito G, Matarese M, Bertolaso M, Elvira M, Grazia De Marinis M. Defining quality of Life: A wild-goose chase? Europe's Journal of Psychology. 2013;**9**(1):185-203. DOI: 10.5964/ejop.v9i1.484

[46] Wish NB. Are we really measuring the quality of Life? Well-being has subjective dimensions, as well as objective ones. The American Journal of Economics and Sociology. 1986;**45**(1):93-99

[47] Diener E, Suh EM, Lucas RE, Smith HL. Subjective well-being: Three decades of progress. Psychological Bulletin. 1999;**125**(2):276-302. DOI: 10.1037/0033-2909.125.2.276

[48] Elavsky et al. Physical activity enhances long-term quality of Life in older adults: Efficacy.Esteem, and affective influences. Annals of Behavioral Medicine. 2005;**30**(2):138-145. DOI: 10.1207/s1524796abm3002_6

[49] Ku PW, McKenna J, Fox KR. Dimensions of subjective well-being and effects of physical activity in Chinese older adults. Journal of Aging and Physical Activity. 2007;**15**(4):382-397. DOI: 10.1123/japa.15.4.382

[50] Brajša-Žganec A, Merkaš M, Šverko I. Quality of Life and leisure activities: How do leisure activities contribute to subjective well-being? Social Indicator Research: An International and Interdisciplinary Journal for Quality-of-Life Measurement. 2011;**102**(1):81-91. DOI: 10.1007/s1 1205-010-9724-2

[51] Broďáni J, Žišková I. Quality of life and physical activity of kindergarten teachers. Physical Activity Review. 2015;**3**:11-21. DOI: 10.16926/par.2015.01.02

[52] Broďáni J, Spišiak M, Paška Ľ. The interaction of physical activity and quality of life of adolescents. Journal of Physical Education and Sport. 2015;**15**(3):518-524. DOI: 0002176727/jpes.2015.03078

[53] Barradas SC, Finck Barboza C, Sarmiento OL. Differences between leisure-time physical activity, health-related quality of life and life satisfaction: Al Ritmo de las Comunidades, a natural experiment from Colombia. Global Health Promotion. 2017. DOI: 10.1177/1757975917703303

[54] Csikszentmihalyi M, Hunter J. Happiness in everyday life: The uses of experience sampling. Journal of Happiness Studies. 2003;**4**(2):185-199

[55] IOM (Institute of Medicine). Educating the Student Body: Taking Physical Activity and Physical Education to School. Washington, DC: The National Academies Press; 2013. Available from: https://www.ncbi.nlm.nih.gov/books/NBK201497/ [Accessed: 18 May 2019]

[56] Kimiecik JC, Harris AT. What is enjoyment? A conceptual/definitional analysis with implications for sport and exercise psychology. Journal of Sport and Exercise Psychology. 1996;**20**(3):247-263. DOI: 10.1123/jsep.20.3.247

[57] Michaelson J, Mahony S, Schifferes J. Measuring Well-being. A Guide for Practitioners [Internet]. 2012. Available from: https://b.3cdn.net/nefoundation/8d92cf44e70b3d16e6_rgm6bpd3i.pdf [Accessed: 12 March 2019]

[58] Šubrt J. Soudobá sociologie III. Diagnózy soudobých společností [Contemporary Sociology III. Contemporary Society Diagnosis]. Praha: Karolinum; 2008. 384 p

[59] Uhláriková J. Analýza životnej spokojnosti adolescentov v kontexte rodiny a rodinneho prostredia [Analysis of life satisfaction of adolescents in the context of family and family environment]. E-Psychológia [E-Psychology]. 2010;**4**(4):10-18

[60] Diener E, Suh EM. Measuring quality of life: Economic, social, and subjective indicators. Social Indicators Research. 1997;**40**(1-2):189-216. DOI: 10.1023/A:1006859511756

[61] World Health Organization. Physical activity and health [Internet]. 2010. Available from: https://www.eufic.org/en/healthy-living/article/physical-activity-and-health [Accessed: 28 January 2019]

[62] Warburton DER, Nicol CW, Brendin SSD. Health benefits of physical activity: The evidence. CMAJ. 2006;**174**(6):801-809. DOI: 10.1503/cmaj.051351

[63] Hennessy CH, Moriarty DG, Zack MM, Scher PA, Brackbill R. Measuring health-related quality of life for public health surveillance. Public Health Reports. 1994;**109**(5):665-672

[64] Inglehart R, Foa R, Peterson C, Welzel C. Development, freedom, and rising happiness: A global perspective (1981-2007). Perspectives on Psychological Science. 2008;**3**(4):264-285. DOI: 10.1111/j.1745-6924.2008.00078.x

[65] Göksoy S. Situations that make students happy and unhappy in schools. Universal Journal of Educational Research. 2017;**5**(12A):77-83. DOI: 10.13189/ujer.2017.051312

[66] Kobau R et al. Well-being Concepts. Centers for Disease Control and Prevention/CDC; 2013. Available from: https://www.cdc.gov/hrqol/wellbeing.htm [Accessed: 30 April 2019]

[67] Jones R, Randall CH. Measuring National Well-being: Quality of Life in the UK, 2018 [Internet]. Office for National Statistics; 2018. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/measuringnationalwellbeing/qualityoflifeintheuk2018 [Accessed: 13 May 2019]

[68] Golemanov L, Zgodavova K. Quality of Life and Well-Being. Improhealth edition. Trenčín: Alexander Dubček University of Trencin Press; 2008. 60 p

[69] Diener E, Tay L. Subjective well-being and human welfare around the world as reflected in the Gallup World Poll. International Journal of Psychology. 2015;**50**(2):135-149. DOI: 10.1002/ijop.12136

[70] Džuka J, Dalbert C. Vývoj a overenie validity škál emocionálnej habituálnej subjektívnej pohody [Development and verification of validity scales of emotional habitual subjective well-being]. Československá psychologie [Czechoslovak Psychology]. 2002;**46**(3):234-250

[71] Casas F, González M, Figuer C, Coenders G. Subjective well-being, values and goal achievement: The case of planed versus by chance searches on the internet. Social Indicators Research. 2004;**23**:123-141

[72] Grant N, Wardle J, Steptoe A. The relationship between life satisfaction and health behaviour: A cross-cultural analysis of young adults. International Journal of Behavioral Medicine. 2009;**16**(3):259-268. DOI: 10.1007/s12529-009-9032-x

[73] Diener E, Chan MY. Happy people live longer: Subjective well-being contributes to health and longevity. Applied Psychology: Health and Well-being. 2011;**3**(1):1-43. DOI: 10.1111/j.1758-0854.2010.01045.x

[74] Zayed KN, Ahmed D, Van Niekerk RL, Ho WKY. The mediating role of exercise behaviour on satisfaction with life, mental well-being and BMI among university employees. Health Psychology. 2018;**5**(1):1-13. DOI: 10.1080/23311908.2018.1430716

[75] Ziółkowski A, Zubrzycki I, Błachnio A, Drobnik P, Zarańska B, Moska W. Influence of sport activity on satisfaction with life and sence of coherence among physically disabled people. Baltic Journal of Health and Physical Activity. 2016;**8**(4):109-116

[76] Bergendiová F. In: Comenius University, Faculty of Physical Education and Sport, editor. Kvalita života športujúcich a nešportujúcich žiakov s telesným postihnutím zo Slovenska a z Rakúska [thesis] [Quality of life of sport active and sport inactive pupils with physical disability from Slovakia and Austria]. Bratislava; 2017

[77] Park N. The role of subjective well-being in positive youth development. The Annals of the American Academy of Political and Social Science. 2004;**591**(1):25-39. DOI: 10.1177/0002716203260078

[78] ISCED 0, 1, 2, 3 [Internet]. 2009. Available from: http://www.statpedu.sk [Accessed: 15 April 2019]

[79] Endicott J, Nee J, Harrison W, Blumenthal R. Quality of life enjoyment and satisfaction questionnaire: A new measure. Psychopharmacology Bulletin. 1993;**29**(2):321-326

[80] Weber M, Harzer C, Huebner ES, Hills K. Measures of Life Satisfaction across the lifespan. In: Boyle GJ, Saklofske DH, Matthews G, editors. Measures of Personality and Social Psychological Constructs. San Diego: Academic Press, Elsevier; 2015. pp. 101-130

[81] Diener E, Emmons RA, Larsen RJ, Griffin S. The satisfaction with Life scale. Journal of Personality Assessment. 1985;**49**(1):71-75. DOI: 10.1207/s15327752jpa4901_13

[82] Pavot W, Diener E. Review of the satisfaction with life scale. Psychological Assessment. 1993;**5**(2):164-172

[83] United Nations, Department of Economic and Social Affairs, Population Division. World Population Prospect: The 2017 Revision, Volume II: Demographic Profiles (ST/ESA/SER.A/400) [Internet]. 2017. Available from: http://esa.un.org/unpd/wpp/Publications/ [Accessed: 06 May 2019]

[84] Frisén A. Measuring health-related quality of life in adolescence. Acta Paediatrica. 2007;**96**(7):963-968. DOI: 10.1111/j.1651-2227.2007.00333.x

[85] Dragomerická E et al. SQUALA: Subjective quality of life analysis: příručka pro uživatele české verze Dotazníku subjektívní kvality života SQUALA [SQUALA: Subjective quality of life analysis: A guide for users of the Czech version of the Subjective Quality of Life Questionnaire SQUALA]. Praha: Psychiatrické centrum Praha; 2006. 68 p

[86] Keng KA, Hooi WS. Assessing quality of life in Singapore: An exploratory study. Social Indicators Research. 1995;**35**(1):71-91

[87] Wohl A. Some remarks on the methodology of research on sociology of sport. International Review for the Sociology of Sport. 1975;**10**(2):5-32. DOI: 10.1177/101269027501000202

[88] Agyar E. Life satisfaction, perceived freedom in leisure and self-esteem:

The case of physical education and sport students. Procedia—Social and Behavioral Sciences. 2013;**93**:2186-2193. DOI: 10.1016/j.sbspro.2013.10.185

[89] Matsumoto D, Konno J. The relationship between adolescents' participation in judo, quality of life, and life satisfaction. Research Journal of Budo. 2005-2006;**36**(1):13-25. DOI: 10.11214/budo1968.38.1_13

[90] Adebayo AK. Sport involvement as a correlate of Life satisfaction among team sports participants in Obafemi Awolowo University Ile-Ife. Osun State. Journal of Tourism, Hospitality and Sports. 2016;**15**:1-6

[91] Wold B, Duda JL, Balaguer I, et al. Comparing self-reported leisure time physical activity, subjective health, and life satisfaction among youth soccer players and adolescents in a reference sample. International Journal of Sport and Exercise Psychology. 2013;**11**(4):328-340. DOI: 10.1080/1612197X.2013.830433

[92] Biddle SJH. Emotions, mood and physical activity. In: Biddle SJH, Fox KR, Boutcher SH, editors. Physical Activity and Psychological Well-Being. London: Routledge; 2000. pp. 88-117

[93] Van Hout RCH, Young MEM, Basset SH, Hooft T. Participation in sport and the perceptions of quality of life of high school learners in the Theewaterskloof Municipality, South Africa. African Journal of Physical, Health Education, Recreation and Dance (AJPHERD). 2013;**19**(3):612-622

[94] Brown KA, Patel DR, Darmawan D. Participation in sports in relation to adolescent growth and development. Translational Pediatrics. 2017;**6**(3):150-159. DOI: 10.21037/tp.2017.04.03

[95] Splengler S, Woll A. The more physical active, the healthier? The relationship between physical activity and health/related quality of Life in adolescents: The MoMo study. Journal of Physical Activity & Health. 2013;**10**(5):708-715. DOI: 10.1123/jpah.10.5.708

[96] Muros JJ, Pérez FS, Ortega FZ, Gámez Sánchez VM, Knox E. The association between healthy lifestyle behaviors and health-related quality of life among adolescents. Jornal de Pediatria. 2017;**93**(4):406-412. DOI: 10.1016/j.jped.2016.10.005

[97] Holstein BE, Ito H, Due P. Physical exercise among school children. A nation/wide sociomedical study of 1671 children 11/15 years of age. Ugeskrift for laeger. 1990;**152**(38):2721-2727

[98] Lehman AF. A quality of life interview for the chronically mentally ill. Evaluation and Program Planning. 1988;**11**(1):51-62. DOI: 10.1016/0149-7189(88)90033-X

[99] Valois RF, Zullig KJ, Scott Huebner E, Wanzer Drane J. Physical activity behaviors and perceived life satisfaction among public high school adolescents. Journal of School Health. 2004;**74**(2):59-65. DOI: 10.1111/j.1746-1561.2004.tb04201.x

[100] Bradford R, Rutherford DL, John A. Quality of life in young people: Ratings and factor structure of the quality of life profile—Adolescent version. Journal of Adolescence. 2002;**25**(3):261-274. DOI: 10.1006/jado.2002.0469

[101] Gilman R, Huebner S. A review of life satisfaction research with children and adolescents. School Psychology Quarterly. 2003;**18**(2):192-205. DOI: 10.1521/scpq.18.2.192.21858

[102] Helseth S, Misvær N. Adolescents' perceptions of quality of life: What it is and what matters. Journal of Clinical Nursing. 2010;**19**:1454-1461. DOI: 10.1111/j.1365-2702.2009.03069

[103] Rodríguez-Fenández A, Zuazagoitia-Rey-Baltar A, Ramos-Díaz E. Quality of Life and physical activity: Their relationship with physical and psychological well-being. In: Vilas Boas AA, editor. Quality of Life and Quality of Working Life. London: IntechOpen; 2017. pp. 53-70

[104] Booker CL, Skew AJ, Kelly YJ, Sackere A. Media use, sports participation, and well-being in adolescence: Cross-sectional findings from the UK household longitudinal study. American Journal of Public Health. 2015;**105**(1):173-179. DOI: 10.2105/AJPH.2013.301783

[105] Washington RL et al. Organized sports for children and preadolescents. Pediatrics. 2001;**107**(6):1459-1462. DOI: 10.1542/peds.107.6.1459

[106] Collins NM, Cromartie F, Butler S, Bae J. Effects of early sport participation on self-esteem and happiness. The Sport Journal. 2018;**20**:1-22

[107] Helliwell JF, Huang H, Wang S. Changing world happiness. In: Helliwell JF, Layard R, Sachs J, editors. World Happiness Report. Vol. 2019. New York: Sustainable Development Solutions Network; 2019. pp. 13-48

[108] OECD Better Life Index. Life satisfaction [Internet]. 2018. Available from: http://www.oecdbetterlifeindex.org/topics/life-satisfaction/ [Accessed: 25 April 2019]

[109] The Legatum Prosperity Index 2018 [Internet]. 2018. Available from: https://www.prosperity.com/rankings [Accessed: 23 April 2019]

[110] The Quality of Life Index for Country 2019 [Internet]. 2019. Available from: https://www.numbeo.com/quality-of-life/rankings_by_country.jsp [Accessed: 23 April 2019]

Chapter 7

Behavioral and Psychosocial Factors as Mediators of the Oral Health Impact on Adolescents Quality of Life

Samuel Veras, Verônica Kozmhinsky, Paulo Goes
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Abstract

The goal of this study was to evaluate the association of behavioral and psychosocial factors as mediators of the oral health impact conditions related to the adolescents quality of life. Cross-sectional study with 1417 students, both sexes, 15–19 years old in a Brazilian city. The impact of oral diseases related to the quality of life was assessed by Oral Impact on Daily Performances (OIDP), dental caries by the decay-missing-filled teeth index (DMFT index), periodontal disease by the Community Periodontal Index (CPI index) and the pain at endpoint. Information on the behavioral and psychosocial factors was collected. Statistical analysis was performed using the chi-square test and multiple logistic regression, with 5% significance level. The majority of adolescents considered that the oral health conditions produced high impact on the quality of life (66.1%). It was evidenced that caries, pain of dental origin, birth order, regular dental care, and high sugar consumption significantly associated with high impact on quality of life related to oral health. The decay and the dental origin pain produce a high impact on the quality of life related to oral health, and these impacts are associated with both behavioral and psychosocial factors.

Keywords: oral health, adolescents, quality of life, epidemiology, caries, impact

1. Introduction

Oral health problems have been increasingly recognized as having significant negative impacts on the daily performance and quality of life of individuals and society. In addition to causing pain, oral diseases cause suffering, psychological embarrassment, social deprivation, difficulties in food and well-being, causing individual and collective damages [1, 2].

Caries is still the most common cause of tooth pain [3–5], and the association between untreated caries and toothache is more frequent in populations with lower access, in groups with lower socioeconomic status and in populations where caries is not widely treated, leading to impact on daily activities [6]. Despite the multifactorial nature of caries, more recent studies have shown a strong association between caries and sociodemographic factors [7–11]. It is also important to highlight the role of socioeconomic, behavioral, and environmental factors as a determinant of self-care and oral complaints [12].

Since the World Health Organization (WHO) changed the concept of quality of life adding social domains on the definition instead of only the absence of disease, oral health has also been included as one of the contributing factors to general health. Thus, oral health is also perceived as an important aspect of quality of life, which includes a variety of aspects or consequences that oral health can have in the physical, social, and psychological domains. Among these aspects, the ability to eat, talk, smile and the occurrence of pain and discomfort are considered, respectively, the positive and negative aspects most related to the mouth and quality of life [13].

At present, great importance has been given to research involving the impact of oral diseases on the quality of life of individuals [1, 4, 14–17], and measuring instruments have been developed and tested that allow oral health status and dental treatment needs are investigated in order to assess the impact of oral health on the lives of children and their families [18].

Studies have shown that there is no linear association between clinical conditions and indicators of quality of life related to oral health. Therefore, these indicators that evaluate not only clinical aspects are associated with personal, social, and environmental factors [19–21]. Socioeconomic status, age, general health perception, and oral health conditions are some of the factors identified as significantly associated with the impact related to the quality of life [22–25].

Adolescents are constantly developing biologically, psychologically, and socially, with negligible behaviors with their health care. Therefore, it is considered a period of increased risk for caries and other oral diseases, due to the precarious plaque control and less care with brushing [26, 27], increased sugar intake, smoking [28], and alcoholic beverages [27, 29].

Considering that studies have shown that oral diseases affect the daily life of adolescents and the need to identify the factors associated with greater or lesser impact on the quality of life of adolescents, the present study aimed to evaluate the association of behavioral and psychosocial factors, such as mediators of the impact of oral health conditions related to adolescents' quality of life.

2. Methods

A cross-sectional study was carried out with adolescents of both sexes aged 15–19 enrolled in public schools (municipal and state) from São Lourenço da Mata (PE), excluding those with systemic diseases, cognitive, auditory, or visual difficulties that compromised their participation in the research.

The sample was calculated using the two-ratio comparison formula, a ratio of 1:1 in the comparison groups, with a power of 80% to detect differences when an odds ratio of 1.5 is observed, with a random error of 2.5% and a confidence interval (CI) of 95%. As part of an oral health survey, the prevalence of 20% nonexposed toothache observed in a previous study was used as a parameter for the sample calculation [30]. The Epi Info 6 calculation program and the Fleiss bibliographic database were used [31]. In this way, a minimum sample of 1380 adolescents was obtained, with a 20% increase to compensate for possible losses and increases the effect of the study, resulting in a total sample of 1656 students.

Regarding the schools participating in the survey, seven were state schools and four municipal schools; they were selected because the students were aged between 15 and 19 in the group of interest and provided the list of students. The list of 15- to 19-year-old students enrolled in the 11 schools totaled 3604 students, from which the draw of the students was carried out with a selected interval of 2.17, thus obtaining the proposed sample of 1656 adolescents.

Before starting to collect data, the five researchers were calibrated, obtaining an inter-examiner agreement that ranged from 0.86 to 0.99, showing an excellent degree of agreement, and the intra-examiner had a concordance greater than 92%.

Data collection was performed from August to November 2012, through clinical and nonclinical data. Nonclinical data were obtained through a self-administered questionnaire, after a previous explanation of the objectives and method of the study, and all the doubts that emerged at the moment of the research were removed.

The dependent variable on the study "impact on the quality of life-related to oral health" was evaluated through the Oral Impact on Daily Performances (OIDP) index [32]. The independent variables were as follows: dental caries evaluated through the DMFT index; periodontal disease evaluated through the PDI index (behavior variables: tooth brushing, flossing, sugar consumption, smoking, alcohol use, and dental care standard); and psychosocial variables (birth order, history of school failure, and family structure).

Data were analyzed through the SPSS program version 17.0. The descriptive analysis was performed for the categorical variables, through simple frequencies, and for the continuous variables, and measures of central tendency and variability. For analytical statistical analysis of OIDP [32], the scores produced were dichotomized, regarding the median to create a binary variable: low and high impact. Inferential analysis was performed using association and correlation tests (Pearson's Chi-square and Multiple Logistic Regression). For regression analysis, only the variables that showed significance in the bivariate analysis were considered, except for sex. The variables entered the block model by the ENTER method, and the consistency of the models was evaluated by the Hosmer-Lemeshow test, and the unadjusted and adjusted estimates were presented with their respective 95% CI. The project was approved by the Research Ethics Committee of the University of Pernambuco, under opinion 105/12 in June 2012.

3. Results

The present study obtained a response rate of 85.5%, resulting in a final sample of 1417 adolescents with a mean age of 16.03 years (SD = 1.16), being 56.2% (797) of the sex female. Among the adolescents surveyed, 66.1% (936) presented at least one of the impacts studied.

Regarding the psychosocial factors, 49.4% (697) of the adolescents had been disapproved, 53% (751) was part of the traditional family, 42% (595) reported being the first child, and 11% (1559) were the fourth child or beyond.

Regarding the behavioral factors, the majority performed regular brushing 95.1% (1348), only 38.7% (549) were using dental floss, and in 57.8% (805), high sugar consumption was observed. Alcoholic beverages had already been tried daily by 59.4% (842) of the adolescents, and of these, 40.8% (344) made regular use, representing 24.2% of the total. Regarding cigarette smoking, 20.5% (291) had already tried it, 30.6% (89) of whom were considered regular smokers, representing 6.3% of the total sample. Only 17% (248) presented a pattern of regular dental care.

Regarding the oral conditions of the adolescents, a caries prevalence of 51.29% (711) was found, with an average DMFT score of 2.72 (SD = 3.10). Regarding the periodontal condition, the prevalence of gingival bleeding was 49.60% (703), the presence of calculus 48% (680) and shallow periodontal pockets 5.4% (77). Toothache in the last 6 months was reported in 73.6% (1042) of adolescents.

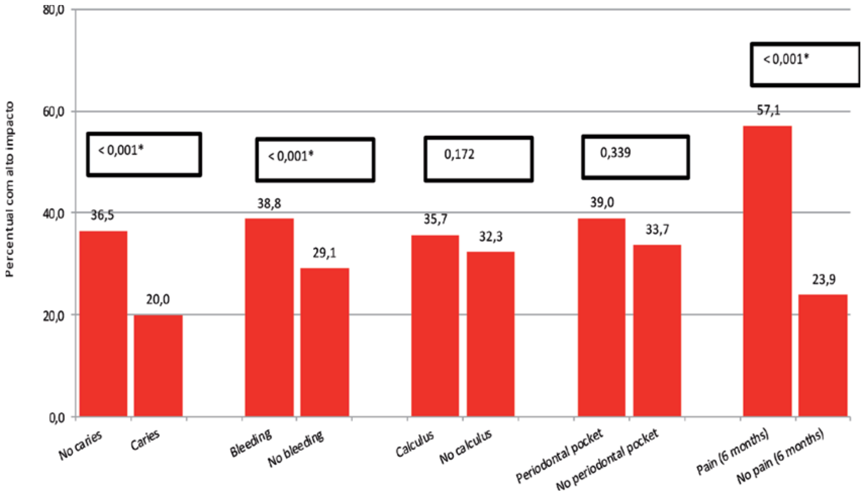

Figure 1.
Impact on quality of life and the oral health status of adolescent students, São Lourenço da Mata/PE, 2014.

Behavioral variables	Impact on quality of life				Total		X^2	P
	Low		High					
	n	(%)	n	(%)	n	(%)		
Brushing								
Regular	901	66.8	447	33.2	936	100.0	6.824	*0.009
Irregular	35	51.5	33	48.5	68	100.0		
Flossing								
Yes	566	65.2	302	34.8	868	100.0	0.718	0.397
No	370	67.4	179	32.6	549	100.0		
Smoking								
Yes	185	63.6	106	36.4	291	100.0	0.906	0.341
No	736	66.5	370	33.5	1106	100.0		
Alcohol consumption								
Yes	541	64.3	301	35.7	842	100.0	2.421	0.120
No	381	68.3	177	31.7	558	100.0		
Has been to the dentist								
Yes	794	65.4	420	34.6	1214	100.0	1.868	0.172
No	140	70.4	59	29.6	199	100.0		
Consultation pattern								
Regular consults	197	79.4	51	20.6	248	100.0	34.07	*≤0.001
Irregular consults	511	60.0	341	40.0	852	100.0		
Do not go to dental consults	162	69.2	72	30.8	234	100.0		
Sugar consumption								
Yes	431	70.4	181	29.6	612	100.0	11.4	*≤0.001
No	368	61.2	233	38.8	601	100.0		

**Statistically significant.*

Table 1.
Impact on quality of life and behavioral variables in adolescent students, São Lourenço da Mata/PE, 2014.

Psychosocial variables	Impact on the quality of life				Total		X2	P
	Low		High					
	n	(%)	n	(%)	n	(%)		
Birth order								
First born child	432	71.6	171	28.4	603	100.00	21.877	*≤0.001
Second child	272	65.7	142	34.3	414	100.00		
Third	120	62.2	73	37.8	193	100.00		
Fourth or more	84	54.2	71	45.8	155	100.00		
Do not know/do not recall	26	55.3	21	44.7	47	100.00		
Failure								
Yes	440	63.1	257	36.9	697	100.0	12.16	*0.002
No	478	70.1	204	29.9	682	100.0		
Do not know/do not recall	16	48.5	17	51.5	33	100.0		
Family structure								
Traditional (father and mother)	476	66.2	243	33.8	719	100.0	1080	0.782
Uniparental (father or mother)	277	64.7	151	35.3	428	100.0		
Other	61	67.0	30	33.0	91	100.0		

Table 2.
Impact on quality of life and psychosocial variables in adolescent students, São Lourenço da Mata/PE, 2014.

There was an association between the impact on quality of life and dental caries variables ($p \leq 0.001$), gingival bleeding ($p \leq 0.001$) and pain ($p \leq 0.001$) (**Figure 1**); tooth brushing ($p = 0.009$), dental care standard ($p \leq 0.001$), and sugar consumption ($p \leq 0.001$) (**Table 1**); birth order ($p \leq 0.001$) and history of disapproval ($p = 0.002$) (**Table 2**).

Variables associated with the impact on the quality of life related to oral health were taken to the multiple logistic regression model. After adjusting the variables for dental brushing, dental care standard, sugar consumption, birth order, and failure history, the statistical significance of birth order ($p < 0.01$), irregular dental care standard ($p < 0.01$), and high sugar consumption ($p < 0.01$) (**Table 3**).

4. Discussion

The data of the present study help to clarify how the association of psychosocial and behavioral factors in determining the impact on the quality of life related to oral health happens. It was evidenced that, in this population of schoolchildren of the public network, a greater impact was reported by female adolescents, who are younger children of families that have more than one child, presenting an irregular behavior of dental care and high consumption of sugar.

The reports of impacts on the quality of life related to oral health have been the subject of several investigations, being universally accepted that the impact of the oral and dental condition on the daily life of the people [1, 3, 15–17, 33]. The present study ratifies these results and brings us to the reflection on the factors involved in this process.

Variables	**Not justified Odds (95% IC)**	**Value P**	**Adjusted Odds (95% IC)**	**Value P**
Brushing				
Irregular	1		1	
Regular	0.71 (0.43–1.17)	0.18	0.53 (0.25–1.11)	0.095
Birth order				
First born child	1		1	
Second	1.31 (1.00–1.72)	0.44	1.22 (0.90–1.65)	0.198
Third	1.53 (1.09–2.16)	0.13	1.49 (1.01–2.22)	0.045
Fourth or more	2.13 (1483–3.06)	<0.01	2.30 (1.49–3.54)	<0.01
Do not know/do not recall	2.04 (1.11–3.72)	0.20	2.07 (1.01–4.28)	0.047
Failure				
Yes	1		1	
No	0.73 (0.58–0.91)	<0.01	0.48 (0.20–1.11)	0.087
Do not know/do not recall	1.81 (0.90–3.66)	0.09	0.35 (0.15–0.81)	0.015
Consultation pattern				
Regular	1		1	
Irregular	2.57 (1.84–3.61)	<0.01	2.47 (1.71–3.57)	<0.01
Do not go to dental consults	1.71 (1.13–2.59)	0.01	1.55 (0.97–2.48)	0.06
Sugar consumption				
High	1		1	
Low	1.50 (1.18–1.91)	<0.01	1.38 (1.07–1.78)	0.012

Table 3.
Results of the multiple logistic regression, São Lourenço da Mata/PE, 2014.

It was demonstrated in this research that the impact related to oral health in this group of adolescents was associated with sex, where the girls reported a greater impact than the boys. It was noticed, based on this findings, that girls are more attentive, perceiving, and enhancing oral health [1, 4, 34, 35] feel more comfortable in reporting their health-related concerns or emotional problems [36] and are more sensitive to the perception of his appearance [4].

Most of the interviewees had gone to the dentist at least once in their lifetime, and a considerable percentage consulted the dental services in less than a year. Similar data were found by other authors [37–39].

In the present study, the pattern of regular dental care was associated with the impact, which is in agreement with the findings of a study conducted in northern Tanzania [38] in which the frequency of having any oral impact had a directly proportional increase with the visit to the dentist. Likewise, another study verified an association of the impact with the recent use of dental services [39]. Studies have found that a greater proportion of participants who had never visited a dentist reported less impact [40, 41]. The possible explanation for this fact may be associated with the pattern of symptomatic dental care, since most adolescents visit the dentist only when they have toothache, have a mouth problem, or their oral health is poor, and statistically, these are more likely to have more regular dental care, according to the results of some studies [3, 4, 7, 37, 42, 43].

In the present study, adolescents with high sugar consumption showed a greater impact on quality of life related to oral health. Sugar consumption has long been reported as one of the relevant factors in the etiology of caries [5, 44] also, lack of access to dental services is generally associated with low socioeconomic status [45, 46]. Untreated caries and its immediate consequence, the pain of dental origin, are the main causes of impacts related to the quality of life in adolescents [47, 48, 53]. Thus, improving behavior among dental visits of low socioeconomic groups would have a greater effect on improving oral health, reducing the impact on quality of life related to oral health [38].

A relevant finding was the fact that behavioral factors related to oral health, especially concerning a higher prevalence of dental caries, such as the pattern of irregular dental care and high sugar consumption were minimized when adjusted for psychosocial factors. This effect may be related to the fact that psychosocial factors seem to act at a level above the determinant chain [39, 41, 42, 49].

Another important finding of the present study was the association between the impact of oral health related to quality of life and the order of birth of school children. Previous studies have shown that younger children in families with more than two children report more pain [1]; they have more caries and more risk behaviors for oral health [50]. One possible explanation for this is the fact that, in socially disadvantaged families, parental care is hampered by the availability of time for the care of the youngest children.

These findings point to the strengthening of the theoretical models of the social determinants of the disease, in which the psychosocial factors point to a strong mediation of these factors with chronic diseases among them oral health [51, 52, 54].

The results of this study should be interpreted in light of its limitations; since it is a cross-sectional study, a cause-and-effect relationship cannot be established. However, the aspects related to its validity should be emphasized, since it is based on other studies, derived from a population sample, and used a universally accepted methodology.

5. Conclusion

The present study demonstrated the independent association between behavioral and psychosocial factors in determining the impact on the quality of life related to oral health. This demonstrates that health promotion actions should be directed not only to specific actions such as tooth brushing and fluoride application but should include broader actions directed at contextual factors where the individual lives and their family structure.

The study also found that oral diseases have an impact on the studied population, mainly in female adolescents, younger children of families with more than one child, an irregular pattern of dental care, and high consumption of sugar. Thus, these results indicate that the vulnerability of social conditions is represented by families with several children, in which oral health becomes more likely to report impact.

Conflict of interest

The authors declare no conflict of interest.

