Chronicity

Chronicity:

Challenges and Perspectives

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FOREWORD

In the context of life and health, the contemporary world faces the challenges posed by chronicity, which can be understood in a variety of dimensions and contexts, which vary according to the reality and demands in which human beings find themselves.

The present work provides clear evidence of this diversification in the scope of chronicity, through the approaches presented in the various stages that lead to chronicity.

Didactically and within an evolutionary process of life, to aid the description and understanding of chronicity in its varied aspects, the chapters of this book have been grouped into 11 guiding axes that will receive their own sequential description, displaying their outcome according to their defining elements.

In this sense, it is believed that adopting this criterion will converge the nuances of chronicity, permeating the understanding of its challenges and prospects.

In axis one, the dimension of "health and quality of life promotion" points out that even in the most diverse contexts from the point of view of health, having an initiative and a goal (health and quality of life promotion) are feasible and can be achieved as long as a broader perspective on health is taken.

Axis two, in turn, emphasizes that "on the wheel of time: from ephemerality to chronicity in life", the facts stand dialectically between two opposing realities. The first one defines ephemeral, brief, transitory, and momentary aspects, while at the other end of events lies something that is defined by the state of events occurring at certain times, with periodicity and no time limit, as is the case with illnesses, where there is a certain period for their onset, but no time limit for their duration.

Through axis three, the authors point out that chronicity, albeit to a lesser extent, is present in childhood and adolescence. It is not exclusive to adulthood and aging. Thus, the main reasons are highlighted, as well as the biological and quality of life compromises suffered by the affected individuals. It is essential to reflect on the life restrictions imposed by chronicity from various points of view.

Successively, the present work in its fourth axis, in a unique and unprecedented way, presents violence against transgender people, as well as the diversification of gender identities, thus emphasizing antisocial behaviors that go against life and health. Differences in gender preference seem to create susceptibility to “chronic” trigger factors of the most diverse natures, such as physical, psychological, and social.

As far as axis five is concerned, chronic communicable and noncommunicable diseases in the community context are becoming more prominent and visible in contemporary times. Presenting this situation via a didactic and scientific tool leads to the reflection that in addition to chronic noncommunicable diseases, there is also the context of those diseases that are chronic, but with the dimension of transmissibility.

The authors quite aptly address the relationship between chronic illnesses in the workplace and competence and quality in axis six. It is known that the occupational environment has been an important trigger for chronic illnesses of an emotional nature. The work environment can lead employees to become ill. A range of physical illnesses can also stem from work activities, such as osteo-articular and postural conditions.

The next theme presented, which is axis seven, focuses on chronicity and the elderly. It is clear that ageism, the role of women in the workplace, black women, and the lack of caregivers due to chronicity are the main factors related to the lack of sustainable development worldwide.

Proposals have been submitted as strategies for establishing sustainability in the wake of these issues. Sustainable development will only be established once new strategies, paradigms, and resources are included in public policies related to aging.

Axis eight, which focuses on palliative care, presents the need and importance of this practice for people who, due to a medical diagnosis, are in a condition of finitude, but who deserve relief from pain, suffering, and measures to improve their quality of life. The patient and family binomial must receive qualitative care in the context of palliative care. This type of care is needed not just for carcinoma patients, but for all those who find themselves within the range of diseases that warrant ordinary care and no more extraordinary treatments.

Finally, this book addresses spirituality in the context of chronicity. It is known that the spiritual dimension aims to establish support networks between those affected and other people such as family, friends, and professionals, which comprise the immanent or horizontal relationship. In the context of spirituality, there is also the human connection with God, which is referred to as transcendence or vertical connection. In this context, spirituality plays a role in human life and, specifically, during vulnerable moments, such as chronicity.

Concluding this presentation of the chapters, it is necessary to clarify that when preparing the book, the multidimensionality of chronicity was considered an important point so that the scope could be expanded and the topic explored comprehensively. According to its conceptual breadth, the book focused on current, relevant, and significant themes. As a result, this book provides scientific knowledge that can be used for teaching, research, extension and care regarding chronicity at the interface of challenges and perspectives.

