

Quality of life among chronic disease patients

Abstract

Over the last decades considerable attention directed to examine the quality of life (QOL) of chronic patients. Chronic disease patients have impaired performance in physical tasks, lower health-related quality of life and high cardiovascular morbidity and mortality. In an attempt to alleviate their medical or mental condition, several studies have examined which factors affect their quality life, as well as, the bilateral relationship between patients QOL and the symptoms severity level of the disease. Even though previous studies already been conducted in the field of HRQOL of chronic diseases, the knowledge gained in this field is still very limited, with many researches that based on poor quality methodologies. Therefore, the QOL of chronic patients require further inquiry in order to answer diverse questions, such as: whether and how the diseases affect the QOL of the patients? Does improving chronic patients QOL alleviating the symptoms of the disease? And which factors and interventions affect the QOL of chronic patients. In the present study, we have assembled the principal literature in the field of HRQOL and HRQOL in the specific context of chronic diseases. In addition, we have assembled the principal criticism methodological problems and literature gaps that so far did not receive empirical attrition and require the implementation of further research.

Keywords: quality of life, chronic patients, chronic kidney diseases, healthcare, critical review

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Abbreviations: HIV, human immunodeficiency virus; HRQOL, health related quality of life; IWB, the index of well-being; QOL, quality of life; QWB, quality of wellbeing; WHOICF, the world health organization international classification

Introduction

Quality Of Life (QOL) has become an increasingly attractive subject in recent decades, drawing attention from both enthusiasts and researchers.¹⁻³ But what is quality of life in fact? Is it defined by our looks? Financial state? Nature or nurture? In truth, people define it by all of the above and many more.⁴ This study, however, intentionally wishes to define the quality of life through the narrow focus lens of the chronic medicine field. There is a good reason why the quality of life of chronic patients has been a popular field of research in the last 20 years. Non-communicable chronic diseases such as cancer, stroke, diabetes, HIV and more have been found to take a staggering annual death toll of 38 million.⁵ It comes with little surprise then, that the HRQOL (Health Related Quality Of Life) of people suffering from such maladies was vastly studied and documented. The research into chronic patients' HRQOL is believed to significantly benefit their bodies and minds. After all, such writings are meant to expose the means to maximize the patient's' quality of life. These means may alleviate the conditions which commonly restrict patients' career-related tasks and their daily activities as well as affording them an extended period of independence.⁶

The research into HRQOL can aid patients by means of exposing the QOL factors that may be affected by chronic disease. With such information, the treatment may be adjusted to specifically handle these factors. Research may also to help to tell apart the ways different diseases can influence QOL. If the quality of life is affected by chronic disease, further study can provide therapists with tools to measure and even predict the effectiveness of their treatments.

One glaring paradox about the wealth of research into chronic patients HRQOL is the fact that HRQOL is a rather poorly defined term. Each research tends to regard QOL differently, using measurements, theories and means of validation that suite only one specific interpretation. In worse cases, the study may even base itself on multiple, contradictory definitions of QOL by the very same researcher. Thus, much is still left to properly define and explore in the field. For these reasons, it is imperative to be skeptical when exploring existing HRQOL literature and heed the words of its critics.

The problematic definition of QOL in chronic medicine literature stands in the heart of this study as it attempts to explore, compare and confront the meanings of the term on different sources. This work will first present examples of the many definitions of QOL and specifically health- related QOL. Secondly, it will move into more detailed explorations of HRQOL in chronic medicine, demonstrating measuring methods, significant factors, research areas and findings as provided by different scholars. Thirdly, works that criticize the research into chronic patients HRQOL will be presented and discussed, particularly works that criticize the measuring methods, the chosen research respondents and the models created to demonstrate the HRQOL concept.

Defining quality of life

Since the beginning of the 80s of the last century, the interest in the field of Quality of Life (QOL) has grown significantly^{1,2} with numerous studies that were conducted in this research area.³ While a wide body of literature already dealt with QOL, the definition of this term is still unclear and raises a debate among researchers and practitioners that are engaged in this field.³ While there is debate among researchers for the definition of QOL, this term has an inherent meaning to most people. QOL comprised of broad concepts that relating global life satisfaction, including health, appropriate housing, employment, sense of security, interrelationships, education, etc.⁷ Many researchers

consider QOL as the general well-being of individuals and societies, outlining negative and positive features of life. Researchers relate to QOL components of happiness and satisfaction with life. For example, Aristotle, one of the first scholars which defined QOL noted: “Both the multitude and persons of refinement ...conceive “the good life” or “doing well” to be the same thing as “being happy” (384-322 BC; 3).