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References

[1] Goes PSA, Watt RG, Hardy R, Sheiham A. Impacts of dental pain on daily activities of adolescents aged 14-15 years and their families. Acta Odontologica Scandinavica. 2008;**66**:7-12

[2] Barbieri CH, Rapoport A. Evaluation of the quality of life of patients rehabilitated with implant-mucous-supported prostheses versus conventional total dentures. Brazilian Journal of Head and Neck Surgery. 2009;**38**:84-87

[3] Caglayan F, Altun O, Miloglu O, Kaya MD, Yilmaz AB. Correlation between oral health-related quality of life (OHQoL) and oral disorders in a Turkish patient population. Medicina Oral, Patología Oral y Cirugía Bucal. 2009;**14**:573-578

[4] Bianco A, Fortunato L, Nobile CGA, Paiva M. Prevalence and determinants of oral impacts on daily performance: Results from a survey among school children in Italy. European Journal of Public Health. 2009;**20**:595-600

[5] Bastos RS, Carvalho E, Xavier A, Caldana ML, Bastos JRM, Lauris JRP. Dental caries related to quality of life in two Brazilian adolescent groups: A cross-sectional randomised study. International Dental Journal. 2012;**62**:137-143

[6] Slade GD. Epidemiology of dental pain and dental caries among children and adolescents. Community Dental Health. 2001;**18**:219-227

[7] Goes PSA, Watt RG, Hardy R, Sheiham A. The prevalence and severity of dental pain in 14-15 year old Brazilian schoolchildren. Community Dental Health. 2007;**24**:217-224

[8] Lewis C, Stout J. Toothache in US children. Archives of Pediatrics and Adolescent Medicine. 2010;**164**: 1059-1063

[9] Crocombe LA, Broadbent JMW, Thomson M, Brennan DS, Poulton R. Impact of dental visiting trajectory patterns on clinical oral health and oral health-related quality of life. Journal of Public Health Dentistry. 2012;**72**:36-44

[10] Nanayakkara V, Renzaho A, Oldenburg B, Ekanayake L. Ethnic and socio-economic disparities in oral health outcomes and quality of life among Sri Lankan preschoolers: A cross-sectional study. International Journal for Equity in Health. 2013;**12**:89

[11] Nélio V, Pereira C, Amaral O. Prevalence and determinants of dental caries in a sample of schoolchildren of Sátão, Portugal. Revista Portuguesa de Estomatologia, Medicina Dentária e Cirurgia Maxilofacial. 2014;**55**:214-219

[12] Petersen PE. The World Oral Health Report 2003: Continuous improvement of oral in the 21st century—The approach of the WHO global oral health programme. Community Dentistry and Oral Epidemiology. 2003;**31**:3-23

[13] Mcgrath C, Bedi R. A national study of the importance of oral health to life quality to inform scales of oral health related quality of life. Quality of Life Research. 2004;**13**:813-818

[14] Bernabé E, Tsakos G, De Oliveira CM, Sheiham A. Impacts ondaily performances attributed to malocclusion using the condition-specific feature of the OIDP index. The Angle Orthodontist. 2008;**78**:241-247

[15] Bernabé E, Krisdapong S, Sheiham A, Tsakos G. Comparison of the discriminative ability of the generic and condition-specific forms of the child-OIDP index: A study on children with different types of normative dental treatment needs. Community Dentistry and Oral Epidemiology. 2009;**37**:155-162

[16] Mashoto K, Åstrøm AN, David J, Masalu JR. Dental pain, oral impacts and perceived need for dental treatment in Tanzanian school students: A cross-sectional study. Health and Quality of Life Outcomes. 2009;**7**:73

[17] Ekuni D, Furuta M, Irie K, Azuma T, Tomofuji T, Murakami T, et al. Relationship between impacts attributed to malocclusion and psychological stress in young Japanese adults. European Journal of Orthodontics. 2011;**33**:558-563

[18] Tesch FC, Oliveira BA, Leão A. Measurement of the impact of oral problems on children's quality of life: Conceptual and methodological aspects. Public Health Notebook. 2007;**23**:2555-2564

[19] Locker D. Measuring oral health: A conceptual framework. Community Dental Health. 1998;**23**:32-36

[20] Sheiham A. Determining dental treatment needs: A social approach. In: Pinto VG, editor. Collective Oral Health. 4th Ed. São Paulo: Santos Publisher; 2000:223-250

[21] Barbosa TS, Tureli MC, Gaviao MB. Validity and reliability of the child perceptions questionnaires applied in Brazilian children. BMC Oral Health. 2009;**9**:13

[22] Sheiham A, Steele JG, Marcenes W, Tsakos G, Finch S, Walls AWG. Prevalence of impacts of dental and oral disorders and their effects on eating among older people—A national survey in Great Britain. Community Dentistry and Oral Epidemiology. 2001;**29**:195-203

[23] Latsou D, Oulis CJ, Papaioannou W, Yfantopoulos J. Oral health related quality of life of Greek adolescents: A cross sectional-study. European Achives of Paediatric Dentistry. 2011;**12**:146

[24] Leão MM, Garbin CAS, Moimaz SASM, Rovida TAS. Oral health and quality of life: An epidemiological survey of adolescents from settlement in Pontal do Paranapanema/SP, Brazil. Ciência & Saúde Coletiva. 2015;**20**:3365-3374

[25] Xavier A et al. Impact of dental caries on quality of life of adolescents according to access to oral health services: A cross sectional study. Brazilian Journal of Oral Sciences. 2016;**15**:1-7

[26] Tomita NE, Pernambuco RA, Lauris JRP, Lopes ES. Oral health education: Use of participatory methods. Dentistry College of Bauru Magazine. 2001;**9**:63-69

[27] Wesselovicz AAG, Sousa TG, Kaneshima EN, Souza-Kaneshima AM. Factors associated with the consumption of alcoholic beverages by the adolescents of a public school in the city of Maringá, state of Paraná. Acta Scientiarum Health Sciences. 2008;**30**:161-166

[28] Åstrøm AN, Wold B. Socio-behavioral predictors of young adults' self-reported oral health: 15 years of follow-up in the Norwegian longitudinal health behavior study. Community Dentistry and Oral Epidemiology. 2012;**40**:210-220

[29] Valente MSG. Adolescence and oral health. Latin adolescence. 2004;**98**(1):170-174

[30] Brazil. Ministry of Health. Basic Attention Department. SB Brazil Project 2010: Oral Health Conditions of the Brazilian Population 2009-2010: Main Results. Brasília: Ministry of Health; 2010

[31] Fleiss JL. Statistical Methods for Rates and Proportions. 8th ed. New York: John Wiley; 1981:38-45

[32] Adulyanon S, Sheiham A. Oral impact on daily performances. In: Slade GD, editor. Measuring Oral

Health and Quality of Life. Chapel Hill: University of North Carolina; 1997. pp. 151-160

[33] Biazevic MGH, Rissoto RR, Crosato EM, Mendes LA, Mendes MOA. Relationship between oral health and its impact on quality of life among adolescents. Brazilian Oral Research. 2008;**22**:36-42

[34] McGrath C, Bedi R, Gilthorpe MS. Oral health-related quality of life - views of the public in the United Kingdom. Community Dental Health. 2000;**17**:3-7

[35] Teófilo LT, Leles CR. Patients' self-perception at the time and after tooth loss. Brazilian Dental Journal. 2007;**1**:91-96

[36] Porritt JM, Rodd HD, Baker SR. Quality of life impacts following childhood dento-alveolar trauma. Dental Traumatology. 2011;**27**:2-9

[37] Lopez R, Baelum V. Factors associated with dental attendance among adolescents in Santiago, Chile. BMC Oral Health. 2007;**7**:4

[38] Crocombe LA, Broadbent JM, Thomson WM, Brennan DS, Poulton R. Impact of dental visiting on oral health and oral health-related quality of life. Journal of Public Health Dentistry. 2012;**72**:36-44

[39] Baldani MH, Pupo YM, Lawder JAC, Silva FFM, Antunes JLF. Individual determinants of recent use of services. Pesquisa Brasileira em Odontopediatria e Clínica Integrada. 2011;**11**:91-98

[40] Mtaya M, Åstrøm AN, Tsakos G. Applicability of an abbreviated version of the child-OIDP inventory among primary schoolchildren in Tanzania. Health and Quality of Life Outcomes. 2007;**5**:40-40

[41] Pentapati KC, Acharya S, Bhat M, Rao SVK, Singh S. Oral health impact, dental caries, and oral health behaviors among the National Cadets Corps in South India. Journal of Investigative and Clinical Dentistry. 2013;**4**:39-43

[42] Mbawalla HS, Masalu JR, Åstrøm NA. Socio-demographic and behavioral correlates of oral hygiene status and oral health-related quality of life, the Limpopo - Arusha school health project (LASH): A cross-sectional study. BMC Pediatrics. 2010;**10**:1-10

[43] Gushi LL, Soares MC, Forni TIB, Vieira V, Wada RS, Sousa MLR. Dental caries in adolescents from 15 to 19 years of age in the State of São Paulo, Brazil. Public Health Notebooks. 2002, 2005;**21**:305-311

[44] Wyne AH, Adenubi JO, Shalan T, Khan N. Feeding and socioeconomic characteristics of nursing caries children in a Saudi population. Pediatric Dentistry. 1995;**17**:451-454

[45] Manhães ALD, Costa AJL. Access and use of dental services in the state of Rio de Janeiro, Brazil, in 1998: An exploratory study based on the National Household Sample Survey. Public Health Notebooks. 2008;**24**:207-218

[46] Davoglio RS, DRGC A, Abegg C, Freddo SL, Monteiro L. Factors associated with oral health habits and use of dental services among adolescents. Public Health Notebooks. 2009;**25**:655-667

[47] Gherunpong S, Tsakos G, Sheiham A. The prevalence and severity of oral impacts on daily performances in Thai primary school children. Health What Life Outcomes. 2004;**2**:57

[48] Bernabe E, Tsakos G, Sheiham A. Intensity and extent of oral impacts on daily performances by type of self-perceived oral problems. European Journal of Oral Sciences. 2007;**115**:111-116

[49] Masalu JR, Åstrøm AN. Social and behavioral correlates of oral quality of life studied among university students in Tanzania. Acta Odontologica Scandinavica. 2002;**60**:353-359

[50] Freire MC. Psychosocial factors, dental caries and oral health behaviors. Aboprev Magazine. 2001;**4**:21-28

[51] Marmot M. From black to Acheson: Two decades of concern with inequalities in health. A celebration of the 90th birthday of professor Jerry Morris. International Journal of Epidemiology. 2001;**30**:1165-1171

[52] Moyses SJ. Inequalities in oral health and oral health promotion. Brazilian Oral Research (Printed). 2012;**26**:86-93

[53] Keles S, Abacigil F, Adana F. Oral health status and oral health related quality of life in adolescent workers. Clujul Medical. 2018;**91**:462-468

[54] Colussi PRG, Hugo FN, Muniz FWMG, Rösing CK. Oral health-related quality of life and associated factors in Brazilian adolescents. Brazilian Dental Journal. 2017;**28**:113-120

Chapter 8

The Impacts of Parental Schizophrenia on the Psychosocial Well-Being of Offspring: A Systematic Review

Sabreena Hussain

Abstract

Previous literature has identified the development and prevalence of psychiatric disorders amongst offspring of those with schizophrenia. Little attention has been given to the investigation of the impacts of parental schizophrenia on the psychosocial well-being of offspring. Thirteen papers were chosen, and the quality was assessed using a quality assessment tool for cross-sectional and longitudinal studies. The results displayed an overall negative impact on aspects of psychosocial well-being on offspring of those with schizophrenia. The negative impacts of parental schizophrenia resulted in a higher prevalence of psychiatric disorders, lower levels of social functioning (social deficits), poorer employment situations, lower levels of self-concept (e.g. self-esteem and self-confidence) and lowered quality of life in comparison to healthy controls (HC) and other high-risk groups. Findings support the diathesis-stress model which suggests negative impacts on the psychosocial well-being of offspring are due to the interplay between genetic and environmental factors coinciding with vulnerabilities in the brain. This provides opportunities for clinicians to develop interventions for offspring of those with schizophrenia and rationalises public health to provide more funding for this group to be used as a preventative method.

Keywords: high-risk, schizophrenia, parental schizophrenia, offspring of parents with schizophrenia, high-risk offspring, psychiatric disorders

1. Introduction

Schizophrenia is a type of ‘psychosis’ which causes individuals to experience distressing symptoms [1] such as the lack of ability to distinguish between reality and one’s own thoughts and beliefs [2]. Schizophrenia consists of positive symptoms which are those that are an addition to the individual (i.e. delusions and hallucinations) and negative symptoms which take away something from the individual (i.e. anhedonia and lack of social interest) according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; [3]). The prevalence of schizophrenia in the United Kingdom is 0.7% amongst a population of 74,176 [4]. The prevalence of schizophrenia in the United States of America is 0.5% amongst a population of 10,000,000 [5]. In a multinational study of 52 countries, the prevalence of schizophrenia is 1.11% amongst a population of 181,445 [6]. This indicates that there is a high prevalence amongst a relatively small proportion of a population, the importance of investigating such individuals as a global concern.

Living with a close relative suffering from a mental illness may cause debilitating negative impacts on that individual such as developing symptoms of schizophrenia or the illness itself [7]. Researchers identified that the closer the relative to the individual with schizophrenia, the greater the incidence of being diagnosed with a psychiatric disorder [8]. Previous research has explored the heritable component of schizophrenia, also considered as the high-risk (HR) perspective in research, whereby the offspring of the individual with schizophrenia are investigated [9]. The genetic risk of developing schizophrenia for relatives of those with schizophrenia is within the range of 60–80% [10]. In addition, it was found that the risk for HR offspring to develop psychotic or other psychiatric conditions ranged between 15 and 40% [11]. Previous studies displaying the risk of developing schizophrenia and other psychiatric disorders identify the relatively high heritability of schizophrenia amongst HR offspring, which further suggests a possible genetic influence of the disorder. This may propose a model indicating the genetic influences of the susceptibility to negative outcomes, such as psychiatric disorders amongst the offspring, thus signifying the importance of investigating such individuals.

Moreover, research has explored the effects of parental schizophrenia on offspring and found that offspring living with one parent diagnosed with schizophrenia has been found to have a 13% risk of developing schizophrenia, in comparison to an increased 45% risk of developing schizophrenia of those with two parents clinically diagnosed [12]. Previous research has also highlighted upon the cumulative incidence across other cultural populations, whereby the cumulative incidence in Denmark for HR offspring was a 16.2% risk of developing schizophrenia [13], 10–15% in Edinburgh [14] and 13.1% in the United States of America [15]. Research also found that HR offspring developed negative symptoms associated with schizophrenia including anhedonia [16]. This builds upon the notion of schizophrenia being highly heritable, thus supporting the idea that there is a strong genetic vulnerability of negative outcomes on the well-being of offspring, such as symptoms of schizophrenia and other psychiatric disorders passed from parent to offspring.

In addition, previous literature has identified an increased risk of HR offspring developing psychiatric conditions other than schizophrenia which include personality disorders [13], thought disorders [17], depression [18] and attention deficit hyperactivity disorder [19]. Previous literature also reports higher comorbidity rates twice that of offspring without a parent with schizophrenia [15], suggesting that parental schizophrenia increases the risk of a dual diagnosis amongst offspring. This signifies the importance of investigating HR offspring, strengthening the idea that schizophrenia amongst parents has a strong genetic influence of negatively impacting well-being.

1.1 Psychosocial aspects

Furthermore, research has identified the impact of parental schizophrenia on the psychosocial well-being of HR offspring. The term 'psychosocial' impact concerns psychological aspects and the interaction between emotions, behaviours, feelings and social factors, e.g. social functioning [20]. Social factors refer to the way an individual lives different experiences via different attitudes and personalities [20]. Poor social functioning is a hallmark of schizophrenia [21]. The term 'well-being 'concerns an individual's optimal functioning level, physically and psychologically [22]. It also involves having a sense of comfort and happiness in one's own everyday living. This also overlaps with having a good quality of life, whereby an individual has a complete sense of physical and mental well-being. Quality of life differentiates slightly from well-being, in terms of the individual's perception of their quality of life. Nonetheless, research has been conducted to investigate the social impacts on HR offspring. It was found that HR offspring present themselves as more socially dysfunctional than the control group [23]. Additionally, some research has found further negative impacts on the psychosocial well-being of HR offspring such as decreased quality of life [7], reduced self-esteem [24], inability to express emotions [25], deficits in social competence [26] and higher rates of behavioural issues [27]. It has also been found that poor social functioning predicts the later development of schizophrenia [28], indicating an association between psychosocial aspects and the diagnosis of schizophrenia amongst HR offspring. This suggests that the genetic influence of negative impacts of parental schizophrenia extend to psychosocial functioning which appears to be impaired amongst HR offspring. This identifies that not only is the HR offspring susceptible to psychiatric conditions but also vulnerable to impaired psychosocial functioning, implying a genetic propensity provided by the parent to their offspring.

In contrast, research has identified other impacts on HR offspring unrelated to the psychosocial aspects previously stated, which includes poor academic performance [29, 30], working memory deficits [31], high offending rates [32], higher mortality rates [33] and poor self-reported physical health [34]. As much research has focused on aspects unrelated to the psychosocial well-being of HR offspring, it is important to focus on the under-researched aspects of the HR perspective. This further highlights the importance of identifying the underlying mechanisms involved.

1.2 Brain abnormalities

As previous research has found schizophrenia to be highly heritable amongst HR offspring [35], this raises questions regarding the underlying mechanisms and processes that make schizophrenia heritable. Studies have explored the neurological pathways amongst those with schizophrenia and have found there to be altered brain connectivity and volumetric brain differences, resulting in symptoms of schizophrenia amongst these individuals [36–38]. It has been found that HR offspring of those with schizophrenia have volumetric deficits in brain connectivity and networks, resulting in abnormal brain functioning and consequently symptoms of schizophrenia [39, 40]. Volumetric brain reductions have also been found amongst HR offspring in the hippocampus, amygdala [41] and the frontal and temporal lobes [42]. These findings indicate the existence of brain abnormalities amongst those with schizophrenia, suggesting that parental schizophrenia negatively impacts HR offspring due to the genetically transmitted brain vulnerability. This also implies that the brain abnormalities are present from birth, and thus, HR studies exploring the developmental trajectories of the illness using longitudinal studies will be able to map out the disorder and biological markers involved. Longitudinal studies can further identify a potential critical period for the development of negative psychosocial impacts on HR offspring.

1.3 Environmental influences

Moreover, the HR perspective has been investigated in different types of environments in which the offspring is living away from the parent with schizophrenia through carrying out adoption studies. Adoption studies aid in eliminating the environmental impacts of living with a parent suffering from schizophrenia. Parental schizophrenia can result in a distorted environment for the HR offspring resulting in negative outcomes such as schizophrenia and other psychiatric conditions. By conducting adoption studies, this will allow a nature and nurture argument can take place [8]. It was found that adopted children were more likely to develop schizophrenia, if they had a biological parent suffering from schizophrenia, in comparison to those that did not [43]. This supports the idea that schizophrenia is genetically transmitted strengthening the notion that neurological pathways are distorted amongst HR offspring as with the parents. Therefore, this indicates that not only is there a genetic influence but there is also an environmental influence, suggesting a gene-environment interaction arising from the development of negative impacts on the psychosocial well-being of offspring.

Moreover, another method to explore the HR perspective is by exploring HR offspring that are twins in studies. This allows an enhanced perspective regarding genetic and environmental influences to be considered. Twin and adoption studies found that the risk of HR individuals developing schizophrenia was 9% for siblings, 13% for HR offspring with one parent suffering from schizophrenia and 46% for HR offspring with two parents [44]. As there was found to be a genetic risk amongst twin and adoption studies for HR offspring, these findings also display an environmental influence as the genetic risk is not 100%. Therefore, there must be other factors within the offspring's environment involved in the development of schizophrenia suggesting a possible diathesis-stress model of schizophrenia. The diathesis-stress model is the idea that mental illnesses are developed from a genetic or biological component of a particular illness (i.e. schizophrenia) which is combined with stressful environmental factors, which all influence the vulnerability for a mental illness. In this particular instance, this involves negative environmental factors interacting with the genetic vulnerability for schizophrenia amongst HR offspring, resulting in an elevation of risk and heritability in the development of negative impacts on the psychosocial well-being of offspring [45].

Furthermore, extending beyond the idea that environmental factors elevate the risk for developing psychological difficulties, much research has been conducted within this area exploring other factors. This includes factors such as unemployment and socio-economic disadvantage [12], childhood sexual abuse [34], marital conflict amongst the parents of HR offspring [46], poor upbringing due to hospitalisation of parents or neglect [47], inadequate parental care [48] and other stressful life events such as loss and traumatic events [49, 50]. Stressful life events have the potential to trigger the onset of symptoms of schizophrenia and other disorders [51]. Such studies, highlighting upon the environmental factors involved in the developmental trajectory of schizophrenia, strengthen the proposed diathesis-stress model explaining why negative outcomes occur in HR offspring. This is by demonstrating that the environment acts as a stressor in increasing the genetic risk and heritability of schizophrenia and symptoms involved.

1.4 The current review

This systematic review is exploring the following psychosocial aspects influencing the well-being of HR offspring: social skills and functioning, self-concept, quality of life, employment situation and the prevalence of disorders and emotional/behavioural symptoms. Regarding the term 'social skills and functioning', this includes self-esteem and self-concept. Due to the limited amount of research within these domains, it would be worthy to investigate and obtain insightful formulations.

A review is needed with recent studies that build upon the HR research but also focus on the psychosocial impacts signifying a diathesis-stress model, linking parental schizophrenia and negative impacts on HR offspring. This is because awareness can be raised and possible support can be given to HR offspring as a preventative technique regarding the prevention of negative psychosocial impacts. Current interventions focus on aiding the parent with schizophrenia but should also be put in place to aid the HR offspring [12].

1.4.1 Aims

To identify the impact of parental schizophrenia on the psychosocial well-being of HR offspring.

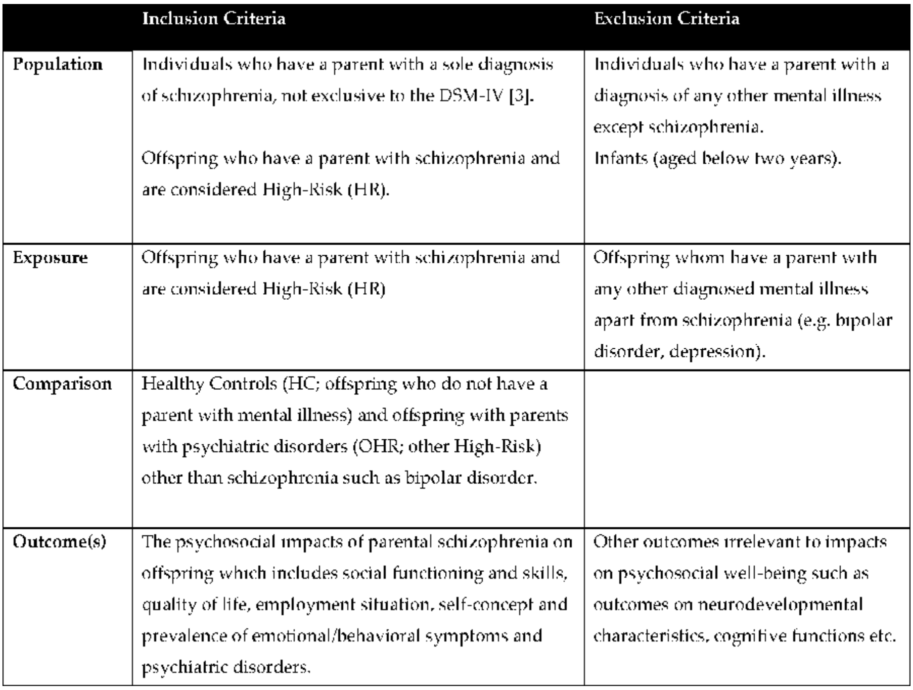
To explore the likelihood that HR offspring will develop schizophrenia or other psychiatric conditions.

2. Methods

This paper is a systematic review compiled of cross-sectional and longitudinal studies. The findings of the articles were presented into a narrative synthesis. An extensive search strategy was adopted to identify relevant papers using applicable terms and synonyms. The process involved a critical evaluation of relevant papers and steps to be followed such as searching databases according to the inclusion/exclusion criterion, data extraction and quality assessments of relevant papers. An electronic database named PROSPERO was also searched to identify pre-existing systematic reviews within the chosen topic to minimise any potential bias and identify the 'grey literature'. The selection strategy of papers was divided into categories comprising of population, exposure, comparator and outcome(s), shown in **Figure 1**.

2.1 Study selection

The articles retrieved from the databases in accordance to the selection criteria were imported into EndNote, an electronic reference manager. Duplicate articles were also deleted and were then examined to be included and excluded in accordance to the stated criterion for PECO. Those that were excluded were justified with



	Inclusion Criteria	Exclusion Criteria
Population	Individuals who have a parent with a sole diagnosis of schizophrenia, not exclusive to the DSM-IV [3]. Offspring who have a parent with schizophrenia and are considered High-Risk (HR).	Individuals who have a parent with a diagnosis of any other mental illness except schizophrenia. Infants (aged below two years).
Exposure	Offspring who have a parent with schizophrenia and are considered High-Risk (HR)	Offspring whom have a parent with any other diagnosed mental illness apart from schizophrenia (e.g. bipolar disorder, depression).
Comparison	Healthy Controls (HC; offspring who do not have a parent with mental illness) and offspring with parents with psychiatric disorders (OHR; other High-Risk) other than schizophrenia such as bipolar disorder.	
Outcome(s)	The psychosocial impacts of parental schizophrenia on offspring which includes social functioning and skills, quality of life, employment situation, self-concept and prevalence of emotional/behavioral symptoms and psychiatric disorders.	Other outcomes irrelevant to impacts on psychosocial well-being such as outcomes on neurodevelopmental characteristics, cognitive functions etc.

Figure 1.
Inclusion and exclusion summary of PECO.

reasons documented. Those articles with only abstract access were also removed due to limited information provided. Those articles that were remaining were also peer reviewed by two other individuals who were MSc students at Queen Mary University to prevent any errors and bias being made during the selection process. This involved a brief peer review examining the chosen article titles, authors and abstracts to identify relevancy to the topic.

2.2 Quality assessment

Articles were assessed to identify the level of quality of each study using the Joanna Briggs Institute Critical Appraisal Checklist for Analytical Cross-Sectional Studies [52]. This tool was utilised to highlight upon any potential limitations in cross-sectional studies. Articles that utilised longitudinal methods were assessed for quality using the Critical Appraisals Skills Programme [53].

3. Results

A total of 13 articles were chosen for this current review. A PRISMA flowchart [54] was produced to allow a visual representation of the selection process

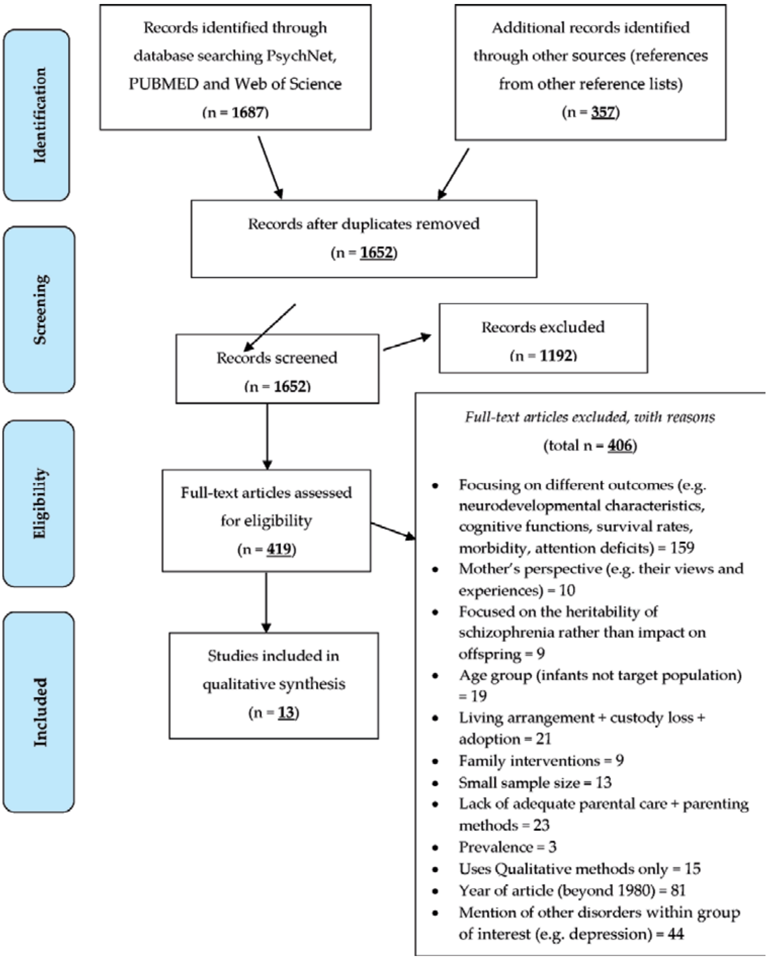


Figure 2.
PRISMA flow diagram displaying the selection process [54].

(see **Figure 2**). A total of 1192 records were initially excluded due to having no relevance at all, to the topic of interest. The remainder of full-text articles was then screened for further relevance (n = 419). As a result, 406 articles were excluded, and relevant reasons were given such as focusing on different outcomes unrelated to the outcomes of this review.

3.1 Participant characteristics

Across all chosen studies, there were a total of 1963 offspring who participated in which ages ranged from 5 to 50 years with mean age ranges from 9 to 43 years (displayed in **Table 1**) from different ethnicities and background.

Article	Sample size	Age	Group of interest	Comparator	Ethnicity
[7]	61 daughters	30–50 years (HR mean = 43, HC mean = 41)	HR = 31 (all female)	HC = 30 (all female)	Recruited from the Israeli foundation mental health centre
[55]	51	18–43 years (mean = 29)	HR = 51 (male = 25, female = 26)	None	Obtained in Tokyo, Japan
[56]	244	19–35 years (HR mean = 19, FE = 25, ME = 36, HC = 22)	HR = 86 (male = 49, female = 37)	HC = 55 (male = 33, female = 22) FE = 50 (male = 30, female = 20) ME = 53 (male = 38, female = 15)	Caucasian 84–93% African American 2–7% Other 5–18%
[57]	150	7–12 years (mean = 9)	Childhood HR = 46 (males = 24, females = 22) Adolescent HR = 32 (males = 20, females = 12)	Child HC = 65 (males = 37, females = 28) Adolescent HC = 58 (males = 35, females = 23) Child OHR = 39 (males = 18, females = 21) Adolescent OHR = 35 (males = 16, females = 19)	Collected from New York, USA
[58]	116	12–22 years (mean = 17)	HR = 41 (males = 21, females = 20)	HC n = 36 (males 22, females = 14) OHR n = 39 (male = 23, females = 16)	Obtained from Jerusalem
[59]	150	5–18 years	High-risk offspring = 50	HC = 5, OHR = 50	Data collected in East Azerbaijan, Tabriz

Article	Sample size	Age	Group of interest	Comparator	Ethnicity
[60]	60	5–16 years (HR mean = 11, HC mean = 10)	HR = 30 (male = 13, female = 17)	HC = 30 (male = 14, female = 16)	Obtained from New Delhi, India
[61]	52	5–19 years (mean = 12)	High-risk offspring n = 17 (male = 7, female = 10)	Healthy control n = 35 (male = 13, female = 22)	HC = 22% non-white, HR = 41% non-white
[62]	157	9–21 years (mean = 16)	HR = 75 (male = 34, female = 41)	HC = 82 (male = 40, female = 42)	Data collected in Western Pennsylvania, Pittsburgh
[63]	90	13–26 years (HR mean = 19, HC mean = 18)	HR = 35 (male = 16, females = 19)	HC = 55 (males = 24, females = 31)	White >50% African American <20% Hispanic <23% Asian <9% other 3%
[64]	60	18+ (HR mean = 21.5, HC mean = 20.7)	HR = 30 (male = 21, female = 9)	HC = 30 (male = 21, female = 9)	Obtained from Bangalore, South India
[65]	431	18+ (mean = 27.6)	HR = 431 (male = 233, female = 198)	No control group	Data collected in Cuiaba, Brazil
[66]	341	Not known	HR = 155	HC = 186	Data collected in Finland

Table 1.
Participant characteristics.

3.2 Comparators

The comparator in all studies included used healthy controls (HC) with the exception of [55], whereby in this study, a control is not stated (see **Table 2**). Some of the studies [56–59] used a comparison of offspring of those with a mental illness other than schizophrenia (OHR).

3.3 Effect size and mean differences

Across all studies within the HR, HC and OHR groups, the mean incidence ratings/scores and effect sizes were similar to that of the control group and also were not 100%.

3.4 Assessment of quality

Overall, the majority of studies used a clearly defined inclusion and exclusion criteria similar to that of this review. Also, the diagnoses of parents with schizophrenia were clearly established using reliable and valid methods amongst all studies (**Tables 3** and **4**).

Article	Aims/objectives	Design	Measures	Population	Exposure	Comparator	Outcomes
[7]	Quality of life in HR offspring	Cross-sectional study	Questionnaires	61 offspring	HR offspring	HC group	Lowered quality of life and negative emotions in HR
[55]	Psychiatric disorder and level of social functioning in offspring and cultural comparison	Longitudinal study	Questionnaires and demographic information	51 HR offspring	HR offspring	No control	Incidence of SZ was 13.7% HR did not significantly affect the risk in Japanese offspring and social functioning
[56]	Social functioning levels in HR individuals	Cross-sectional study	Questionnaires	244 participants	HR offspring	HC, offspring experiencing first episode of psychosis (FE), offspring experiencing multi-episode psychosis (ME)	Significant deficits for HR in social functioning long before onset of potential psychosis
[57]	New York High-Risk Project, social competence and affective deficits amongst offspring	Longitudinal cohort study	Child and parent report and counting broad smiles assessed via interviews	150 offspring	HR subjects	HC and OHR group	HR adolescents the greatest social and affective deficits
[58]	Symptoms in offspring	Longitudinal cohort study	Records collected (1991–1995) and structured clinical interviews	116 adolescents from 61 families	HR offspring	HC group and OHR group	Greater prevalence of disorders in HR group, greater for males
[59]	Prevalence of emotional and behavioural disorders	Cross-sectional study		150 offspring	HR offspring	HC group and OHR group	Higher prevalence of emotional and behavioural symptoms in HR group
[60]	Psychosocial effects in offspring	Cross-sectional study	Questionnaires and interviews	60 offspring	HR individuals	HC group	HR group significantly scored greater on internalising/externalising behavioural problems

Article	Aims/objectives	Design	Measures	Population	Exposure	Comparator	Outcomes
[61]	Social deficits amongst high-risk offspring	Cross-sectional study	Questionnaires and interviews	52 offspring	HR offspring	HC group	The HR had worse social skills, assertion and empathy outcomes
[62]	Prevalence of psychopathology in HR offspring	Cross-sectional study	Interviews	157 offspring	HR individuals	HC group	HR offspring had increased risk for one or more psychiatric disorders (60%)
[63]	Social development (i.e. personality traits) and psychopathology amongst HR individuals	Longitudinal study	Seven tests and questionnaires assessing psychopathology, personality traits and social development	90 offspring	HR subjects	HC group	HR displayed less positive involvement, poor physical anhedonia and less cooperation
[64]	Self-concept in HR offspring	Cross-sectional study	Questionnaires	60 subjects	HR group	HC group	Poorer self-concept in HR
[65]	Social impacts in HR offspring	Cross-sectional study	Questionnaires	431 offspring	HR individuals	No control group	HC—poor employment situations and lowered marriage rates
[66]	Prevalence of psychopathology in adopted offspring	Cross-sectional study	Interview and questionnaires	341 offspring given up for adoption	HR offspring	HC group	HR has a higher percentage of psychiatric disorders

Table 2.
Data extraction table.

Article	Outcome 1	Outcome 2	Effect size/mean difference
[7]	HR group had significantly lower quality of life and greater negative emotions than positive emotions	Lower levels of family functioning, greater resource loss and lower resource gains	Mean scores: quality of life score HR = 2.85, HC = 3.42 Negative emotions: HR = 2.56, HC = 3.35 Positive emotions: HR = 3.22, HC = 3.8
[55]	Psychiatric disorder prevalent amongst HR offspring	Social functioning not significantly impacted by parental schizophrenia	Incidence for schizophrenia amongst Japanese offspring was 13.7%
[56]	Deficits in social functioning prior to onset of psychosis in HR group	HR group scored higher for quality of life in comparison to ME and FE group	Mean scores of social functioning HR = 125.29, FE = 129.14, ME = 136.53, HC = 161.65
[57]	Greater social and affective deficits amongst HR group	Poorer social competence, affective flattening and reduced smiling per minute. Higher scores for social competence and affective flattening reflect greater pathology	Mean incidence of social/affective deficits: social competence child HR = 0.17, adolescent HR = 0.49, child OHR = 0, adolescent OHR = −0.06, child HC = −0.11, adolescent HC = −0.19 Affective flattening Child HR = 0.42, adolescent HR = 1.1, child OHR = 0.38, adolescent HR = 0.62, child HC =0.46, Adolescent HC = −0.68 Smiling Child HR = 0.58, adolescent HR = 0.49, child OHR = 0.63, adolescent OHR = 0.93, child HC = 0.72, adolescent HC 0.97
[58]	HR at highest prevalence disorders amongst the schizophrenia spectrum, avoidant personality disorder and anxiety	Highest prevalence in males	Incidence of disorders: HR = 17.1%, OHR = 7.7%, HC = 2.8%
[59]	HR group displayed significantly greater prevalence of emotional and behavioural symptoms in HR group ($p < 0.01$)	No significant difference in gender and age distribution, family income, education levels and socio-economic status in HR group	Incidence of emotional/behavioural symptoms (standardised means-effect size): HR = 1.33, HC = 0.43, OHR = 0.71
[60]	Highest prevalence of internalising/externalising behavioural problems for HR group	No significant differences in education, religion, employment, monthly income and gender	Mean incidence of internalising/externalising behavioural problems: HR = 39.13, HC = 31.53

Article	Outcome 1	Outcome 2	Effect size/mean difference
[61]	HR group scored worse on social adjustment across all periods of development. HR group had poorer social skills than HC group Majority of social skills deficits were within domain of assertion and empathy	Anomalous findings were that eight subjects in HR group displayed excellent social skills and nine subjects in HR group displayed below normative scores with none in the mid-range No differences observed in age, education and occupation level	Mean score for social skills: HC = 109.5, HR = 99.2 Lower scores represent poorer social skills

Table 3.
Summary of outcomes.

Article	Outcome 1	Outcome 2	Effect size
[62]	Greater risk for one or more psychiatric disorders amongst HR group	No significant difference amongst age or gender	Incidence of psychopathology; HR = 60%
[63]	Lowered positive involvement, poor physical anhedonia and less cooperation in HR offspring	HR offspring 17 years and above displayed poor physical anhedonia and positive involvement whereas older HR displayed less cooperation	Cohen's d: Social difficulties = 0.88 (HR > HC) Physical anhedonia = 0.66 (HR > HC) Cooperativeness = −0.57 (HR < HC) Positive involvement = −0.69 (HR < HC)
[64]	HR group had lower scores on self-concept indicting poorer self-esteem and self-confidence in comparison to HC group Positive correlation between duration of parent illness and self-esteem in HR group	Duration of illness of parent was 11.67 years. Early-onset subjects (<10 years of age) showered lower scores on self-esteem than late-onset subjects (>10 years of age). Mean age of onset 10.6 years	Mean self-concept: Personal self-esteem: HR = 64.43, HC = 75.3 Self-confidence: HR = 66.07, HC = 76.03
[65]	Offspring had poor employment situations indicating poorer social adjustment HR offspring	24.8% of male offspring had a reported mental disorder, and 16% of female offspring had a reported mental disorder	Employment: 66.7% Married = 61.4% Mental disorder = 21%

Article	Outcome 1	Outcome 2	Effect size
[66]	HR group had a greater prevalence of psychiatric disorders than HC group	Psychiatric disorder occurred in disturbed familial environments	No diagnosis: HR = 51%, HC = 57% Personality disorder: HR = 19.4%, HC = 13.4% Psychosis: HR = 8.4%, HC = 0.5% Schizophrenia: HR = 5.2%, HR = 0.5%

Table 4.
Summary of outcomes.

4. Discussion

This review presented evidence for the impacts of parental schizophrenia on the psychosocial well-being of offspring. There appears to be many similarities across the studies such as similar negative outcomes, i.e. the greater incidence of psychiatric conditions amongst HR offspring in comparison to controls. The findings identified the negative impacts of parental schizophrenia on the psychosocial well-being of offspring highlighting upon the heritability of schizophrenia, extending beyond those that are clinically diagnosed.

4.1 Prevalence of disorders

A preliminary synthesis of the research found that HR offspring had a greater prevalence of behavioural and emotional disorders in comparison to those without a parent with schizophrenia. It was also found there to be a greater prevalence of psychiatric disorders amongst HR offspring; for example, it was found there to be a 13.7% prevalence of psychiatric disorders amongst HR offspring [55]. Furthermore, HR offspring are at greater risk in developing at least one or more psychiatric conditions. It appeared that the greatest prevalence was for personality disorders amongst HR offspring. This signifies the negative impact parental schizophrenia has on the psychosocial well-being of HR offspring, regarding the development of a psychiatric disorder.

4.2 Social skills

Research identifies a negative influence of parental schizophrenia on HR offspring, arising deficits in social skills in the domains of social competence, reduced smiling, affective flattening, assertion, empathy, cooperation, positive involvement, physical anhedonia, self-esteem, self-confidence, social adjustment and employment situation. This emphasises upon the debilitating negative impacts of parental schizophrenia on the psychosocial well-being of offspring.

4.3 Internalising and externalising behavioural problems

Furthermore, it was found there to be a greater prevalence of internalising and externalising behavioural problems amongst HR offspring in which the incidence was greater for the HR group than the HC group [60]. HR offspring were also found to have *fewer positive emotions*, *greater negative emotions and reduced quality of life*, all of which differed from the HC group in mean scores [7]. This highlights upon the behavioural issues experienced for HR offspring further indicating a negative impact on the psychosocial well-being of HR offspring.

The findings of this review build upon the idea that parental schizophrenia influences the development of psychiatric disorders amongst HR offspring [7, 8, 10–15, 17–19, 35, 43–45, 62] which have also identified the development of psychiatric conditions amongst HR offspring. Moreover, the stated findings also build upon the idea that parental schizophrenia arises social deficits amongst HR offspring as also detailed in previous literature [7, 12, 23–28]. Overall there is a negative impact of parental schizophrenia on the psychosocial well-being of offspring as displayed across all studies. This signifies a genetic propensity being passed from the parent with schizophrenia to the offspring.

There were several interesting findings unrelated to the psychosocial well-being of HR offspring. Firstly, it was found that the prevalence for psychiatric disorders in HR offspring was higher for males than females, arising questions into potential gender characteristics, such as different coping mechanisms resulting in differed psychosocial distresses [58, 65]. The predominance of males in some studies and females in other studies may aid in differentiating the impacts of gender on the psychosocial well-being of HR offspring. Moreover, social functioning amongst HR Japanese offspring was not significantly impacted, which suggest cultural differences amongst HR offspring regarding psychosocial well-being [55]. Overall, studies included in this review cover a broad range of cultures, allowing the conclusions of this review to be generalised to many cultures, whilst building upon previous literature and highlighting upon the cumulative incidences across cultures [13–15]. Future research may look into examining western and non-western cultures to make comparisons along with the investigation of gender differences.