José Vitor da Silva

PREFACE

The book entitled “Chronicity: Challenges and Perspectives” addresses contemporary challenges related to chronicity in the context of life and health. The book is structured across 11 core axes to aid healthcare professionals in understanding the topic. The axes address issues such as health promotion and quality of life, the transition from ephemerality to chronicity throughout life, the presence of chronicity in childhood and adolescence, violence against transgender people, the coexistence of communicable and noncommunicable chronic diseases in the community, work-related chronic diseases, chronicity in the elderly, and strategies for sustainable development in this context. It discusses the importance of palliative care for patients facing finitude and explores the role of spirituality in coping with chronicity. In summary, the book aims to present a comprehensive and multidimensional perspective on chronicity, providing valuable insights for the teaching, research, extension, and care sectors.

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PART 1 - CHRONICITY AND THE DIMENSIONS OF CARE IN THE HEALTH NETWORK

CHAPTER ONE

HEALTH PROMOTION AND QUALITY OF LIFE IN CHRONICITY

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Introduction

Health promotion measures cannot be reduced to lifestyle changes, as they are individual actions from a behavioral and preventive perspective (Becker and Heidemann 2020).

Health promotion seeks to replace the biomedical model focused on medical care and serves as a transformative process by addressing the community's broader needs. It is a holistic, intersectoral process of community empowerment, strengthening popular participation, equity, action on the social determinants of health, and developing sustainable and varied measures (Becker and Heidemann 2020).

It is necessary to go beyond individual actions to promote health and move towards the emancipatory logic of people and communities through their empowerment and natural solutions to their problems.

Various health promotion models have emerged in Primary Healthcare (PHC) in this context. Among them, the Chronic Care Model, the Risk Pyramid Model, and the Dahlgren and Whitehead Health Determination

Model are highlighted. From these references, the Chronic Conditions Care Model (CCCM) stands out, with direct application to the Brazilian Unified Health System (SUS) (Mendes 2012). In this approach, the author outlines population care and stratifying health conditions.

The CCCM considers the social determinants of health, which vary between intermediate and established; the risks that affect each group or individual; and the levels of intervention, allowing PHC to manage the varying health conditions of the population.

American researchers developed the Chronic Care Model (CCM) emphasizing two axes: the first refers to the healthcare system, comprising the network's organization, service delivery, clinical decision support, clinical information system, and supported self-care; the second axis refers to resources and the bond with the community (Paula et al. 2022).

The CCM proposes a new perspective for managing health conditions to achieve satisfactory clinical results. It favors continuous monitoring with the participation of users and the co-responsibility of individuals over their health (Ghiyasvandian et al. 2021; Wagner 1998).

Challenges such as the sector's underfunding and the inconsistencies between the population's needs and how the SUS is organized impact the management of chronic health conditions (Mendes 2012).

In this perspective, the Ministry of Health has reissued the Strategic Measures Plan to Respond to Chronic Diseases and Noncommunicable Diseases: 2021-2030, with Integral Healthcare as one of its axes (Brasil 2021a).

The strategic measures in this axis emphasize, among other factors, the need to incorporate new technologies aimed at chronic NCD, expand the production of medication for the treatment of chronic NCD, promote healthy aging with specific therapeutic processes for older adults, emphasize professional training with emphasis on multi-professional teams, and strengthen integrative practices in PHC (Brasil 2021b).

Thus, the intensification of measures with emphasis on health promotion through Integrative and Complementary Practices, recognized in the National Policy for Integrative and Complementary Practices in the SUS, such as acupuncture, homeopathy, herbal medicine, anthroposophy, thermal therapy-crenotherapy, has also been consolidated; 15 more integrative practices were included in 2017 and 2018, currently totaling 29 Integrative and Complementary Practices in the SUS, in line with the objectives and guidelines of the SUS and the National Health Promotion Policy (Brasil 2015).

In this scenario, models and initiatives aiming to promote health and manage the care of people with chronic conditions are proving promising.

However, political and managerial obstacles must be faced to ensure the optimum healthcare provision to the population. This is intended to reduce harm, prevent disability, and avoid premature death.

Health Promotion Model

Health promotion measures cannot be reduced to lifestyle changes, as they are individual actions from a behavioral and preventive perspective (Becker and Heidemann 2020).

Health promotion aims to overcome the biomedical model centered on medical care and should be considered a transformative process, as it addresses the community's broader needs. It is a holistic, intersectoral process of community empowerment, strengthening popular participation, equity, action on the social determinants of health, and developing sustainable and varied measures (Becker and Heidemann 2020).

To promote health, we must go beyond individual actions and move towards the emancipatory logic of people and communities through their empowerment and real solutions to their problems.