However, against the above definitions, many researchers raise the question - what constitutes happiness, well-being or “good life”? It is important to note that different people giving different meanings to QOL.^{3,8} According to Megari⁹ people giving different connotations to QOL, this term can be perceived as not reliable because it is not objective. For instance, to low/middle-class socioeconomic people, QOL might family vacation once a year or purchasing a private house. Conversely, to high economic status people quality of life might mean buying a yacht or unlimited vacation around the world. In addition, very often, the same individual says different things at different time and/or circumstances.³ Therefore, it does not seem that QOL definition amounts only dimensions of joy and happiness. Following that, Harris Rackham, noted that a more accurate definition of QOL should refer to ‘well-being as a state of feeling and a kind of activity.’³

Other researchers suggest that QOL is a global individual assessment of a single dimension, which may be the result of a variety of other distinct dimensions. Therefore, QOL is a one-dimensional concept with multiple causes.¹⁰ It encompasses the entire range of human experience, states, perceptions and spheres of thought concerning the life of an individual or a community. The objective and subjective QOL includes a variety of dimensions, such as cultural, physical, psychological, interpersonal, spiritual, financial, political, temporal and philosophical aspects. QOL reflects values which dependent on communities, groups and individuals experience.¹¹

Beyond the above, it is important to note that scholars distinguish between subjective vs. objective definition of QOL.¹² In this regard, while the subjective definition of QOL takes into account one subjective appraisal of one well-being, fulfillment, satisfaction and happiness, the objective definition based and relates on objective indicators of health, such as socio-demographics, the standard of living, housing, marital circumstances, etc.¹³ This distinction lays at the heart of an integrated and comprehensive understanding of QOL.¹⁴ However, according to several reviews, most researchers believe that both subjective and objective information is necessary to the construct.¹² Another distinction of QOL relates to culture-dependent vs. universal definition of QOL. In this regard, while there are scholars who refer to QOL as a global measure, others argue that the basic elements of QOL should overcome cross-cultural differences.^{15,16} Following the absence of universally accepted definitions of QOL, several researchers claim that most people, in the Western world at least, have an intuitive understanding of what it comprises.

Beyond issues regarding the definition of QOL, reviewing of the literature in the field of QOL, raise five different philosophical approaches to determining individual’s QOL:

- i. Economic approach
- ii. Social approach
- iii. Subjective approach
- iv. Adaptive approach
- v. Cultural approach.^{17,18}

In short, the economic approach describes characteristics of the good life that are dictated by normative ideals based on a religious, philosophical, or other system. For instance, we might believe that the good life must include helping others because this is dictated by our religious principles. The social approach for QOL is based on the satisfaction of preferences. In this tradition the definition of the quality of life of a society is based on whether the citizens can obtain the things they desire. The third definition of quality of life is in terms of the experience of individuals. If a person experiences his life as good and desirable, it is assumed to be so. In this approach, factors such as feelings of joy, pleasure, contentment, and life satisfaction are paramount. This approach to defining the quality of life is most associated with the subjective well-being tradition in the behavioral sciences.¹⁸ The adaptive approach suggests people tend to homeostasis, consequently, as time passes they get used to any level of pleasure or misery. Therefore, when considering the QOL components we should take into account that the factors that shaped one’s QOL perceptions today are not necessarily used as a dominant factor tomorrow. Additional aspect for QOL referral is the cultural differences approach. This approach takes into account the cultural differences that may shape people QOL perceptions. People that grow up in different cultures (between/within country), attributes different importance to different aspects of their lives, such as-religion, leisure, family, work and education and so on. Additional approach that relates to the quality of life is the quality of life in the context of health. We will discuss this approach in detail in the next section.

Health related quality of life

The term quality of life is discussed in diverse contexts, including quality of life employment, body image, politics, family, education, wealth, religious beliefs, international development, finance, environment and so on.⁴ Additional field for which the concept of QOL is investigated, which we will discuss widely in the current review, it is the health filed.¹⁹⁻²¹ In this regard, for matters related to health care, the QOL has been applied specifically to the life concerns that are affected by health or illness, termed “health-related quality of life” (HRQOL).⁷

The link between QOL and patients’ health was established for the first time in the fifties of the last century.³ Generally speaking, HRQOL relates to patients’ experiences, beliefs, expectations, and perceptions of their current level of functioning, as well as satisfaction with it, compared to what they believe to be ideal.⁹ Assessment of HRQOL represents an attempt to determine how variables within the dimension of health (e.g., a disease or its treatment) relate to particular scopes of life that have been determined to be important to people in general or to people who have a specific disease. Most conceptualizations of HRQOL emphasize the effects of disease on physical, social, psychological/emotional, and cognitive functioning. Additionally, symptoms, health perceptions, and overall quality of life are often included in the concept domain of HRQOL.²² We note that HRQOL includes both positive and negative health aspects. The negative aspect includes disease and dysfunctions. Conversely, the positive aspect includes feelings of mental and physical well-being, functioning level, physical fitness, adjustment, etc.²³

HRQOL must be distinguished from quality of life as we defined it earlier in that it more focused on aspects of life quality that are influenced by, or that can influence one’s health status directly.⁷ While QOL is a broader concept which covers all aspects of life, HRQOL has a focus specifically on the effects of illness and on the impact

treatment may have on QOL.²⁴ These aspects can include symptoms of disease and treatment side effects, treatment satisfaction, physical functioning and well-being, social functioning, life satisfaction, and mental health, including emotional well-being and cognitive functioning. HRQOL does not typically include aspects of life that are often associated with the broader concept of QOL, such as income, financial resources, nutrition, and environmental conditions such as air quality, climate, political and personal freedoms, and public safety (crime).⁷ While HRQOL can help us understand the distinction between aspects of life-related to health, QOL can help us understand those aspects of life that extend beyond health such as education and the social environment.²⁴