In addition, an anomalous finding arose, in which eight HR offspring had excellent social skills and nine HR offspring displayed below average scores, none of which were within the average on measures of social skills [61]. This suggests that offspring within this study had extreme scores on each end but may have been due to the relatively small sample size. Interestingly, it was also found that poor physical anhedonia and positive involvement were present in those aged 17 years and below, whereas those aged above 17 years displayed lower cooperation levels [63]. This highlights differences in age, in which future studies could address by comparing different age groups. Findings presented strengthen the diathesis-stress explanation. In addition, this may indicate possible ideas for intervention strategies targeted for different age groups. Therefore, these particular results can inform clinicians and therapists of the psychosocial impacts parental schizophrenia has on different age groups.

Moreover, another study found [7] lower levels of family functioning and a greater perception of losses in resources and lowered resource gains. This suggests that there are negative impacts of parental schizophrenia unrelated to the psychosocial outcomes as the environmental stressors involved in this study were lowered levels of family functioning. These environmental stressors regarding family functioning could have been maltreatment, neglect or an unidentified stressor. This finding could identify as a confounding factor, as these outcomes may have resulted in the lowered quality of life and greater negative emotions. Therefore, it may be difficult to examine a causal relation between parental schizophrenia and the impact this has on the psychosocial well-being of HR offspring. Future research may consider investigating these aspects to distinguish the extent to which this impacts HR offspring. It was also found that those within the HR group had higher scores on measures of quality of life than the ME and FE group [56]. This suggests that there are confounding factors influencing the findings in an opposite direction. Highlighting upon the existence of possible confounding factors, there was a greater prevalence of psychiatric disorders amongst HR offspring in disturbed familial environments [66]. This implies that the environmental factors surrounding HR offspring may play an important role in the development of negative impacts on the psychosocial well-being of HR offspring.

4.4 Confounding factors

Environmental factors are important to identify, as these alone can result in negative outcomes such as the incidence of psychiatric conditions amongst HR offspring. This is because the offspring may experience an upbringing whereby the environment is distorted, thus elevating the risk for negative impacts on the psychosocial well-being of offspring. Across all findings, the effect sizes and mean differences between the HR groups and control groups were not 100%, suggesting other factors influencing the onset of negative psychosocial distress and difficulties. Also, there were not vast differences between the HR group and control groups regarding the effect sizes and mean differences, for example, it was found there to be mean incidence of 39.15 for externalising/internalising behavioural issues amongst HR offspring, in comparison to a 31.53 mean incidence for the HC group [60]. This supports the idea that the environmental factors play a role in the negative impacts, further strengthening the idea of a diathesis-stress explanation.

The direction of the findings may have been due to the participant size across studies. Most studies included had a relatively large sample size [56–59, 62, 63, 65, 66]. However, some studies had a relatively small sample size. The small sample size amongst these particular studies may have resulted in the effect size and mean incidence scores/ratings produced and thus reducing the statistical power and generalisability of these findings. Therefore, future reviews may aim to include studies consisting of a relatively larger sample, similar to each other and the control groups, to prevent biased findings.

There were many confounding factors which were not mentioned or described such as environmental factors, including maltreatment, child abuse, marital conflict and other stressful life events as detailed in previous literature [12, 34, 44–49, 51]. This may imply that poor psychosocial functioning may not be due to having a parent with schizophrenia but rather the surrounding environment of the offspring. Previous literature identifies a link to the negative impacts on the psychosocial well-being of HR offspring which may suggest and support the diathesis-stress model of the development of these outcomes. This model suggests that environmental factors increase the risk of developing psychological difficulties, particularly amongst HR offspring as they have a genetic vulnerability as mentioned in previous literature [36–42] in which an environmental stressor occurs which triggers a negative outcome (i.e. the onset of a psychiatric condition or symptom), also stated in previous literature [43, 44]. To summarise, findings cannot establish which factor causes the outcome; therefore, future research must aim to address this by incorporating the measures for environmental factors.

Moreover, findings revealed there to be a positive correlation between the duration of parental schizophrenia on the self-esteem of HR offspring [64] which suggests that the longer the parent was diagnosed with schizophrenia, the greater the self-esteem scores within the HR group (mean duration of parental illness = 11.67 years). This is a confounding result, as it implies that parental schizophrenia in the long-term had an almost reversal effect on scores of levels of self-esteem. This may have been due to the HR offspring being able to adjust and adapt to their parent's mental illness over time, which also further suggests confounding factors involved in this outcome. All other studies included did not sufficiently state the duration of parental illness or age of offspring at which parent diagnosis occurred. This is an important aspect for future studies to address.

Furthermore, it was also found that HR offspring had lower self-esteem in early-onset offspring, in comparison to later onset offspring in which self-esteem scores were higher (mean age of onset = 10.6 years) [64]. This indicates that the younger the offspring is when their parent is diagnosed, the worse the impact this has on

HR offspring's self-esteem levels. This further indicates that age has an impact on the vulnerability of HR offspring, in which developmental literature can address in future research, by conducting more longitudinal studies to map the trajectory of this vulnerability and make comparisons between different age groups (i.e. less than 10 years old and greater than 10 years old). Moreover, parental physical illness was incorporated by eliminating HR offspring of those that were suffering from chronic physical illnesses [64], to minimise the effect of this stressor. This is because this may cause greater significant stress on the HR offspring, which may impact the psychological difficulties the HR offspring may encounter. Therefore, to minimise bias amongst the findings, these particular HR offspring were excluded from the study.

Considering living arrangements amongst HR offspring, the HR perspective was explored amongst those adopted offspring living away from the biological parent suffering from schizophrenia [66]. Findings revealed that HR offspring still displayed a greater prevalence of psychopathology in comparison to the HC group. This finding highlights upon a predominant genetic vulnerability amongst HR offspring, despite being reared away from their biological parent with schizophrenia. This builds upon previous literature [36–42] highlighting upon the idea that brain abnormalities are genetically transmitted to HR offspring, thus supporting a diathesis-stress explanation.

4.5 Clinical implications

The findings build upon the idea that parental schizophrenia negatively impacts the psychosocial well-being of HR offspring regarding the following aspects: the prevalence of emotional and behavioural symptoms, internalising and externalising behaviours, psychiatric conditions, lowered quality of life, poorer self-concept, social adjustment, social functioning and employment situation. The greatest impact across studies in this review was the impairments in social functioning, which can be interpreted using the diathesis-stress explanation. The genetic vulnerabilities appeared to have been transmitted from parent to offspring, whereby environmental factors and stressors surrounding these individuals triggered an onset of these impairments. This review provides a more current set of findings with the inclusion of social impacts as well as psychological impacts, in comparison to the previous systematic review based solely upon the development of psychiatric conditions of HR offspring [11].

The current findings can aid public health authorities in raising awareness for this HR population by means of prioritising education in mental health, mass media and by increasing public funding. Revelations can also encourage early visits to mental health centres for screenings and evaluations to prevent and provide support [12]. It can also inform clinicians about targeted intervention strategies for HR offspring, such as taking into consideration the developmental differences in the onset of psychosocial distress. All these aspects can either prevent the later emergence of psychosocial difficulties or reduce experienced.

5. Conclusions

Overall, the implications for having a parent with schizophrenia have a negative impact on the psychosocial well-being of offspring. There are also implications concerning the development of psychiatric conditions including schizophrenia amongst HR offspring. Future research will be able to develop upon ideas and notions gathered, regarding the extent to which parental schizophrenia impacts the psychosocial well-being of offspring. This review highlights upon the demands and needs of HR offspring, which requires greater awareness to be made, allowing not only the parent to receive support but also the HR offspring.

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References

[1] Lewis DA, Levitt P. Schizophrenia as a disorder of neurodevelopment. Annual Review of Neuroscience. 2002;**25**(1):409-432. DOI: 10.1146/annurev.neuro.25.112701.142754

[2] Cannon TD. How schizophrenia develops: Cognitive and brain mechanisms underlying onset of psychosis. Trends in Cognitive Sciences. 2015;**19**(12):744-756. DOI: 10.1016/j.tics.2015.09.009

[3] American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders (DSM-5®). American Psychiatric Pub; 2013

[4] Bamrah JS, Freeman HL, Goldberg DP. Epidemiology of schizophrenia in Salford, 1974-84. Changes in an Urban Community over ten years. The British Journal of Psychiatry. 1991;**159**(6): 802-810. DOI: 10.1192/bjp.159.6.802

[5] Wu EQ, Shi L, Birnbaum H, Hudson T, Kessler R. Annual prevalence of diagnosed schizophrenia in the USA: A claims data analysis approach. Psychological Medicine. 2006;**36**(11):1535-1540. DOI: 10.1017/S0033291706008191

[6] Nuevo R, Chatterji S, Verdes E, Naidoo N, Arango C, Ayuso-Mateos JL. The continuum of psychotic symptoms in the general population: A cross-national study. Schizophrenia Bulletin. 2010;**38**(3):475-485. DOI: 10.1093/schbul/sbq099

[7] Alkan O, Kushnir J, Bar M, Kushnir T. Quality of life of adult daughters of women with schizophrenia: Associations with psychological resource losses and gains. Comprehensive Psychiatry. 2016;**68**(1):11-17. DOI: 10.1016/j.comppsych.2016.03.002

[8] Heston LL. Psychiatric disorders in Foster home reared children of schizophrenic mothers. The British Journal of Psychiatry. 1966;**112**(489): 819-825. DOI: 10.1192/bjp.112.489.819

[9] Wan MW, Abel KM, Green J. The transmission of risk to children from mothers with schizophrenia: A developmental psychopathology model. Clinical Psychology Review. 2008;**28**(4):613-637. DOI: 10.1016/j.cpr.2007.09.001

[10] Lichtenstein P, Yip BH, Björk C, Pawitan Y, Cannon TD, Sullivan PF, et al. Common genetic determinants of schizophrenia and bipolar disorder in Swedish families: A population-based study. The Lancet. 2009;**373**(9659):234-239. DOI: 10.1016/S0140-6736(09)60072-6

[11] Hameed MA, Lewis AJ. Offspring of parents with schizophrenia: A systematic review of developmental features across childhood. Harvard Review of Psychiatry. 2016;**24**(2):104-117. DOI: 10.1097/HRP.0000000000000076

[12] Manning C, Gregoire A. Effects of parental mental illness on children. Psychiatry. 2006;**5**(1):10-12. DOI: 10.1016/j.mppsy.2008.10.012

[13] Parnas J, Cannon TD, Jacobsen B, Schulsinger H, Schulsinger F, Mednick SA. Lifetime DSM-III-R diagnostic outcomes in the offspring of schizophrenic mothers: Results from the Copenhagen high-risk study. Archives of General Psychiatry. 1993;**50**(9):707-714. DOI: 10.1001/archpsyc.1993.01820210041005

[14] Johnstone EC, Ebmeier KP, Miller P, Owens DG, Lawrie SM. Predicting schizophrenia: Findings from the Edinburgh high-risk study. The British Journal of Psychiatry. 2005;**186**(1): 18-25. DOI: 10.1192/bjp.186.1.18

[15] Erlenmeyer-Kimling L, Adamo UH, Rock D, Roberts SA, Bassett AS,

Squires-Wheeler E, et al. The New York high-risk project: Prevalence and comorbidity of Axis I disorders in offspring of schizophrenic parents at 25-year follow-up. Archives of General Psychiatry. 1997;**54**(12):1096-1102. DOI: 10.1001/archpsyc.1997.01830240052008

[16] Cannon TD, Mednick SA, Parnas J. Antecedents of predominantly negative and predominantly positive-symptom schizophrenia in a high-risk population. Archives of General Psychiatry. 1990;**47**(7):622-632. DOI: 10.1001/archpsyc.1990.01810190022003

[17] Gooding DC, Coleman MJ, Roberts SA, Shenton ME, Levy DL, Erlenmeyer-Kimling L. Thought disorder in offspring of schizophrenic parents: Findings from the New York high-risk project. Schizophrenia Bulletin. 2010;**38**(2):263-271. DOI: 10.1093/schbul/sbq061

[18] Sørensen HJ, Mortensen EL, Reinisch JM, Mednick SA. Parental psychiatric hospitalisation and offspring schizophrenia. The World Journal of Biological Psychiatry. 2009;**10**(4-2):571-575. DOI: 10.1080/15622970701472078

[19] Sanchez-Gistau V, Romero S, Moreno D, de la Serna E, Baeza I, Sugranyes G, et al. Psychiatric disorders in child and adolescent offspring of patients with schizophrenia and bipolar disorder: A controlled study. Schizophrenia Research. 2015;**168**(1-2):197-203. DOI: 10.1016/j.schres.2015.08.034

[20] Frosh S. Psychosocial studies and psychology: Is a critical approach emerging? Human Relations. 2003;**56**(12):1545-1567. DOI: 10.1177/00187267035612005

[21] Couture SM, Penn DL, Roberts DL. The functional significance of social cognition in schizophrenia: A review. Schizophrenia Bulletin. 2006;**32**(1):S44-S63. DOI: 10.1093/schbul/sbl029

[22] Ryan RM, Deci EL. On happiness and human potentials: A review of research on hedonic and eudemonic well-being. Annual Review of Psychology. 2001;**52**(1):141-166. DOI: 10.1146/annurev.psych.52.1.141

[23] Parnas J, Schulsinger F, Schulsinger H, Mednick SA, Teasdale TW. Behavioural precursors of schizophrenia spectrum: A prospective study. Archives of General Psychiatry. 1982;**39**(6):658-664

[24] Williams OB, Corrigan PW. The differential effects of parental alcoholism and mental illness on their adult children. Journal of Clinical Psychology. 1992;**48**(3):406-414. DOI: 10.1002/1097-4679(199205)48:3<406::AID-JCLP2270480320>3.0.CO;2-L

[25] Goldstein MJ. Psychosocial issues. Schizophrenia Bulletin. 1987;**13**(1):157-171. DOI: 10.1093/schbul/13.1.157

[26] Goodman SH. Emory University project on children of disturbed parents. Schizophrenia Bulletin. 1987;**13**(3):411-423. DOI: 10.1093/schbul/13.3.411

[27] Mowbray CT, Bybee D, Oyserman D, MacFarlane P, Bowersox N. Psychosocial outcomes for adult children of parents with severe mental illnesses: Demographic and clinical history predictors. Health & Social Work. 2006;**31**(2):99-108. DOI: 10.1093/hsw/31.2.99

[28] Tarbox SI, Pogue-Geile MF. Development of social functioning in preschizophrenia children and adolescents: A systematic review. Psychological Bulletin. 2008;**134**(4):561. DOI: 10.1037/0033-2909.34.4.561

[29] Jundong J, Kuja-Halkola R, Hultman C, Långström N, D'Onofrio BM, Lichtenstein P. Poor school performance in offspring of patients with schizophrenia: What are the mechanisms? Psychological Medicine. 2012;**42**(1):111-123. DOI: 10.1017/S0033291711001127

[30] Lin A, Di Prinzio P, Young D, Jacoby P, Whitehouse A, Waters F, et al. Academic performance in children of mothers with schizophrenia and other severe mental illness, and risk for subsequent development of psychosis: A population-based study. Schizophrenia Bulletin. 2016;**43**(1):205-213. DOI: 10.1093/schbul/sbw042

[31] Diwadkar VA, Goradia D, Hosanagar A, Mermon D, Montrose DM, Birmaher B, et al. Working memory and attention deficits in adolescent offspring of schizophrenia or bipolar patients: Comparing vulnerability markers. Progress in Neuro-Psychopharmacology and Biological Psychiatry. 2011;**35**(5):1349-1354. DOI: 10.1016/j.pnpbp.2011.04.009

[32] Valuri GM, Morgan F, J ablensky A, Morgan VA. Impact of social disadvantage and parental offending on rates of criminal offending among offspring of women with severe mental illness. Australian & New Zealand Journal of Psychiatry. 2017;**51**(10):1032-1040. DOI: 10.1177/0004867416688099

[33] Suvisaari J, Häkkinen L, Haukka J, Lönnqvist J. Mortality in offspring of mothers with psychotic disorder. Psychological Medicine. 2008;**38**(8):1203-1210. DOI: 10.1017/S0033291707002383

[34] Gallagher SK, Mechanic D. Living with the mentally ill: Effects on the health and functioning of other household members. Social Science & Medicine. 1996;**42**(12):1691-1701. DOI: 10.1016/0277-9536(95)00296-0

[35] Niemi LT, Suvisaari JM, Haukka JK, Wrede G, Lönnqvist JK. Cumulative incidence of mental disorders among offspring of mothers with psychotic disorder: Results from the Helsinki high-risk study. The British Journal of Psychiatry. 2004;**185**(1):11-17. DOI: 10.1192/bjp.185.1.11

[36] Camchong J, MacDonald AW, Bell C, Mueller BA, Lim KO. Altered functional and anatomical connectivity in schizophrenia. Schizophrenia Bulletin. 2009;**37**(3):640-650. DOI: 10.1093/schbul/sbp131

[37] De Zwarte S, Brouwer RM, Tsouli A, Cahn W, Hillegers MH, Pol H, et al. Running in the family? Structural brain abnormalities and IQ in offspring, siblings, parents, and co-twins of patients with schizophrenia. Schizophrenia Bulletin. 2018;**50**(4):201-216. DOI: 10.1093/schbul/sby182

[38] Li P, Fan TT, Zhao RJ, Han Y, Shi L, Sun HQ, et al. Altered brain network connectivity as a potential endophenotype of schizophrenia. Scientific Reports. 2017;**7**(1):5483. DOI: 10.1038/s41598-017-05774-3

[39] Bhojraj TS, Prasad KM, Eack SM, Francis AN, Montrose DM, Keshavan MS. Do inter-regional gray-matter volumetric correlations reflect altered functional connectivity in high-risk offspring of schizophrenia patients? Schizophrenia Research. 2010;**118**(1-3):62-68. DOI: 10.1016/j.schres.2010.01.019

[40] Repovs G, Csernansky JG, Barch DM. Brain network connectivity in individuals with schizophrenia and their siblings. Biological Psychiatry. 2011;**69**(10):967-973. DOI: 10.1001/archpsyc.1982.04290060020005

[41] Seidman LJ, Faraone SV, Goldstein JM, Goodman JM, Kremen WS, Matsuda G, et al. Reduced subcortical brain volumes in non-psychotic siblings of schizophrenic patients: A pilot magnetic resonance imaging study. American Journal of Medical Genetics. 1997;**74**(5):507-514. DOI: 10.1002/(SICI)1096-8628(19970919)74:5<507::AID-AJMG11>3.0.CO;2-G

[42] Cannon TD, Van Erp TG, Huttunen M, Lönnqvist J, Salonen O,

Valanne L, et al. Regional gray matter, white matter, and cerebrospinal fluid distributions in schizophrenic patients, their siblings, and controls. Archives of General Psychiatry. 1998;**55**(12):1084-1091. DOI: 10.1001/archpsyc.55.12.1084

[43] Tienari P, Lahti I, Sorri A, Naarala M, Moring J, Wahlberg KE, et al. The Finnish adoptive family study of schizophrenia. Journal of Psychiatric Research. 1987;**21**(4):437-445. DOI: 10.1016/0022-3956(87)90091-4

[44] Faraone SV, Taylor L, Tsuang M. The molecular genetics of schizophrenia: An emerging consensus. Expert Reviews in Molecular Medicine. 2002;**4**(14):1-13. DOI: 10.1017/S1462399402004751

[45] Wahlberg KE, Wynne LC, Hakko H, Läksy K, Moring J, Miettunen J, et al. Interaction of genetic risk and adoptive parent communication deviance: Longitudinal prediction of adoptee psychiatric disorders. Psychological Medicine. 2004;**34**(8):1531-1541. DOI: 10.1017/S0033291704002661

[46] Rutter M, Quinton D. Parental psychiatric disorder: Effects on children. Psychological Medicine. 1984;**14**(4):853-880. DOI: 10.1017/S0033291700019838

[47] Sadock BJ, Sadock VA. Kaplan and Sadock's Synopsis of Psychiatry: Behavioral Sciences/Clinical Psychiatry. Lippincott Williams & Wilkins; 2011

[48] Harris T, Brown GW, Bifulco A. Loss of parent in childhood and adult psychiatric disorder: The role of lack of adequate parental care. Psychological Medicine. 1986;**16**(3):641-659. DOI: 10.1017/S0033291700010394

[49] Brown GR, Anderson B. Psychiatric morbidity in adult inpatients with childhood histories of sexual and physical abuse. American Journal of Psychiatry. 1991;**148**(1):55-61. DOI: 10.1176/ajp.148.10.1423

[50] Harris T, Brown GW, Bifulco A. Loss of parent in childhood and adult psychiatric disorder: A tentative overall model. Development and Psychopathology. 1990;**2**(3):311-328. DOI: 10.1017/S0954579400000791

[51] Nuechterlein KH, Dawson ME, Gitlin M, Ventura J, Goldstein MJ, Snyder KS, et al. Developmental processes in schizophrenic disorders: Longitudinal studies of vulnerability and stress. Schizophrenia Bulletin. 1992;**18**(3):387-425. DOI: 10.1093/schbul/18.3.387

[52] Joanna Briggs Institute. The Joanna Briggs Institute Critical Appraisal Tools for Use in JBI Systematic Reviews: Checklist for Qualitative Research. Austria: The Joanna Briggs Institute; 2016

[53] Critical Appraisal Skills Programme (CASP). CASP Randomised Controlled Trial Checklist. 2014. Available from: http://www.casp-uk.net/casp-tools-checklists

[54] Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. Annals of Internal Medicine. 2009;**151**(4):264-269. DOI: 10.7326/0003-4819-151-4-200908180-00135

[55] Nishida A, Sasaki T, Harada S, Fukuda M, Masui K, Nishimura Y, et al. Risk of developing schizophrenia among Japanese high-risk offspring of affected parent: Outcome of a twenty-four-year follow up. Psychiatry and Clinical Neurosciences. 2009;**63**(1):88-92. DOI: 10.1111/j.1440-1819.2008.01892.x

[56] Addington J, Penn D, Woods SW, Addington D, Perkins DO. Social functioning in individuals at clinical high risk for psychosis. Schizophrenia Research. 2008;**99**(1-3):119-124. DOI: 10.1016/j.schres.2007.10.001

[57] Dworkin RH, Cornblatt BA, Friedmann R, Kaplansky LM, Lewis JA, Rinaldi A, et al. Childhood precursors of affective vs. social deficits in adolescents at risk for schizophrenia. Schizophrenia Bulletin. 1993;**19**(3): 563-577. DOI: 10.1093/schbul/19.3.563

[58] Hans SL, Auerbach JG, Styr B, Marcus J. Offspring of parents with schizophrenia: Mental disorders during childhood and adolescence. Schizophrenia Bulletin. 2004;**30**(2): 303-315. DOI: 10.1093/oxfordjournals.schbul.a007080

[59] Seidy BVA. A comparative study on the prevalence of emotional and behavioural symptoms in children and adolescents born to mothers with schizophrenia and other psychotic disorders. Acta Medica Iranica. 2003;**41**(4):254-259. Available from: acta.tums.ac.ir/index.php/acta/article/view/2674

[60] Malhotra M, Kumar D, Verma R. Effect of psychosocial environment in children having mother with schizophrenia. Psychiatry Research. 2015;**226**(2-3):418-424. DOI: 10.1016/j.psychres.2014.11.028

[61] Horton LE, Smith AA, Haas GL. The nature and timing of social deficits in child and adolescent offspring of parents with schizophrenia: Preliminary evidence for precursors of negative symptoms? Schizophrenia Research. 2014;**159**(1): 27-30. DOI: 10.1016/j.schres.2014.07.007

[62] Keshavan M, Montrose DM, Rajarethinam R, Diwadkar V, Prasad K, Sweeney JA. Psychopathology among offspring of parents with schizophrenia: Relationship to premorbid impairments. Schizophrenia Research. 2008;**103**(1-3):114-120. DOI: 10.1016/j.schres.2008.03.006

[63] Glatt SJ, Stone WS, Faraone SV, Seidman LJ, Tsuang MT. Psychopathology, personality traits and social development of young first-degree relatives of patients with schizophrenia. The British Journal of Psychiatry. 2006;**189**(4):337-345. DOI: 10.1192/bjp.bp.105.016998

[64] Manjula M, Raguram A. Self-concept in adult children of schizophrenic parents: An exploratory study. International Journal of Social Psychiatry. 2009;**55**(5):471-479. DOI: 10.1177/0020764008094732

[65] Terzian ACC, Andreoli SB, De Oliveira LM, de Jesus Mari J, McGrath J. A cross-sectional study to investigate current social adjustment of offspring of patients with schizophrenia. European Archives of Psychiatry and Clinical Neuroscience. 2007;**257**(4):230-236. DOI: 10.1007/s00406-007-0714-6

[66] Tienari P, Wynne LC, Moring J, Lahti I, Naarala M, Sorri A, et al. The Finnish adoptive family study of schizophrenia: Implications for family research. The British Journal of Psychiatry. 1994;**164**(23):20-26. DOI: 10.1192/S0007125000292696

Section 5

Social Perspectives

Chapter 9

Quality of Life from the South, Local Knowledge, Socio-Ecological Relationships, and Citizen Participation in Times of Global Climate Change

Jorge Rojas Hernández and Javier Lastra Bravo

Abstract

The quality of life in the South is coping with several problems and tensions that require solution: poverty, socio-territorial and climatic inequalities, lack of scientific and technological development, corruption, migration, lack of access to services, obsolescence of public institutions, and low citizen's participation in the social affairs. There is a global crisis of the Anthropocene's development model. Currently, this context explains multiple mobilizations such as social, environmental, gender, ethnic, working class, and student ones in the South, especially in Latin America. The mobilizations tend to deepen to the extent that the underlying problems are not solved with due urgency, depth, and focus on the human dignity. However, most people and communities value, practice, and aspire to improve their levels of quality of life. This is based on experiences and traditions—such as Living Well—that they have cultivated, beyond the empire of colonizing forces and based on common goods that have learned in a closer relationship with nature. In the South, there is cultural diversity, good coexistence practices, cooperative traditions, food quality, and biodiversity that are the bases for deepening the dreaming quality of life.

Keywords: quality of life, public policies, local knowledge, Buen Vivir, climate change

1. Introduction: quality of life in the South

Quality of life is a relatively new topic in theoretical discussion and the application of public policies in modern societies. As societies progressed in the industrial age, especially in developed countries, particularly in Europe, quality of life began to take on importance in coexistence. Indeed, the crisis of industrialism—supported by the Enlightenment ideology of progress—highlighted the environmental and health problems brought about by this essentially economic growth. Mass production for mass consumption began to be questioned due to its socio-environmental impacts. In this context, which favored the emergence of a new citizen consciousness, the discussion began on the need for a paradigm shift—from a socio-ecopredatory growth paradigm to sustainable development that includes social, economic, and environmental dimensions, with a sort of utopian balance among these components. Indeed, in the late 1960s, the capitalist system was shaken by the emergence of new citizen movements bearing new subjectivities, principles, and values, which fought for and demanded social, cultural, and political changes, an equation not at all easy to solve. Globalization processes have weakened the role of the nation state and thus have diminished the role of politics in the society. The global economy, businesses, and multinational corporations dominate the stage and aggressively expand their interests with little regard for limits on growth and unsustainable exploitation of natural resources imposed by climate change.

Despite it all, quality of life has advanced as a result of the struggles of workers, professionals, women, young people, boys, girls, and indigenous peoples. Naturally, a fundamental quality of life paradigm would profoundly question the neoliberal development model and policies predominant in many countries and continents. It would also question the environmental policies of the Anthropocene Era that threatens biodiversity and the survival of the planet.

It should be noted that there is no universal definition of quality of life that is valid for everyone. Europe was the continent that advanced fastest in defining it, establishing key concepts, criteria, and indicators that are applicable and thus verifiable. This process began in the early 1970s and deepened and sharpened over the following decades, as established in this chapter. In addition, the advancing development of societies around the world led to the emergence of new areas and dimensions of quality of life, which as a result of the same process became more complex and multifaceted. Of course, there are still millions of people around the world in a daily struggle for survival, who neither know of nor enjoy even a basic quality of life, including adequate, safe, quality food, a roof, decent work, rights, landscape access, and good human coexistence. Inequalities of all types help make poverty and the vulnerable state in which a significant part of the world population survives invisibly. Latin America and the Caribbean, along with a significant part of the population of Africa and Asia and the new poor of developed countries (the so-called "losers" of globalization), suffer daily through this unbearable reality of unfulfilled dreams and desires.

In any case, at this point in the development of the modern society and humanity, the idea of quality of life has taken its place as a development parameter and legitimate aspiration of the people. Advances in science, technology, information, and knowledge, as well as intercommunication on social networks, have contributed to increasing subjective and collective demands for continuous quality of life improvements. A society with greater awareness of its rights constantly aspires to live better.

In the South, there is a multicultural variety of good practices; indigenous communities; rural and Andean communities; cooperative work traditions; cultures that value quality food; biodiversity, and the landscape; and historical legacies and epistemological narratives that serve as the basis for continuing to construct and deepen quality of life.

2. Historical context and meaning of quality of life

Quality of life is a concept that emerged in the 1960s as a critic of the conception of development and well-being as necessary products of economic growth. Such criticism had already been expressed by various authors in the early twentieth century, but it was during the post-World War II era that this perception and the related debate deepened. Later—within the framework of the post-development discussion—the Enlightenment idea of "progress" would even be questioned. Influential modern thinkers of the eighteenth and nineteenth centuries and part of the twentieth century thought and spread the idea that progress—now supported by science and technology—would be an uninterrupted, continuous process, but they were wrong ([1], p. 27). Progress advances and retreats over time in modern societies in accordance with the era, class interests, and social groups and the way in which social, political, and environmental conflicts are resolved. In addition, progress does not benefit all sectors of the society equally. Inequality is an ever-present phenomenon that accompanies the development of capitalist societies [1]. It is an inherent, intrinsic characteristic of the system of domination that varies and transforms as societies advance.

Industrialization has produced not only consumer goods and progress but also pollution problems, occupational illnesses, the stress of modern life, exploitation of ecosystems, human communication problems, and various forms of repression of freedom in its multiple expressions [1]. Industrialization has tended to standardize lifestyles, hemming in the individual and limiting or impeding personal fulfillment, with long days of alienated work to achieve a livelihood that enables the consumption of perishable and durable goods. The value of the relaxed, happy life does not figure in the culture or the paradigm of economic growth policy or the ideology of so-called progress ([1], p. 27).

Against this backdrop, heavy, deep criticisms of the development model emerged that encompassed even the so-called real socialisms, not considered as genuine alternatives for human and social development ([1], p. 27). Malaise took hold in the consciousness of citizens. In 1964 Herbert Marcuse published *One-Dimensional Man* [2]. A representative of critical social theory, in this work, which had a great impact in intellectual and youth circles, the author addressed the totalitarian trends or traits of advanced societies. According to Marcuse, the system would create false needs through mass media, advertising, and the integration of workers into the industrialized consumption society ([1], p. 27). The system would function with a strong dose of individualism. Societies would be controlling, containing social change without opposing it. The industrial society would operate one-dimensionally, without spaces for exercising criticism, real democracy, and human freedom.

Thus, quality of life arose as a reform of advanced industrial society, aiming to improve the living conditions of the general population. It exists within the framework of the establishment of the so-called welfare state that developed in European countries in particular, with lower-quality peripheral expressions in the most industrialized and politically advanced Latin American countries ([1], p. 28). It was introduced as a way of quantitatively measuring development amid the growing complexity of the social structure and measuring the impacts of state intervention in economic, social, political, and cultural matters.

Quality of life aims to be a universal, scientific system of measuring the satisfaction of human needs in developed countries [1]. From the beginning there has been a debate on the quantitative and qualitative parameters of quality of life. This debate has been particularly relevant in the creation of objective and subjective social quality-of-life indicators. The objective indicators would be measurable, while the subjective indicators would be intangible and vary according to individual perception. Over time, subjective human needs have taken on increasing importance.

In 1970 the Organisation for Economic Co-operation and Development (OECD) launched a program to create social quality of life indicators in order to measure social well-being, a result of political concern for social matters ([1], p. 28). In 1973 the OECD defined eight areas of concern: (1) health, (2) personal development through the acquisition of knowledge (education), (3) employment and quality of life at work, (4) free time and leisure, (5) available goods and services, (6) physical environment, (7) personal safety and the administration of justice, and (8) participation in collective life ([3], p. 74).

Other quality-of-life models have also been developed in Europe. For example, Germany created the "SPES System of Social Indicators," which measures both objective and subjective needs, as well as the evolution of personal well-being ([1], p. 28). Well-being surveys are occasionally conducted, data from which are presented to the public via reports. The Universities of Frankfurt and Mannheim,

Social concern	Indicator
Health Life span Life in good health	• Life expectancy • Perinatal mortality rate • Temporary disability • Permanent disability
Education and acquisition of knowledge Use of educational opportunities Acquisition of knowledge	• Regular schooling • Adult education • Functional literacy rate
Employment and quality of work life Access to employment	• Unemployment rate • Involuntary part-time work • Discouraged workers • Average work duration • Commute time • Yearly paid vacations • Atypical schedules • Salary distributions • Fatal work accidents • Workplace hazards
Free time and leisure Use of time	• Free time • Free time activities
Ability to acquire goods and services Income	• Income distributions • Low incomes • Material deprivation • Asset distribution
Physical environment Housing conditions Access to services Environmental nuisances	• Housing, interior space • Access to outdoor space • Basic elements of comfort • Proximity to certain services • Exposure to air pollution • Noise exposure
Social environment Social integration	• Suicide rate
Personal safety Risk exposure Threat perception	• Fatal physical injuries • Severe physical injuries • Personal safety fears

Source: OECD [4].

Table 1.
OECD list of social indicators.

with financing provided by Forschungsgemeinschaft (DFG, German Research Foundation), investigated and created the System of Social Indicators in 1972. They selected 10 areas, subdivided into 196 indicators. The areas are: (1) population, (2) social status and mobility, (3) employment and work conditions, (4) income and income distribution, (5) consumption, (6) transportation, (7) housing, (8) health, (9) education, and (10) participation ([3], p. 91).

In 1982 the Organisation for Economic Co-operation and Development defined a list of social indicators based on 15 social concerns broken down into 33 indicators (**Table 1**) [4].

These quality-of-life indicators obviously cannot be automatically replicated in Latin America. Nonetheless, in recent decades there have been frequent discussions on quality of life in Latin America between governments and research centers. In this context, Latin American countries can use these indicators as an important reference framework for guiding public policies, as it occurs in Europe and in other developed countries. It is understood that these social indicators are not mere conventional constructs, but rather that they contain exhaustive specifications and forms of measurement and influence the creation and application of public policies in the countries in which they are used ([1], p. 30).

In Latin American countries, these social concerns are of the utmost interest to citizens but are still in the early stages—although with different emphases—in the public sphere as a result of the implementation of neoliberal policies in basic areas of social life such as education, health, and social security ([1], p. 30). In other areas such as work and housing, there is a lack of regulations and public control that would guarantee quality, for instance, work quality. Social housing, meanwhile, does not conform to human interior space requirements or due access to the natural landscape. In addition, free time is practically nonexistent. "Free time," indispensable for the exercise of liberty and personal fulfillment, is consumed by long workdays and endless commutes in megacities thrown into disarray by transport or is spent in various survival occupations. Life expectancy has increased considerably, but its quality has improved little. Likewise, social integration continues to suffer, with high levels of socio-territorial segregation and inequality [1].

In short, quality of life is certainly a fundamental concept but the one that has yet to be delved into and implemented in our societies. There must be advances in public policy and citizen awareness. Civic malaise resulting from abuses in various areas of social life, services, and consumption in general constitutes signs of exhaustion and a crisis of the neoliberal model that fosters great expectations—quality of education, health, social security, salaries, housing, pollution-free environments, etc.—that cannot be met due to the inequitable distribution of assets and the lack of citizen participation and social inclusion.

3. Environmental problems, climate change, and quality of life

Climate change is the most severe, complex environmental problem affecting the planet and facing humanity in the twenty-first century. For thousands of years, the temperature remained at a global average that enabled the existence of humans and diverse species in a state of interdependence with ecosystem biodiversity. Since the beginning of the Industrial Age, there has been increasing temperature alteration as a result of global warming caused by increases in carbon dioxide emissions from the fossil energy mix that has dominated the Anthropocene Era [5] in which we live. Indeed, we went from an atmospheric CO_2 concentration of 280 parts per million (ppm) in the pre-industrial age (reference date: 1750) to nearly 400 ppm in 2015, with an ensuing increase in the Earth's average temperature.

Life has historically existed and reproduced—and been made possible—in a regulated and, to a certain extent, autoregulated system of interdependent relationships among living, dynamic ecosystems that constantly transform, especially upon reaching points or moments of saturation of a given stage of contradictory development tensions. The human being is only one of its inhabitants, which, distinguished from other species by the use of reason—particularly in the modern age—intervenes in and violently alters movements of reproductive energy in the biosphere, the diverse macrohabitat that houses and enables life, which human activity has brought past its limits of vulnerability.

Human beings have pushed the planet's ability to autoregulate to its limit. The damage has been so great that even if resource extraction, deforestation, food production, and air and ocean pollution ceased, the Earth would take more than a thousand years to recover from the damage that has been done to date ([6], p. 24). This situation reflects the complex moment in which humanity finds itself, in which it is urgent to implement policies to correct and halt the historical consequences of our exploitation of the Earth; these policies must focus on improving *quality of life* through an approach that considers the environmental and human spheres in an attempt to mitigate the effects of the severe damage done to date. Along the same lines, Lovelock [6] indicates the need for a coordinated international effort and a carefully planned project that takes charge of the consequences of environmental exploitation and implements new policies that allow past actions to be corrected, for example, replacement of fossil fuels with purer, renewable sources of energy.