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In this scenario, models and initiatives aiming to promote health and manage the care of people with chronic conditions are proving promising. However, political and managerial obstacles must be faced to ensure the optimum healthcare provision to the population. This is intended to reduce harm, prevent disability, and avoid premature death.

Definition and models of HRQoL in chronicity

Quality of life (QoL) assessments emerged in the social sciences and have grown in health. There are various definitions of the term quality of life, but three characteristics are common: subjectivity, multidimensionality, and bipolarity. The concept of QoL can vary from one individual to another and must encompass all aspects of life; in addition, it suffers from cultural and historical influences and depends on social stratification (Minayo, Hartz, and Buss 2000).

In the health field, the assessment of QoL has become essential since the 1980s, as the results demonstrate the consequences of the disease; it assesses the results of treatment, detects the side effects on the patient’s life, evaluates the cost/benefit, and the patient’s preferences. The term used is health-related quality of life (HRQoL), which is used as a synonym for perceived health status. The main objective of these assessments is to check how much the disease or chronic condition, in addition to its symptoms, interferes with an individual's daily life, i.e., how much the manifestations of the disease or treatment are felt by them (Fayers and Machin 2016).

Considering that chronic NCD leads to significant changes in people's daily lives, assessing HRQoL in these conditions is extremely important. As it is a subjective construct, assessing HRQoL is a challenging task; another relevant aspect is that there is no gold standard, and it is dynamic. It can be assessed in several ways, such as using generic or specific instruments in the form of an interview or self-administered.

The instrument selection will depend on the population's characteristics; if it is specific, specific instruments will be used, while generic HRQoL instruments can be used in different populations but have the disadvantage of needing to be more sensitive to capture specificities. Specific instruments capture the specificities of a situation but need to provide a complete understanding of the phenomenon. To assess HRQoL in chronic diseases, the most commonly used instruments found in the literature are the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36), the Nottingham Health Profile (NHP), and the EuroQol (EQ5D). It is necessary to have these instruments translated and validated in different languages and countries in order to use them (Cella and Nowinski 2002).

Another important point is the use of a QoL theoretical framework. The absence of an explicit theoretical model to guide the development of QoL research has limited the use and generalizations of QoL assessment in clinical research (Gitleman and Kleberger 2014), so the use of a Theoretical Framework is desirable as it provides greater data generalization.

There are various theoretical models of QoL, such as Calman's Expectancy Model, the Needs Model, the Existential Model, multidimensional models, and the Ashing-Giwa HRQoL model. The models can use various approaches, such as the utilitarian approach, which aims to enable decision-making under uncertainty, considering the cost and benefit of treatments and the individual's preferences. The psychological approach considers the individual's perception of becoming ill and the disease.

Therefore, the evaluation of HRQoL in research and clinical practice is of paramount importance, as it portrays the impact of the disease and treatment on individuals' daily lives, provides more individualized data, and considers patients' preferences about treatment and provides guidance in the planning of nursing care for chronic diseases.

Health education, self-care, and patient empowerment

Health education is characterized as a direct and low-cost way of producing and applying knowledge, which favors changes in certain behaviors and aims to promote human development. This strategy meets the population's social, mental, biological, and economic needs to promote health and improve the QoL of those participating (Silva et al. 2010).

Health education can be carried out by various professionals who are trained and qualified to perform the educational process in all sectors of healthcare (primary care, referral centers, and hospitals). Health education is given a context in which users take responsibility for their health conditions and the way they live. The practices involve the professionals, the managers who support these professionals, and the population, the latter of which needs to build up its knowledge and increase its autonomy in individual and collective care (Souza 2001).

This knowledge is essential for promoting self-care, which is defined as a set of practices and a continuous dynamic process that an individual carries out to maintain physical, mental, and emotional health, which, although being an individual responsibility, involves social, cultural, and environmental factors (Orem 1987).

Changes in health can affect the capacity for self-care. Among these changes in the patient's life are chronic diseases. Thus, diseases such as diabetes, hypertension, cardiovascular disease, and osteoporosis can negatively influence the ability and capacity to carry out basic activities in daily life, such as feeding, bathing, and getting dressed (Siqueira et al. 2011). In addition, the presence of multiple chronic diseases can lead to an overload in self-care management, especially when it involves the need to use medication and pay attention to diet and physical activity.

Self-care is an essential practice at all stages of life, encompassing aspects such as physical exercise, healthy eating, meditation, and therapy. It is essential for reducing stress, promoting emotional balance, and preventing physical and mental diseases (Unicovsky et al. 2021).