Makai et al.¹¹ define health related quality of life (HRQOL) as the value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy. According to Wilson & Cleary,²⁴ HRQOL is an individual's satisfaction or happiness with domains of life insofar as they affect or are affected by "health". In fact, HRQOL represents a subjective appraisal of the impact of illness or its treatment.²⁵ Furthermore, Health-related quality of life (HRQOL) can be formally defined as: "The extents to which one's usual or expected physical, emotional and social well-being²⁶ are affected by a medical condition or its treatment.²⁷ The last definition following the World Health Organization defined health as "the state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". This definition incorporates two widely accepted aspects of quality of life: subjectivity and multidimensionality.²⁸ Similarly to health, HRQOL is also multi-dimensional and incorporates domains related to physical, mental, emotional and social functioning.²⁹

A wide body of literature attributes great importance to the researching field of HRQOL. In this regard, research revolving around HRQOL is extremely important because of the implications that it can have on current and future treatments and health protocols. Thereby, validated HRQOL research findings can become an integral part of clinical trials in determining the trial drugs' value in a cost-benefit analysis. The information of research in the HRQOL filed can be used by multiple levels of government or other officials to "increase quality and years of life" and to "eliminate health disparities" for equal opportunity.

Accordingly, this field has grown significantly in the last decade, with hundreds of new studies and better reporting of clinical trials. These studies have focused, inter alia, on the assessment of quality of life among heart illness, cancer patients, mental illness patients, etc. In this regard, clinicians and public health officials have used HRQOL to measure the effects of chronic illness, treatments, and short- and long-term disabilities.²⁹ The premise of these studies is that healthcare has great importance to the quality of human life and all the more significant when people get sick. In this regard, several studies indicate that HRQOL is prognostic for survival in some diseases and patients. Research findings show high correlations between self-reported well-being and health status. Well-being, morale and overall QOL have long been associated with Good levels of physical and mental functioning and health status.³⁰ In the next part of the review we will review the literature which relating to the term HRQOL in the specific context of chronic patients.

HRQOL of chronic patients

Chronic diseases are usually a long-term issue for patients, though

the severity of their symptoms and the functionality of their bodies can always change, for better or worse. In recent years more and more people find themselves subjected to chronic disease which, may, in turn subject their quality of life to changes.⁹ A Brazilian survey from 2003 demonstrated how commonplace chronic diseases are, finding over two-thirds of the post 60 years old Brazilians suffered from one chronic disease at least, over a quarter of the group endured through more than two diseases of that sort.³¹ The recent rise in chronic diseases results not only in changes to many people's quality of life but also in deaths, 38 million per year according to the World Health Organization (WHO).⁵ Some commonly known chronic diseases are cancer, diabetes and HIV and what they all share is their long duration and treatment. Researchers believe that throughout the duration of most chronic diseases, the patient is at constant risk of deteriorating health, dysfunctionality and decreased HRQOL.^{9,32}

How is HRQOL measured in studies?

There is not a single commonly accepted mean of measurement for HRQOL, several different ways were developed and will be discussed here. First there is Sullivan's 11 categories index, suggested in 1971, which views HRQOL as states of satisfaction and physical health. The index is essentially a checkbox statement of the patient's displeasure, physical functionality and state (comatose or dead). Five years later, Fanshel and Bosh have elaborated the 11 categories index into "the index of well-being" (IWB). The IWB classifies the state of HRQOL according to 4 factors such as mobility and social activity. In the following decade, the IWB evolved again, changing some of its terminology and becoming the "Quality of Well being index" (QWB).³³ Contrary to the IWB/QWB, another index called EQ-5D was designed by European health researchers as a useful but simple standard of QOL measurement in medical research (www.euroqol.org). The EQ-5D is a 5 questions multiple choice questionnaire with 3 choices on each question. The questions individually address five dimensions- mobility, functionality, pain, anxiety and depression. The 3 choice responses address whether a dimension is vastly, slightly or not at all problematic. The EQ-5D can classify patients into large varieties of health states and can be filed by doctor, patient, observer, interviewer or any proxies. Despite criticism about its ability to measure psychological states, the EQ-5D is counted among the most widely used directories.³⁴

The SF-36 is a more modern HRQOL index and is the widest used. The test can be filled by both the sick and an interviewing party. It measures 8 dimensions through 36 items. They include dimensions measured in the previous indexes plus- vitality, mental health and general health.³¹ The test results are calculated into two subscales which separately indicate physical and mental functioning. The results range 0-100 with higher scores indicating better health. The SF-36 is meant to measure solely HRQOL aspects that may be prone to any disease at any age or social group- particularly the physical, emotional and social functioning. The SF-36 later got scrutinized by British health economists who claimed its measures are not useful since they rely too greatly on the patient's self-perceived state rather than provide the scholar with a fixed, objective system of measurement. In order to improve its validity, the British scholars modified the SF-36, reducing the number of items and dimensions by uniting the role-physical and role-emotional dimensions and scrapping the self-rated general health dimension.

The last index to be presented is PedsQL 4.0. It is a 23 item questionnaire targeted at school aged people. Besides physical,

emotional and social functioning PedsQL 4.0 also measures functioning in school. The items describe problems and the examined party is asked to recall the number of times such problems occurred to them in the past month. The score is calculated by the sum of the problem frequencies being linearly transformed into a standardized score between 0-100 (higher score means better functioning and HRQOL). In order to compare the subjects' QOL though, one needs to calculate the total average of the problem occurrences.³⁵

HRQOL of chronic patients - what is already known?