Scientific research in recent decades, especially IPCC reports, which systematize and interpret thousands of international studies, have predicted and sounded the alarm about increases in greenhouse gas emissions and their impact on temperature and ocean-level increases and precipitation decreases in various parts of the Earth, as well as the intensification and frequent appearance of extreme climate phenomena such as droughts, heat and cold waves, intense rains, floods, fires, and landslides caused by torrential rain, along with more frequent and intense hurricanes. Extreme events are increasingly frequent and affect the whole world, especially Latin America and the Caribbean, degrading and threatening the quality of life of vast sectors of the population.

Various regions, towns, and countries have been affected lately by long, severe droughts. Such is the case with the State of São Paulo in Brazil, with 41 million inhabitants. Marcelo Cardoso, a representative of the Alliance for Water, an organization of ecologists that emerged amid the water crisis that affects many towns in Brazil, particularly the State of São Paolo, describes the water stress drama that affects thousands of urban families; thus: "Water is intimately linked to personal dignity. When one cannot wash herself, go to the bathroom, or take care of her children, she panics." ([7], p. 31).

Water scarcity is a consequence of climate change, which, in the case of Brazil, has been exacerbated by the devastation of the Amazon rainforest to make way for soy and livestock. Indeed, the highly economically important agroindustry consumes almost 70% of the country's water, transferring approximately 112 billion liters of freshwater abroad each year. It is known that the Amazon produces a large amount of moisture; currently 18% of the Amazon is logged and 29% degraded ([7], p. 32). Similarly, various Latin American countries are subjected to extreme events such as droughts or drastic decreases in precipitation, including Chile (10 years of megadroughts), Mexico, Brazil, Peru, Bolivia, and Central American countries, as are the Andes region and Latin America in general. For instance, the United Nations considers Chile and Mexico vulnerable to climate change because they meet seven of the nine requirements to be declared as such.

In this context, it is heartening that the Conference of the Parties of the United Nations Framework Convention on Climate Change [8], which brought together representatives of 195 nations in Paris, reached an accord that could partially halt the irreversible advance of global climate change. Indeed, the Paris Accords of December 2015 heed some of the warnings of scientists and open doors to the promotion of renewable energy, highlighting the need to generate resilience capacities in developing countries through environmental education and knowledge and technology transfer and obligating developed countries to contribute financial resources to support the mitigation and adaptation policies of the developing countries most affected by climate change. The accords compel the protection of the most vulnerable sectors of the population, the poor, and ecosystems and emerge as a means of reducing the greenhouse effect by implementing policies to reduce global gas emissions: "Recognizing that deep reductions in global emissions will be required in order to achieve the ultimate objective of the Convention and emphasizing the need for urgency in addressing climate change." ([8], p. 2).

One of the most debated topics in prior conferences and in the Conference of the Parties in Paris was the provision of resources to grapple with climate change mitigation and adaptation processes, especially in the developing countries most vulnerable to extreme events. The conference adapted financial measures that will hopefully be met and actually contribute to halting climate change. The measures include: "… prior to 2025 the Conference of the Parties serving as the meeting of the Parties to the Paris Agreement shall set a new collective quantified goal from a floor of USD 100 billion per year, taking into account the needs and priorities of developing countries" ([8], p. 9). Similarly, "Developed country Parties shall provide financial resources to assist developing country Parties with respect to both mitigation and adaptation in continuation of their existing obligations under the Convention" ([8], p. 31).

To conclude the accords, the Conference of Parties expressed its concern regarding the food supply, which is severely threatened by the effects of climate change around the world: "Increasing the ability to adapt to the adverse impacts of climate change and foster climate resilience and low greenhouse gas emissions development, in a manner that does not threaten food production." ([8], p. 24).

Finally, the Conference of Parties in Paris highlighted the universal nature of the problem and impact of climate change—almost as if it were an attribute of humanity or the age itself—and thus the need to adopt adaptation measures while taking into account and respecting the human rights of indigenous communities, local communities, women, and vulnerable groups: "Acknowledging that climate change is a common concern of humankind, Parties should, when taking action to address climate change, respect, promote and consider their respective obligations on human rights, the right to health, the rights of indigenous peoples, local communities, migrants, children, persons with disabilities and people in vulnerable situations and the right to development, as well as gender equality, empowerment of women and intergenerational equity." ([8], p. 23).

As we have shown, although the accords are very necessary, in practice they have arrived too late. For decades governments have turned a blind eye to studies, and the clear warnings of scientists and groups of ecologists seriously worried about the climate change problem and its consequences for economic activity, quality of life, and the protection of the planet.

There is thus an urgent need to implement new processes and accords among international organizations committed to fighting and mitigating climate change, with concern for the *quality of life* not only of the current population but also of future generations.

The environment affects and determines the circumstances of societal and individual life. All people need and deserve to live in healthy environments free of pollution and danger. Unfortunately, the current landscape is a long way from providing these ecosystem services: underdeveloped countries are disadvantaged in terms of environmental conditions and poverty, with enormous effects on the quality of life of their inhabitants. Thus, thought must be given to sustainable, socio-ecological development with consciousness, focused on diminishing the effects of the environmental crisis currently affecting the planet and quality of life. We believe that climate change is very important when debating and studying quality of life, as it is a determining factor in the future of humanity.

4. Quality of life in the South: the Latin American debate

The topic of quality of life arose much later in the Latin American debate, specifically in the post-dictatorship period in the 1980s, during which a profound re-democratization process unfolded, allowing the emergence of new social movements that were also concerned with improving quality of life, reviving past axioms on social matters. They included new union, environmental, human rights, student, women's, and ethical movements. Amid this period of democratization and social effervescence, concern for quality of life and its improvement in Latin American countries arose and developed.

The Latin American debate on quality of life is currently closely tied to the need to overcome high levels of inequality, vulnerability, and poverty, which exist in practically every country. According to poverty data measured in Latin America between 2010 and 2014 [9] by the Economic Commission for Latin America and the Caribbean (CEPAL), while inequality in the region continues to grow, poverty and extreme poverty levels are decreasing.

This poverty reduction process has made relative improvements in most countries in the region, which have been accompanied by an improvement in quality of life compared to the prior situation. Indeed, the poverty gap in the analyzed period decreased at high annual rates and fell faster than the poverty rate in countries such as Uruguay (−15.9%), Peru (−12.3%), Chile (−10.5%), Brazil, Ecuador, Paraguay, Colombia, and Bolivia (a drop of between about 8 and 10%) ([9], p. 20). Meanwhile, poverty severity decreased in the same countries to an annual equivalent rate of between 9 and 14% ([9], p. 20).

While the data demonstrate that poverty has decreased, wealth distribution indices have indicated increasing inequality, which could be explained by the current globalization process—along with the implementation of neoliberal privatization policies—which has accelerated the global and regional trend of increasingly uneven wealth distribution, the most acute manifestation of which is in Latin America, translating into new segments of the population being excluded from the basic conditions and services and thus having a lower quality of life. Although it is true that certain resources are scarce and superexploited around the world, the exclusion processes are neither explained nor justified by this scarcity, but rather by wealth and asset accumulation favored by an instrumental rationale that hegemonizes the actions of capital and private interests, the media, and the most influential political class in the world.

Ulrich Beck portrayed the new global reality early on as the dawning of the second modernity, which he identifies and defines as a difficult-to-govern "world risk society." He maintains that control problems can lead to a state of "organized irresponsibility" regarding the risks affecting the planet: "… the new prominence of risk connects, on the one hand, individual autonomy and insecurity in the labor market and in gender relations, and, on the other hand, the sweeping influence of scientific and technological change. World risk society opens public discourse and social science to the challenges of ecological crisis, which, as we now know, are global, local, and personal at one and the same time. Nor is this all. In the 'global age,' the theme of risk unites many otherwise disparate areas of new transnational politics with the question of cosmopolitan democracy: with the new political economy of uncertainty, financial markets, transcultural conflicts over food and other products (BSE), emerging 'risk communities,' and, last but not least, the anarchy of international relations. Personal biographies as well as world politics are getting 'risky' in the global world of manufactured uncertainties." [10].

This risk in the global society is undoubtedly among the important subjective factors that influence quality-of-life indices and individual perceptions. Nonetheless, poor segments of the population have developed new abilities to survive in a flexible, unstable, inequitable, unprotected, rootless, and fractured world, seeking with their own actions to mitigate their hardship and improve their quality of life in the short and long term. Many of their actions remain in the sphere of precariousness and instability, although some manage to establish themselves over time, blazing trails of progress and hope.

As we have mentioned, income distribution in most Latin American countries—and around the world—has deteriorated. In neoliberalism income distribution and redistribution are forbidden words, taboos, simply unnecessary: "... the collapse of collective redistribution claims (and more generally, the replacement of the criteria of social justice by those of respect for difference reduced to cultural distinction) and the growth of inequality running wild are intimately related. There is nothing incidental about this coincidence. Setting claims for recognition free from their redistributive content allows the growing supply of individual anxiety and fear generated by the precariousness of 'liquid modern' life to be channeled away from the political area – the sole territory where it could crystallize into redemptive action and therefore be dealt with radically – by blocking its social sources." [11].

Development as such must overcome the narrow concept of "growth" or "productivism" based only on economic or income factors in order to encompass a more holistic vision linked to socio-environmental protection and promotion of quality of life, that is, quality of life not associated with the unlimited accumulation of wealth and assets. Material goods are necessary and essential in life, but equally indispensable are intangible values related to freedom, democracy, the landscape, beauty, culture, solidarity, human coexistence, friendship, and participation. Here the idea of a sustainable development model based on ethical environmental and human values such as respect for nature and its own laws of conservation and reproduction; respect for human rights; respect for freedom; guaranteed equal access to education, health, infrastructure, and recreation; and the right to democratically participate and decide fundamental public matters of concern to subjects and citizens comes into play.

Stable, decent, and quality work is undoubtedly an important determining factor in improving quality of life, as well as a central element of social sustainability. Precarious or unstable work destroys the identity of the individual who does it, transforming it into a mere provider of daily sustenance, something disposable, replaceable, and expendable, negatively affecting psychological well-being and quality of life. By contrast, quality work generates social security, stability, and peace. Work that adds value, in which highly-qualified workers enjoy autonomy and make decisions, as exists in developed countries [12], fosters the subjectivity of the individual, increases quality of life, and advances social progress. Latin America currently presents high levels of unemployment and loss of centeredness and work meaning. Workdays have lengthened, and prevailing poverty means that more than one job is required. Most of the population cannot sustain itself on flexible and precarious work. As André Gorz expresses it well, "We are leaving work-based society behind without replacing it by any other form. Each of us is aware, emotionally and intellectually, that we are potentially unemployed, potentially under-employed, potentially insecure or temporary workers, potential 'part-timers" [13]. Work has become a "scarce" good, necessitating a rethinking of it. A new concept of work is required, redefining it as, for example, community and environmental activities of social value and meaning that undoubtedly improve quality of life.

Another important aspect related to quality of life, which has not been taken into consideration in traditional theory, is the human need for landscapes and green areas. Studies carried out by Jorge Rojas [14] between 2001 and 2003 demonstrate the importance of the landscape—a fundamental element in the organization and sustenance of the daily lives of citizens—in quality of life. Our sense of belongingness to the nature manifests itself in our desire to return to it, in some manner of attraction to the natural landscape. This is also influenced by the worldviews of indigenous peoples of Latin America. The close relationships between indigenous communities and their territories and landscapes have influenced the rest of the Latin American society. Thus, we deem the need for landscapes and their relationships with individuals important to mention as a central aspect of quality of life.

Nonetheless, poor people generally lack quality landscapes and green areas. They live not only in crowded conditions but also amid rough, degraded, polluted, barren, and dirty landscapes. Poor landscapes make people sick, depress them, and infect them with their vulnerability. Therefore, every human needs a territory in which to settle, put down roots, create a story, reproduce, and build hopes. Where the social groups that inhabit it, through social practices and the set of social relationships in the territory, take ownership of the space, making it part of their identity and uniqueness [15], in this space, there is a confluence of the basic elements of the social identity of the community and the historical elements of the common past and the community's worldview. However, in Latin America there have been severe externalities, negatively affecting natural systems, territories, landscapes, and quality of life. Even so, in most Latin American countries, there is enough space to allow each person, family, and community access to adequate territorial sustenance, thereby improving quality of life.

Citizen participation is another substantial factor in individual quality of life and modern society, as in the current modern society those who do not participate remain on the margins of life and events and ultimately the margins of society. From a quality-of-life perspective, participation cannot be limited—as it is often understood in our countries—to the mere act of keeping informed of the decisions that will change some important aspect of our daily existence (whether a megaproject, a constitutional change, an educational reform, the installation of a dump near a residential area, etc.). Participation in a modern sense entails citizen involvement, the ability of people (individually and collectively) to decide and influence the social, political, and cultural matters that will affect and shape life in the society. This means broadening and deepening democracy, respecting the people and cultural diversity, and strengthening regions and social organizations. We are still far from establishing a fully democratic system that allows and ensures citizen participation. Elections are a minimum modality of democracy. In developed countries, there has recently been discussion on the "democratization of democracy" [16], a concept that indicates structural and paradigm changes regarding the components and characteristics of the first modernity. It also involves the behavior and role of the people and the active exercise of citizenship, which is still far from occurring in Latin America.

5. New criteria for the study of quality of life: social baseline—a tool for the defense of the common

As we have seen, today there are various aspects of quality of life; it appears necessary to us to create an instrument with which these aspects can be analyzed and the quality of life of individuals protected amid interventions such as the development of projects. Taking international experiences into account, the social baseline can be understood as a tool that allows a deep assessment of the community affected by an intervention and encompasses the set of factors and dimensions that make up and shape quality of life [1]. A project should not worsen current quality-of-life conditions, as it tends to occur. Rather, it should improve the living conditions of the community, which rarely happens. It is known that in general every project or intervention alters social life. It can do so positively or negatively, and the alterations can be of very diverse sorts. They depend on personal perceptions, which must be considered and respected. Perceptions can be studied and measured with scientific precision.

Social baseline means being aware of and understanding the system that makes up individual quality of life, spanning the productive, social, cultural, and interpersonal aspects of the community ([1], p. 25). It does not mean, as it often occurs in Environmental Impact Assessments (EIA), that only some general socioeconomic characteristics are described in order to subsequently deduce possible social impacts, which the consultants responsible for the sociocultural studies tend to minimize ([1], p. 25). Only deep knowledge of the human habitat in all its systemic complexity and interdependence with the nature that surrounds it allows the projected social impacts of an energy megaproject or other such development on the human community to be analyzed.

In an investigation that we carried out in Patagonia related to the possible impact of the HidroAysen megaproject on community values, we were able to establish that in the Cochrane community, for example, one of the main fears regarding the project was that the arrival of outside workers, without families, would disrupt the good customs, values, and traditions of the community ([1], p. 25). The construction of dams, according to the people of Cochrane, would bring money, prostitution, corruption, and crime, which would affect their community life based on trust, respect, and neighborliness. Trust is a fundamental value that has been present throughout the difficult history of the settlement and (isolated) subsistence of the Aysén Region. It has allowed the formation of social networks and friendships and the organization of communities based on solidarity and mutual support, indispensable values in geographic regions isolated from the rest of the country and, in a sense, abandoned by the government, as has been the case with the Chilean Patagonia, as various investigations have shown [1].

As EIAs discuss the baseline of the natural system, a *social baseline* that describes the impacts that implementation of a project would have on the basic makeup of neighboring communities, taking into account the various aspects of quality of life, should also be considered. Indeed, a community has history, organization, culture, traditions, social practices, modes of action and interaction, norms and values that regulate it, and desires and aspirations to improve individual and collective living conditions. Society, furthermore, is not a mere statistical data point, but rather a dynamic, changing reality in a continuous process of transformation that must be taken into account if a foreign body is to be added to its history, landscape, and daily life [1].

A social baseline in a study should include the following aspects or indicators ([1], p. 26):

- **Human development index of the community**. Developed by the UNPD, it includes (i) income level, (ii) schooling level, and (iii) life expectancy. This index can be complemented by the **Gini coefficient or index**, which measures income distribution levels.

- **Quality-of-life system of the community**: social support networks, levels of trust/distrust, internal cohesion, sense of social well-being, subjective perception of quality of life, and urban landscape. It can be measured using surveys/ interviews or other instruments.

- **Access to facilities and infrastructure**: health, streetlights, drinking water network, schools, public transport, commerce, recreation areas, playgrounds, etc. Municipalities have these data.

- **Level of basic needs fulfillment**: food/nutrition, housing, health, sanitary services, heating, clothing, etc.

- **Employment quality**, unemployment, poverty, and inequality levels.

- **Levels of territorial segregation/integration**, neighborhood violence, and safety.

- Human load carriage levels of the territory/area or region and transregional justice.

- **Level of community identity and sense of belongingness** to its area and surroundings.

- **Local knowledge** [17]. It is represented by local knowledge and practices related to production, ecosystems, medicinal plants, indigenous food systems, climate change adaptation strategies, the philosophy of "Buen Vivir," and quality of daily life.

These criteria are relatively broad and not intended to be the only criteria or exclude others that could eventually be added or integrated, but they are basic and necessary to consider in a social baseline ([1], p. 26). However, they can be hierarchized, establishing which of them could be more important in a given study. As a structuring perspective, the hierarchization must consider the commons, all that which from an ontological perspective makes up the socionatural and cultural foundation that sustains human life. There are already data on some aspects and indicators in the public system such as the Human Development Index or Gini index, as well as data on infrastructure, access to basic services, employment and unemployment, and age structure of the population ([1], p. 27). But quantitative and qualitative studies must be done in order to obtain other information, for example, to measure quality of life, spatial segregation, and levels of territorial inequity regarding interregional human load, identity, and sense of belongingness.

6. Distributive territorial transregional justice and improvement of quality of life: human love and understanding

Territories are made up of ecosystems of various natures and levels of vulnerability, with given productive potentials, ecosystem capacities, and abilities to assimilate human activities. Therefore, it is unfair for some regions to be repeatedly loaded by environmental and social externalities to the point of saturation or existential collapse, worsening the quality of life of their inhabitants [1]. Regions or towns are frequently overloaded due to their comparative advantages in terms of natural resources (rivers, for instance) and levels of poverty and social exploitation, with little capacity for action or negotiation with businesses or public institutions. There are many examples: the *HidroAysen* project in Chile, hydroelectric projects and deforestation in the Amazon, and mining projects in Mexico and Peru, among others. In general, the local community becomes "enchanted" by job creation and promises to install a cutting-edge technology. But the promises tend to fade over time, with the local community left bearing new externalities added to its already diminished quality of life and deteriorated environment.

Transregional justice means weighing the cost-benefit perception of the entire region, with specific focus on quality of life ([1], p. 14). Often there is a perception that "only other regions or the producer or distributor will benefit" or that a region will be harmed by a polluting project that was not accepted by another region. For example, the groups that criticized *HidroAysen* rightly argued that the ecosystems of the Patagonia would be affected and that the electricity would be produced especially to meet the energy demands of mining operations in the North of the country [1].

Therefore, transregional justice should be a fundamental criterion for assessing an investment project with territorial and social impacts. In other words, a balance among regions must be fostered, avoiding overloading one region or town with environmental or social liabilities, in order to maintain quality of life levels in all regions. It means seeing to an equitable distribution of benefits and liabilities and supporting the most economically and socially depressed communities with benefits.

For Sergio Boisier, a territorial planning expert, development requires the deployment of the endogenic planning capacities of a territory: "First, endogeny means a growing capacity for autonomy for the territory to make its own development choices, choosing, for example, a style consistent with its traditions or culture, or simply a collectively 'invented' mode of development. This growing autonomy is completely inseparable from a similarly growing decentralization process, which leads to the conclusion that well-understood development is necessarily decentralized." ([18], p. 102).

Boisier defines four planes that must be articulated and strengthened as a condition of endogenous development. The second plane refers to the "growing capacity of the territory to appropriate a portion of the economic surplus generated there for local reinvestment" in order to ensure sustainable development and diversify the material base of the territory, making it less vulnerable to economic fluctuations [18]. The third plane "means that the territory must have a capacity for generating innovations that cause structural changes therein, not only an increase in scale. This assumes the existence of a local science and technology system..." The fourth plane "means the existence of a territorial culture that generates an identity that connects the collective being to the territory" ([18], pp. 102, 103).

So-called procedural justice must be incorporated into transnational justice. There are often inconsistencies between different levels of regulations. In Latin America, in Chile, for example, it may—and does—happen that a project is rejected by a regional agency and approved by a national one [1]. This occurs due to the prevailing centralism. Centralism in decision-making impedes more independent and sustainable regional development. For justice to be applied, neither a declaration of principles nor the mere existence of legal standards is sufficient. Nor is a declaration of respect for human dignity or a certain social empathy for those affected by a given project enough ([1], p. 33).

Indeed, many economic interventions are carried out with contempt for social groups, especially when they are poor or have "traditional" ways of life that are not considered "modern," as occurred with the construction of hydroelectric centers in Mapuche territories in the Upper Biobío in the Biobío Region. This is frequently the case with megaprojects that intervene in the ancestral territories of indigenous communities in Latin America. Thus, author Nussbaum rightly states that for justice to be effective it must be accompanied by real webs of feelings that intrinsically entail the mutual understanding of the human quality of the subjects participating in a social process strained by interests and suffused with fair aspirations [1]: "Respect on its own is cold and inert, insufficient to overcome the bad tendencies that lead human beings to tyrannize over one another. Disgust denies fundamental human dignity to groups of people, portraying them as mere animals. Consequently, respect grounded in the idea of human dignity will prove impotent to include all citizens on terms of quality unless it is nourished by imaginative engagement with the lives of others and by an inner grasp of their full and equal humanity." "Love, then, matters for justice – especially when justice is incomplete and an aspiration (as in all real nations), but even in an achieved society of human beings, were such to exist." ([19], p. 459).

7. Citizen participation, democracy, and quality of life

Citizen participation is the modern democratic mechanism that ultimately grants social legitimacy to any project that intervenes in a territory and affects the quality of life of the community, as generally occurs. Citizen participation must be included in all stages of the planning process. Participation currently has great legitimacy in a society, as it is a method of building cities and societies and developing with a conception and perspective of social inclusion ([1], p. 34).

Nonetheless, the liberal conception of citizen participation is quite restrictive, as it refers only to legal-formal characteristics: "The emphasis liberalism puts on the reclaiming of citizen rights is to the detriment of responsibilities, which, except for obeying laws and paying taxes, are scarcely mentioned. This gives the liberal conception of citizenship a marked legal-formal character, which is why it is considered a weak citizenship. The existence of citizen rights is a necessary but insufficient condition for citizenship. The liberal conception represents an impoverished version of citizenship, in which citizens are reduced to passive bearers of rights, whose freedom consists of being able to pursue their individual interests (or conceptions of a good life)." ([20], p. 123).

Similarly, Fierro states: "From a communitarian perspective, citizenship entails both individual rights and social responsibilities, with a better balance between the two important to attain. Only then will an individual achieve full citizenship, as it entails a strong moral commitment" ([20], p. 124). For real citizen participation to exist, it must be considered early and organized throughout the development and decision-making process of a given project.

Participation first requires public will, in the sense of wanting and facilitating it, which is not always an assumption during the creation of a project. It also requires substantive legal backing and provisions that make it obligatory and clearly define its course. Participation goes hand in hand with trust-building, which means explaining the true environmental and social implications of the project to the public ([1], p. 34).

There are often asymmetries among actors in citizen participation processes, which obviously complicate decision-making, harming the general public, which will endure the externalities. Asymmetries refer to different levels of organization and negotiating capabilities, different economic capacities, different levels of access to the local and national authorities that will make the final decision (influence and lobbying capacity), and different levels of professional capacity to understand the technical designs of projects and procedural codes, in short, different access to information and limited professional advice ([1], p. 35).

This discrepancy must be considered at the beginning of the process and remediated as much as possible. Approving a project without citizen participation means building a future social conflict: "Critiques of liberal democracy (citizens exercise sovereignty by voting) have led to the emergence of various alternative models, including social democracy (which aspires to greater levels of socioeconomic equality), deliberative democracy (which emphasizes the importance of the deliberation process in public debate and the public use of reason), participatory democracy (which stresses the creation of new forms of direct participation in decision-making, including public hearings, referenda, plebiscites and electronic inquiries) and republican democracy (which revives the concept of freedom as self-determination and not non-domination)." ([20], pp. 302, 303).

Most Latin American countries still have low-intensity democratic systems. Dictatorships violently denied and destroyed the forms of popular representation achieved by various countries in the twentieth century [1]. Nowadays progress toward better forms of democracy is slow and complicated. Demands for social inclusion are the best indication of the political and social reality; that is, social exclusion continues to be a serious problem in practically every country. The same holds true for participation, which is cast as a political demand. It is also an indication of the existence of traditional structures of domination and organization of power. Much remains to be done to progress to forms of social, deliberative, participatory, or republican democracy. There is a lack of political will among the groups in power and, more important, a need to better organize and strengthen civil society. There is also a need for real civic development, which is in a state of emergency. Developed countries, especially in Europe, underwent long, complex processes of social, political, and cultural struggle in order to achieve better levels of social and participatory democracy, which is constantly exposed to dangers and threats of destabilization, as is currently the case with tensions resulting from discussions on immigration and the emergence in various countries of far-right movements and parties, known as "right-wing populists," which threaten democracy, social rights, and freedoms won by peoples who have fought for their emancipation ([1], p. 35).

A more direct, civic, and participatory democracy creates conditions consistent with the current development of people's subjectivity and, supported by a more informed society provided with greater and better knowledge and communication systems, undoubtedly contributes to improving the quality of life of the population to the extent that it has access to these new qualities of the globalized modern world.

8. Traditional knowledge on quality of life: *Buen Vivir* as alternative to development

The traditional knowledge of indigenous peoples and their communities, which have survived the passage of time and modernity, is of great importance in Latin America. Some of this traditional knowledge is closely related to the understanding of quality of life, including the *Küme Mogen* concept of the Mapuche people, *Sumak Kawsay* of the Quechua peoples, *Suma Qamaña* of the Aymara peoples, and

Ñamde reko of the Guaraní [21–24]. All these concepts can be seen as manifestations of the ideas of *Buen Vivir* (which roughly translates as “good living”) that have been addressed theoretically by Acosta and Gudynas, although *Buen Vivir* ideas are a current topic for various intellectual groups in Latin America, who gather ancestral ideas to grapple with development by rethinking it as a development focused on quality of life and the environment.

Buen Vivir is not a completely settled concept, as it is in a constant process of updating, incorporating ideas from indigenous groups and their traditional knowledge, the citizenry, and Latin American academia. A review of the literature indicates that its basic precepts are sustainable living, justice, democracy, a solidary, community economy, reciprocity, and the combination of different logics of production and work, fostering the appreciation of ancestral practices and knowledge and complementarity rather than competition as the foundation of the economic and production model.

The concept of *Buen Vivir* bursts into Latin American political discourse, public policies, and academic debate more than a decade ago. It has also been incorporated into the constitutions of Bolivia (2009) and Ecuador (2008). It bears mentioning that while the two constitutional systems have similarities, the Ecuadorian constitution presents *Buen Vivir* as a set of rights, while the Bolivian document presents it more as a fundamental ethic to take into consideration. Likewise, various processes and realities went into the creation of the concept; for example, the Bolivian discussion on *Suma Qamaña* was driven by the hard work of indigenous communities and indigenous intellectuals such as Simón Yampara, while in Ecuador the discussion was led mainly by the economist Alberto Acosta.

The concept of *Buen Vivir* appeared in the political sphere in the late 1990s, drawing on the *Buen Vivir* culture of indigenous origins [17, 25, 26]. It has been shaped by both global and local discourses, focusing on the search for post-development alternatives rooted in indigenous and citizen discourses in Latin America.

As we have stated, *Buen Vivir* is centered on a critic of development, putting forth the idea that the social and the ecological overlap and are mutually related, thus taking on equal importance [27–29]. It is therefore considered a biocentric position, in which natural elements have intrinsic value: “They are, therefore, subjects. It is precisely this position that allowed the rights of nature to be recognized in the new constitution of Ecuador” ([28], p. 8). The foregoing undoubtedly has many implications, since, when developing legal proposals, the defense of the rights of nature must be taken into consideration.

Thus, *Buen Vivir* is a pluralistic concept [22, 28], a conceptual platform for understanding the world, and, in the case of indigenous people, a worldview consistent with each specific national and community context. Therefore, it could be said that there are various “Buen Vivires” specific to local situations. As Eduardo Gudynas puts it: “As Buen Vivir is pluralistic, it could be stated that any indigenous position, or any critique of development, is a synonym of Buen Vivir.” ([28], p. 9).

In keeping with the idea of the pluralistic nature of *Buen Vivir*, the concept has recently been used extensively in the discourse of Mapuche political organizations who have revived the ancestral idea of *Küme Mogen*, linking it to environmental and territorial problems in the Araucanía region. Through *Küme Mogen*, the Mapuche people offer an alternative to development from a perspective of “sustainability with identity,” through which it is sought to implement an alternative guided by principles of balance and human harmony with the environment, thereby displacing western assumptions on the environment viewed in terms of the needs of man. Thus, the concept of *Küme Mogen* guides action by promoting values of respect and the Mapuche moral code *Ad Mapu*, which regulates good relations and reciprocity among all the elements of nature, whether animals, trees, rivers, plants, or rocks.

The guiding element through which the practices of *Küme Mogen* is articulated is based on the principle of "duality/transgression," which is present in many American indigenous cultures, and "constitutes a public subsystem of the Mapuche religion, open to the non-Mapuche world, to preserve nature and sustainably use the resources of their territory" ([30], p. 94).

9. Ontology of the commons and quality of life

Good and efficient participation requires a guarantee of transparency, great clarity, and information on the process a project will follow, its objectives, contents, costs, impacts, deadlines, and means of citizen participation, as well as the careful establishment of real possibilities for neighboring communities to influence its course [1, 31].

Social experience indicates that communities affected by interventions in their territories generally react and base their arguments on the defense of their individual and collective interests ([1], p. 36). They defend their heritage of common goods, whether water, an ecosystem, a landscape, clean air, a wetland, traditional crops, forms of coexistence, or local cultures. Thus, for a consultation system to be truly democratic and generate conditions for dialog and possible consensus, transparency regarding interests, common heritage, and the motivations of the actors participating in the project proves essential [1]. Concealing the underlying interests and motivations is detrimental to project acceptance. And the interests are not entirely rational; they also involve experiences and emotional expressions: "… more deeply, the public culture needs to be nourished and sustained by something that lies deep in the human heart and taps its most powerful sentiments, including both passion and humor. Without these, the public culture remains wafer-thin and passionless, without the ability to motivate people to make any sacrifice of their personal self-interest for the sake of the common good." ([19], pp. 61, 62).

Another important aspect to consider in a project is the possibility of creating added value for regions. Many projects merely extract raw materials without adding value; such projects keep regions poor, turning them into mere suppliers of cheap natural resources. By contrast, development projects that add value contribute to personal development (through the demand for qualified personnel) and that of the region/town through value chain momentum, the creation of knowledge and technology, and the improvement of trade. Along with adding value to what it produces, a project must also consider the identity of the town or region. It is known that some projects degrade or even destroy regional identity. The identity of a region is closely related to its ecological, productive, social, and cultural history. Identity unites a region and strengthens its inhabitants' sense of belongingness to and respect for its ecological and human habitats. And identity has an irreplaceable and immense value, as it nourishes the social and individual life of the community [1].

Before the appearance of private property and the capitalist mode of production, communities occupied territories with a vision, culture, and practices based on the commons or the common good [1]. "Commons im Pluriversum" (the common in various worlds), in Escobar's words, takes on an ontological character [32]. The ontology of the commons bases its philosophy on a world or various worlds with common senses and belongings that serve as a foundation for and enable the emergence of human life within the framework of a habitable and interdependent natural habitat [1]. Thus: "the emergence of 'the common' as a political rallying cry initially grew out of dispersed social and cultural struggles against the capitalist order and the entrepreneurial state. As the central term use to denote an alternative to neoliberalism, the common became the effective principle for struggles and movements, that, over the past two decades, have resisted the dynamics of capital and given rise to original forms of activism and discourse. In order words, the common is far from a purely conceptual invention: the common is rather the concrete product of social movements and various schools of thought dedicated to opposing the dominant tendency of our era, namely the extension of private appropriation into every sphere of our societies, out cultures and out very lives." ([33], p. 21).

This ontological view of the world based on sharing inalienable common goods (alienable goods would have been inconceivable) prevailed for thousands of years until the arrival of capitalism—along with private accumulation—as a mode of production and construction of social life and culture took hold of the modernization processes of the Modern Age and buried the ancient traditions of ecological life still present in indigenous communities and local coexistence practices beneath a culture of trade. Defending local identity is not easy. Amid the globalizing trends in motion today, it means going against the flow, as argued by studies by noted thinkers such as Zygmunt Bauman and Edgar Morin: "With globalization, identity becomes a heated matter. All the landmarks are canceled, biographies become jigsaw puzzles whose solutions are difficult and mutable. However, the problem is not the single pieces of this mosaic, but the way they fit in with each other." ([34], p. 104) "Identity, let us be clear about it, is a 'hotly contested concept.' Whenever you hear that word, you can be sure that there is a battle going on. A battlefield is identity's natural home. Identity comes to life only in the tumult of battle; it falls asleep and silent the moment the noise of the battle dies down. Cutting both ways cannot therefore be avoided. It can perhaps be wished away (and commonly is, by philosophers striving for logical elegance), but it cannot be thought away, and even less can it be done away with in human practice. 'Identity' is a simultaneous struggle against dissolution and fragmentation; an intention to devour and at the same time a stout refusal to be eaten…" ([34], pp. 163, 164).

Globalization tends to "devour" the local and disintegrate and fragment what remains of community life and culture to subject it to standardizing "technoeconomic" logics, as analyzed by Morin [35]. Nonetheless, the local does not disappear. It moves and endures in the appreciation of the commons, which unites, creates, and gives a sense and feelings of belongingness to a living human community in constant transformation.

The Latin American scientific community can make a significant contribution to the addition of value to the productive, social, and ecological life of the region [14]. Added value is urgently needed to overcome the region's considerable delay and advance toward sustainable development and improve the quality of life of its population. Creative capacities exist in all countries and areas. The defense of water—a vital resource—for instance, and natural resources in general in times of fierce global competition and irreversible climate change, is the only way to guarantee the construction of a truly sustainable ecosocial order. To this end, we must think less linearly and more circularly in order to sync the movement of the planet's ecosystem components with the complex movements of human life in the biosphere. In truth, everything is a common good, as even that which is paradoxically called "private" is the result of interactions of common goods and values.

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References

[1] Rojas J. Participación ciudadana, calidad de vida y justicia transregional territorial: una línea base social del bien común. Ambiente y Sociedade. 2017:21-42

[2] Marcuse H. One Dimensional Man. s.l: Beacon Press; 1964

[3] Seiten M. Indicadores sociales de calidad de vida. Un sistema de medición aplicado al Pais Vasco. Madrid: Centro de Investigaciones Sociológicas (CIS); 1993

[4] Organisation for Economic Co-operation and Development (OECD). The OECD List of Social Indicators. Paris: OECD; 1982

[5] Christian D. La gran historia de todo. Barcelona: Edicion Planeta; 2019

[6] Lovelock J. La venganza de la Tierra. La teoría de Gaia y el futuro de la Humanidad. Barcelona: Planeta; 2007

[7] Bigna A. Los efectos de la deforestación de la Amazonía. San Pablo Seco. [aut. libro] Friedrich Ebert Stiftung. Desafíos del Cambio Climático. Santiago de Chile: Editorial Aún Creemos en los Sueños; 2015

[8] United Nations. Conference of the Parties. Framework Convention on Climate Change. Paris: ONU; 2015

[9] CEPAL. Panorama Social de América Latina. Santiago: CEPAL ONU; 2015

[10] Beck U. World Risk Society. Cambridge: Polity Press; 1998

[11] Bauman Z. Community: Seeking Safety in an Insecure World. s.l: Wiley; 2001

[12] Castells M. La era de la Información. Madrid: Alianza; 1998

[13] Gorz A. Miserias del presente, riqueza de lo posible. Buenos Aires: Paidós; 2000

[14] Rojas J. Sociedad y Naturaleza. El paisaje en la calidad de vida urbana. Estudios comparativos de Talcahuano y San Pedro de la Paz (Chile) y de Halle (Saale) (Alemania). In: Breuste J et al., editors. Nutzung und Management von Natur und Landschft in Stadtregionen. Vol. 36. Leipzig: UFZ; 2003. pp. 43-69

[15] Velazquez E. El territorio de las políticas de Soteapan, Veracruz: transformaciones en la organización y apropiación del espacio. s.l.: Relaciones; 2001. pp. 17-47

[16] Beck U. Freiheit oder Kapitalismus. s.l.: Clothbound; 2000

[17] Santos BS. Refundación del Estado en América Latina. Perspectivas desde una epistemología del Sur. Lima: Instituto Internacional de Derecho y Sociedad; 2010

[18] Boisier S. Territorio, estado y sociedad en Chile. La dialéctica de la descentralización: entre la geografía y la gobernabilidad. Santiago de Chile: Mago Editores; 2010

[19] Nussbaum M. Emociones políticas. ¿Por qué el amor es importante para la justicia? Barcelona: Paidos; 2014

[20] Fierro J. La ciudadanía y sus límites. Santiago de Chile: Editorial Universitaria; 2016

[21] Beling A, Gomez F, Vanhlust J. Del Sumak Kawsay al Buen Vivir: filosofía andina como base para una racionalidad ambiental moderna. In: Gomez C, editor. Religión y religiones en el tiempo post-secular. Hacia un diagnóstico del lugar de las religiones en el mundo contemporáneo. Bogotá: CETRE, Universidad del Rosario; 2014

[22] Gudynas E, Acosta A. El buen vivir más allá del desarrollo. In: Revista que hacer. 2011. pp. 70-81

[23] Huanacuni F. El buen vivir/vivir bien: Filosofía, políticas, estrategias y experiencias regionales andinas. Lima: Coordinadora Andina de Organizaciones Indígenas; 2010

[24] Rivera S. Oprimidos, pero no vencidos. La Paz: WA-GUL; 2010

[25] Altmann PE. Buen Vivir como propuesta política integral: Dimensiones del Sumak Kawsay. Revista Latinoamericana de Políticas de Acción Publica. FLACSO. 2016:55-74

[26] Altmann P. El Sumak Kawsay en el discurso del movimiento indígena ecuatoriano. Indiana. 2013:283-299

[27] Acosta A. El Buen Vivir. Sumak Kawsay, una oportunidad para imaginar otros mundos. Barcelona: Icaria; 2013

[28] Gudynas E. Alternativas al desarrollo y buen vivir. In: Garcia F, Guardiola J, editors. El buen vivir como paradigma societal alternativo. Madrid: Economistas sin Fronteras; 2016. pp. 6-11

[29] Sempere J. Enfoques sobre bienestar y Buen Vivir. s.l.: CIP Ecosocial y FUHEM; 2010

[30] Grebe ME. El subsistema de los ngen en la religiosidad mapuche. Revista chile de antropología. 1993

[31] Laval C, Dardot P. Común. Ensayo sobre la revolución en el siglo XXI. Barcelona: Editorial GEDISA; 2015

[32] Escobar A. Commons im Pluriversum. In: Helfrich S, Heinrich-Böll-Stiftung D, editors. Bollier. Die Welt der Commons. Muster Gemeinsamen Handelns. Bielefeld: Editorial Transcript; 2015. pp. 334-345

[33] Laval C, Dardot P. Común. Ensayo sobre la revolución en el siglo XXI. Barcelona: Gedisa; 2015

[34] Bauman Z. Identidad. Buenos Aires: Losada; 2005

[35] Morin E. La vía para el futuro de la humanidad. Barcelona: Paidós; 2011

Chapter 10

Services for Children with Disabilities and Their Families: The Impact on the Family's Life Quality

Tamara Džamonja Ignjatović

Abstract

Families that have children with disabilities are faced with numerous difficulties in Serbia mostly due to the prolonged effect of social and economic crises. Besides insufficient adequate and diverse community-based services, they often experience social isolation and poverty, too. During the last decades, there were efforts to improve support for parents by introducing community-based services for their children with disabilities. This chapter is based on the findings of the study that explored the effect of those services on the families' quality of life. Although the findings confirmed that the services generally improved their life quality, particularly for those who perceived the lowest quality of life before, there are some additional observations about "side effects" that should be useful guidelines for developing flexible individually tailored service that support families' needs and suit them best.

