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Literature Reviews

Defining Quality of Life: A Wild-Goose Chase?

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Abstract

In the last decades there has been a growing interest towards the concept of "Quality of Life" (QoL), not only in the bio-medical field, but also in other areas, such as sociology, psychology, economics, philosophy, architecture, journalism, politics, environment, sports, recreation, advertisements. Nevertheless QoL does turn out to be an ambiguous and elusive concept – a precise, clear and shared definition appears to be a long way off. In this article an analysis of how QoL is interpreted and defined in various scientific articles published in the last two decades, is offered. In addition, an illustration of how widespread the use of this concept is in different fields of knowledge, the difficulties in reaching a shared understanding of QoL, the problems involved in stating clearly the construct, and a presentation of some of its conceptualizations, are provided. The importance of subjectivity in the definition of what QoL is, emerges as a key aspect. This personal and subjective dimension could be the starting point for a more thorough and holistic understanding of this concept, in which standardized sets of valid, reliable and evidence-based measures of, e.g., psychological and spiritual dimensions, are encompassed in the person's quality of life evaluation.

Keywords: quality of life, subjectivity, acceptance, multidimensionality, physical health, psychological health, ethics

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Introduction

Quality of life (QoL) seems to be an obscure concept, or at least "a multi-level and amorphous concept" (Brown, Bowling, & Flynn, 2004, p. 6), to the extent researchers are said not to know what they are talking about when mentioning QoL. We may have a vague idea, but its definition is very complicated, insomuch that in some scientific articles a definition of the concept is not even attempted, and QoL is only measured and meant as an indicator. The purpose of this article is to contribute to the scientific reflection on QoL, by analyzing how it is conceptualised and whether a definition is offered or not in various scientific articles which have been published in the last two decades. In addition, we shall provide an illustration of how widespread the use of QoL is in different fields, highlight the difficulties in reaching a shared understanding of this concept, as well as pinpoint which articles attempt to define the concept of QoL and which ones use it just as an indicator. As a matter of fact, only a minority of studies provide an original conceptualisation of QoL, while others rely on other authors' formulations, some do not even attempt a theoretical conceptualisation, some are more concerned with measuring reliably QoL without defining it theoretically and many others consider QoL as a determinant or an indicator of something else.

For the preparation of this manuscript, the search for articles has been made electronically. Publications were found through key word searches in PsycINFO, Ovid MEDLINE and Scopus with search terms *quality of life*, *well-being*, *life satisfaction* (1990-2011). After having selected the papers (either in English, French, Spanish or Italian) – among ca. 6.600 articles – on the basis of their abstract, approximately 80 articles were read in full: Only those articles which made a contribution to the conceptual definition of QoL and to its understanding have been included.

Throughout the present article we have tried to maintain consistency in the use of the technical terms. However, as it has been rightly highlighted by Galloway, Bell, Hamilton, and Scullion (2006), in quoting the papers of other researchers the ambiguity existing in the literature over the concept of QoL will inevitably appear.

Providing a Definition of Quality of Life: Mission Impossible?

In the last decades there has been a growing interest towards QoL, since progress in treatments and in medical technology have contributed to increase survival rates, and the focus has shifted from quantity of life (longevity) to quality of life, in its many facets. The concept of "Quality of Life" is one of the most used in the bio-medical field, almost overworked, but its use has become widespread in many other fields as well, to the extent that in recent years it seems to have become ubiquitous, with the risk of turning into a trivial commonplace.

In a way, QoL suffers from an embarrassing richness of possibilities (Scanlon, 1993): What is a good QoL? What kind of conditions makes life good? When research focus on QoL, what are they measuring? When a definition of QoL is not provided in scientific articles, but it is just considered as an indicator, what do they mean by QoL? And is it possible to decide the criteria which make a life valuable from an objective point of view? Is QoL measurable? Can we reach a shared understanding of QoL?

It is not a matter of splitting hairs, it is instead ethically pivotal. As a matter of fact, it can be a question of life and death: Let's just consider how fundamental the concept of QoL is in legal and ethical matters, and how a lack of distinctness in its definition can affect people's lives. The criterion of quality of life is often used when decisions about severely disabled or otherwise ill patients have to be taken (Barcaccia, 2013). It is, therefore, a crucial concept "when it is necessary to decide about a person's life, that is, in the context of withholding or withdrawal of life-sustaining medical intervention" (Marcos Del Cano, 2001, p. 91). The author rightly questions about what is meant by QoL in situations like the one above and whether it is possible to make this criterion objective.

It is obvious that different interpretations of QoL, different points of view, different definitions, will lead to different decisions on very important topics. In truth, ethical consequences stem from different QoL definitions: Health professionals often make quality of life judgments when making decisions about the care of patients and their perspective on expected quality of life is the crucial factor in deciding whether treatment for a life-threatening condition will be administered or not (Addington-Hall & Kalra, 2001). In such cases, it seems very clear that trying to define QoL is not a quibble, on the contrary it is an ethical issue, and robust research should be conducted in order to improve our knowledge of this field of study.