Recent literature deals with quality of life of chronic patients. Understanding how cancer, stroke, diabetes, hepatitis C, HIV and others affect HRQOL can aid countering the effects, thus enabling the sick individuals to maintain functionality, independence and general satisfaction from their lives for longer durations. Hypothetical HRQOL measurements have become very important tools for medical researchers who wish to improve treatments and practices. Not only do they present the effectiveness of a treatment against every symptom, the HRQOL tests also reflect the personal input of the patient. The physician uses this data to select the best treatment for each individual case. Some studies even suggest that lower QOL is directly related to patient mortality rates.³⁶

It is important to remember much of the above is academic conjecture. HRQOL literature has many questions to deal with: Can chronic disease actually harm a patient's QOL? Can medical and psychological treatments improve it? Which medical factors constitute HRQOL? Which factors decrease or increase it? While many factors related to QOL may come to mind, it is the job of researchers to point out which factors truly influence well-being, mental constitution and disease symptoms. A few factors proven to affect HRQOL are: General health, longstanding illness, and functional ability, satisfaction with health care environment, with community health care, patient compliance with physician's orders, cognitive age, gender, socioeconomic status, social support and number of symptoms. Specific disease symptoms, such as depression, distress, physical state and functionality were pointed out by studies to strongly affect QOL as well.

HRQOL measures are useful for determining the effectiveness of therapy both as a primary and secondary outcome. Even if the main goal of a therapy is focused on a certain symptom or functionality, it is nonetheless important to note the potential side effects on HRQOL. It is, in fact, uncommon to find treatments which see HRQOL as their main goal. But when a therapy like that is examined, as any therapy should be, its impact on HRQOL must always be taken into account. But with the number of chronic patients on the rise, it becomes more and more essential for the treatments to be suited to the patients' individual needs in order to be efficient. Nominal HRQOL can only be guaranteed for chronic patients if every aspect of their maladies and treatments is measured and handled in accordance to the evaluation of their HRQOL effects.³⁷

Studies did not only hypothesize about HRQOL but also bring solid findings into the light. Research demonstrates different relationships between various chronic diseases and their patients HRQOL.^{9,38-40} For instance, according to Avis, Crawford & Manuel HRQOL of cancer patients is particularly prone to social and sexual issues, body image and maladaptive cognitive restructuring (not coping with negative thoughts and notions).³⁸ The HRQOL of heart-disease patients with post-symptoms outburst such as chest pain seemed to indicate the

chances of the patient becoming morbid and even dying.⁴⁰ Carod-Artal et al. have indicated how several works link dwindled HRQOL of stroke patients to depression, troubled coordination and movement as well as hemispherical localization of the lesion.³⁹

We looked into selecting few of the great many literature works regarding chronic patients' HRQOL; the common hypotheses of connection between quality of life, physical mental and social factors and disease symptoms; the HRQOL measurements as tools in the hands of various medical researchers and into the particular connections between specific chronic diseases and HRQOL. Yet many more chronic diseases remain poorly studied in this aspect. Scientists also question the means by which much of the existing literature validates its hypotheses but more on that later.^{23,41} First, we must examine in further detail the concept of HRQOL itself as it has been defined and established within the existing research canon.

HRQOL models

Medical researchers have conceived several models which present HRQOL as a more perceivable concept.^{9,42} Three important such models will be presented: Wilson et al.,²⁴ Bowling et al.,⁴³ and models that inspired by the WHO's health definition.⁴⁴ Wilson and Cleary's model from 1995 was devised with the notion that understanding HRQOL can help planning treatments, making sure they treat issues with QOL alongside other symptoms. The result is a model that presents HRQOL as a system with several physical and mental aspects serving as its parts. The model consists of 7 individual system parts and the nature of their relationship. The system's five physical and psychological core domains influence one another in a linear path-biological functions directly affect symptom status which directly moves functional status which directly influences general health perceptions which finally affects the overall HRQOL as perceived by the patient. Outside the core, there are two more factors which may directly affect any and all domains. Emotional characteristics such as depression can influence HRQOL even without any problem with the four other domains.⁴⁵ Individual characteristics such as the environment a person lives in, organizations that deeply affect him and personal traits such as personal outlook and beliefs can also influence HRQOL perception as well as other core domains. Wilson and Cleary's model serves as a mean to demonstrate HRQOL of people from various backgrounds with chronic sicknesses Figure 1.

Bowling, et al.⁴³ model is simpler and deals mainly with illness-health scale and dependency. The model essentially shows the impact which sickness can have on the measurement of mental and physical disabilities and their effect on daily activities. The model focuses on daily living and mobility (e.g. self-care), instrumental daily living (e.g. housework) and social role obligations. This model is apparently designed to measure the duration of a patient's normal functions recovery, if possible. It can also help to examine changes in HRQOL over time.⁹

Many other HRQOL models are created in the mold of the broad definition of health by WHO which was created in light of common health risks such as obesity, chronic diseases like diabetes and asthma and both general and cause-specific mortality rates. WHO covers the conservative aspects of health-mental, physical and social well-being, positive health and self-rated health status. The definition is based on the lack of negative health and functionality elements and uses positive classifications such as life satisfaction, good shape and strong spirit.⁹ A recent influence on the broad models is "WHO

ICF” (The World Health Organization International Classification of Functioning, generally illustrated in Figure 2). WHO ICF is meant to serve as a standard form to describe and explain various states of health with no boundary between cultures or medical theories.⁴⁴