Keywords: quality of life, children with disabilities, family support services, evaluation of services

1. Introduction

Serbia has been trying to implement important reforms in the area of social welfare in the last two decades, as a part of process for integration into the European Union. One of the main courses of reforms is in the area of child protection. Therefore, it has been necessary to develop a wide range of community-based services for supporting families to improve their quality of life and provide optimal conditions for the child development. As a part of that process, different services for children with disabilities and their families have been established, in contrast to the old, mostly overcome practice to "unburden" families by an institutional placement of their children that lead to their social and educational exclusion. The main reason for that turnover from institutional care to community-based services is based on the fact that children function optimally in their families included in the community if they obtain proper support.

Families who take care of children with disabilities are exposed to challenges of intensive and demanding, sometimes lifelong, care. They could face discrimination and increased risk of socioeconomic difficulties, too [1–3]. While the children with severe difficulties were placed in institutions, the majority of families had to rely on their own resources and provide permanent care for child with (or often without) help of other family members. It was difficult to find qualified persons for childcare, and it was too expensive for most of those families. That is, the reason why mothers often have to leave their work and stay at home to take care of their child. Increased expenses for childcare and decreased income because one or even both parents are unemployed have been keeping those families in poverty. There were some daycare centers but only in several larger cities in Serbia.

Another difficulty for them is very slow process of inclusion of those children in education system. Legislation rules support children with disabilities to be enrolled into public schools, but there was a lot of resistance to that processes. Teachers or even parents were not prepared for adopting such changes. Teachers who are not trained lack special skills and knowledge to deal with those children. Struggling to harmonize their needs with needs of other children and requests of educational programs, teachers experience additional burden and often feel burnout due to "useless effort" [4]. Parents are usually afraid of social rejection and failure of children compared with their peers.

In the last decades, the services have been focused on the child's needs but also were oriented to provide support to families as well [5]. The family-centered approach is based on the holistic perspective, considering families as unique. Therefore, it was important to adjust the services to the family's specific needs and unique experience of how the fact of having a child with disabilities influences the whole family. It must be carefully considered what should be the individual aims of the service, anticipating possible impact of that support. In other words, it should be considered which kind of specific activities could contribute to the optimal outcomes, reducing negative and promoting positive effects for families and children [6, 7]. The service users used to be the "objects of intervention" that assumes passive reception of services with a little control over the process. Their position slowly evolves to partnership that includes participation in the process of needs assessment, planning, and decision-making in order to individualize the content and way of service provision to the greatest possible extent [8]. Families and service providers contribute together to decisions based on information about the available services, considering the strengths and needs of all family members [9]. This approach is based on the assumption that parents are competent and eligible partners who know their children best.

All services were intended to support the children to remain within the family environment promoting their inclusion in the local community and to help the family to deal with daily difficulties intending to improve their life quality. Those services include daycare centers, "respite" care, and assistance at home. Children should be provided with a stimulating experience that is based on the individual planning with the case manager and service provider, whether services are received at home or outside in daycare centers. Daycare centers are available every day, except weekends, usually 8 h. The children spend time in small groups, engaging in different games or other stimulating activities. Home assistance provides activities with child at home 2–4 h usually 2 days per week. During that time, parents have time for other obligations at home or outside or free time to reset, which is a significant help for them. Even if these services have been focused primarily at children needs, parents could benefit from getting some useful advices and support for everyday care, but it does not include structured parent training focused on parents' skills, strengthening their coping capacities, or improving their relation with the child.

The results of different studies confirm that support programs in the community, especially the ones focused on the family, increase parental self-confidence and competence, improve parental skills, or reduce parental stress [10–13].

One of the most important measures in verifying the effectiveness of different policies, programs, and treatments is the impact of services on the quality of life of family members who are taking care of children with different types of disabilities [1, 3, 14, 15].

Quality of life is a multidimensional construct that includes objective indicators and subjective evaluation of physical, financial, social, and emotional well-being [16]. Besides the objective indicators such as material well-being, living condition, health, employment, education, social security, etc., it is important to include personal subjective perception of well-being. Cognitive evaluation of personal life and emotional experience of more positive than negative effects are the basic components of subjective well-being [17]. Although it is important to discern how a person lives and functions, it is also important to understand how somebody feels and how they perceive their own life. One of the most important components of subjective well-being is not just individual experience but also social relations and integration. It is determined by the individual's perception of the effect of the social environment to personal benefit [6, 15].

According to the concept of general life quality, the family quality of life is defined as a valuable outcome of services and policies for children with disabilities and their families. It is important to emphasize that sometimes "child" is adult person who still needs help from his/her parents.

In the last few decades, there have been many studies about conceptualization and measurement of the quality of life of people with disabilities. Schalock et al. [18] defined eight domains of their quality: emotional well-being, interpersonal relations, financial well-being, personal development, physical well-being, self-determination, social inclusion, and disability-related rights.

The comparative studies of Brown and others [14] further contributed to the development of this theoretical concepts and its measurement. They included health, financial (material) well-being, family relationships, other people's support, services and staff support, caregivers and care tools, spiritual and cultural life, free time, and community involvement as key components of life quality.

Based on a qualitative study of families, Poston defined the nine domains of life quality [15], but later analyses supported the solution of final five domains of family life quality: family interaction, parenting, emotional well-being, physical/financial well-being, and disability-related support [19, 20].

It is obvious why the focus on life quality is so important for those families who sometimes feel overwhelmed by the increased demand for care and support for their children with disabilities facing with limited financial resources and environmental support in a long term [21]. Even if they are facing specific difficulties related to certain types and levels of disability, the results of numerous studies indicate that parents and other family members have a lot of common difficulties, concerns, and needs for support that reflect their quality of life.

2. Aims and method of the study

Based on those findings, we conducted the study to analyze the effects of community-based services for children with disabilities on the quality of life of their families [22]. We were interested to find out if there is any improvement in the general perception of family life quality after 1 year of using the services and in which specific domain of life quality the changes are the most significant. Also, it was interesting to explore who has benefitted from the services the most, based upon the level of family quality of life at the beginning of receiving services as well as upon the level of the severity of disability of the child.

We examined 153 parents of children with disabilities who participated in the study at the beginning of using services and 1 year later. The services were offered to families, no matter what their socioeconomic status or child's age or type of disability is. The parents were from different regions in Serbia, from rural and urban settings where services were offered. Most families used home assistance (55.6%), some of them used a daycare center (26.1%), and some used respite care (18.3%), which was sometimes combined with the other two services.

The data were collected by the Family Quality of Life Scale (FQOL), developed by Hoffman et al. [19]. The FQOL scale consists of 25 items that are grouped in five domains: (a) *family interaction* is a subscale that describes the quality of communication in the family, mutual support of family members, and the time they spent with each other; (b) *parenting* is a subscale that assesses a parental support to their children and feeling of closeness with them; (c) *emotional well-being* is a domain intended to evaluate the availability of social support from social environment, including extended family member and other people as an important stress regulator; (d) *physical/material well-being* is a subscale that measures the availability of various community services and the general feeling of security; and (e) *disability-related support* is a domain that evaluates the provision of specific external support for educational improvement, skills' development, and inclusion in community, including contacts with the service provider.

The "family interaction" and "parenting" domains represent subjective perception of "internal" family recourses, while the other three domains are related to the perception of external support available to the family and child that contributes to their quality of life. Of course, the external support could significantly affect the first two domains.

The reliability of the subscales of the FQOL in our sample ranged from 0.81 to 0.94, which is similar compared with other results in different cultures [19].

3. Results

First of all, our findings confirmed that most of the families had been facing a lot of difficulties in everyday life. The fact that half of the families (49.7%) had no income from employment was an important indicator of their financial difficulties, so their quality of life, besides the permanent care for child, was affected by poverty, too. Most mothers (66.7%) were unemployed, due to the necessity of staying at home for childcare, but over one third of fathers (37.9%) were unemployed, too. Both parents worked only in 15.8% of cases. One third of families (32.7%) had income below 200 euros per month, including social benefits. Almost half of the mothers (42%) and a quarter of the fathers (24.2%) had a low level of education (only 4–8 years of education) which diminishes possibilities for employment or finding a well-paid job. Obviously, they cannot afford some external help, except from extended family members when it is available.

Another factor that influenced life quality is the fact that one third of mothers are a single parent (33.1%). This is higher than the average rate of divorce in Serbia, particularly in rural areas where half of the parents from the sample have lived. It is well-known that difficulties like permanent care for a child could affect partner's relationship. The poverty and increased obligations at home could contribute to the social exclusion or isolation of the parents, particularly single one, and additionally interfere with their life quality.

Another factor that contributes to the lower level of life quality is the fact that almost one third of "children" (28.5%) were over the age of 18, which indicated prolonged, persistent, and sometime exhausting care for child. Most of those children

	Pretest		Posttest		F	dfb	dfw	sig.	η^2	d_{RM}
	M	SD	M	SD						
Family interaction	23.84	7.36	26.73	5.10	23.28	1	152	0.000	0.13	0.39
Parenting	22.89	7.01	26.18	5.14	27.58	1	152	0.000	0.15	0.42
Emotional well-being	13.00	4.87	15.53	4.31	27.77	1	152	0.000	0.15	0.43
Physical/material well-being	16.11	5.73	19.01	5.40	27.87	1	152	0.000	0.16	0.43
Disability-related support	14.98	4.94	17.25	3.34	27.31	1	152	0.000	0.15	0.42
Family quality of life total score	90.82	24.07	104.71	18.83	39.70	1	152	0.000	0.21	0.51

Table 1.
Analysis of variance with repeated measures on the FQOL scale (N = 153).

(44.2%) had multiple disabilities, and according to the criteria based on the required additional support [23], 35.3% of them had severe or profound disabilities.

The family life quality was measured at the beginning and 1 year after using services for the child at home or in the daycare centers. The perception of families' life quality confirmed positive significant changes in general life quality, as well as positive changes in all domains of life quality (**Table 1**).

The association between specific services (daycare center, assistance in the home, and respite care) and changes in family's quality of life showed that there were no significant differences between the families who had been using different types of services ($F(2, 150) = 1.03$, $p = 0.361$). The life quality was improved after 1 year of using service regardless of the type of services ([22], p. 5).

We were interested in understanding not just *what* has been changed but also *who* has been changed the most or who has not experienced changes at all, depending on the level of family quality of life at the beginning of receiving services. Therefore, we divided sample on three groups with high (33.3%), middle (31.4%), and low (35.3%) quality of life (by LCA). Analysis of variance shows that there is a strong interaction effect between level of family quality of life at the beginning of service provision and effect of service provision to the family quality of life after 1 year ($F(2, 150) = 38.12$; $p < 000$, $\eta^2 = 0.34$). The perceived quality of life increased the most in the families who had the lowest scores at the FQOL scale at the beginning of using the services (**Figure 1**). On the other hand, the group that perceived the quality of their life very high at the beginning of service did not improve or in some cases even slightly decreased.

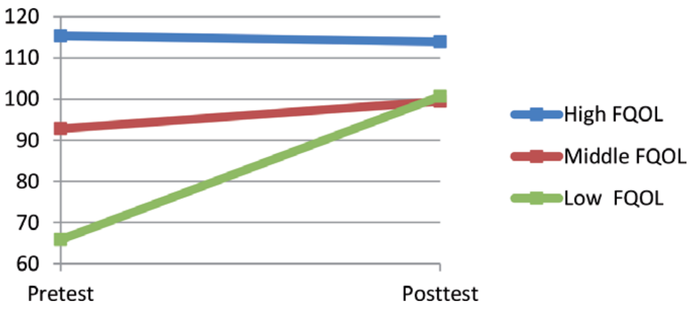

Figure 1.
Changes in the FQOL of groups based on the level of quality of life before services.

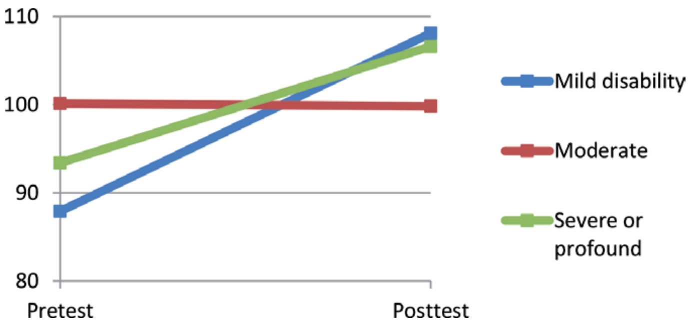

Figure 2.
Changes in the FQOL according the level of child disability.

Also, in order to understand who has been improving depending on the level of severity of child disability, we compared the three groups of families with mild, moderate, and severe disability. Analysis of variance showed that there is an interaction effect between level of severity of disability and effect of service provision regarding family quality of life ($F(2, 133) = 4.63$; $p = 0.011$, $\eta^2 = 0.07$). The most significant improvement of life quality was obtained in the families with children with mild disabilities. The families with children with severe or profound disability significantly improved, too, but for the group with the children with moderate disability, there was no evidence of positive effect of services (**Figure 2**). At the same time, they had the highest level of the FQOL at the beginning.

Although the differences of pretest level of life quality among the groups were not significantly different, it is interesting to notice that the families with children with a mild disability have the lowest quality of life before services. At the same time, there is significantly higher percentage of single-parent families (43.1%) in this group comparing to families with children with moderate (34.8%) and severe disability ((20.8%), $\chi^2(2, N = 134) = 6.32$, $p = 0.042$, Cramer's V is .22) ([22], p. 5). Also, those families mostly live in rural areas (58.6%) where external support is less available ($\chi^2(4, N = 136) = 12.67$, $p = 0.013$, Cramer's V is .22).

The results showed that there is no interaction effect between age of child and effect of service provision regarding family quality of life ($F(3, 137) = 0.37$; $p = 0.776$).

4. Discussion

According our main goals that were to explore whether there have been improvements in the perception of different aspects of family life quality, it was expected that, after a year of using services, improvement was reflected in aspects of the quality of life on which the services had direct impact. The results of the study confirmed that expectations. Besides the general improvement of life quality, the changes were evident in the domains that initially had the lowest scores—material well-being, emotional well-being, and disability-related support. Those domains are mostly dependent on the services that were designed to affect these specific aspects of the family life quality.

Although the services were not particularly focused on communication and relations among family members, nor at the parenting practices, there was improvement in these domains, too. It seems that the services affected them indirectly. When families get more external support, they could experience some relief that might contribute to the improvement of interpersonal relations between parents, as well as to their parenting. It is interesting to emphasize that *family interaction* and *parenting* were initially rated higher. Those domains have important role as internal family strengths in dealing with the everyday problems related to childcare in the context of a lack of external support. That is supported by other authors [24] who emphasized that the quality of life is dependent on establishing and maintaining a harmonious relationship within the family members and with external environment.

Results showed that the life quality was improved regardless of the type of services. We could assume that type of service would specifically contribute to different aspects of life quality, but any kind of proper support has an impact on positive changes in general. According to the systemic approach, the family is a dynamic system, so the change in some domain influences other domains and reflects improvement of system as a whole. For example, during home assistance services, parents were usually present, and they can observe the activities and interactions between the child assistant and child. That could contribute to improvement of parenting skills (how to stimulate child, play with him/her, etc.). On the other hand, daycare service could be more useful for child socialization, where children have opportunity to play and communicate with other children or adults and spend some time out of home. Those observations were confirmed through interviews with parents. But any positive change in some aspect reflects on other aspects of family life and their perception of child improvement.

We were also interested to find out who benefited from the services the most based upon initial level of life quality and severity of child disability. The results indicated that the quality of life improved the most in the families who had the lowest scores on the FQOL at the beginning of services. It is important to notice that the effects of services are the best for the families that needed them the most. On the other hand, the changes were not significant in the group who had higher scores on the FQOL before service use. Although particular progress was not expected among those who were already satisfied with their quality of life, this does not mean that they do not face difficulties and does not imply that they do not need any services. But it is also important to notice that their level of FOQL even decreased slightly (although not significantly). These findings suggest that, when designing community-based services, it is important to respond differently to the specific needs of families and tailor service to them individually. The question is what specific service they really need and how should it be provided. If the services strongly contribute to the improvement of life quality for families who needed them the most, that means that other families need something different. The practice of social work still has a lot to learn from families how they are facing difficulties, and, in that respect, it is important to assess family strengths and ways of adaptation to those persistent difficulties. It is necessary to flexibly adapt service support to them without minimizing their personal competencies. Probably, in the cases where we noticed a slight reduction of life quality after using services, parents could experience disregard of their coping skills or homeostatic balance. If they get what they might need and do not get what they did not ask for, it could be more helpful for them and will not be wasting the time and resources of families and service providers.

Our findings confirmed that the level of disability has impact to the quality of family life. The permanent care for the child with severe disability is often additionally burdened by poverty, which is much more challenging and might lead to physical and emotional exhaustion. Those families experienced significant benefit from services regarding life quality, too, although the level of progress is limited. But, it is interesting to notice that families who have a child with mild disability and experienced a lower level of life quality at the beginning of services compared to the other families who have children with moderate or severe disability progressed the most. Needs of those families and their children could be neglected from the service providers (assessed as "easier cases" who are not the priority of system's support), so the external support is less available to them. Also, there is significantly higher percentage of single-parent families (43.1%) among that group than the other two groups. This finding is in accordance with our previous study that confirmed higher divorce rate in families who have child with less severe disability [25]. Less possibility of sharing care and obligations could contribute more pressure and lower life quality for a single parent. In comparison with parents who share efforts together and who get more external support, it seems reasonable to expect that it contributes to their lower level of life quality. So, when they get some external help, they progress the most.

But how could we explain that the parents of a child with severe or moderate disability have fewer divorces rate and experience higher life quality? Do the difficulties of everyday life contribute to them staying together, uniting their efforts, and relying on each other, which they can appreciate as an important part of their life quality? It should be the explored in future studies.

There is a lot of evidence that the age of the disabled person contributes to caregiver burden [26–28]; however, we did not confirm that prolonged and permanent care for the child contributes to lower life quality. It seems that there is a different experience of difficulties of the caregiver in parent-child (even grown-up child) relationships, than in other form of relations between caregivers (family member, but not parent) and adults with disability. Probably they develop some coping strategies and adaptation skills over time that diminishes the potentially negative effect of perennial care to their life quality. Parents with older children could be exhausted, but adapted and skillful, while families with younger children may still struggle with difficulties of acceptance of the child difficulties and the new organization of their life. It seems that each phase has specific challenges.

Besides the benefits of services, there are still a lot of problems that should be kept in mind during planning and establishing new services. First of all, there is a problem of sustainability of implemented services. That means that the service which had been provided for a while, without permanent support of local community, could be discontinued after the termination of project financial support. It may have impact to diminishing life quality, even to the lower level then before services had implemented. There were no monitoring or evaluations studies of those effects if families that faced with restriction of support on which they used on.

The other risk is that the services have been offered to all who might need them without careful assessment what exactly they need. The diversity of services had not yet been worked out or individualized according to specific family's needs, and they depended more on service providers' personal skills and resources. So, that increases the chances of imposing something that is not suitable (best fit) for service users. Anyway, the availability of support of the services contributes to positive change much more that that could damage it.

Most studies have confirmed that quality of life is a multidimensional construct [14, 15, 18, 24, 27]. Therefore, it would be useful to explore mutual influences of objective and subjective factors that play a role in life quality such as parents' age, gender, health condition, attitudes, spiritual beliefs, level of stress, coping strategies, skills, social and family networks, etc. That would be a very helpful information for creating services, as well as for creating criteria to be used for them.

The importance of service evaluation has been highlighted in the last decade in Serbia. This requires the development of standardized and reliable instruments for the evaluation of the effects of services, which can measure specific aspects of the services. This would enable researchers to explore and understand what are the most helpful or effective aspects of service provision. That could provide useful information for researchers and policy makers, as well as for practitioners and service users.

The study confirmed benefits of community-based services to the family life quality, exploring some specific aspects and range of change, as well as the influence of level of child disability and previous perception of life quality to the extent of change. Unfortunately, there are still a large number of socially excluded families who live in poor communities that had no chance to use the services and experience an improvement in their quality of life. Social workers still have difficulties in providing sustainable services, which need to be overcome in the future. Meanwhile, the results of this study might be useful for planning further steps in developing and evaluating community services for children with disabilities and their parents who should receive flexible and individually tailored service that suits their specific needs best.

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References

[1] Dunst CJ, Trivette CM, Hamby DW. Family Support Program Quality and Parent, Family and Child Benefits. Asheville, NC: Winterberry Press; 2006

[2] Hughes R. An investigation of coping skills of parents of children with disabilities. Education and Training in Mental Retardation and Developmental Disabilities. 1999;**34**:271-280

[3] Turnbull AP, Turnbull HR, Erwin E, Soodak L. Families, Professionals, and Exceptionality: Positive Outcomes through Partnerships and Trust. 5th ed. Upper Saddle River, NJ: Merrill/Prentice Hal; 2007

[4] Jovanović V, Karić J, Mihajlović G, Džamonja-Ignjatović T, Hinić D. Work-related burnout syndrome in special education teachers working with children with developmental disorders—Possible correlations with some socio-demographic aspects and assertiveness. European Journal of Special Needs Education. 2019. DOI: 10.1080/08856257.2019.1572092

[5] Turnbull HR, Beegle G, Stowe MJ. The core concepts of disability policy affecting families who have children with disabilities. Journal of Disability Policy Studies. 2001;**12**:133-143

[6] Samuel PS, Rillotta F, Brown I. The development of family quality of life concepts and measures. Journal of Intellectual Disability Research. 2012;**56**:1-16

[7] Summers JA, Poston DJ, Turnbull AP, Marquis J, Hoffman L, Mannan H, et al. Conceptualizing and measuring family quality of life. Journal of Intellectual Disability Research. 2005;**49**:777-783

[8] King GA, Teplicky R, King G, Rosenbaum PL. Family-centered service for children with cerebral palsy and their families: A review of literature. Seminars in Pediatric Neurology. 2004;**11**:78-86

[9] Law M, Hanna S, King G, Hurley P, King S, Kertoy M, et al. Factors affecting family-centered service delivery for children with disabilities. Child: Care, Health and Development. 2003;**29**:357-366

[10] Dunst CJ, Trivette CM, Hamby DW. Meta-analysis of family-centered helpgiving practices research. Mental Retardation and Developmental Disabilities Research Reviews. 2007;**13**:370-378

[11] Emerson E, Fujiura GT, Hatton C. International perspectives. In: Odom SL, Horner RH, Snell M, Blacher J, editors. Handbook on Developmental Disabilities. New York: Guilford Press; 2006

[12] Emerson E, Barron DA, Blacher J, Brehmer B, Clinch S, Davidson PW, et al. Better Health, Better Lives: Research Priorities. Copenhagen: WHO European Regional Office; 2012. Available from: http://www.euro.who.int/data/assets/pdf_file/0018/174411/e96676.pdf [Accessed: 12 September 2014]

[13] Gabovitch EM, Curtin C. Family-centered care for children with autism spectrum disorders: A review. Marriage & Family Review. 2009;**45**:469-498

[14] Brown RI, MacAdam-Crisp J, Wang M, Iarocci G. Family quality of life when there is a child with a developmental disability. Journal of Policy and Practice in Intellectual Disabilities. 2006;**3**:238-246

[15] Poston D, Turnbull A, Park J, Mannan H, Marquis J, Wang M. Family quality of life outcomes: A qualitative inquiry launching a long-term

research program. Mental Retardation. 2003;**4**:313-328

[16] Falce D, Perry J. Quality of life: Its definition and measurement. Research in Developmental Disabilities. 1995;**16**:51-74

[17] Diener W, Ryan K. Subjective well-being: A general overview. South Africa Journal of Psychology. 2009;**39**(4):391-406

[18] Schalock RL, Brown I, Brown R, Cummins RA, Felce D, Matikka L, et al. Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. Mental Retardation. 2002;**6**:457-470

[19] Hoffman L, Marquis J, Poston D, Summers AJ, Turnbull A. Assessing family outcomes: Psychometric evaluation of the beach center family quality of life scale. Journal of Marriage and Family. 2006;**68**:1069-1083

[20] Park J, Hoffman L, Marquis J, Turnbull AP, Poston D, Mannan H, et al. Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. Journal of Intellectual Disability Research. 2003;**47**:367-384

[21] Baker-Ericzén MJ, Brookman-Frazee L, Stahmer A. Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. Research and Practice for Persons with Severe Disabilities. 2005;**30**:194-204

[22] Dzamonja Ignjatovic T, Milanovic M, Zegarac N. How services for children with disabilities in Serbia affect the quality of life of their families. Research in Developmental Disabilities. 2017;**68C**(2017):1-8

[23] Decision on the Criteria for Disaggregating the Children with Developmental Disabilities and on the Method of Work of Commissions in Charge of Examining the Children with Disabilities, The Official Gazette of the SRS, 16/86

[24] Albrecht LG, Devlieger JP. The disability paradox: High quality of life against all odds. Social Science & Medicine. 1999;**48**(8):977-988

[25] Dzamonja Ignjatovic T. Handbook of the Health Psychology. Belgrade: Excelsior; 2005

[26] Avolio M, Montagnoli S, Marino M, Basso D, Furia G, Ricciardi W, et al. Factors influencing quality of life for disabled and nondisabled elderly population: The results of a multiple correspondence analysis. Current Gerontology and Geriatrics Research. 2013;6:Article ID 258274. DOI: 10.1155/2013/258274

[27] McCullagh E, Brigstocke G, Donaldson N, Karla L. Determinants of caregiving burden and quality of life in caregivers of stroke. Stroke. 2005;**36**:2181-2186

[28] Ra YA, Kim WH. Impact of employment and age on quality of life of individuals with disabilities: A multilevel analysis. Rehabilitation Counseling Bulletin. 2016;**59**(2):112-120

Chapter 11

Socioeconomic and Demographic Characteristics of Living Conditions of Elderly Quilombolas from Maranhão, Northeast Region, Brazil

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Abstract

The elderly from Quilombola communities are groups socially vulnerable with specific needs. Quilombola communities are territories made up of descendants of escaped slaves, located in remote rural areas. This study aims to describe the socioeconomic, sanitary, and demographic characteristics of the living conditions of the elderly. A household survey was conducted with 208 older persons from 11 Quilombola communities in the Maranhão, Northeast, Brazil. Among the 208 elderly people interviewed, 54.3% were women, 48.6% were between 60 and 69 years old, 59.1% declared themselves black, 35.6% were married, and 54.3% did not know how to read and write. About 81% of the elderly are in the worst income stratum. Among 59.6% of households, the water supply comes from a well/spring on the property itself, and garbage was burned/buried in 89.4% of the houses. In overall, housing construction, 64.4% of the elderly had appropriate materials used on the walls, 89.9% in the construction of the roof, and only 30.7% in the construction of the floor. The majority of the elderly did not have adequate construction of ceiling, floor, and walls according to sex and age. It was observed that the elderly live in a situation of vulnerability and precarious living conditions.

Keywords: older persons, life conditions, groups of African descent, health surveys

1. Introduction

Brazil is a country known for its wide cultural variety, and although most of its inhabitants have black African descendants, the suppression of their ethnic and cultural values is present, preventing this group from exercising its right to full citizenship, including access to health services and good quality of life, even though it is legally insured. In this context, there are the remnants of Quilombola communities existing in several Brazilian regions [1].

The Brazilian black population's historical trajectory shows that these individuals have been seeking better living and health conditions through social struggles, which allowed them to achieve some social rights: the universal right to health and social participation. However, in order to address social inequalities, it is necessary to reduce the level of poverty, as well as to enable a more equitable distribution of goods and services that allow achieving the well-being and quality of life [2].

On February 7, 2007, the *Política Nacional de Desenvolvimento Sustentável dos Povos e Comunidades Tradicionais* was instituted, by Decree No. 6040. According to it, these people and communities are understood as culturally differentiated groups that recognize themselves as such, which have characteristic forms of social grouping, and that, through traditionally generated knowledge and practices, use territories and natural resources as a condition for reproducing their cultural framework [3].

Quilombola communities are examples of social groups that constitute traditional communities [4]. These represent approximately 5 million Brazilians. Due to their historical characteristics of fighting racial discrimination and specific conditions of poverty and inequality, they live in relative geographic isolation and have little access to governmental public policies, factors that make them more socioeconomically vulnerable [4].

According to the Brazilian legislation (Decree No. 4887, November 20, 2003), Quilombola communities are groups according to criteria of self-attribution, which have a historical trajectory, with a presumption of black ancestry related to the resistance to the historical oppression suffered. They are socially more vulnerable and have a predominantly rural geographical position [5]. The Palmares Cultural Foundation has been responsible for the recognition and certification of communities [6].

According to Law 7668, from Brazilian Government, the Palmares Cultural Foundation was created on August 22, 1988, linked to the Ministry of Culture in order to promote the preservation of cultural, social, and economic values arising from the black influence in the formation of Brazilian society [7].

There are almost 2 million people living in about 2997 Quilombola communities that are certified by the Palmares Foundation. Officially recognized Quilombola communities are found across all regions of Brazil. Their geographical distribution is related to the racial formation process and settlement policy implemented during the period of Portuguese colonization (from the discovery of the country in 1500 to independence in 1822) and the imperial governments (from independence in 1822 to the abolition of slavery in 1888 and subsequent emergence of the Republic in 1889). The majority of Quilombola communities are concentrated in the country's Northeast Region (63%) [8]. So, the distribution of these communities among the regions of Brazil reflects the structure of occupation and territorial exploitation made by the Portuguese crown during the colonization process. The great flow of enslaved black labor was concentrated in the Northeast Region of the country.

In the northeast of Brazil, there are 2061 Quilombos Remnant Communities (CRQ) certified by the Palmares Foundation (until May 2019) distributed among the federative units of this region: Bahia, 801 (38.8%) CRQs; Maranhão, 787 (38.2%) CRQs; Pernambuco, 161 (7.8%) CRQs; Piauí, 87 (4.2%) CRQs; Alagoas, 69 (3.3%); Ceará, 50 (2.4%) CRQs; Paraíba, 41 (1.9%) CRQs; Sergipe, 36 (1.7%) CRQs; and Rio Grande do Norte, 29 (1.4%) CRQs [9].

The *Baixada Maranhense* region has historically been home to a large number of Quilombola communities since the second half of the nineteenth century and currently represents one of the state's regions with the largest number of remaining Quilombola communities [10].

2. Aging and Quilombola communities in Brazil

Population aging is a global phenomenon and is strongly linked to socioeconomic and health status, lifestyle, and social and health behaviors. In Brazil, several population surveys with the elderly have shown that there are important inequalities in this group in their quality of life and health, being inequalities in the living conditions and health status of older persons particularly more pronounced among vulnerable groups living in remote area, such as older persons living in Quilombola communities [8].

In Brazil, initiatives related to the well-being of the elderly population are still scarce. Although the concept of quality of life has an extensive field of variability between population groups, the promotion of good physical, mental, and emotional health should always be encouraged, as it is known that with advancing age, health problems in overall tend to increase [8, 11].

The aging of the Brazilian population, characterized by the increase of the average age of the individuals, is evidenced (comparing the data from the censuses of the year 2000 and the year 2010) by the decrease of the population growth (in the urban and rural areas) and by the increase of the proportion of people aged 60 and older. Maranhão showed the largest reduction in population growth in urban areas when comparing the two periods: in the 2000 census, the growth rate was 6.1% and in the 2010 census, 2.1%, which corresponds to a decrease of 67.5% [12, 13].

Regarding the increase in the proportion of the population over 60, comparing the census data from 2000 to 2010, there was an increase of 41.6%. Also, when comparing the data from these same periods, there was an increase of 30.6% in the individuals who declared themselves white, 57% for those who declared themselves as part of the black population, 124.6% for yellow population, 60.8% for brown-skinned population, and 6.8% for those classified as indigenous [12–14].

Over the years, Quilombola communities face obstacles and struggles for ethnic-cultural and historical recognition. Among the problems faced are racial prejudice, territorial losses to irregular occupations, insufficient family income, extreme poverty, and ineffective health services [1].

The literature on the quality of life and living conditions of the Quilombola population in the country is scarce, and the existing data are mostly directed to those located mainly in Bahia, whose results show that this population group lives in a vulnerable situation and has less access to goods and services [15].

The interest in this research is due to the identification of the reality faced and the sociodemographic and epidemiological problems in the studied communities and how it can possibly contribute to the planning and development of policies and actions that take into account the social, political, and environmental context of these communities.

This research is perceived as fundamental because it allows the population and the public power to develop strategies that effectively meet the many needs of the Quilombos Remnant Communities recognized by the Palmares Foundation and located in the municipality of Bequimão.

As it is a historically abated population and for generations it has suffered the absence of social investments to improve their living and health conditions, it is expected that the results of this study point to the health reality of the Quilombola elderly and that this is marked by a set of vulnerabilities and socioeconomic needs.

Thus, this study aims to describe the socioeconomic, sanitary, and demographic characteristics of living conditions of the elderly in Quilombola communities in a city of Baixada Maranhense region.

3. Methodology

3.1 Study area and population

This study is part of the project *Population Survey on Living and Health Conditions of the Quilombola Elderly from a City of Baixada Maranhense* (IQUIBEQ Project). This is a cross-sectional, home-based study conducted in 11 CRQs in the municipality of Bequimão, MA. All 11 Quilombola communities are officially recognized as remnants of blacks who escaped slavery by the Palmares Cultural Foundation and the Ministry of Culture (**Figure 1**).

The municipality of Bequimão is inserted in the northern mesoregion and microregion of Maranhense Western Baixada. Geographically, it is located by the edge of the MA-211 road, at a point equidistant from the São Luís capital and the Federal University of Maranhão Campus located in the city of Pinheiro, MA. In 2010, the total area of the municipality of Bequimão was 761.49 km^2, and the census population was 20,344 inhabitants (67.5% in the rural area and 12.3% elderly). The Human Development Index (HDI)[1] was 0.601, and the gross domestic product per capita was R$ 2754.37 [17]. The Palmares Foundation recognizes and certifies 11 CRQs: Rio Grande, Ramal de Quindiua, Conceição, Mafra, Santa Rita, Juraraitá, Marajá, Pericumã, Siberia, Sassuy, and Ariquipá [9].

The study population consisted of elderly people ≥ 60 years old living in the communities. These were selected from the articulation with the Municipal Secretary of Social Assistance and the Community Health Agents (*Agentes Comunitários de Saúde*, ACS) of the respective communities. The ACS conducted a previous survey and built a nominal list with information on gender and date of birth, accounting for 220 elderly. All of these were invited to participate in the research, but after refusals and difficulties to find the elderly in the community in two attempts on different dates, the final population consisted of 208 elderly.

The data collection was carried out on weekdays during commercial hours between July and October 2018. A pilot study was performed to adjust the instruments and train the interviewers. During the collection, the interviewees could consult a manual to clarify doubts, besides being accompanied by the researchers responsible for the research.