Patient empowerment stands out among the measures to promote health education for chronic NCD; it is essentially an educational process (Taddeo et al. 2012). Patients who are more informed, engaged, and empowered in their care perform more productive and individualized information exchanges and interact increasingly with healthcare professionals. Empowerment is aimed at developing patient autonomy, enabling them to take control of personal, environmental, and socioeconomic factors that affect their health through knowledge, skills, and actions (Taddeo et al. 2012; Nobre et al. 2020).

To this end, healthcare professionals need to be able to provide individualized care, adapting patient care according to their unique needs, focusing on the person and not on the disease (Taddeo et al. 2012; Silva et al. 2015). The patient is the protagonist of their health and well-being, and it is up to professionals to promote the tools and build educational bridges so that they cannot just deal with the disease itself but adapt their lives despite the disease (Silva et al. 2015). Therefore, patient empowerment and self-care are the most critical and influential health education tools for dealing with chronic diseases, allowing patients to take control of their health problems (Taddeo et al. 2012).

The integrative reviews available as a whole show that diseases are responsible for changes in the individual's life and that one of the essential tools that strengthen autonomy is the adoption of healthy practices and the provision of advice in health education (Marques et al. 2023).

In addition, other reviews on chronic NCDs, such as Diabetes and Hypertension, cite them as significant challenges for the health system since they have a significant impact on the economy due to treatment and complications. The same studies show that this problem can be mitigated with lectures, conversation circles, and interactive dynamic activities, i.e., health education as a critical element in the process of self-care, the management of chronic NCD, and the resulting reduction in healthcare costs (Silva et al. 2009; Azevedo et al. 2018).

Integration of care, approaches for population health, and access to health services

Healthcare integration generally refers to a combination of services provided. The World Health Organization (WHO) defines integration as integrating various services or operational programs to ensure and maximize collective results. This process includes streamlining referrals between various services, all of which are based on the need to offer a complete and comprehensive approach to healthcare (World Health Organization 2009).

Based on the diversity of existing concepts, the World Health Organization (2009) establishes three different definitions for the integration of care:

Process-based definition: Considered a harmonious set of approaches and models regarding funding, management, organization, service provision, and clinical aspects, which were created to establish connections, alignment, and collaboration between the various care sectors. Its purpose is to improve the quality of care and the QoL of patients, increase the satisfaction of the individuals cared for, and increase the efficiency of the health system, encompassing various services, providers, and contexts (Santana 2021).

Patient-based definition: Care is organized so professionals work together, prioritizing the patient and their caregivers. The main focus is ensuring the coordination and provision of services to achieve the best possible outcomes (Santana 2021).

Health system-based definition: integrated healthcare is an approach that aims to strengthen patient-centered health systems by promoting comprehensive, high-quality services that cover the entire life cycle of the individual. These services are coordinated harmoniously, based on the best evidence available, and always focus on the continuous search for improvement (Santana 2021).

The theme of care integration has received particular attention in the context of health services (Santana, 2021). Therefore, the primary aim of integrating care is to improve the quality of the services provided and the user experience while simultaneously increasing the cost-effectiveness of health and social services.

The preventive intervention is divided into two groups: the high-risk approach and the population-wide approach. The importance, severity, and vulnerability of the problem must be considered when choosing an epidemiological approach. The local situation and the health demands of the population must also be considered (Brasil 2010).

The high-risk approach concerns the choice of high-risk groups for implementing preventive measures, which have several benefits. This approach is compelling as it allows the intervention to be personalized for each person, which strongly encourages adherence. Cost efficiency is guaranteed, and healthcare professionals are encouraged to participate. Due to the focus on a high-risk group, the interventions are justified as they theoretically lead to more benefits for the patient than harm (Brasil 2010).

The population-wide approach is considered extreme as it aims to eliminate susceptibility, reach more people, and become adequate in behavior. Vaccination, the use of seat belts, and guidance on lifestyle changes are some examples. However, as it caters to the population as a whole and most people are healthy (something familiar to PHC professionals), this strategy leads to the paradox of prevention, i.e., it leads to more health benefits to the population as a whole, but too few benefits on an individual level (Brasil 2010).