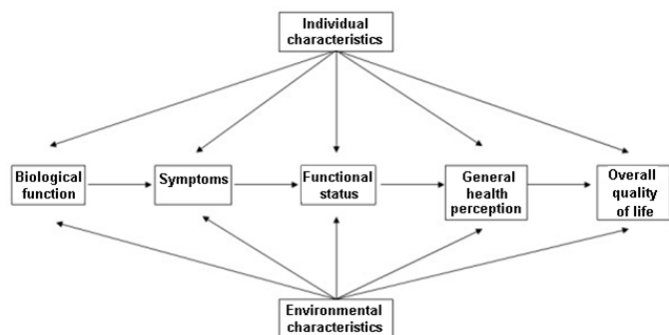


Figure 1 General description of Wilson and Cleary HRQOL model.

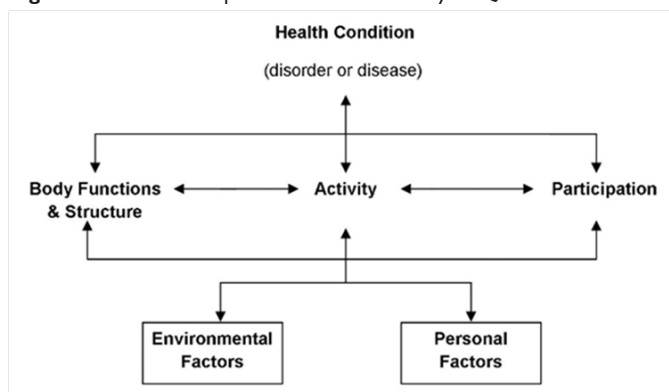


Figure 2 General description of WHO ICF model.

Figure 2 demonstrates the different parts of the WHO ICF system such as body function and structure, activities, and participation which examine the presence of disability. The other parts are related to individual (like environmental and personal) aspects. This model is made out of generally accepted concepts and comes with detailed explanations for each result.⁴⁴ But despite the presence of so many conceptualizations and suggested models, every field of research comes with an accompanying body of criticism, which will be examined next.

Discussion

Criticism on HRQOL research field

QOL has been explored by science for decades, although the plentiful research was not without its flaws. The dimensions of QOL in the health field, the related measuring methods and the defined factors of influence were all questioned. Despite the wealth of practical research and proven theories, the validity of methodologies, operationalization, theoretical models and reliance on multiple HRQOL definitions have been questioned by scientists. Coming next is a presentation of criticism on modern HRQOL research, especially methodological issues in measuring and defining HRQOL, response shift and theoretical models criticism.^{23,41}

Criticism of HRQOL measurement

HRQOL measurements grow ever more popular in medicine. But

as patients of more and more varied diseases are being examined, the lack of a proper standard HRQOL definition, even internally within many measurement methods, is sorely missed. HRQOL measurement cannot be operationalized if it fails to cover the theoretical core HRQOL factors in the realms of psychological, physical and social functioning, disease-specific variations are also needed. Garratt and colleagues⁴⁶ suggested every HRQOL measure method has to be inspected for proper reliability, validity, precision, responsiveness, acceptability, and feasibility. Other works of criticism on HRQOL often feature 7 main measurement problems: objectivity versus subjectivity, generic versus specific, one-dimensional versus multidimensional, self-report versus proxy report, reliability, validity, and the criteria for selecting HRQOL.^{23,47}

Objectivity versus subjectivity: HRQOL consists of both factors related to personal experiences such as depression, emotions, general outlook etc. (subjective) and factors related to empirical-medical observations such as disabilities and other symptoms (objective). Examining the two factors would require two sets of methods that may not be easily used together to define one thing. HRQOL tests usually aid physicians to observe the subjective effects of a treatment against objective problems. The testing of both aspects is believed possible and may help to evaluate patient treatments as well as the overall influence of complications on daily life.²³

Generic versus specific measures

Generic measures are means by which a very wide collective of aspects is examined, such as health profiles.⁴⁸ Specific measures cover only a certain particular aspect of any test subject.⁴³ Generic HRQOL measurement is ought to cover physical, emotional and social functioning as well as self-perception of health and satisfaction. The use of Generic measurements is mainly comparative, observing the differences between patients, health statuses, diseases, and treatments. Specific measurements are useful for observing any disease or population (old, young) specific phenomenon and response to particular treatments.⁴⁸ The choice between measurement types is directly tied to the research goal, its main theory, and its subjects. In many cases it is best to mix the two measurements, reinforcing generic results with specific ones.⁴⁹

One-dimensional versus multidimensional measures

HRQOL measurement results can come as either a single comprehensive result or as profile score, showing a number of related ratings. The first kind of result, one-dimensional is meant to present a single global HRQOL overall score. It's the kind of score one will get for merely asking a patient "How would you rate your overall quality of life during the past week?" or asking them to tick or not tick a box near the statement "I am content with the quality of my life right now".⁵⁰ Both of these questions exist in HRQOL tests but are not sufficient in the eyes of most experts. A single measure result cannot cover more than one dimension (aspect or behavior), while researchers consider HRQOL to encompass many dimensions.⁵¹ For this reason, most HRQOL measuring tools like EORTC Health Organization Quality of Life Assessment, investigate deeper into the patients HRQOL than just its overall rating. They also focus on the various types of functioning that commonly define HRQOL.²⁵