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[1] The HDI is a social index. It is composed of the agglutination of three previous simple indicators (longevity, income, and education). The use of this indicator in the analysis of living and health conditions is justified due to the simplicity and capacity of these indices to synthesize situations in which whether you need to have a general comparative assessment of well-being, quality of life, or level of socioeconomic status of human collectivities, while allowing them to orient themselves more objectively, and the prioritization of resources and actions of social and health policies for different places [16]. This indicator can take any value between 0 (zero) and 1 (one). The HDI measures the level of human development. Cities can be classified into below HDI (<0.5), medium HDI (0.5 and 0.8), or high HDI (>0.8) [16].

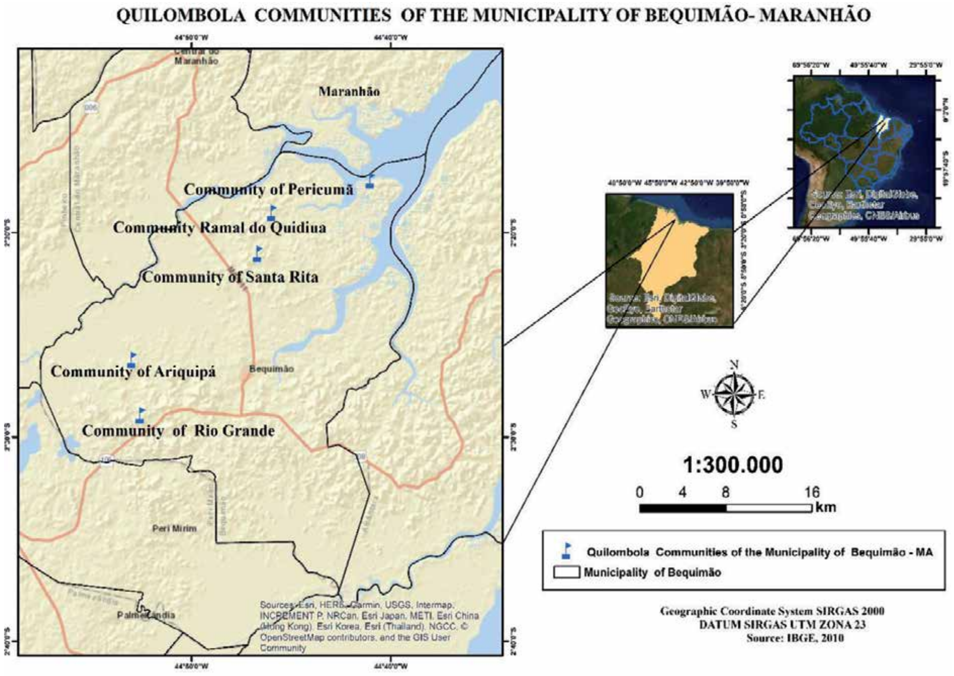

Figure 1.
Geographic localization of Quilombola communities in Bequimão, Maranhão, Brazil, 2018.

3.2 Data collection and research instruments

Four questionnaires were applied: a socioeconomic one; one on the population's health conditions, access to and use of health services, and surveillance for noncommunicable chronic diseases and the associated risk factors; a questionnaire on dietary patterns and anthropometry; and the Mini-Mental State Examination (MMSE). The first two were adapted from the 2013 National Health Survey (*Pesquisa Nacional de Saúde*, PNS) questionnaire.

For this study, only the data obtained from the first questionnaire were used, using the following variables: gender; age; race/skin color; marital status; number of residents per household; ability to read and write; family income in reais (R$); economic stratum according to social class by the New Criteria Brazil (ABEP) of the year 2018 [18]; receipt of retirement/pension benefit; *bolsa família* benefit; appropriate material used in the construction of the wall (masonry with or without coating), roof (tile, slab), and floor (ceramic, cement); number of rooms; water supply; drinking water treatment; and sewage.

3.3 Inclusion and exclusion criteria

The study included individuals ≥60 years old of both sexes and resident in the communities certified by the Palmares Foundation in the municipality of Bequimão and who were able to communicate with the interviewer. Those who are <60 years of age, with inability to communicate with the interviewer, and those with impaired cognitive function were excluded from the study.

3.4 Data analysis

After collection, data were entered into an Epi Info version 7® statistical program with double data entry technique. Data were then analyzed using the Stata®

version 14 program (StataCorp LP, College Station, Texas, United States). The absolute and relative frequencies of the variables considered in the study were estimated.

3.5 Ethical considerations

The research was approved by the Research Ethics Committee of the University Hospital of UFMA (favorable opinion: 2,476,488 of January 28, 2018), and all participants signed the informed consent form prior to collection.

4. Results

Among 11 CRQs, 208 seniors were interviewed. **Table 1** shows this data. Among these, 54.3% were women, 48.6% were between 60 and 69 years old, and 19.2% were ≥80 years old. Regarding race/skin color, 59.1% declared themselves to be black and 28.9% brown, and 12.0% were classified in other racial groups. The data on marital status indicated that 35.6% are married or have a stable union; 13.5% said they were separated, unmarried, or divorced; and 25% were widowed.

Regarding education 54.3% could not read and write. Most (57.7%) lived with ≥3 people at home and 15.4% lived alone. About 36.0% had family income of less than 1 minimum wage, and 63.9% had income between 1 and 2 minimum wages. Regarding the socioeconomic strata, no elderly were classified in social strata A and B. Most of the elderly were in stratum E (81.3%), 91.8% reported receiving retirement or pension benefits, and 6.7% received *bolsa família*.

Water was supplied by a well or river on the property (59.6%), and only 68.7% had proper water treatment at home. Regarding household toilets, 56.7% have access to a septic tank to dispose dejects, and 14.9% have to do it in the open. Most of the elderly burned household waste (89.4%).

Most resided in four- to seven-room households (68.3%), with 64.4% of the elderly having appropriate material used in the construction of their home walls, 89.9% being constructed of appropriate roofing materials, and only 30.7% had appropriate floor construction material.

Figure 2 presents the housing conditions and suitability, considering simultaneously the quality of the material used in the construction of the ceiling, walls, and floor of the houses according to the gender and age of the Quilombola elderly.

The proportion of elderly people residing in households considered inappropriate in relation to the material used in the construction of houses was higher at the extremes of age, reaching the highest prevalence among men aged 60–69 years (88.5%) and ≥80 years (92.9%) and women 67.3% and 65.4% at their respective ages, suggesting a growing gradient of worsening material living conditions.

The highest percentages of houses with roofs, walls, and floors built with appropriate material were in the age group of 70–79 years, for both sexes—36.8% of the houses belonging to women and 44.8% of those belonging to men were inadequate.

Most of the elderly live in households with low amount of appliances. The number of electronic equipment in homes is an important indicator of the infrastructure for the quality of home life. Around 53.0% of the elderly lived in homes with up to two appliances, 75.0% with up to three, and 95.7% with up to five. Only 0.5% lived in households with 10 appliances (**Figure 3**).

Variáveis	**(N = 208)**	**%**
Sex		
Male	95	45.7
Female	113	54.3
Age bracket (years)		
60–69	101	48.6
70–79	67	32.2
≥80	40	19.2
Skin color/race		
Blacks	123	59.1
Browns	60	28.9
Others	25	12.0
Marital situation		
Married	74	35.6
Separate/divorced	28	13.5
Widower	52	25.0
Single	54	25.9
Can read and white		
Yes	95	45.7
No	113	54.3
Number of residents per household		
Only	32	15.4
Two	56	26.9
Three or more	120	57.7
Household income at minimum wage 954.00 (in reais)		
<1 minimum wage	75	36.1
1 and 2 minimum wage	133	63.9
*Stratum socioeconomic**		
C	4	1.9
D	35	16.8
E	169	81.3
Receive benefits from		
Retirement/pensions	191	91.8
Bolsa família	14	6.7
Number of rooms per household		
≤3	4	1.9
4–7	142	68.3
≥8	62	29.8
Suitable material used in the construction of		
Walls	134	64.4
Roof	187	89.9

Variáveis	**(N = 208)**	**%**
Floor	64	30.7
Water supply		
General network	37	17.8
Well or river on the property	124	59.6
Well or river outside the property	45	21.6
Other ways	2	1.0
Home water treatment		
Appropriate	143	68.7
Not appropriate	65	31.3
Destination of sewage from bathrooms/toilets at home		
Septic tank to dispose dejects	118	56.7
Rudimentary septic tank	59	28.4
Sewer dumped on public road	31	14.9
Waste collection forms		
Dumped on public roads	22	10.6
Burnt/buried	186	89.4

**There were no elderly in social strata A and B.*

Table 1.
Socioeconomic, demographic, and health characteristics of Quilombola elderly people ≥60 years old, Bequimão (IQUIBEQ Project), Maranhão, Brazil, 2018.

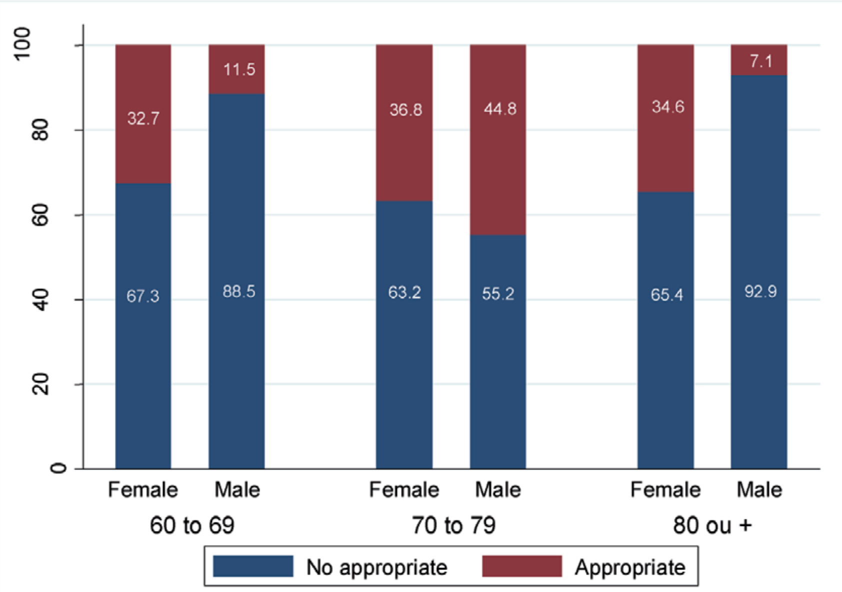

Figure 2.
Adequate housing condition of ceiling, floor, and walls simultaneously according to gender and age of Quilombola elderly ≥60 years, Bequimão (IQUIBEQ Project), Maranhão, Brazil, 2018.

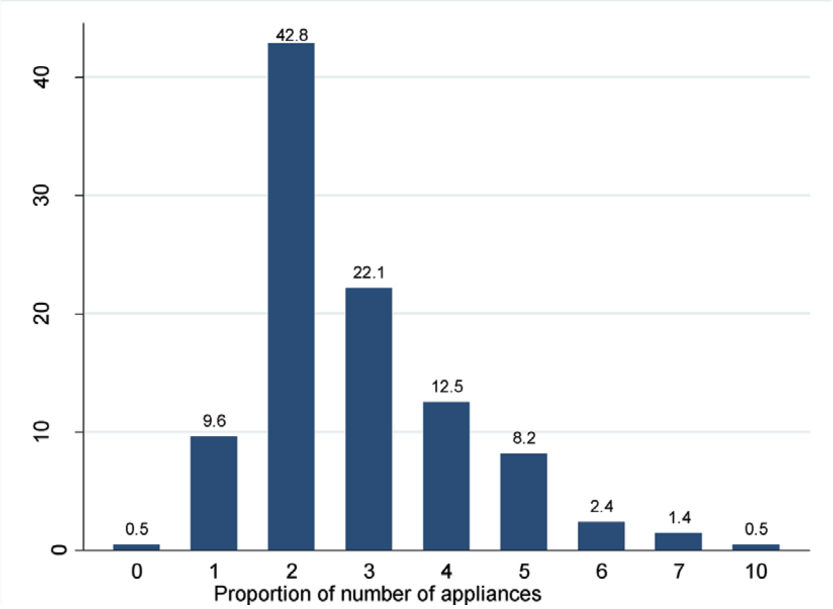

Figure 3.
Proportion of the number of appliances in homes of Quilombola elderly people ≥60 years old, Bequimão (IQUIBEQ Project), Maranhão, Brazil, 2018.

5. Discussion

The results of this study show that older Quilombolas experience significant overlapping inequalities and vulnerabilities, characterized by poor socioeconomic status and inadequate household and community sanitation facilities.

Previous studies have shown that older brown and black people in Brazil are disadvantaged in terms of socioeconomic and demographic indicators too [11, 19]. This picture tends to be worse for older black persons living in rural areas. These stark inequalities are deeply woven into the fabric of society. Ever since the period of slavery to the present day, the material conditions of life and health of black people have been worse than those of white people. Typically located in rural areas, Quilombola communities tend to be isolated, increasing their level of exposure inequalities. Historical processes of racial segregation and discrimination have meant that these communities have accumulated disadvantages across life cycles and generations [8].

The aging of the Brazilian population is marked by different rhythms and flows, constituting heterogeneous processes. According to the projections of the Brazilian Institute of Geography and Statistics (IBGE) (2013), by 2042 in Brazil, the number of deaths will have exceeded the number of live births, thus stopping the growth of the Brazilian population. By 2060, estimates indicate that the cohort aged 65 and over is expected to be 26.7% (58.4 million) and life expectancy will approach 81 years [20].

Following this panorama and the gradual prolongation of longevity, the topics and themes related to old age in communities located in remote areas such as Quilombola communities have become privileged objects of investigation in different areas of knowledge, bringing paradoxes, challenges, and dilemmas about public policy to emerge. In the general elderly population, according to the data from the 2000

Population Census, for example, there were gender differences in the aging process, as more than 55% of the population aged 60 and over were women, and this number increases proportionally to the age cohort. This phenomenon was called the "feminization of aging" and brings up discussions about gender experiences to gerontology [21].

Other aspects that exacerbate the differences in the aging process of the Brazilian population are the inequalities between rural and urban areas. Similar to other studies, our results indicate that the indicators present a rural reality in which poverty, geographic isolation, low educational levels, precarious residences, transportation limitations, chronic health problems, and distance from social and health resources in urban centers predominate. This reality is the result of a historical process of inequalities associated with the social and regional development project in the country, which is rooted in the process of discrimination, stigma, and enslavement of the black and brown population, often poorer and poorly educated [22].

In this way, studies reveal that the variable *race/ethnicity* corroborates profound differences regarding the composition of sociodemographic indicators, health conditions, and use and access to health services in the Brazilian elderly population [23]. Black and brown elderly compared to white elderly predominate in the younger age groups (60–69 years), with high dependence exclusively on public health services, less education, and lower income quintile, and live in areas with worse social and health indicators in the country [11].

Quilombola communities are expressions of resistance to the history of social exclusion suffered by black people in Brazil. They are made up of descendants of people who were enslaved and organized into quilombos, spaces that allow the expression of traditional values and practices, based on African ancestry. In these communities, racial inequities translate into vulnerabilities that contribute to the maintenance of material misery, restriction of political participation, and spatial and social isolation.

6. Conclusions

With this research it was possible to identify the sociodemographic, health, and demographic characteristics of the elderly being interviewed. They represent a social group whose majority are self-declared black; are unable to read and write; have a family income of 1–2 minimum wages, most receive retirement and pension; and are characterized as part of the E socioeconomic stratum. Sanitary and housing conditions are inadequate, lacking a general water supply, adequate garbage collection, and better household and community material conditions.

The findings of this study suggest that the living conditions and health status of this population group are poor and worse than those experienced by the general older population in Brazil, revealing the need for effective actions to reduce the inequalities and weaknesses that jeopardize the well-being and quality of life of this group. Major efforts are urgently needed to promote the health and well-being of older Quilombolas in order to meet the needs and reduce the health inequalities identified by this study.

Then, the problems identified may guide the planning of actions consistent with the reality experienced by this population and the implementation of measures that may improve the socioeconomic conditions of Quilombolas.

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References

[1] Freitas IA, Rodrigues IL, Silva IFS, Nogueira LMV. Perfil sociodemográfico e epidemiológico de uma comunidade quilombola na Amazonia Brasileira. Revista Cuidarte. 2018;**9**(2):2187-2200. Available from: http://dx.doi.org/10.15649/cuidarte.v9i2.521 [Accessed: 05 April 2019]

[2] Santos VC, Boery EN, Pereira R, et al. Condições socioeconômicas e de saúde associadas a qualidade de vida de idosos quilombolas. Texto Contexto Enfermagem. 2016;**25**(2). Available from: http://www.scielo.br/pdf/tce/v25n2/pt_0104-0707-tce-25-02-1300015.pdf [Accessed: 31 July 2019]

[3] BRASIL. Presidência da República. Decreto no 6040, de 07 de fevereiro de 2007. Institui a Política Nacional de Desenvolvimento Sustentável dos Povos e Comunidades Tradicionais. Available from: http://www.planalto.gov.br/ccivil_03/_ato2007-2010/2007/decreto/d6040.htm [Accessed: 06 June 2019]

[4] BRASIL. Secretaria da Justiça, Trabalho e Direitos Humanos. Conselho dos Povos Indígenas e Comunidades Tradicionais alinha demandas com Escritórios Regionais da Sejuf. Governo do Estado do Paraná. [Internet]. 2019. Available from: http://www.justica.pr.gov.br/modules/noticias/article.php?storyid=2881&tit=Conselho-dos-Povos-Indigenas-e-Comunidades-Tradicionais-alinha-demandas-com-Escritorios-Regionais-da-Sejuf [Accessed: 24 June 2019]

[5] Oliveira SKM, Pereira MM, Guimarães ALS, Caldeira AP. Autopercepção de saúde em quilombolas do norte de Minas Gerais. Ciência & Saúde Coletiva. 2015;**20**(9):2879-2890. Available from: http://www.scielo.br/pdf/csc/v20n9/1413-8123-csc-20-09-2879.pdf [Accessed: 31 July 2019]

[6] BRASIL. Presidência da República. Decreto no 4887, de 20 de novembro de 2003. Regulamenta o procedimento para identificação, reconhecimento, delimitação, demarcação e titulação das terras ocupadas por remanescentes das comunidades dos quilombos de que trata o art. 68 do Ato das Disposições Constitucionais Transitórias. *Diário Oficial da União* 2003. Available from: http://www.planalto.gov.br/ccivil_03/decreto/2003/d4887.htm [Accessed: 05 April 2019]

[7] BRASIL. Presidência da República. Lei N° 7668 de 22 de agosto de 1988. Autoriza o Poder Executivo a constituir a Fundação Cultural Palmares—FCP e dá outras providências. Avaolable from: http://www.planalto.gov.br/ccivil_03/LEIS/L7668.htm [Accessed: 31 July 2019]

[8] Costa ASV et al. Survey of the living conditions and health status of older persons living in Quilombola communities in Bequimão, Brazil: The IQUIBEQ Project. Journal of Public Health: From Theory to Practice. 2020. DOI: 10.1007/s10389-020-01198-y

[9] BRASIL. Fundação Cultural Palmares. Certificação Quilombola. Brasília. 2019. Available from: http://www.palmares.gov.br/?page_id=37551 [Accessed: 18 July 2019]

[10] Almeida MCP. O movimento quilombola na Baixada Ocidental Maranhense: História, memória e identidade de comunidades remanescentes de quilombos em Pinheiro. Associação Nacional de História-ANPUH-BRASIL. XXVII simpósio Nacional de História. Natal, 22 a 26 de junho de 2013. Anais. pp. 1-13. Available from: http://www.snh2013.anpuh.org/resources/anais/27/1371343653_ARQUIVO_OMovimentoquilombolna BaixadaMaranhense.pdf [Accessed: 24 June 2019]

[11] Oliveira BCA et al. Racial inequalities in the socioeconomic, demographic and health conditions of elderly from Maranhão State, Legal Amazon, Brazil: A population-based study. Acta Amazônica 2014;**44**(3):335-344. Available from: http://www.scielo.br/pdf/aa/v44n3/a06v44n3.pdf [Accessed: 31 July 2019]

[12] Instituto Brasileiro de Geografia e Estatística (IBGE). Censo demográfico 2010: Características da população e dos domicílios, resultados do universo. Rio de Janeiro: IBGE; 2011. Available from: https://biblioteca.ibge.gov.br/visualizacao/periodicos/93/cd_2010_caracteristicas_populacao_domicilios.pdf [Accessed: 05 April 2019]

[13] Instituto Brasileiro de Geografia e Estatística (IBGE). Censo demográfico 2010: Características da população e dos domicílios, resultados do universo. Rio de Janeiro: IBGE; 2011. Available from: https://biblioteca.ibge.gov.br/visualizacao/periodicos/93/cd_2010_caracteristicas_populacao_domicilios.pdf [Accessed: 18 July 2019]

[14] Instituto Brasileiro de Geografia e Estatística (IBGE). Censo demográfico 2000: Características gerais da população resultados da amostra. Rio de Janeiro: IBGE; 2000. Available from: https://biblioteca.ibge.gov.br/visualizacao/periodicos/83/cd_2000_caracteristicas_populacao_amostra.pdf [Accessed: 18 July 2019]

[15] Gomes KO, Reis EA, Guimarães MDC, Cherchiglia ML. Utilização de serviços de saúde por população quilombola do Sudoeste da Bahia, Brasil. Caderno de Saúde Pública, Rio de Janeiro. 2013;**29**(9):1829-1842. Available from: http://www.scielo.br/pdf/csp/v29n9/a22v29n9.pdf [Accessed: 31 July 2019]

[16] Jannuzzi PM. Indicadores sociais no Brasil. 4th ed. Alínea: Campinas; 2009

[17] BRASIL. Instituto Brasileiro de Geografia e Estatística—IBGE. Conheça cidades e Estados do Brasil. 2017. Available from: https://cidades.ibge.gov.br/brasil/ma/bequimao/panorama [Accessed: 18 July 2019]

[18] ABEP—Associação brasileira de Empresas de Pesquisa. Critério Brasil 2018. 2018. Available from: http://www.abep.org/download [Accessed: 25 June 2019]

[19] Oliveira BLCA, Thomaz EBAF, Silva RA. The association between skin color/race and health indicators in elderly Brazilians: A study based on the Brazilian National Household Sample Survey 2008. Cadernos de Saúde Pública, Rio de Janeiro. 2014;**30**(7):1438-1452

[20] Miranda GMD, Mendes ACG, Silva ALA. O envelhecimento populacional brasileiro: Desafios e consequências sociais atuais e futuras. Revista Brasileira de Geriatria e Gerontologia, Rio de Janeiro. 2016;**19**(3):507-519. DOI: 10.1590/1809-98232016019.150140. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1809-98232016000300507&lng=en&nrm=iso [Accessed: 06 November 2019]

[21] Ferreira JP, Leeson G, Melhado VR. Cartografias do envelhecimento em contexto rural: Notas sobre raça/etnia, gênero, classe e escolaridade. Trabalho, Educação e Saúde, Rio de Janeiro. 2019;**17**(1):e0017612. DOI: 10.1590/1981-7746-sol00176. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1981-77462019000100508&lng=en&nrm=iso [Accessed: 06 November 2019]

[22] Tavares DMS, Ribeiro AG, Ferreira PCS, Martins NPF, Pegorari MS. Idosos octogenários nos contextos urbano e rural: Comparação socioeconômica, morbidades e qualidade de vida. Revista Enfermagem UERJ [Internet]. 2015;**23**(2):156-163. Available from:

http://www.facenf.uerj.br/v23n2/v23n2a03.pdf

[23] Silva A et al. Iniquidades raciais e envelhecimento: Análise da coorte 2010 do Estudo Saúde, Bem-Estar e Envelhecimento (SABE). Revista Brasileira de Epidemiologia [online]. 2019;**21**(Suppl 02):e180004. Available from: https://doi.org/10.1590/1980-549720180004.supl.2 [Accessed: 06 November 2019]. Epub 04 Fev 2019. ISSN: 1980-5497. DOI: 10.1590/1980-549720180004.supl.2

Section 6

Spiritual Perspectives

Chapter 12

Spirituality and Hansen's Disease: Spirituality' Conceptual Structure and Hansen's Disease History - Part One

Makiko Kondo, Mikako Yamaberi, Hitomi Yamao,
Masato Muguruma, Kayoko Furochi, Shiho Oka
and Aiko Matsushita

Abstract

There have been suicides at the Hansen's disease sanatoria in the past. What is the level of suffering that makes a person think of suicide? This study is divided into two reports. In the first report, we demonstrate the conceptual structure of spirituality and the relationship between quality of life (QOL) and spirituality, and the history of Hansen's disease. In the second report, based on the first report, we will show spiritual pain and spiritual well-being experienced by Hansen's disease survivors through an analysis of their life reviews. When our daily lives are calm and mundane, we do not notice spirituality. However, when we confront hardships of life, for example, diagnosed with leprosy and isolated in a sanatorium for lifetime, we notice spirituality as an existential distress. On the other hand, the development of individuality and imperturbability by overcoming hardship is spiritual well-being. Spirituality serves as the existential foundation for human existence and is important for the relationship with "something greater than self." Spiritual well-being is one of multiple dimensions of QOL.

Keywords: Hansen's disease, spirituality, spiritual pain, suicide, spiritual well-being, gerotranscendence, life review, Leprosy Prevention Law

1. Introduction

Hansen's disease has been stigmatized from ancient times. Patients were forced to live in sanatoriums for their entire life, and this forced some of them to commit suicide. Although a sanatorium was a medical institution, it had a crematorium, an ossuary, and religious facilities (see **Figures 1**–**4**). Religion was used for saving the patient's soul.

What is the level of suffering or "spiritual pain" that makes a person consider suicide? What causes spiritual pain in those suffering with Hansen's disease? The experiences of Hansen's disease survivors are important to order identify the essence of spiritual pain, which remarkably decreases their QOL. On the other hand, Hansen's disease survivors who had suffered spiritual pain were eventually freed of their

Figure 1.
First Ossuary. The 674 people who passed away between 1901 and 1936 are buried here. The oldest remains are dated June 12, 1901 (Ōshima Sanatorium opened on April 1, 1901).

Figure 2.
Ossuary. A majority of the residents lived here for the rest of their life and were cremated here. Those whose remains were not returned to their hometowns are kept in this ossuary on the island.

sufferings and went on to become latter-stage elderly living vividly with purpose of life, even though it was minor. Is it possible to develop an individuality wherein one can experience spiritual well-being despite having experienced spiritual pain? This is an important theme, as spiritual well-being constitutes a part of QOL.

Figure 3.
The 88-statue circuit within Oshima Seisho-en property. A total of 88 stone images are enshrined on the property to permit the 88-temple Shikoku pilgrimage to be carried out on-site.

Figure 4.
Dance of the Wind. The title, "Dance of the Wind," is based on the following wish: "at least let the spirit of my dying words ride the wind away from the island, freely released to return to my native home." It was built by approximately 1000 volunteers in 1992. The pointed conical monument on the front represents "everything in the heavens and space above," while the conical platform in the back represents "everything under the sun on earth." The round area with flagstones is a stage on which souls are thought to dance with the wind before setting off to their hometowns. The conical monument contains ashes of many individuals that did not entirely fit within their funerary urns.

This study is divided into two parts. In the first report, we describe the conceptual structure of "spirituality" and the relationship between spirituality and QOL. In the second report, we show the spiritual pain and spiritual well-being of Hansen's disease survivors through a review analysis and discuss spirituality and QOL. A table content of the first and second report is presented in **Table 1** as an overview of the entire study.

2. Quality of life and spirituality

2.1 What is quality of life (QOL)?

Characteristics of QOL include considering the health and happiness from the perspective of the subject. It emphasizes subjective over objective evaluation,

Part one	Part two
Spirituality's conceptual structure and Hansen's disease history	Accounts of spiritual pain and spiritual well-being by Hansen's disease survivors
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4.Life review of Hansen's disease survivors 4-1. Introduction to the National Sanatorium Oshima Seisho-en, where the survivors who have shared their life review live 4-2. The life review book of Hansen's disease survivors	**4. Spiritual well-being of aging Hansen's disease survivors** 4-1. How do individuals live energetically despite having experienced extreme situations? 4-2. Construction of spiritual well-being; Introduction of the study
5. Conclusion	**5. Conclusion**
	Appendix Mr. Takahisa Yamamoto's life review (An excerpt only from the section that discusses spiritual pain)

Table 1.
Table contents about the first report and the second report about 'Spirituality and Hansen's disease'.

and the evaluation of multiple dimensions rather than a single dimension. The primary goal of nursing is enhancing the QOL of a subject and the results of nursing intervention can be evaluated by the QOL.

By Haas' QOL model [1], if the four dimensions that are physical, psychological, social, and spiritual, indicate well-being, the QOL is high.

2.2 What is spirituality?

The Old testament, states: "God made person from mud and breath in its nose, and then the mud figure become living human." Therefore, we believe that the source of life is from the breath given by God. Spirit comes from the Latin word "Spiritus," and the elements that make the human are body, mind, and spirit.

When we encounter a crisis in life and lose our identity or the existing framework for living like other human beings and leading life in our own way, we seek the framework of transcendent power that exists outside us or the ultimate core within us. This function is known as spirituality [2].

Figure 5 shows the relationship between spirituality, spiritual pain, and spiritual well-being. At the time when we have control over our life and can live in our own way and like other human beings, we tend not to notice spirituality, as we are not philosophers who think about life and death everyday see (**Figure 5(a)**). Although when faced with a crisis, for example the news that we have cancer or Hansen's disease, or see our own people dying, lose family members in an earthquake, or face other sufferings that make us think of committing suicide, we feel spiritual pain and notice spirituality see (**Figure 5(b)**). On the other hand, spiritual well-being became apparent in some people, for example, those who have a peaceful death or are deeply religious see (**Figure 5(c)**).

2.3 Development of spiritual pain into cancer terminal care

Spiritual pain has been important in terminal care for cancer patients. The reasons for this are mentioned below. The first, cancer has the stigma of death attached. After being diagnosed with cancer, patients have to reconsider their life plan and think about where they want to live, who do they want to live with, and how do they want live the rest of their life. The second, dying patients can see the signs of their end coming closer as their physical condition and activities of daily living (ADL) decline gradually. Facing one's death leads to despair and spiritual pain. The third, the understanding that their family will lose a loved one. Death of a loved one means losing the future of living with the loved one, therefore to deal with this grief a lot of psychological energy is needed.

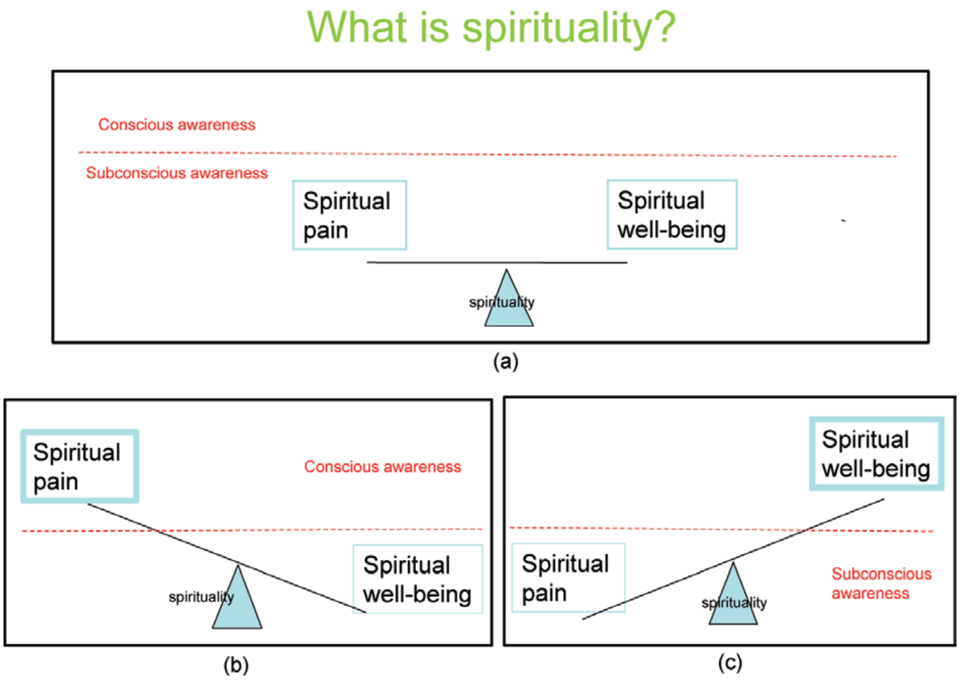

Figure 5.
(a) Not actualized spiritual pain and spiritual well-being (life as usual); (b) actualized spiritual pain; and (c) actualized spiritual well-being.

2.4 Spiritual pain and total pain

The experience that terminal cancer patients undergo is called "Total Pain." Total pain encompasses physical, psychological, social, and spiritual pain [3]. Physical pain includes various factors like body aches, difficulty in breathing, fatigue, and also difficulties in ADL like eating, sleeping, and moving. Psychological pain includes feelings of anxiety, loneliness, anger, irritation, etc. Social pain is related to work problems, financial issues, problems in the family, inheritance issues, etc. Spiritual pain implies questioning the meaning of life, pursuing God, changes in the value system, a search for the meaning of suffering, fear of death, feeling of guilt, etc.

It is difficult to distinguish between psychological and spiritual pain. Psychological pain implies that the mind is functioning against the body, on the other hand, spiritual pain means questioning the relationship with something greater than self or something that is transcendent [4]. Therefore, spiritual pain exists when we question the meaning of life and existence. For example, when we cannot meet a loved one or a partner and feel lonely because of the physical distance, it is psychological pain, but when we lose a loved spouse and suffer and contemplate suicide and blame God for the loss, it is spiritual pain.

Spiritual pain is expressed as: (1) unfairness: why did I get this disease?; (2) unworthiness: I do not want to become a burden on my family; (3) hopelessness: there is no meaning in doing that; (4) guilt: it is my fault; (5) isolation: no one understands me; (6) vulnerability: I do not have the ability; (7) abandonment: God is not helping me either; (8) punishment: I am being punished and that is why I have cancer; (9) confusion: why must I suffer even if there is God; (10) meaninglessness: my life is meaningless [5].

2.5 What is spiritual well-being?

There are very few patients who have a sense of gratitude and peace as they face death as compared to the number of patients who have total pain. There are some who try to find the meaning of suffering when they are afflicted with hardships of life like, a massive earthquake, loss of a loved one, loss of work, divorce, etc. Spiritual well-being implies being in harmony with self, others, nature, and something greater than self, and the process of finding the best meaning [2]. People who have faith in God in daily life can find the meaning of suffering and are peaceful while facing death and hardships as compared to people who do not have faith. Therefore, it can be said that religion leads to spiritual well-being. At the same time, religion is not the same as spirituality. All persons with or without faith have spirituality. Therefore, all humans have the potential to develop at the level of the soul even in extreme situations until the moment of death.

2.6 Quality of life and total pain

By Haas' QOL model [1], if the four dimensions that are physical, psychological, social, and spiritual, indicate well-being, the QOL is high. QOL and total pain are the two sides of the same coin, which implies that if the four dimensions are painful, then the patient has total pain, and if the dimensions indicate well-being, the patients level of QOL is high. Ensuring a patient's well-being in all four dimensions is the aim of the practice of nursing.

3. Overview of history of Hansen's disease in Japan

It would be help to divide this into four periods to facilitate better understanding: (1) From the ancient times to the end of the feudal era (the Edo period); (2) From establishing a modern nation (the Meiji government) to the end of World War II; (3) From developing the magic bullet "Promin" to abolishing the Leprosy Prevention Law (Act No. 214 of 1953; らい予防法); (4) After abolishing the Leprosy Prevention Law.

3.1 From the ancient times to the end of the feudal era (~1867)

Leprosy existed in Japan from the ancient times and statements about the disease were mentioned in Nihon Shoki (AC.720), which is one of the two oldest written documents in Japan. According to the concept of defilement, Hansen's disease patients were considered to be defiled beings because of their change in appearance. In Buddhism, leprosy is considered as a punishment from heaven and a disease caused because of karmic retribution. Patients stayed at home so that they do not stand out, or lived in areas that were designated for the feudal outcast group and thus coexisted in society. Patients who could no longer live in their hometowns would beg at the gates of temples and shrines, or depart on wandering journeys and were called "wandering lepers."

3.2 From establishing a modern nation (the Meiji government) to the end of World War II (1868–1945)

During the Edo shogunate (1603–1868) the society was peaceful and there was no war for 250 years, but this was broken by a bloodless revolution, the Meiji Restoration and the Meiji government was established. The new government made an effort to create a modern nation, make the country economically sound, encourage new industries, and to strengthen the army, in order to prepare for the threats from the Western powers. Unfortunately, the government was a part of the World War II and lost the battle in 1945.

After the Meiji government was established, Hansen's disease was considered as a "national disgrace disease," in addition to a "heavenly punishment disease" and "defilement disease." The Government believed that the sight of patients begging at shrines was symbol of a country that was not civilized. This was considered a national disgrace as the government aimed to make the country a civilized country. According to the concept of national purification and the idea of supremacy, patients with Hansen's disease as well as weak and disabled people were excluded. In line with militarism, Hansen's disease patients were treated coldly during the war because they did not contribute to military strength and the disease was mostly seen in young men.

In addition, bacteriology and the study of public health were introduced, leading to the use of isolation to prevent infection. By similarly to the acute infectiousness of cholera according to theory of social protection, general people misunderstood as terrifying infectious disease.

Based on the above background, the government forced lifelong isolation and internment in order to eradicate Hansen's disease, and established sanatoria and legislations to legalize forced isolation. In 1907, the Leprosy Prevention Law (Act No. 11 of 1907; 癩予防ニ関スル件) was enacted in order to force patients who did not have relatives and were known as "wandering lepers," to intern at sanatoria. Five sanatoria were established across the nation. In 1931, the Leprosy Prevention Law (Act No. 58 of 1931; 癩予防法) was enacted to isolate patients living at home and did not force internment by police authority. In 1929, the Leprosy-Free Prefecture Movement started spreading. This movement was aimed at tracking all patients, reporting them, and interning them at the sanatoria so that there would be no patients living in the prefecture. As a result of this movement, the feeling that Hansen's is a horrible infectious disease took root among the populace.