Supported self-care entails a connection between the knowledge of caring for oneself and the knowledge of caring for others, especially when chronicity is involved. This is reflected in choosing problems, defining priorities, setting goals, joint care plans, monitoring goals, and addressing health challenges. Supported self-care can be applied in various ways: individually, in the context of a clinical appointment or home visit, in groups, in collective appointments, remotely, by telephone, and/or via the Internet (Brasil 2014). Mendes addresses this perspective in one of the health promotion models, exploring this approach in detail. In this context, the author highlights the importance of understanding and applying collaboration between healthcare teams and individuals to strengthen healthcare effectively (Mendes 2012).

The primary role of PHC, primarily through the Family Health Strategy (FHS), is to establish a connection with other networks in the Unified Health System (SUS). Family Health Units provide care through multidisciplinary services. Private services in Brazil work complementary to the SUS guidelines through health plans and insurance or in institutions such as hospitals, clinics, laboratories, and practices (Aragão et al. 2023).

Technologies and innovation in chronicity

Chronic diseases represent a significant challenge for global health, affecting mortality and generating high economic costs (Roth et al. 2018).

Patients' active involvement in the self-management of their diseases is vital for healthcare models (Mattison et al. 2022).

In this context, wearable devices, known as "wearables", play an important role in providing feedback on patients' physiological parameters, enabling self-management, and increasing awareness of their health condition. These devices include pedometers, smart bands, virtual and augmented reality systems, flash systems for monitoring glucose, and smart shoe insoles (Mattison et al. 2022).

A review study found positive and neutral results regarding the influence of wearables on healthcare outcomes in chronic diseases. These devices have been associated with improvements in QoL and self-efficacy in chronic disease management. However, economic evidence is needed to prove their cost-effectiveness. Regulatory, security, and data privacy challenges also need to be addressed to adequately implement wearables in healthcare (Mattison et al. 2022; Segura Anaya et al. 2018). In addition, more research is needed to strengthen the evidence on the use of wearables in chronic disease management.

Another innovative technology is the use of wearable biosensors to monitor chronic disease biomarkers through sweat. These biosensors play an important role in the early diagnosis and treatment of chronic diseases, offering broad applications in personal health monitoring and in the management of chronic diseases such as melanoma and Parkinson's disease (Yuan et al. 2023). With the advances in nanotechnology and the continuous development of sensors, this field is expected to have great potential for development in terms of chronic NCD management.

In the Health Information Technology (health IT) field, a systematic review found IT technology interventions designed for people with multiple chronic conditions, dividing the results into three domains: self-management, care coordination, and advanced analytics. However, the results were mixed about telemonitoring and health IT platforms, as care coordination did not positively impact the quality of life and daily life activities (Samal et al. 2021). In addition, privacy, security, and ethics issues need to be addressed in developing algorithms and implementing artificial intelligence to support clinical decision-making (Segura Anaya et al. 2018; Samal et al. 2021). The COVID-19 pandemic has stimulated and encouraged the improvement of remote monitoring technologies, promising in managing chronic diseases.

Final remarks

Health promotion models in PHC have evolved to incorporate broader and more stratified measures, going beyond individual interventions. A notable example is the Chronic Conditions Care Model (CCCM), which emphasizes the consideration of social determinants, the stratification of health conditions, and its direct application in the (SUS). In addition, the CCCM favors well-organized healthcare systems and the co-responsibility of individuals for their health.

Healthcare integration, approaches for population health, and access to health services are interlinked components that aim to improve people's quality of life and promote more equitable and sustainable health for society. However, challenges still need to be overcome, such as the lack of adequate funding and the discrepancy between the population's needs and the health system's structure. The Ministry of Health has released strategic plans to address these challenges, including expanding Integrative and Complementary Practices as part of health promotion.

Other vital aspects are health education, self-care, and patient empowerment, essential for health promotion and addressing chronic NCD. Health education provides knowledge about healthy practices and empowers individuals to make informed decisions concerning their health. It transcends social, mental, and cultural barriers, allowing for changes in behavior and improvements in QoL.

Therefore, promoting health education, fostering self-care, and empowering patients are interlinked strategies that can improve people's QoL, reduce the burden of chronic diseases, and improve the effectiveness of the health system in its entirety. Transforming the patient's role from a mere recipient of care to an active partner in managing their health is an approach that should be appreciated and implemented comprehensively.

Health Information Technology also plays an important role, especially in the context of multiple chronic diseases. Technological interventions can facilitate self-management, care coordination, and the use of advanced analytics. However, the results are mixed, and it is essential to address privacy, security, and ethical issues, especially regarding algorithms and artificial intelligence.

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