Self-report versus proxy report: HRQOL related patient reports are sometimes filled by a patient's relatives or caretakers instead of the patient due to disease-related or cognitive restrictions. While HRQOL

proxy reports are necessary in order to understand patients who cannot answer by themselves, the accuracy of these reports is debatable. In a study to ascertain the accuracy of proxy reports, capable patients and their relatives simultaneously filled the Sickness Impact Profile questionnaire. There was an incomplete correlation between the results of patients and proxy's,⁵² greatly depending upon the specific HRQOL domain being measured.⁴⁸ It was concluded that physical functioning is rated similarly between patient and proxy but not any of the psychological aspects.⁵³ Therefore it is generally preferred to rely on patient HRQOL reports and limit the use of proxy reports in studies.

Reliability

As in any other science, an HRQOL test can only be accepted after it proves to be consistent over time. HRQOL measures reliability can be further classified into internal consistency, tester test reliability, and inter-rater reliability. Internal consistency is related to the items in a test, it is the ability of all items to actually measure the same domain as they are supposed to. Tester test reliability is the ability of test results to remain similar for the same subject while being tested at two different times. Inter-rater reliability is the consistency of outputs in the test score that are supposed to remain the same no matter who fills the test. Each type of reliability is tested differently⁵⁴ and has a different minimum.

Validity

A valid test is a test proven to measure primarily the variable it claims to measure.⁵⁵ An HRQOL questionnaire is not valid if its results do not actually reflect HRQOL. Validity is divided into - content validity, criterion validity, and constructs validity. Content validity is the understanding that all aspects which are measured in the test are indeed the aspects that completely encompass the concept under measurement.⁵⁶ Criterion validity is the level of correlation between the examined measurement and an already accepted and proven measurement. Construct validity is the level in which the test results represent what the test claims they represent. Construct validity can be measured by factor analysis, confirmatory factor analysis, and multitrait-multimethod modeling.⁵⁷

Selection of HRQOL measures

There is no ideal measurement tool for HRQOL from the many that exist at present but there are tools that are ideal for measuring specific details.⁵⁸ Researchers recommend choosing the method of measurement according to several criteria: appropriateness- how much method fits the research subject; reliability; validity; responsiveness- how sensitive the test is to important changes; precision- the accuracy of the measure's output; interpretability- the meaning of scores; acceptability- how well does the tested person agree with the results; and feasibility- how taxing is the measure on the researcher, therapists and patient. HRQOL measures may also be improved by using standard rating scales, using more test items to ascertain results and rating severity and importance.⁵⁹

Criticism of HRQOL definition

QOL is a term that defines many studies, yet its own definition is still a hot topic. Up to this very day, the subject is still being plagued by disagreements even among people who agree upon most dimensions of QOL as they may not agree on the dimensions names and how many there are.^{60,61} The lack of consensus over the QOL definition

is worsened by the fact that many writers on the subject treat the meaning of quality of life as self-evident and do not bother to define it within the context of their work. It results in severe implications for the understanding of their research by readers a nulls much of its potential contributions to the QOL field.⁶² The authors that do define QOL are often no better, shaping the meaning according to their field of expertise, focusing on just the social, physical or mental function aspects of QOL instead of all of them.⁶³ Others go as far as dismissing QOL as a synonym for "happiness", "satisfaction" or "well-being".⁶²

The recent popularity of the QOL field leads to the creation of several systems for HRQOL measurement. As seen in the following literature there has been plenty of written discussion on this matter: (e.g., 48, 59, 61). Varrcchio has noted that most of these systems were made with very particular purposes in mind and may not serve any different purpose.⁶⁴ Psychometric properties are also rarely considered during an HRQOL system's conception.⁶⁰ The reason for neglecting psychometric properties is the length of time it requires and the meticulous testing needed to prove psychometric quality.⁶⁴ Researchers seem to haste towards creating the measurement method rather than making it psychometrically reliable, hampering the quality of the method's test results.

In the previous decade, Taillefer et al.⁶⁵ extensively examined and scrutinized 68 different and randomly selected HRQOL models devised from 1965 to 2001. Two people had to check each model for the following criteria- Sophistication, QOL definition by the model's author, differentiation between elements that affect HRQOL and elements that are parts of it. Finally, each model got a global score for quality. It was found that 35% of these models were simple, 15% belonged to the most sophisticated group and the rest (above 50%) were in between. Less than 50% of models explained which factors are external to QOL and which are internal. While 78% authors point out which tools they use for measuring but only less than 3% obtained the maximum overall rating. The above research indicates improvement in QOL models over time, though difficulties with the definition of QOL in relation to each model (vague, contradictory or absent definitions) greatly hampered the analysis. Conclusively, the absence of sophisticated models and a clear QOL definition are issues that must be dealt with.