The treatment offered to the patients at the sanatoria during that period had serious issues from humanitarian and ethical perspectives. For example, the patients were forced to undergo sterilization surgery in order to prevent the them from having child, they were forced to enter the punishment room, officers had disciplinary arrest rights which was the right of the sanatorium director to punish or confine patients who disobeyed the rules at his own discretion, sanatorium scrip which was an attempt to prevent runaways by converting money to a currency that could only be used in the sanatorium, changing names to an internal alias, forced labor, establishment of diseased/non-diseased boundary, autopsy, and so on. One of the biggest issue was that the Hansen's Disease Prevention Law did not have any stipulations about being discharged. Therefore, once a person entered a sanatorium, there was no possibility for them to get discharged.

3.3 From developing the magic bullet "Promin" to abolishing the Leprosy Prevention Law (Act No. 214 of 1953; らい予防法) (1943–1996)

Japan lost the Second World War in 1945 and a new constitution which respected basic human rights and advocated democracy was established in 1946. In addition, the magic bullet "Promin" was developed in USA in 1943, and after the success to synthesize the chemical in Japan in 1946, treatment using the same was started in 1947. The conventional law, the Leprosy Prevention Law (Act No. 58 of 1931；癩予防法) was amended and the Leprosy Prevention Law (Act No. 214 of 1953; らい予防法), which emulated the conventional law and continued to grant disciplinary arrest rights and forced internment, was established. This was going backwards and was against the intent to promote respect for basic human rights and democracy after the war, and was adopted even though the disease could be cured with Promin. In addition, in spite of furious opposition, through hunger strikes and abandonment of sanatorium work, by the National Hansen's Disease Sanatorium Residents' Council, the opinion of authority in the Leprosy academic meeting at that time were adopted.

The National Hansen's Disease Sanatorium Residents' Council negotiated with the government persistently, which led to the buffering on the regulation on going out, but this came to a standstill in operational mitigation because of the abolition of the Leprosy Prevention Law (Act No. 214 of 1953; らい予防法) in 1996.

3.4 After abolishing the Leprosy Prevention Law (1996~)

After the abolition of the Leprosy Prevention Law (Act No. 214 of 1953;らい予防法) in 1996, during the National Redress Suit in 2001, the government was convicted to have committed a mistake by promoting the policy of isolation. The government, including the Prime Minister; the House of Representatives and the House of Councilors; and the Minister of Health, Labor, and welfare, apologized to the Hansen's disease survivors. Only a few Hansen's disease survivors could return to social existence as the average age of these people was over 60 years. The Law on Promoting a Resolution for the Hansen's Disease problem was established in 2009. This law directs that these patients are guaranteed that they would be able to lead a normal life, get treatment, return to the society and will be offered aid for social life, also that assistance would be provided to redeem their reputation, protection would be provided for family members, and the dead would be memorialized.

The average age of Hansen's disease survivors currently is 86, and the total number of people with the disease has decreased to 1175 as of 2019. There will be no cases of Hansen's disease in Japan soon. Now, high quality nursing is provided in the sanatoria. With this we hope that the aging Hansen's disease survivors, who have previously experienced suffering and hardship, can have a peaceful life and live with purpose. We are hopeful that the survivors, who do not have children and grandchildren because of the sterilization surgery, are well cared for by the nursing staff and can have a peaceful death.

4. Life review of Hansen's disease survivors

4.1 Introduction to the National Sanatorium Oshima Seisho-en, where the survivors who have shared their life review live

A national sanatorium, Oshima Seisho-en was established under the Leprosy Prevention Law (Act No. 11 of 1907; 癩予防二関スル件) and it has 110 years of history. Oshima island is in Seto inland sea, and one can get there on a ship. The distance from the nearest harbor in the mainland is 8 km. Oshima is a small scenic island with a total area of seven kilometers, and has a mild climate. The island is seven kilometers. The number of residents recorded during the war was about 740. As of August 2019, the number of residents is 52, the average age is 84.3, and the length of stay of these residents is 57.6 years. After the abolition of the Leprosy Prevention Law, many people have visited the sanatorium to learn about human rights, and some foreigners visit the island during the Setouchi Triennale. See **Figures 6** and 7**(a)** and **(b)**.

4.2 The life review book of Hansen's disease survivors

We published a life review book about 19 Hansen's disease survivors living at Oshima Seisho-en [6]. From chapter 2 to 20, each chapter describes the experiences of one person. Each survivor talks about their childhood before having Hansen's disease, the shock and suffering that followed the diagnosis, till the time that they entered the sanatorium, discrimination and exclusion in their hometown, the parents affection and worry to protect them, inconvenience faced by their brothers and sisters, various symptoms and cures, the bad experiences in the sanatorium, romantic alliances, support from friends at the sanatorium, fighting against the government, current feelings and thoughts in their old age. The subject of the book is summarized as "Deeply Deeply Closing Our Eyes in Order to See What We Truly Should See," which is the subtitle of the book and has been penned by poet Ms. Yoshiko Takagi.

The significance of the book is discussed in the following eight points.
(1) Negative history about medical care and administration at the sanatoria has been mentioned from the perspective of the survivors as a subjective experience, therefore, their narration is important as a primary resource to share the history of the disease with later generations. (2) When the principles of medical ethics including, respect for autonomy, beneficence, non-maleficence, justice and/or equality, were violated, what happened? The reality is shared. (3) Discrimination and exclusion against diseases with stigma in not just limited to Hansen's disease. If there is an outbreak of an unknown or lethal infectious disease (ex. Ebola hemorrhagic fever) in future, these experiences will become the lessons to ensure that the mistakes are not repeated again. (4) Their narratives hold value for ethnology, for example, the 88-temple Shikoku pilgrimage accepted wandering lepers and handed them secret medicines from the major Buddhist Kobo Daishi (774–835), and the discrimination and customs of the neighborhood groups in the agricultural society. (5) Their accounts give an insight about the wisdom and strength that made them overcome terrible hardships, and the clear vision that made them accept their life positively. This wisdom and strength has universal value for all human beings and is also

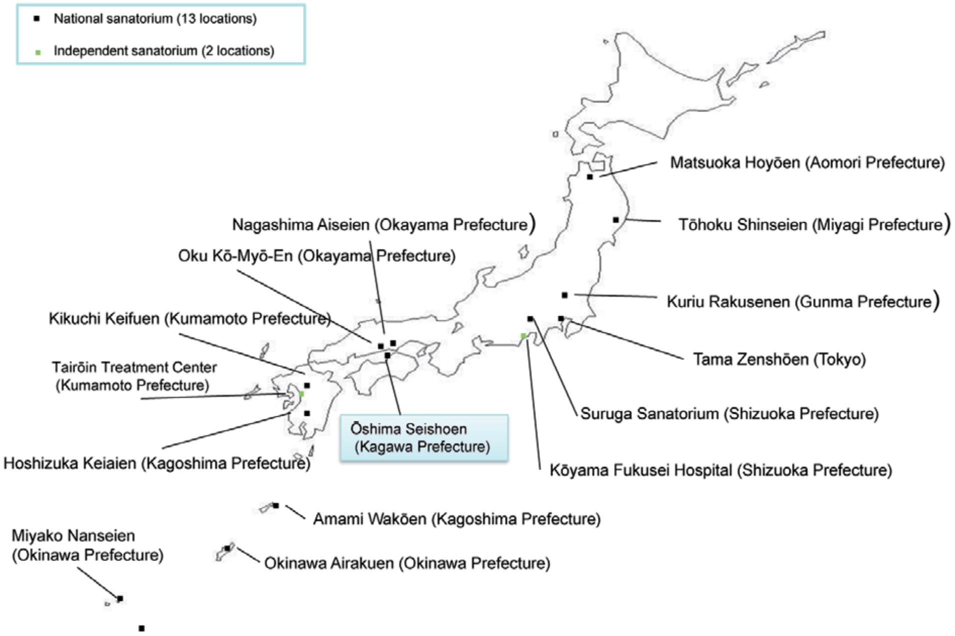

Figure 6.
Hansen's disease sanatoria nationwide.

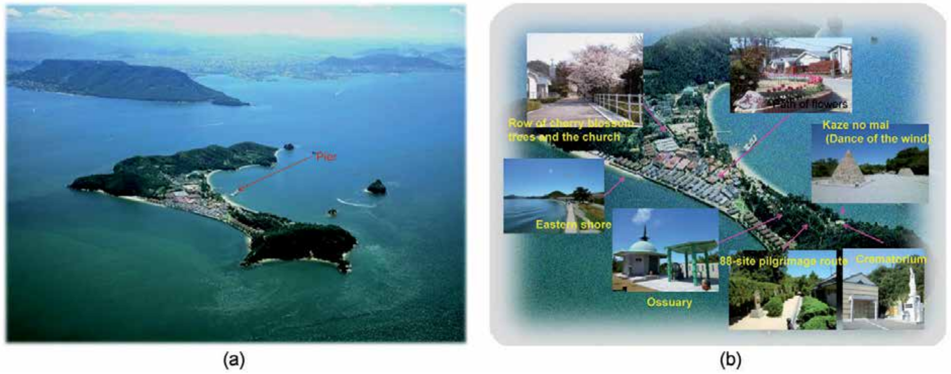

Figure 7.
(a) View of the entirety of the Ōshima Seishoen (in the background are Yashima and Takamatsu harbor); and (b) view of Ōshima Seishoen.

useful for people who are currently suffering. (6) The nurses at the sanatorium were the listeners of their life review. This book has also recorded the nursing practices. This interaction also increased the ability of the nurses to listen, empathize, understand, and deepen the relationship between them and the survivors. Through this, the nurses also got the opportunity to care for the survivors who do not have their own children. (7) The book was made by using qualitative and inductive methods in order to arrange the composition and express it in a narrative tone, therefore even elementary students can read it to learn about human rights. (8) New patients of Hansen's disease have been found only in developing countries like India, Brazil, and Indonesia. They account for about 80% of the total patients. The developed countries are not concerned about the disease. We hope that by increasing the awareness in developed countries, through the stories of the survivors, the wisdom and strength for solving problems in future will be shared.

In the second report, we introduce Mr. Takahisa Yamamoto's life review which clearly defines spiritual pain and shows the result of an analysis of questions such as why does a person experience spiritual pain, what is the identified nature of spiritual pain, and how can one recover from spiritual pain.

5. Conclusion

This study comprises the first report and the second report. In the first report, we describe the conceptual structure of spirituality, the relationship of spirituality and QOL, and the history of Hansen's disease. Spirituality was developed as a part of the studies relating to terminal cancer patients who must confront their own death. When our daily lives are calm and mundane, we do not notice spirituality. However, when we confront hardships of life, for example, when we are exposed to the dangers of life, we notice spirituality as an existential distress. On the other hand, the development of individuality and imperturbability by overcoming hardship is spiritual well-being. Spirituality serves as the existential foundation for human existence and is important for the relationship with "something greater than self." In common understanding, QOL is evaluated not objectively but subjectively, and not as a single dimension but as multiple dimensions. Spiritual well-being is one of multiple dimensions of QOL.

In the second report, we will show the spiritual pain and spiritual well-being of Hansen's disease survivors who have lived harsh lives via an analysis of their life review based on the findings of spirituality and QOL from the first report.

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Conflict of interest

We have no financial relationships to disclose.

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References

[1] Barbara K. Haas: Clarification and integration of similar quality of life concepts. Journal of Nursing Scholarship. 1999;**31**(3):215-220

[2] Kubodera T. Introduction of Spiritual Care Study (Japanese title: spiritual care gaku jyosetsu). Tokyo: Miwa-shoten; 2004

[3] Yodogawa Cristian Hospital (ed.). Palliative Care Manual Ver. 5. Tokyo: Saisinigakusha; 2007

[4] Post-White J, Ceronsky C, Kreitzer M, et al. Hope, spirituality, sense of coherence, and quality of life in patients with cancer. Oncology Nursing Forum. 1996;**23**:1571-1579

[5] Kaye P. Note on Symptom Control in Hospice & Palliative Care. Machiasport: Hospice Education Institute; 1989. pp. 261-267

[6] Kondo M. Oshima Seisho-en: Life Review of Aging Japanese Hansen's Disease Survivors-Deeply Deeply Closing our Eyes in Order to See What We Truly Should See. USA: Horizon Research Publishing; 2019

Chapter 13

Spirituality and Hansen's Disease: Spirituality' Conceptual Structure and Hansen's Disease History - Part Two

Makiko Kondo, Mikako Yamaberi, Hitomi Yamao,
Masato Muguruma, Kayoko Furochi, Shiho Oka
and Aiko Matsushita

Abstract

There have been suicides at the Hansen's disease sanatoria in the past. What is the level of suffering that makes a person think of suicide? Through the analysis of a Hansen's disease survivor's life, we clarified that the nature of sufferings is spiritual pain that is brought by the "loss of autonomy and independence for carving out my life." The patient was stuck in a negative cycle for about 20 years: All my dreams and hopes cut off → Despair → I want to die but cannot die easily → Lethargy·Desperation·Nihilistic → Momentary pleasure by gambling → I do not feel like living → I ask myself why am I alive → Self-criticism → Repeat again. Recovery from spiritual pain was achieved with time and by reflection. The bellwethers led to a turning point that helped to change the flow of his life. He also started using time effectively. Spiritual well-being of aging survivors has a trilaminar structure, comprising the following: (1) establishing the existential foundation of a sustained self; (2) living in the moment while contemplating the future; and (3) dovetailing within the society and transcending space and time. It indicates that they can achieve the developmental tasks related to old age, personal integration containing spirituality, and the wisdom and strength to get over difficulties. This study consists of the first report and the second report.

Keywords: Hansen's disease, spirituality, spiritual pain, suicide, spiritual well-being, gerotranscendence, life review, Leprosy Prevention Law

1. Introduction

Due to social stigma, people with Hansen's disease are usually targets of discrimination, exclusion, and persecution. In modern times, those suffering with Hansen's disease were targeted by forced detention and lifelong isolation and in a manner of speaking were socially quarantined. Due to living in this extreme state, the experiences of Hansen's disease survivors actualize the existence of spirituality as spiritual pain and express human strength and the development of individuality as spiritual well-being. Therefore, their experiences are very important and similar to those experienced by Auschwitz or atom bomb survivors.

In this two-part study (see **Table 1**), we discuss spirituality though the experiences of Hansen's disease survivors. In the first report, we discuss the conceptual structure of spirituality and QOL and explain the history of Hansen's disease. In the second report, we answer the following questions through an analysis of a Hansen's disease survivor's life review: What is the level of suffering or 'spiritual pain' that makes a person consider suicide? What causes spiritual pain in those suffering with Hansen's disease? Furthermore, why do people with Hansen's disease experience spiritual well-being and development of individuality despite their spiritual pain?

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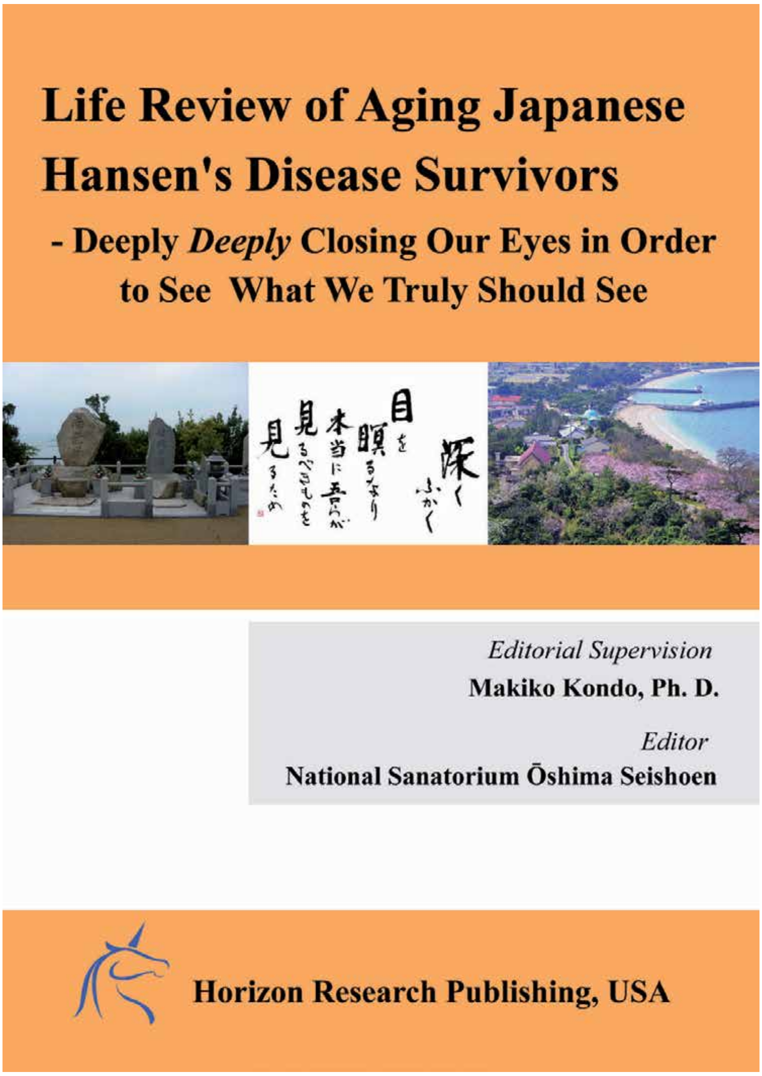
Table 1.
Table contents about the first report and the second report about 'Spirituality and Hansen's disease'.

2. Spiritual pain experienced by a Hansen's disease survivor

2.1 The life review of Hansen's disease survivors

Our book contains life reviews of 19 Hansen's disease survivors living in Oshima Seisho-en (see **Figure 1**) [1]. The significance of publishing the book is explained in the first report. Each survivor talks about their childhood before having Hansen's disease, the shock and suffering that followed the diagnosis, till the time that they entered the sanatorium, discrimination and exclusion in their hometown, the parents affection and worry to protect them, inconvenience faced by their brothers and sisters, various symptoms and cures, the bad experiences in the sanatorium, romantic alliances, support from friends at the sanatorium, fighting against the government, and current feelings and thoughts in their old age. The subject of the book is summarized as "*Deeply Deeply Closing Our Eyes in Order to See What We Truly Should See,*" which is the subtitle of the book and has been penned by poet Ms. Yoshiko Takagi.



Life Review of Aging Japanese Hansen's Disease Survivors
- Deeply *Deeply* Closing Our Eyes in Order to See What We Truly Should See

深く
ふかく
目を
瞑るなり
本当に吾らが
見るべきものを
見るため

Editorial Supervision
Makiko Kondo, Ph. D.
Editor
National Sanatorium Ōshima Seishoen

Horizon Research Publishing, USA

Figure 1.
Our life review books [1].

In this paper, we select the life review of Mr. Takahisa Yamamoto, who discusses the reality of spiritual pain. His detailed account is added as an Appendix 1.

2.2 Overview of Mr. Takahisa Yamamoto's life review

Mr. Takahisa Yamamoto was a bright boy who aimed to enter the national university to become a doctor or join a trading company. He was hopeful that his parents would give him the independence to achieve his dream. He was diagnosed with Hansen's disease at the age of 15. He received treatment from Dr. Noboru Ogasawara at Kyoto university hospital and at home. Dr. Ogasawara opposed forced internment and advocated outpatient treatments. Yamamoto decided to enter the sanatorium at the age of 19. After entering the sanatorium, he indulged in reprobate conduct and began gambling and tried to escape from working. He also suffered and felt lonely as he could not go out. He married at the age of 31. The friends of his wife opposed the marriage and his wife asked him, Will you change your habits after getting married?", but his reprobate conduct continued. The turning point for him was at the age of 48 when he was selected as a representative in Oshima Seisho-en for the National Hansen's Disease Sanatorium Residents' Council, and he moved to Tokyo. He came back to Oshima Seisho-en at the age of 52 and became the chairman of Residents' Committee in Oshima Seisho-en. At the age of 60, he was introduced to ceramics, and that became his passion. When he told us about his life, he was 81 years old. He spent the rest of his life as the chairman and continued making ceramic products. He died at the age of 83 in 2016, and his remains were collected in a handmade ceramic cinerary urn and kept at the ossuary in Oshima Seisho-en.

2.3 Analysis method for construction

First, we underlined his experiences about spiritual pain and created a shadow summary to explain it. Second, we extracted a shadowed summary and sorted it based on similar meanings. Third, we schematized Mr. Yamamoto's experience. Perspectives analyzed were: "why did Mr. Yamamoto have spiritual pain?" and "what was the identity of the spiritual pain?" Lastly, we checked if the figure could show his experience and clarify the mechanism of why he had spiritual pain and the essence of his spiritual pain.

2.4 Construction of Mr. Takahisa Yamamoto's spiritual pain

We illustrate the construction of Mr. Yamamoto's spiritual pain in **Figure 2**. *Italic letters* show the same concepts as **Figure 2**.

Mr. Yamamoto was *full of enthusiasm for the future* and *wanted to become independent and set out on my own*; therefore, he was a boy with *strong autonomy and independence*. When he was *diagnosed with Hansen's disease*, and he knew *I cannot go out of the sanatorium till I die*. He realized that *all his dreams and hopes cut off*, and *he cannot set out on his own and carve out his life.* He *crashed by despair*, he thought "*My life is over and I can only keep breathing*." Mr. Yamamoto *wanted to die*, but he *could not die easily*. Therefore, he felt *lethargic, slapdash, desperate, let things take their own course, nihilistic, and "no matter what I do, it will all be in vain,"* and he began to *shirk patient labor*, getting *momentary pleasure by gambling*, and *stay outside the system and rule*. *He did not feel like living*, and *he asked himself 'why am I alive'*, and he wallowed in *self-criticism*; *he scolded himself about spending without purpose again today, saying "Are you even human? Is it not normal to die?"*

This negative cycle was *enhanced* by comparison with others. To begin, he *compared himself and his classmates who were setting out on their own*, and he thought "*I was the only dropout*" and felt *miserable*. In addition, he noticed that *there were*

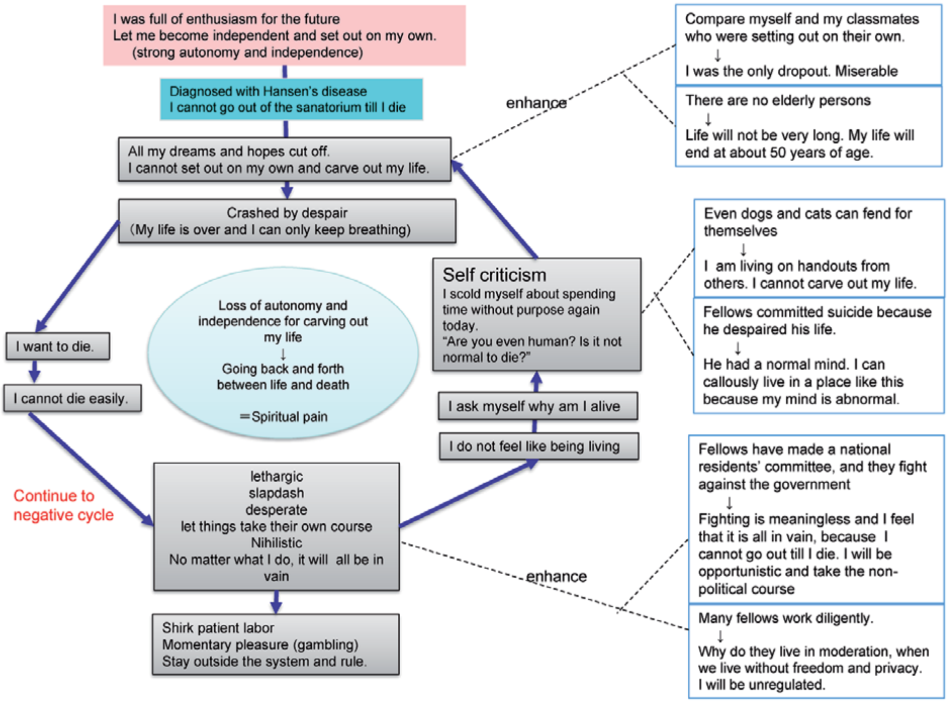


Figure 2.
Spiritual pain experienced by Hansen's disease survivor Mr. Takahisa Yamamoto.

no elderly persons in the sanatorium, and he realized "*life will not be very long, my life will end at about 50 years of age,*" therefore he thought "my life is over", and this deepened his despair.

Next, although *fellows made a national residents' committee, and they fight against the government*, he believed that this *fight was meaningless, and I felt that it was all in vain, as I cannot go out until I die. I will be opportunistic and take the non-political course*. In addition, although *many fellows work diligently*, he thought "*why do they live in moderation, when we live without freedom and privacy. I will be unregulated.*" These thoughts enhanced his irresponsible attitude.

At last, he compared himself with *fellows who committed suicide because they despaired their life*, and Mr. Yamamoto thought "*fellow had a normal mind. I can callously live in a place like this because I have an abnormal mind.*" In addition, he compared dogs and cats, and thought "*Even dogs and cats can fend for themselves. I am living on handouts from others. I cannot carve out my life.*" This comparison enhanced self-criticism.

Negative cycle (I cannot set out on my own and carve out my life→Crashed by despair→I want to die→I cannot die easily→slapdash・Nihilistic→ I do not feel like living→ I ask myself why I am alive→self-criticism) continued for 10 to 20 years. Essentiality of the negative cycle, in other words, Mr. Yamamoto's spiritual pain is *Loss of autonomy and independence for carving out my life*, and for that reason, he was *Going back and forth between life and death*.

3. The process of recovering from spiritual pain for a Hansen's disease survivor

Mr. Yamamoto's recovery from spiritual pain can be seen at two turning points. The first, when he visited the Tokyo office of the National Hansen's Disease Council at 48 years. The second, when he discovered his love for ceramics at the age of 60. These turning points, respectively, came about 30 years after his diagnosis at 15 years and entering the sanatorium at 19 years.

The analysis of his recovery from spiritual pain was conducted in the same way as the analysis of construction of spiritual pain. His life review about recovering from spiritual pain is omitted because of lack of space. The process of Mr. Yamamoto's recovery from spiritual pain is shown in **Figure 3**.

3.1 What sustained Mr. Takahisa Yamamoto through the suffering?

Mr. Yamamoto's spiritual pain indicated a negative cycle: I cannot set out on my own and carve out my life→Crashed by despair→I want to die→I cannot die easily→slapdash・Nihilistic→I do not deserve to be alive →I ask myself why am I alive→Self-criticism. The first period of sustained suffering of 30 years was for the affection of his family. He had no one to blame for his sickness and he had no opportunity other than to vent to his mother. He blamed his mother; she accepted his lashing and continued to visit him regularly. His brothers could not tell their spouses and children about his disease, but his sisters visited and expressed their affection as they felt sorry for him. In his married life, his unrelenting misconduct had an impact on his wife, but her maturity and common sense prevented the marriage from breaking. In addition, the elders in Oshima Residents' Committee and the group for the blind continued to care for him even though he did not have a good reputation in the patient community in Oshima Seisho-en.

The second period of suffering was seen in his gambling and the glimmers of love with a student nurse during his adolescence. Gambling brought momentary pleasure and helped him to forget the despair temporarily; therefore, he got the opportunity to let off some of the negative energy from the negative cycle.

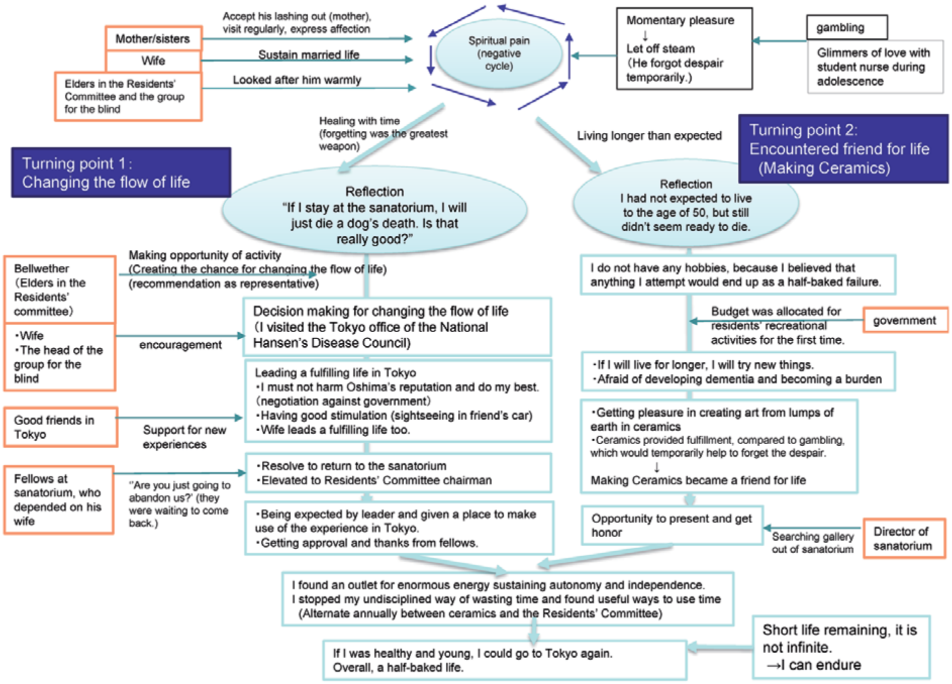


Figure 3.
Recovery from spiritual pain of Hansen's disease survivor, Mr. Takahisa Yamamoto.

In addition, he met a nurse from the nursing school that was established in Oshima island in 1953, and this brought a little pleasure in his insipid life.

3.2 Relieving sufferings; preparing to accept turning points

Although the turning points in his life occurred about 30 years after entering the sanatorium, for about 10 to 20 years, the negative cycle did not change, and gradually the feeling of despair decreased. Mr. Yamamoto said "Forgetting was the greatest weapon to survival and the insight that eased suffering," maybe this indicated that he was on the path of healing. In addition, as the suffering eased, he reflected "If I stay at sanatorium, I will just die a dog's death. Is this really good?" and he started to review himself objectively.

3.3 Turning point 1: changing the flow of life

The first turning point was the visit to the Tokyo office of the National Hansen's Disease Council. This opportunity was created by the elders in the Residents' committee. As they had looked after him during his period of suffering, they could notice his reflection and the internal changes. They knew that they could change the flow of his life in anticipation of the better times ahead; therefore, they are referred to as "bellwethers." In addition, his wife and the head of the group for the blind agreed that this would be a chance to change his life. This was contrary to his expectations and it encouraged him. Mr. Yamamoto himself was ready to proceed to the next step by reflecting that it was time for a change, but he did not have the power to make the change in his flow of life.

Living in Tokyo was a fulfilling experience for him. He negotiated with the government and did his best to not harm the reputation of the Oshima Residents' committee. On vacations, his good friends took them for sightseeing in their car and his wife enjoyed this time as well. She also led a fulfilling life in Tokyo.

After 4 years here, his friends at the sanatorium, who were waiting for him to come back said "Are you just going to abandon us?" and Mr. Yamamoto and his wife resolved to return to the sanatorium. After returning, he was elevated to the position of the Residents' Committee's chairman in the sanatorium. This implied that he was expected to be a leader and was given a position where he could use his experience. This was a sign of approval from his friends and associates and a way of expressing gratitude.

3.4 Turning point 2: meeting a friend for life (ceramics)

The second turning point was his introduction to "ceramics" (see **Figure 4**). When he entered the sanatorium, there were no elderly patients. Therefore, he had not expected to live to the age of 50; this strengthened his despair and he turned to gambling to dissipate the negative energy. After he crossed the age of 50, he realized that he still did not seem to be ready to die. A budget was allocated for residents' recreational activities for the first time. He did not have any hobbies, because he believed that anything that he attempted would end up being merely half-baked. At this point, he thought that "if I will continue to live, then I will try new things." In addition, he was also afraid of developing dementia and becoming a burden on others. This is when he stared making ceramics.

Making ceramics brought him pleasure as he realized that he could create something from a lump of earth. It gave him fulfillment that could be compared to the same that he got from gambling. This could temporarily make him forget the

Figure 4.
Ceramics made by Mr. Takahisa Yamamoto.

despair. Therefore, ceramics became his friend for life. When he successfully made a shape, he wanted other people to see his artwork. The head of the sanatorium sent his work to a gallery off the island, and this gave him the opportunity to present his work and get honor.

3.5 After the turning point

Mr. Yamamoto was a boy with a strong sense of autonomy and independence to carve out his life, and he hoped to have the independence to do so at an early age. His spiritual pain occurred as he was trapped in an environment where he could not carve out his own life. In other words, his strong desire to carve his life was lost and he stagnated; as a result, he blamed himself, and this negative energy brought despair. Gambling helped him to get rid of this negative energy. Being the Chairman of the Residents' Committee and making ceramics helped him to channelize his energy. It gave him an outlet for the enormous energy, and he stopped wasting time and found useful ways to use his time.

Although initially he could not endure the same as life seemed to be dull and infinite, he believes that he can endure it now, as he believed that as he had aged, and he did not have as much time left. Therefore, if he was still healthy and young, he could go to Tokyo, again, but at this age, he preferred to stay at the sanatorium. Finally, he generalized his life saying that it was "Overall, a half-baked life," and he therefore did not have the sense of accomplishment of having carved his own life.

4. Spiritual well-being of aging Hansen's disease survivors

4.1 How do individuals live energetically despite having experienced extreme situations?

Half of the life of Hansen's disease survivors was filled with suffering because of discrimination and exclusion, containment and lifelong isolation, human right violation in sanatorium, loss of opportunity of coming back to the society by delay or abolition of the law, etc. Now the average age of these survivors is 86, and some of them have dementia, while others exhibit withdrawal symptoms. On the other hand, there are some survivors who are living energetically. How do they manage this despite having experienced extreme situations? In this section, we introduce the aging Hansen's disease survivors' spiritual well-being, which is clarified by five survivors selected strictly from 77 survivors (at that time of interview) of Oshima Seisho-en.

4.2 Construction of spiritual well-being; Introduction of the study

Construction of spiritual well-being as shown in **Figure 5** [2].

Purpose: To clarify the spiritual well-being of aging survivors of Hansen's disease and explore the question "How do individuals live energetically despite having experienced extreme situations?"

Method: (1) Participants: aging Hansen's survivors living in the sanatorium, living with vigor and liveliness, who were selected in a strict manner. (2) Data collection: semi-structured interviews. (3) Analysis: qualitative and inductive methods.

Results: (1) Characteristics of the selected survivors are as follows: relatively younger, fewer unmarried, entered the leprosarium at teenage, had held a managerial position in the sanatorium, fewer sequelae, and believed in religion, compared to all the residents in the sanatorium. (2) Narrative data were integrated through the following seven categories: <1. Continue to have strong bonds with one's spouse and memory of parents' family>, <2. Healed sufferings by living in a sanatorium located on an island with a beautiful view>, <3. Possess the self-confidence to overcome the difficulties>, <4. Live daily life with delight and worth even on a secluded island>, <5. Continue one's efforts despite aging>, <6. Obtain social approval>, and <7. Engage in social interactions with the next generation and outside the island>.

Discussion: The spirituality of survivors of Hansen's disease had a trilaminar structure, comprising the following: establishing the *existential foundation of a sustained self*, *living in the moment but contemplating the future as well*, and *dovetailing within the society and transcending space and time*. The participants had achieved the developmental task of ego integrity in old age. If compensatory mechanism is met, we might be able to develop an existential foundation for the sustained self and

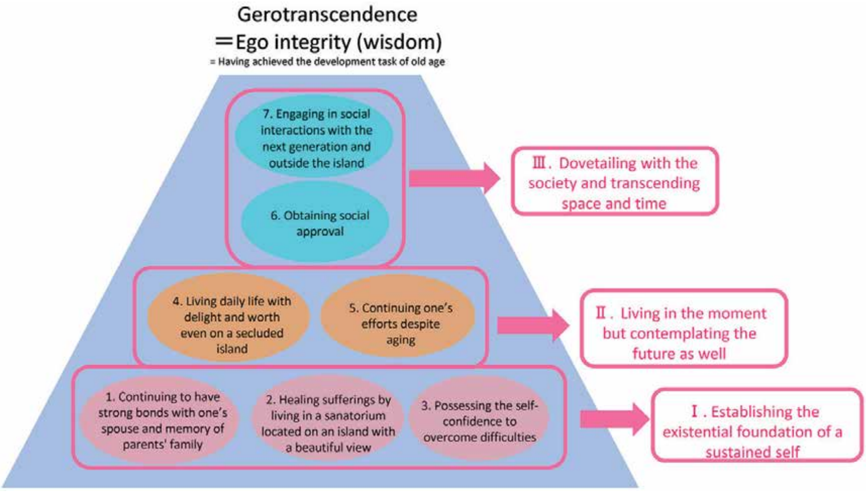


Figure 5.
Structure of spiritual well-being in aging survivors of Hansen's disease. Transcription from Yamao et al. [2].

achieved ego integrity at old age despite having to live in unfortunate circumstances. Thus, if we support such individuals, we can promote compensatory mechanism.

5. Conclusion

In this study, after discussing the conceptual structure of spirituality in the first report, we conducted an analysis of spiritual pain and discussed Mr. Takahisa Yamamoto's experience as a Hansen's disease survivor. In addition, we introduced our research on the spiritual well-being of aging Hansen's disease survivors.