Response shift

The effect of changes in health over time on QOL has recently become an attractive topic for social and medical academics, as the importance of QOL perception grows in the health and social research. A phenomenon that must be reckoned with in such kind of research is the response shift.⁴¹ Response shift is a change in perception or beliefs (of QOL and other things), empowered by health state changes.⁶⁶ Unfortunately, many of the QOL studies easily assume that just because the healthy researcher's standards and attitude regarding life and health are stable, so are everyone else's. However, the response shift is an HRQOL related change of state which has to be considered no less than changes in the state of health.⁴¹ Researchers who do not neglect the response shift define it as a change in the way a person sees and evaluates a certain concept due to either a change in the person's individual standards, a change of the person's values in such a way that makes him redefine the hierarchy of concept's dimensions or a direct change of the individual's definition of the concept. Empirical researches into response shift make it more a concrete matter to be considered in studies. Patients undergoing group therapy, for example, seem to be especially prone to the phenomenon. Comparing their state

to that of their peers often tends to give patients a new perspective on the severity of their situation, affecting their standards for better or worse. Patients further report group sessions aid them in facing their situation, reconsidering what is truly important to them in light of their condition, thus changing their values and QOL definition.

Many methods have been suggested in order to include response shift into ongoing and future clinical studies such as individualizing the measurements, making successive comparisons of results over time, improved statistics and improved qualitative approach. And yet the negligence of response shift plagues the majority of scholars to this day, threatening the very legitimacy of their hard labors and contributions in the field.

Criticism of HRQOL models

It is of no surprise that HRQOL theory development is booming, yet the blunt models that were devised by such theories are less than satisfactory. The three prominent HRQOL models have been previously introduced as the Wilson and Cleary model,²⁴ Bowling, Bannister et al.⁴³ and the WHO's (World Health Organization) health definition.⁴⁴ These models have all been a subject for criticism. Wilson et al.²⁴ model presents HRQOL as a product biomedical and social domains. The five core domains of the model are also defined very well by the authors- biological, symptoms, function, general health perception, and overall HRQOL. The two other domains are the focus of the model's critics as individual and environmental characteristics seem to be vaguely explained within the model's context and yet they are domains that affect all the others.

As a result of Wilson et al.²⁴ HRQOL model's criticism, a revised model by Ferrans et al.⁶⁷ was published. The five core domains remained the same while individual and environmental characteristics were properly explained and contextualized. The relationships presented in the model were streamlined with no mention of non-medical factors. The revision also includes further theoretical references and practical guidelines.⁶⁸ The revisions authors also claim they further explored the relations between the dimensions beyond the one way causality and into the possibility of two ways relations. It is hoped that the revision can serve a general purpose and that all and any medical procedure can be improved if the model's relations are factored into it.

The World Health Organization International Classification of Functioning, Disability, and Health (WHO ICF) have gone through several evolutions, as was detailed in a previous chapter. Suffice to say it created the closest thing to an HRQOL standard definition there is, with items based on positive health elements. The most important thing to know about WHO's definition of HRQOL is that it greatly depends upon the patient's perception of his situation.⁶⁹ However, WHO's model is so rich with elaborated health concepts, functioning and environmental factors that it marginalizes HRQOL itself. One should not view an all purpose tool which might as well be used to summarize a nursing and therapy procedure of a stroke patient⁷⁰ as the best tool for examining HRQOL.

HRQOL is well defined within all models but they all seem to lack the dimension of the therapy and its demands on the patient's spirit. If for example a model is used to assess HRQOL of a diabetic, it would mainly deal with the symptom's affects, hypoglycemia, and pretty much ignore the effects of the frequent glucose level checks. These checks can be just as strong factor on HRQOL though. Specifically,

the WHO's model has a dimensional overlap issue between activities and participation. Ferrans et al.²⁹ model bests Wilson and Cleary's model²⁴ due to much needed revisions and the non-core dimensions definitions. Ferrans et al.²⁹ model also clarifies the somewhat vague relations between the dimensions on Wilson and Cleary's model. Though the relations that Wilson and Cleary and Ferrans et al.²⁹ model's merely contemplate as two ways relations are explicitly presented as such by the WHO ICF.

The three models can be further compared in the context of operational application. All three seem to aim at similarly low expenses, are at similar stages of development and arise from similar fields (biomedical and social sciences) and have a similar scope of explanation about complex dimensional relationships. They all seem applicable and have been applied in practical situations. It is important to remember though that the output of Wilson et al.²⁴ models is meant to present HRQOL while the WHO ICF's results correspond more generally to health and functionality. The models also do not suite the same types of respondents Wilson and Cleary and Ferrans et al.²⁹ models are aimed at individuals while WHO ICF model can examine groups as small as families or as large as nations. The former two models might also be useful for reporting the state of groups and people who require proxy respondents, but only after proper modification. Very little evidence exists regarding any model's impact on intervention research. Ferrans model and the WHO ICF model do seem though to be potential tools for developing theories that can be applied in practical treatments. WHO ICF may further and better be used for classification and quality assurance of existing treatment methods because its main purpose is classification.

Summary

Relatively to the thousands of years of delving into the different properties and aspects of human health, the modern quality of life research is a recent yet fascinating venture. Empirical research points out towards the benefit of self-reported QOL from chronic patients since it is a good statistical indicator for certain developments in their condition such as mortality. Many scholars believe that observing and monitoring a chronic patient's quality of life can testify to the efficiency of his treatment in real time and aid therapists in making necessary adjustments if they need to.

With such great promises, the research field of QOL and HRQOL (specifically health-related QOL) was very fertile and the body of literature grew and became quite substantial. Yet the relative novelty of QOL research is also a throne at its side. For much of the quickly amassed studies took great liberties with defining their most fundamental concept, QOL. Is it self-rated happiness? Reported satisfaction in life? Is it an objective or subjective definition? The one thing that appears researchers agree upon is that they disagree with it. Arguing that even people who may agree on the values that constitute quality of life may find that each one of them has a dramatically different thing in mind when thinking of happiness, satisfaction etc.

Health-Related Quality Of Life (HRQOL) is easily distinguished from QOL by being focused on the aspects of QOL which effect or are affected by health. But its definition is no less troublesome, with literary sources citing both subjective concepts like satisfaction and perception of one's health and objective concepts such as functionality. While the popular definitions of HRQOL tend to combine both objective and subjective dimensions, it takes a great deal of theoretical adjustments to fit all of HRQOL's suggested components under the same umbrella.

Troubled definitions or not, the scholarly work related to HRQOL has produced a number of measurement indexes- questionnaire formats- to be filled by a chronic patient or a therapist. The indexes tend to cover most mental and functional aspects of HRQOL but each one of them has its own advantages and shortcomings in measuring HRQOL. Therefore the person who chooses the particular index has to consider what sort of patient he examines and what he wishes to infer from the results.

Despite hardships, HRQOL researchers have been assured by observations that there are proven connections between health and HRQOL. There have been particular disease symptoms and treatment methods that were found to affect HRQOL such as the health of the physician or chest pains. Different diseases were found to impact HRQOL in different ways and it has also been proven to be a good predictor of certain symptoms. The measurements of HRQOL have been further re-enforced with a variety of models with the three most prominent ones covered in this paper and shown to indicate complex relationships between the objective and subjective dimensions of HRQOL as well as present the effects of the environment and the uniquely individual aspects on HRQOL.

The comparatively heterogeneous nature of many HRQOL studies has invited a great deal of criticism in an attempt to create a scientifically appropriate consensus over HRQOL and improving future studies altogether. The measurement of HRQOL has been questioned for focusing too much on subjective self-assessment which do not provide proper global objective measurements that can be easily compared. There should also be better clarity about the measurement methods target, general HRQOL or specific aspects of it. The measurement results themselves often yield a single number which tells very little in regard to the multiple HRQOL dimensions that compose it. It is also notable that many measurements do not regard reports by a patient's proxy to be less reliable than reported by the patients in certain matters such as perception. Critics also call for testing each HRQOL measurement method for reliability, looking for similar results on similar subject but on several separate measurements. Whether the results of a measurement actually represent HRQOL and not something else is another matter for consideration. Finally, with so many methods in existence, critics have formulated a system for scholars to use in order to choose the HRQOL measurement method which is most appropriate to their needs.

Beyond measurement of HRQOL, the definition of it is by far the most heavily criticized aspect in the field. Critics point out how all existing models and indexes through which HRQOL is defined are still lacking in psychometric values and in the proper representation of the sophisticated connections between the internal aspects of HRQOL and its external factors. Critics blame the field of HRQOL study for greatly ignoring the response shift, a change in values, views and ideals that can occur in patients as a result of their advancing condition and treatment, altering their perceptions of health and quality of life. Such changes can have a direct effect on HRQOL in general and works that overlook it may lose a great deal of credibility at present and in the future despite the best intentions of their authors.

Conclusion

In light of the comprehensive literature on the subject, we believe that the disagreements among scholars regarding HRQOL go beyond healthy academic discourse. The current problem with defining HRQOL could someday severely hurt the progress of its valuable

research and of its practical applications in the field of health and medicine. To our opinion, the absence of professional consensus on the matter of HRQOL leads to fundamental problems in related studies. The negligence of proper differentiation between self and proxy HRQOL ratings, of the response shift and of many other matters noted by critics are examples of such problems.

There are two solutions that come to mind regarding the consensus about HRQOL. The first solution is to gather experts in the field together in a committee that would end up publishing a global standard definition of HRQOL, to be considered and acknowledged by all researchers in the field with no exceptions. Studies which ignore this definition will be considered amateur and will not be held by academic standards. It does not mean of course that all researchers have to agree with the global HRQOL definition but they will have to present their disagreement in their studies, showing that they are at the very least aware of the definition and openly challenge it. The creation of such a definition would require considerable resources though and there is not enough evidence regarding how many parties in the field of HRQOL are actually troubled by the lack of consensus. As it seems that many writers just feel much of the facts regarding HRQOL are self-evident. The second solution might be more feasible, yet less satisfactory. It involves the preparation of several studies that will indicate HRQOL cannot be standardized. The consensus they would call for is that HRQOL should be the name of the field of research alone while the single dimensional measurement of HRQOL will be considered as a mere heuristic for statistical purposes only. The standard for HRQOL measurement would be that it has to be a profile result detailing the exact dimensions being measured in regard to the patient's quality of life. There will be many multi and single purpose HRQOL measurements and their authors will be required to provide recommendations for the specific uses of their methods.

The first solution can be truly revolutionary, it may give advocates of the consensus a goal to preserve it and its opponents a goal to challenge and put it in check. The second solution however, is a state that resembles the more current state of the HRQOL field and would require much less support and resources in order to be applied- it might even naturally occur in the near future. Either solution would need to be backed up by a vast body of research and criticism. It is our hope that no matter what the HRQOL field will flourish and open a new window into the understanding of chronic disease and disease in general that would one day provide a whole new arsenal of cures and solutions to conditions that may appear incurable today.

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Conflict of interest

The author declares no conflict of interest.

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