Mr. Yamamoto's spiritual pain was because of *Loss of autonomy and independence for carving out my life* and *Going back and forth between life and death*, and he was stuck in the negative cycle for almost 20 years. In a psychiatric study on differences between the mental condition of condemned criminals and life imprisoned criminals, condemned criminals acted violently and were easily distracted and stressed, while the life imprisoned criminals exhibited emotional paralysis and regression. [3] The reason for this difference is that while condemned criminals faced their death every day, because the date of execution is notified to the condemned criminal only on the morning of the appointed day, life imprisoned criminals repeat the same daily life until they die. In other words, the life of condemned criminals is condensed to 1 day, while that of life imprisoned criminals is diluted across their lifetime. Mr. Yamaomto's sufferings are similar to that of criminals imprisoned for life, as both experience difficulties with delight and hope, owing to a repetitive and unchanging daily life. As a matter of truth, Hansen's disease is not crime, although it is one of the many diseases in which human rights were violated. We must hand down this information and stop it from being forgotten, because Hansen's disease has a cautionary tale to ensure that the same mistake is never repeated.

Next, Mr. Yamamoto's recovery from spiritual pain was achieved with time and reflection, and then the bellwethers, who continued to be there during his time of suffering time, led to a turning point to change the flow of his life, and he spent a substantial amount of time to get approval from others and to meet their expectations. By then, he had stopped his undisciplined way of wasting time and had found out how to use his time productively. Some aging Hansen's disease survivors tend to withdraw as they are not able to get a catharsis against the past bitter experiences. In addition, right now, some young people have lost or cannot find their reason to live, and they withdraw or become desperate, therefore recovering from spiritual pain is a universal issue throughout ages. In Mr. Yamamoto's recovery process, there were some people who were affectionate toward him and were concerned about him. These people included his mother and sisters who expressed their affection, his wife, who sustained their married life, the elders in the residents' committee who created the opportunity for changing the flow of his life, good friends in his new world, and old friends who were awaiting his return. It is evident that humans can only be healed by humans. Success in recovering from spiritual pain is dependent on people who continue to support a person during their suffering and recovery. If we think about the support for people who are lost or unable to find the hope to live, creating a support system in the period of suffering and recovery is important. In the current times, human relationships are sparse and require patience.

The construction of spiritual pain and recovery from it in the chapter is from the point of view of one survivor; therefore, the analysis cannot get be universal. We must continue to analyze the information. In addition, a certain survivor said, "I will take real my sufferings to my graveyard." Talking about sufferings is difficult for Hansen's disease patients/survivors. We must realize that it is also difficult to understand the real pain of the suffering, and we must have intellectual humility.

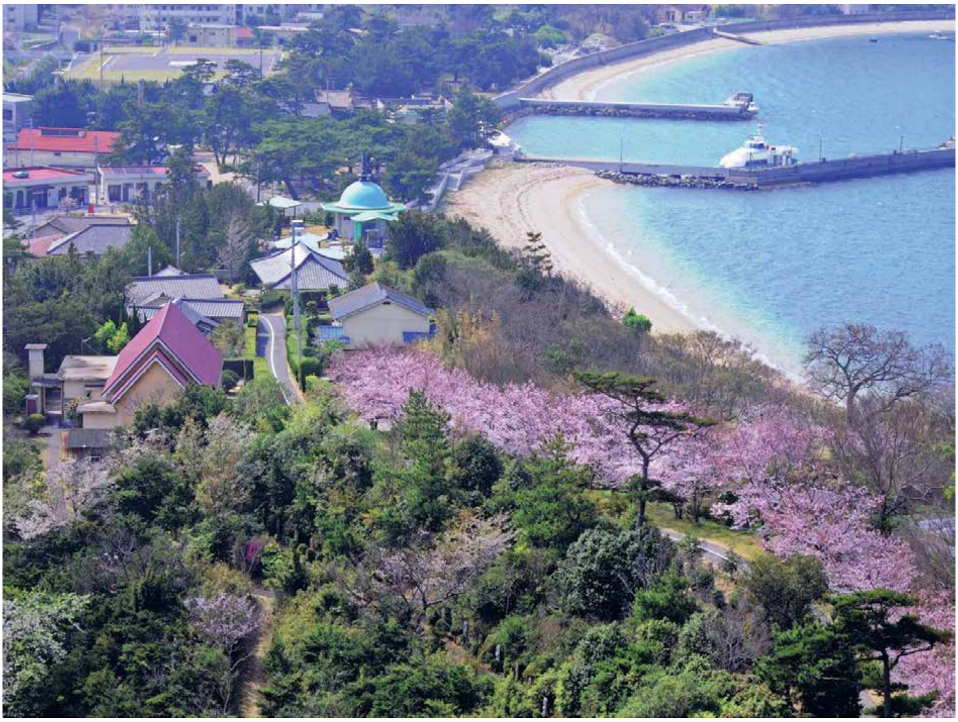


Figure 6.
Ōshima at springtime (the green roof in the center is the ossuary) (Photograph by: Kiyoshi Wakibay).

Finally, the spiritual well-being of aging Hansen's disease survivors is a trilaminar structure, comprising of the following: *establishing the existential foundation of a sustained self*, *living in the moment but contemplating the future as well*, and *dovetailing within the society and transcending space and time*. Development tasks of old age include integration vs. despair (wisdoms). The existence of spiritual well-being in aging Hansen's survivors shows two things. The first, when we experience unbearable hardship, if the compensatory mechanism works, we can sublimate sufferings and achieve incomplete development tasks at each stage. The second, "integration" of old age's development task means the person completes integration with spirituality. This shows that "gerotranscendence" as stated by Erikson [4] is seen in Hansen's disease survivors. Although a lot of negativity has been focused on Hansen's disease, utilizing the survivors' wisdom and strength for solving problems in future will help to regain their reputation. Finally, we append "Oshima at springtime" through photographs, taken by Mr. Kiyosi Wakibayashi during his life. He is one of Hansen's disease survivors who is an example of spiritual well-being (see **Figure 6**).

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Conflict of interest

We have no financial relationships to disclose.

Appendix: Mr. Takahisa Yamamoto's life review (an excerpt only from the section that discusses spiritual pain)

Transcription below:

Makiko Kondo. Oshima Seisho-en: Life Review of Aging Japanese Hansen's Disease Survivors - Deeply Deeply Closing Our Eyes in Order to See What We Truly Should See. USA: Orizon Research Publishing; 2019

Chapter 3: The Story of Hansen's Disease Survivor Takahisa Yamamoto (Listener: Mikako Yamaberi)

I. Troubled times

1. From contracting the disease until arrival at the sanatorium

1) Contracted the disease during junior high school under the old system (7th–11th grades); hospitalized at university hospital; returned to hometown to continue school

-Contracted the disease in 9th grade; diagnosed with macular leprosy at university hospital

Yamamoto: I contracted the disease at the end of 9th grade. Once 9th grade ended, I immediately submitted a request for a leave of absence from school and was examined at the Kyoto University Hospital. I was told, "There's no mistake, this is macular leprosy." When I asked, "do you have inpatient facilities," I was told they did. Instead of returning home, I assembled the items I would need as an inpatient from a rental bedding store and was admitted to the hospital immediately.

Listener: Wasn't Kyoto University Hospital where Dr. Noboru Ogasawara was, who opposed forced quarantining?

Yamamoto: Yes, Dr. Ogasawara was there, although I did not have much direct contact with him.

-Hospitalization for one year at the university hospital; return to hometown and to schooling

So, I was hospitalized at the university hospital. Since my condition did not change after more than a year had passed, and because I was young and hospital life was boring, I decided to return home. At the time of my return, the doctor said to me, "You must be careful. You won't be able to have peace of mind without being careful for 3–5 years, so even if you go home you will have to go to the hospital again. If you don't want to come here, send money for the medicine and we will send it to you."

By the time I was back home, the educational system reform had changed the schools. The school that I commuted to by train had been incorporated into a high school built in my local area. A teacher from that school came to invite me to enroll, saying "How about resuming your education? You can come back at any time without having to take a test." I entered that new high school.

2) Disease worsens; prepare to enter the sanatorium

-Money for medicine spent for fun; new macules; it was too late, there was no choice but to enter the sanatorium

I started school, but instead of sending the medicine money from my parents to Kyoto, I had a fun life with my friends. I had just one red macule [as one of the initial symptoms of Hansen's disease, white or reddish-brown, flat or slightly raised spots called macules appear on the skin and are not characteristically painful or itchy] on my thigh, but then one appeared on my face too, and I thought, "Ah, now it's all over."

I made up my mind. I learned enough information while I was at the hospital that I realized that I had no choice but to enter the sanatorium.

3) Overcame parental opposition and decided to enter the sanatorium

-Parents said the staff would have no patience for me, and if I go to the sanatorium I had better prepare to run away and never come back

But my parents opposed this and said, "Even if you go to the sanatorium they will have no patience for you there." At the time, the general public had strong judgments about macular leprosy, so I was told, "If you run away there and then come back you will shame the family and we will no longer be able to live here. If you go, be prepared to never come back."

-Full of despair that my life was over; was indecisive for one year before entering the sanatorium

Before I went, I was filled with indecision, had no desire to study, and was in just complete despair. I believed all my hopes and dreams had been extinguished.

I thought that my life was over no matter what I did, and it did not matter when I entered the sanatorium since I had no future anyway. I'd just be kept alive until I die like a cow or a pig. I milled about with indecision for nearly a year, but in the end, I persuaded my parents and came here myself. That was April 1, 1952.

4) Surprise at the beauty of the sea around Ōshima

-Surprise at the beauty of the sea around Ōshima; people from mountain villages do not know the sea

When I came here, I thought that it would be a poor place for human habitation. My strongest impression when I arrived was surprise at how beautiful the ocean scenery was, since I was from a mountain village and had never known the sea.

5) Hard to determine how to shirk patient labor

-Difficult living here; was given a lot of slack in my upbringing so I was especially slipshod and let things take their own course

I strongly felt that it was a lot of trouble to live here, at least at that time. Before I came here, I lived comparatively free, as you could say that I was given a lot of slack in my upbringing, so my lifestyle here was inevitably much too negligent. What I understood from others here was that I did not do a single thing; this is because I did not feel like doing anything and so I slacked off every day, living a haphazard life and really letting things take their own course.

-How to shirk patient labor

When I arrived, patient labor was waiting for me. I was immediately given my share of work, but all I could think about was how to shirk my duties.

Listener: What kind of work was it?

Yamamoto: It was called outpatient treatment assistance and involved things like wrapping bandages and giving injections after the nurses had changed wound dressings. In the injection room, we had to sharpen the needles and sterilize them by boiling. After this was over, we helped the nurses clean.

The work was easy, but the hygiene was poor. I got out of most difficult work, like attendant work or nursing work at the sick ward, because I had other people do it for me.

-My work was covered by a patient working fervently to support his wife and children living off the island

Listener: Were there people who immediately would do the work for you?

Yamamoto: There were. Unlike me, who had no work experience and came straight from student life, there were people there who were married but their household was not yet on firm footing. They had children and so even though the wages were meager, they would work double or triple shifts to send money back to their wives. This kind of person would even take on unpleasant work, and I would ask people like that to cover my work.

-Poor reputation; pushing around adults despite being young and energetic; did not worry about criticism

I had a bad reputation. People would say, "He's young and energetic but he doesn't do work like the others and instead pushes around his elders." People thought so badly of me they would chew me out, but I did not care too much about that. Since I was living a hopeless life after coming here anyway, I did not worry much about being told what to do.

2. Troubled times

1) My life was over; thought about death

-My life was over, and I could only keep breathing

Listener: After discovering that you were sick and before you formed the resolve to come to the sanatorium, I believe you had significant internal conflicts. What are your thoughts on this?

Yamamoto: Yes, I thought, "1) My life is over. I'll just let the cards fall where they may. The only thing left for me is to keep breathing. 2) If I find myself going in too dire of straits, I should just end it all right there." But I wasn't able to die that easily, either.

-Death was constantly in the back of my mind; I asked myself why I was alive

3) But about death... I constantly had the idea of death in the back of my mind. When I came to the sanatorium there were 11 of us in a 24-mat size room (about 40 square meters). 4) I could only be free during bedtime, so when night fell, I would lay out my sleeping area, get inside, and think about why I was alive until I fell asleep. 5) I always thought long and hard about that, even though it was troublesome, since I did not have any goals or hope for being alive. I could not help asking myself this question.

-Lived a slack life during the day and thought seriously during the night; scolded myself saying, "Are you even human? Isn't it normal not to remain alive?"

6) I had two selves: during the day I would slack off and live carelessly in the moment, but at night I would think very seriously. One of my selves scolded the other: "I lived another day even though I have no purpose. What are you even thinking about? Are you even human? Isn't the truth that humans can't stay alive?"

-Even dogs and cats can fend for themselves, but living off of handouts from others does not feel like being alive

7) "Even dogs and cats can find their own food to eat." I was in the position of being given my rations, which I ate even while complaining about the taste. I was just living off of handouts from others. I had absolutely no initiative to keep myself alive.

-Going back and forth between life and death; might commit suicide tomorrow

At night, I could not stop thinking about death, and I went back and forth between truly wanting to live and wishing to die. This continued for how long? About 10 years—no, for 20 years...

I would just keep thinking, 8) "Maybe tomorrow I will say goodbye to this world." I only thought this, however, and never took any action; I could not have anyhow.

2) Knew what kind of future the patients would have; came to the sanatorium as if running away

-Understood the kind of future Hansen's disease-affected individuals have; left school thinking it would be a problem if others found out

When I returned from the university hospital, I understood to a certain extent what kind of future was in store for people with this disease. After leaving school, everything was just completely dull and uninteresting. I quit school in my second semester of 11th grade. I left thinking, "Ah, this is no good at all. I can't let people find out."

-Contacted the sanatorium myself; came as if running and hiding; there were rumors among my school friends, but they thought it best to leave me alone

I disappeared suddenly. This is because I felt I could not just tell my classmates upfront that these were the reasons I had for leaving school and them. I heard about the location of this sanatorium and asked them to come and meet me at a rendezvous point at the top of a mountain. I really felt like I was running to the sanatorium to hide. I suddenly stopped showing up to school, and so there were rumors.

"What happened? He hasn't been here at all lately."

"I heard he quit."

"I heard he was quarantined."

They said, "If that's the case we shouldn't look for him," and left it at that.

-When I returned from the university hospital, I was slovenly and did not feel like doing anything; this was the bitterest time of my life

Even before I quit school, 9) when I returned from the Kyoto University Hospital, I really had no inclination to do anything and was careless about everything. It was a tough time for me then and for the next 20 years or so. At night, whether I was awake or asleep and dreaming, I thought about this.

-Went back and forth between living and dying

Thinking back after all this time has passed, I lived my daily life in a spaced-out way, so that I cannot remember how I felt when I first got sick. 10) My inner conflict at that time caused me to worry day in and day out. Going back and forth between life and death probably refers to times like that.

3) Suicide of fellow resident—I can callously live in a place like this because I have an abnormal mind

-Suicide of resident; rumored to be due to his younger sister's broken engagement, but it was actually because he despaired his life

There were three people about my age who hanged themselves. At the time, I wondered if it was real.

One person got sick while attending T High School and so was around the same age as I was when I came here. His younger sister was to be married, but it was said the engagement was broken off when the groom's family found out about his disease. 11) People said, "He died because he was bitter about the broken engagement," but it was not that simple. He really did it because of his despair about his life and abandonment of hope. After all, I was the same way—always despairing. I think that is why I cannot recall what was going on with me back then.

-He had a normal mind so he killed himself; I have an abnormal mind so I could callously live in a place like this

12) Around the time when I arrived, there were a number of older people who hanged themselves on a pine tree. I thought, "Ah, that one has a normal mind." I'm still alive here, having gotten this illness and having to live out my life in this small space, and I cannot see suicide as the answer. I simply cannot. I felt that, since there is an abnormality in my mind somewhere, I can keep living callously even in a place like this."

4) I became sick when I was full of enthusiasm for the future

-I was full of enthusiasm for a future in which I would have nothing else to ask of my parents if they let me graduate from college, after which I would become independent

This is a subject I am most emotional about. I contracted the disease at the end of 9th grade.13) I was just so full of enthusiasm.

If my parents let me get through college, I would ask nothing else of them. I believed this from an early age. In the old educational system, after graduating from junior high school, the next step was college. I felt that if my parents put me through college, after that I would become independent. Kids nowadays become high school students and do not even think about what they what to be in the future. I think that's much too indulgent, and it's because they have too many material things.

5) Became saddened by comparing myself to classmates who were setting out on their own

-The academic advancement and job placement of my classmates vexed me; I was saddened when I compared myself to them

14) I would also think about things that could not be helped, like "I wonder which of my classmates went to college. I wonder which school they went to. I wonder what they've become now that they've graduated." I thought about such things whenever the time came for such events to occur. I did get a certain amount of information from my little sister, which made me feel especially wretched. If I was asked "well what are you then," I was just languishing in the sanatorium. So, it wasn't only 10 years that I lived a tiresome life, but nearer to 20.

6) Even if, by some miracle, I could leave the sanatorium, I would already be late out of the gates in starting my life

15) I had useless thoughts like, "If I endure and work hard, I wonder what unexpected miracle will take me by surprise."

But still, all I could think about were passive, backward-looking thoughts like, "By this point even if there is a miracle and I can leave the sanatorium, I'm already too late out of the gates to start my life."

7) Crushed by the despair of having all my hopes and dreams cut off

-I wanted to be a trading company employee, a federal public servant, or a doctor

Listener: When you were studying, did you know what you wanted to become, like a teacher?

Yamamoto: I would pass on teaching, although I think that if I did become one I would cultivate good students, since I have knowledge of both positive and negative things students might do; this is because when I was in junior high and high school, I did 'bad' things for the thrill of it, half out of mischief and half for fun.

When I took the entrance exams and matriculated at the old style junior high school, I had already decided which university I would go to. I told my parents that if they put me through college, I would ask them for nothing more. If they would only put me through college, I could blaze my own path myself from then on.

I wanted to be an employee at a first-rate trading company or a public servant at the national level. I'm small in stature so I was often very calculating and in planning to first become a public servant (even though I did not know which office I would want to work in), work my way up the ladder to a certain extent and then sidestep into the private sector.

What my parents told me most often—and what I thought perhaps I should do—was to become a doctor. If you become a doctor you never have to go hungry, so my parents told me to become a doctor. At any rate, all this about becoming a doctor or whatever all went out the window in 10th grade.

-I was crushed more by hopelessness than having to give up my academic advancement; it was the bitterness of my hopes and dreams being cut off that I could not overcome

Listener: You were thinking about your academic advancement, and you were forced to give that up. How did you get over that?

Yamamoto: 16) I did not get over it.

Giving up on academic advancement was secondary. More than that, getting sick put me in the position of feeling hopeless about life. Being quarantined and never being able to leave meant that I had to be prepared to give up all the hopes and dreams that I had conjured up by that point, of which academic progress was one part. That is why coming here crushed me so. I did not feel like doing anything at all.

8) An island without elderly people—life itself is not so long

-There were no elderly people; life ends in our 50s, and what's more I could not have hopes for life; became desperate and nihilistic

I was told by my parents too that if I came here, I would be isolated and be forced into a poor, destitute lifestyle, but 17) when I actually arrived, there were no elderly people. I got the sense that life ended for patients at around 50 years of age.

As for my own future, I increasingly thought, "Life itself is not so long." This encouraged in me the idea that I should not have any hopes for the future. "Whatever I do, nothing will come of it." As a result, my life became desperate and my feelings became nihilistic. To do anything was to do it in vain.

9) Forgetting was the greatest weapon to survival and the insight that eased suffering

-Greatest weapon was to forget

18) Bit by bit, thoughts like that started to fade or be forgotten. I thought, "The greatest weapon we have as humans is the ability to forget," and felt strongly that if I cannot forget this then I'll definitely hit a dead end, which would be intolerable.

-After about 20 years, the troubles faded and have now passed by

19) After about 20 years, those kinds of troubles suddenly started to fade. Now I'm pretty old. While I was lying there by myself, I never once imagined this would happen. Now, I do not think that way at all. Things like that have gone away. I've forgotten them.

3. Did not take part in the system

1) Bitterness of having no freedom

-I had no freedom with respect to society or on the island; I had no privacy; the old had power

Listener: After moving here, what was difficult?

20) Yamamoto: I came here in 1952, and what I considered a very severe living situation continued both psychologically and physically for decades. Until the 1980s, I feel like there were some questionable aspects of the living situation at the sanatorium, at least in the case of Ōshima.

The most difficult part of this was the lack of freedom. We were restrained and were legally prohibited from leaving the island, and even on the island there was no recognition of privacy. The older people had all the power, and so there was no freedom either with respect to society or in terms of life on the island. That was the most difficult thing to accept.

2) Did not take part in the system, ignored conflicts

-Stay outside of the system; unregulated

Listener: I would think that having no freedom caused you stress.

21) Yamamoto: In my case, I did not intentionally rebel, but instead as part of my intrinsic nature I could not accept becoming part of this system, so I was fine living a life away from all of that. It was rather constraining to do so, but I wasn't about to give in to relocating.

My life was really unregulated and slapdash, and I let the cards fall where they may, so it was very difficult for me to fit into a single role or to be a cog in the wheel.

-Ignored conflicts at the National Hansen's Disease Sanatorium Residents' Council and the Residents' Committee

When I came here, there was the Residents' Committee, and in the previous year a national organization was formed called the National Hansen's Disease Patients' Council (now called the National Hansen's Disease Sanatorium Residents' Council). Among their activities, including at the Ōshima Residents' Committee, they sought the revision or abolishment of the Hansen's Disease Prevention Law. Our freedom was restricted, we were put to forced labor, and the head of the sanatorium had the power to discipline and detain us through extraterritoriality.

He could detain people who did something wrong to punish them and had the right to reduce meal rations. There was a sense of opposition to these social inconsistencies. These organizations were very active when I arrived. There were often labor strikes and hunger strikes.

22) I had very slipshod feelings at that time and turned my back, thinking "Isn't it too late to be doing this?" That is why I thought, looking at it objectively, having no freedom was bitter and placed a large weight on my shoulders, but since my daily life involved letting the cards fall where they may, I did not trouble myself over it much.

3) The conflicts of the National Hansen's Disease Council ended in vain, but things improved gradually in unseen ways

-Despite the hunger strikes and labor strikes, the Hansen's Disease Prevention Law conflict ended in vain and the law continued until 1996

Listener: Did anything get better because the others had gone on strike?

Yamamoto: Nothing got extremely better. Until the 1980s, there was nothing that suddenly got better one day or improved at a particular time. It happened vaguely and gradually.

There were organizing activities and opposition activities that drove facility operations into an untenable situation, such as hunger strikes and labor strikes, but in the end, they cannot be said to have changed anything. This is because at the conclusion of the conflict over the law, they were not able to deal a blow to the national government. Ultimately, the law remained in place until 1996. Since the conflict with its large goal ended in vain, I feel the people at its forefront must have felt quite despondent by that point.

-Things got invisibly better a little at a time

At any rate, when I say things changed, it was a tiny bit at a time in invisible ways. For example, among medical issues, things like a significant bump in the health care budget, a sudden jump in the number of medical staff, or a groundbreaking reform in the new year did not occur at the Hansen's disease sanatorium.

Since the residents, who had until then meekly been doing what they were told to, began to use shows of force during the prevention law conflict, the government thought, "We had better think about this situation a little," and implemented improvements a little bit at a time. Even though, practically speaking, the conflict ended in vain, the government did raise the working wage slightly, increase medical expenditures, and increase the number of workers by one or two people. I feel that the government had an inflated view of these small changes and felt very self-satisfied about them. As these built up a little at a time, if I look back over a long period of time of 15 years, instead of 5 or 10, I can say things got better. This is the extent of the improvement we are talking about.

4) Did not listen to criticism for not participating in the conflict

-Criticism for not participating in the conflict

Listener: During the organized movement, did any of your peers say to you, "Why are you not participating with us?"

Yamamoto: I was not directly scolded like that.

Nevertheless, I had a new acquaintance who said to me, "You are still young and energetic and can do what others can do too. Why are you not participating? Shouldn't you also join the fight and put in even a small effort to improve your own living situation?"

-Circumstances without freedom; since freedom was in vain, I chose an opportunistic, non-political course

Despite someone saying that to me, I did not join the activities, thinking, "What's the point now? I've been hurtled into these circumstances without freedom where I can't leave the island, and I have no future, dreams, or hopes of my own. No matter what I do, it will be in vain, so I'll just let the people who want to participate do so. I'll be opportunistic and stay non-political."

5) Guilt at reaping the benefits of the conflict without effort

-Guilt at just reaping the benefits instead of joining the conflict

Nevertheless, after things became a little better, I was unable to enjoy those improvements. This is because I often felt guilty that I was benefiting from the work of others at their expense.

6) No medical care—how can I protect my life?

-No medical care; can I secure my own life with meager care?

One of the severe conditions was that, despite being a national sanatorium, there was no medical care. Now, we are all getting old and becoming immobile and there are pressing issues with nursing and caretaking, but when I first arrived, I was young and healthy. Even though I did not suffer in from this disease at the time, there was no care for when I got sick, and so there was a constant uneasy undercurrent over how I would secure my own life amidst this meager medical care. By chance, I have made it to today without getting sick very much, so in that sense I have been very blessed.

4. Whether to have a reunion after 65 years with school friends—too much of a difference in the paths we have taken

-A school friend saw me appear on television and recognized me; invited me to see each other

There is a Hansen's disease forum in Tokushima this year. I sometimes make short appearances on television, so there were people who thought, "Th… that's Yamamoto!" and recognized me. They're already 80 years old and past the mandatory retirement age. One person ended up becoming the principal of an elementary school. Another graduated from one of the national universities and became a school principal. During high school, we were in a group of five buddies who were always together.

-Classmates steadily progressed through lives of their own choosing, while I have been groaning at the bottom of the ravine of life; I thought perhaps it would be better not to meet

These two former classmates contacted me and said, "Let's meet up" at our hometown. This was really depressing. When this sort of thing occurs, you are forced to look at the past. My schoolmates have been steadily progressing through lives of their own choosing, have at least followed their own paths, and are now practically ready to graduate from life. My own circumstances just involved groaning at the bottom of the ravine of life until my own time of graduation came. I thought, "There's no point in meeting. What will we talk about?" I was full of worries like that. "I should just not meet with them," I decided.

-I was the only dropout; could not leave no matter how much I struggled; was miserable

Of our group of five, one person had worked at a bank and retired when he reached the mandatory age. Another person, who was the smartest of us, was someone I expected to look beyond our local university, and just as I thought he had attended one of the former Imperial universities.

23) In the end, I fell off the cart along the way and the other four all graduated from college. I was miserable that I was the only one who did not make it. Since I could not leave here no matter how much I struggled, I had no inclination to do anything and felt only resignation. Getting this illness really stained everything and nothing could be done about it, because one way or another it all ends up like this. I was invited to our class reunion, and some of those in our group said they went. I was glad I did not go. Even if somebody had become the prime minister, all I would have to say to them would be, "How are you doing?" [Laughs].

II. Changing flow of living

1. By the recommendation of elders who warmly looked after me, I visited the Tōkyō office of the National Hansen's Disease Council

-The flow changed; elders in the Residents' Committee warmly looked after me

Listener: From that hopeless state, was there something that triggered a change or the gradual re-emergence of hope?

Yamamoto: Instead of hope, a kind of flow started forming and that flow is all that changed.

When I say the flow changed, there were some people who warmly looked after me even though I was not living a very admirable life at all. They were Mr. S and Mr. M., who were elders in the Residents' Committee. At the time, I had a terrible reputation of being a slovenly fellow despite my youth and vigor.

-Activities of the Residents' Committee; idiotic

I thought even the activities of the Residents' Committee were idiotic. I thought, "I have no hopes or dreams. What's the point of being active in Residents' Committee activities in this place that I can never leave?" I was really opportunistic.

-Was nominated to be a representative for three sanatoriums to the main office (Tōkyō) of the National Hansen's Disease Council

At any rate, in 1980 there was an organizational problem with our Residents' Committee and we needed to select and send a central executive committee member from our block within the Seto Inland Sea, which consisted of three sanatoriums (Oku-Kōmyō-En, Nagashima Aiseien, Ōshima Seishoen), to the national organization. When it was Ōshima's turn, they were unable to select someone, so one day I was suddenly asked by Mr. S, "Would you go to the main office of the National Hansen's Disease Council for us?"

"You say that, but I've ordinarily taken a non-political stance and I don't know what the objectives of the organization's activities are or what the current situation is. There is no way I can go and do this. It's completely impossible!"

"I'll collect the documents you'll need, so just go for us."

-If I stay at Ōshima I'll just die a dog's death, and since the work will involve negotiations with Nagata-cho and Kasumigaseki [the elected government and the civil service], it might be stimulating

My feelings changed to wanting to go for the completely wrong motivation, which was "If I just stay at Ōshima, I'll die like a dog." If I did what they asked and went to Tōkyō, my main work would be to go to places in Nagata-cho [the center of the elected government] and Kasumigaseki [the center of the civil service] like the Ministry of Health, Labor and Welfare and the Diet Members' Building for legislators. After that, I would write reports to send to the various branch offices about what demands I made under which themes, the results that followed, and the nature of responses from legislators and the Ministry of Health, Labor and Welfare. That is all I needed to do, and the rest would be free time. I thought I might have a different lifestyle in Tōkyō, so I did as Mr. S said and departed.

2. Life in Tōkyō

-Life in Tōkyō: Tough at first

For over a month after I arrived, it was tough for me because I did not know what kind of work it was. At the time, there was a council system with seven Central Executive Committee members, so the seven people were selected and sent from their respective blocks. I learned a lot about the organization's activities, although it was tough at first when I had no previous knowledge.

-Mustn't harm Ōshima's reputation.

I was selected from Ōshima, and it would be out of the question to be noticeably inferior to the other six members, so my work had to be comparable to the others.

It wasn't on par with the Olympics like we have now, but I felt, "I mustn't harm Ōshima's reputation." So I did work hard for the organizational activities.

3. Effect of wife's encouragement and assistance

-Approval from wife approval and friends; wife hoped this would trigger a change in me.

Soon, my wife started wanting to go. I had to raise my standard of living or else our relationship would become a battleground. If I stayed here, I would not do much good for anyone and would live life on the sidelines, since I just played a lot of Mahjong and such. But it seems my wife thought, "maybe going will cause a change." So she said, "Maybe it would be good to try going to Tōkyō. I also want to have a peek at Tōkyō, instead of spending all my time here at Ōshima." I actually though she would be opposed to the idea. She did have an uncle and aunt here, after all.

I also had thoughts pulling me in the other direction, namely, how could I go to Tōkyō and leave behind the people who were always concerned for me even though I was usually up to no good, like Mr. I and Mr. T, as well as the head of the group for the blind. Nevertheless, those people also told me, "Just go and learn from it. Then, when you return, make use of what you learned." They encouraged me to think more forwardly.

-Four years in Tōkyō; blessed with good friends, visited various places, and had good stimulation

I was in Tōkyō for about four years, and there were a number of people I could get along with who treated me very well. My friends in Tōkyō would take me to all sorts of places in their cars, and I think that time was stimulating for me.

-Wife thought that life in Tōkyō was the best

It seems that it was fun for my wife too. It was tough to be told, "The only good times were in Tōkyō, and after that not a single thing was good."

4. Resolve to return to the island

-Returned to the island without extending my stay so as not to abandon my friends on the island

I was there for four years over two terms, and was asked, "Please extend your stay." Right around the time my term ended, there was a change in the system for the executive office chairperson, and I was asked to stay as the next chairperson. However, Mr. and Ms. O at Ōshima said to us, "Are you just going to abandon us?" It is tough and painful being asked that, and I thought that since they were depending on my wife more than I was to such an extent, she should take care of them. I felt that this would be hard for my wife too.

I asked my wife, "What should we do?" She said, "We can stay, or we can go back," so I decided, "In that case we'll return."

-Life in Tōkyō would have been impossible without my wife's help

Listener: Did your wife support you through this?

Yamamoto: Yes. Working at the head office could not have been successful without her. For someone like me, it would be tough to go alone. I worked all day at the office and so would have to make my own meals when I returned home, and then I would have to clean the rooms and wash the sink and do the laundry. I could not do that myself. There is the saying, "Maggots grow in a widower's home," and there really might have been maggots without her.

5. Return to the island; elevated to Residents' Committee chairperson

-My standing was reversed before and after going to the Tōkyō office; was recommended for the Residents' Committee chairperson at Ōshima to take advantage of what I learned at the head office.

After returning to Ōshima, my standing had undergone a complete reversal from four years prior. I was quickly elevated to Residents' Committee chairperson at the next election with the hope that I would take advantage of what I learned during my four years of work at the head office. When I returned, there were still over 600 patients here. When I was raised to this high position, my way of life started to change a little.

6. Was able to come to terms with time

-Hadn't done anything decent until then

Until that point, I had not really done a single thing to get praise from others, and even now I'm not doing anything praiseworthy. But after the age of 60, I did some ceramics. Until then I went fishing and when summer came I would go diving.

-It is tough to come to terms with the time I have left; I had lived without goals in a workaday way

At this point, it was clear I do not like work and do not have anything to do day in and day out. This is also something that is bitter to me in terms of being alive—to come to terms with the time I have left. Unless you accept this completely, you cannot come to terms with it at all. I only drank and gambled, so I really lived without goals or meaning in my life.

-Slack way of living

That is why as a human, I saw my way of living as completely slack. I very much regret this now. It would be better if I could come to terms with things through a sense of fulfillment like other people, but it's difficult when you just slack off.

-Work as the Residents' Committee chairperson; avoiding boredom as one way to come to terms with time

By doing the work of the Residents' Committee, I could avoid boredom because things had to get done whether I liked it or not. That process is pretty much the same now, as well. Sometimes there is work that makes me think, for example something that does not make sense, in which case I know I have to do something about it and dive in headfirst. For me, this is a way to come to terms with time, and I can avoid boredom. That's all.

Listener: But I feel like you were actively pursuing a lot of activities.

Yamamoto: I did not normally think about things for other people or fight for human rights. It's just that while I'm alive, I have not been able to come to terms with time very well, so doing these kinds of activities becomes a way to do this.

-Here, the sciences were of no use, but in the liberal arts I could have engaged in literature as a way to come to terms with time

Even while I was a student, I liked math and the sciences more than the liberal arts, and so I was completely useless after coming here. I think, "I could have used my time well in the humanities. What a mistake." Coming here, instead of using my body to do something, I would have made something spiritual, a literary work. A novel or critical commentary would be beyond me, but I think it's possible that making *haiku* or *tanka* poems would be within my reach, although I might be scolded by people who have studied those forms and tell me that I'm underestimating them.

-If I were healthy, I could go to Tōkyō again, but my body was on the decline

There came a time when the main office talked about sending me to Tōkyō again. The organization is in trouble right now, so if my eyes and ears were in good shape I would go at my own expense, but now my sight and hearing are no good. I would not want to always need an attendant to do the work if I went all the way to Tōkyō.

-Short life remaining; even if it must be endured, it is not infinite, so I could just spend it at Ōshima

I think, "I can just stay at Ōshima and do what I can here to pass the time." I do not have that much time left. Even if it is a matter of endurance, there is not an infinite amount of time that must be endured, so I think that leaving things as they are is fine.

7. Overall, a half-baked life

-Looks like life will end with me still a good-for-nothing

At any rate, I'm starting to see that my life will end without having done anything and as still good for nothing. It seems a 'good-for-nothing' remains a good-for-nothing to the end. Even with the work of the Residents' Committee, if you want to do it with a relaxed attitude in your spare time you can do it all in a relaxed way, and if you want to dive in headfirst and do things seriously, you will have to put in the appropriate effort. You have to read books about organizations, social order, and welfare, and study specialized topics. Just understanding these things does not mean that you have the will to put them into action. That is because you will compromise and think, well as long as I can manage to not fall behind, it will be good enough.

-Half-baked way of life; cannot find words to leave behind to the subsequent generations

Listener: If you were to leave behind something of what you experienced at Ōshima to future generations, is there anything you know you would like to say?

Yamamoto: No, I have not thought about such things before. I cannot give a quick answer to questions like that.

If it is about what I have done at Ōshima, until I passed the age of 40, I was obsessed with Mahjong and gambling and that's about all I did. After that, there wasn't anything that I could tell other people, "This is what I've done."

Looking back, my entire way of life has been half-baked. If I myself had lived even a little more ready for my own life, I would now have words or things I wanted to leave behind. I've just been a slacker, and there were few times I could be completely serious; usually it happened momentarily or temporarily. At times when I'm working, I do think in my own way about things like, "Which perspective should I speak from next time," when, for example, I am at a Hansen's disease forum or when someone comes to me to talk. It's pretty haphazard. I do not have the knowledge or room to be irresponsible. Since one should not be haphazard, I do in my own poor way think about what I should say next.

(The following is omitted.)

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References

[1] Kondo M. Oshima Seisho-en: Life Review of Aging Japanese Hansen's Disease Survivors—Deeply Deeply Closing our Eyes in Order to See What We Truly Should See. USA: Horizon Research Publishing; 2019. ISBN: 978-1-943484-20-1. Available from: http://www.hrpub.org/books/bookinfo.php

[2] Yamao H, Mugurima M, Furochi K, Mikami J, Tsuge Y, Kondo M. Spiritual well-being of aging Japanese survivors of Hansen's disease: How do individuals live energetically despite having experienced extreme situations? Journal of Comprehensive Nursing Research and Care. 2017;**105**:1-18. DOI: http://dx.doi.org/jcnrc/2017/105

[3] Kaga O. Psychology of Condemned Criminal and Imprisonment for Life. Tokyo: Kongo Shuppan; 2008

[4] Erikson EH. The Life Cycle Completed: A Review. New York, NY, US: WW Norton & Co.; 1985

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This book is a collection of chapters addressing various aspects of quality of life and health psychology from a biopsychosocial perspective. Chapters cover crucial issues, both clinical and social. Starting with an analysis of the concept of quality of life as it is described by the World Health Organization, subsequent chapters of the book examine the biological, psychological, social, and spiritual issues related to the concept. The book explores how health, climate, psychiatric diseases, and social conditions of specific geographical areas can impact quality of life.

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