So far scholars have not yet reached a shared understanding of what QoL is, sometimes it is considered as the measure of subjective well-being, in other cases it is used as an indicator of physical health, etc. Gasper explains the existence of many different conceptualisations of quality of life arguing that this concept "refers to an evaluation (an evaluative judgment) about selected aspects or the entirety of a life situation and that it doesn't refer to one unitary or objective entity" (Gasper, 2010, p. 351). This concept should be understood as an abstract noun, an

"umbrella term" (Gasper, 2010, p. 359), covering many different meanings. These evaluative judgments can be made in many different ways and the author distinguishes six dimensions which affect one's evaluations: "focus of attention, values used, research instrument used, guiding purposes, standpoint adopted and theoretical framework employed" (Gasper, 2010, p. 359).

What should we do with these diverse conceptualisations? The author suggests to consider them as having different roles in different occasions and warns us to take care before trying to add them all together in an "eclectic heap" (Gasper, 2010, p. 359) that seems to provide us with evident paradoxes rather than with a better understanding of the concept.

Therefore, one of the main problems to be faced is trying to provide a definition of QoL; this attempt is made also more difficult by the spread of the concept's use in so many different branches of research: It is a concept very much used in the biomedical area, but it has also mushroomed in various, and sometimes distant fields of study such as medicine, nursing, economics, geography, architecture, visual arts, literature, philosophy, recreation, transport, environment, etc. A lot of confusion has ensued as a consequence, since now the term "quality of life" lends itself to more than one interpretation and when used, it is not always meaning the same, but is affected by the context in which the QoL consideration takes place.

Moons, Budts, and De Geest (2006), quoting Feinstein (1987), state that "quality of life often seems to be an umbrella term, covering a variety of concepts, such as functioning, health status, perceptions, life conditions, behaviour, happiness, lifestyle, symptoms, etc." (Moons et al., 2006, p. 891).

Culture is also a dimension that cannot be disregarded in this search for what QoL actually is. As a matter of fact, culture has a big influence on variations in perceptions of "health and sickness, interpretations of symptoms, the meaning of QoL and expectations of care" (Kagawa-Singer, Padilla, & Ashing-Giwa, 2010, p. 62). That's why the authors propose the Ashing-Giwa theoretical model (Ashing-Giwa, 2005) that includes *culture* as a "macro component" of quality of life. This model accounts for the influence of cultural and socio-ecological context on QoL, and the authors propose a conceptual definition of QoL: "QoL is a subjective, multidimensional experience of well-being that is culturally constructed as individuals seek safety and security, a sense of integrity and meaning in life, and a sense of belonging in one's social network" (Kagawa-Singer et al., 2010, p. 59).

Cross-cultural comparisons are therefore necessary for a better understanding of what QoL actually is. Moreover, as already mentioned, it must be also considered that there are not many other concepts which have prospered as QoL has in different fields. The price we pay for this success is having the term QoL transformed in a sort of buzz word: It is in fashion talking about QoL, its use is ubiquitous

> from television and magazine advertisements to political speeches and newspaper headlines: the increasing appearance of the term 'quality of life' in these formats says something about its importance to us as a concept, or even an ideal. However, the term quality of life is not only used in everyday speech, but also in the context of research it is linked to various specialized areas such as sociology, psychology, medical and nursing science, economics, philosophy, history and geography (Farquhar, 1995, p. 1439).

The situation is quite different when we reflect upon just one feature of the QoL construct, that is Health-Related Quality of Life, HRQoL (Barcaccia, 2013). Benito-León et al. (2011) maintain that "HRQOL is a concept that involves those aspects of quality of life or function, which is influenced by health status and is based on dimensions (i.e., physical, psychological, and social aspects), which can be measured" (Benito-León et al., 2011, p. 676).

A Brief History of QoL

In order to better understand the difficulties in providing a shared definition of QoL concept, it is useful to record when and how the history of Quality of Life kicked off, and its domino effect on almost every field of human existence. The term "quality of life" started to disseminate after World War Two. Lyndon B. Johnson[1] is considered to be among the first ones who used it in a 1964 address, even though, as noticed by Lelkens (2005), the expression "quality of life" could already be found in the socio-political literature of the 1950s. In his speech, Johnson stated that the goals he was pursuing could not be evaluated in terms of money but had to be assessed in terms of "quality of life"[2]. From that time onwards, the notion "quality of life" began to spread and became commonplace in enormous amounts of writings, speeches and programs. Wood-Dauphinee (1999) highlights that in 1977, "quality of life" started to be a keyword in the Medical Subject Headings of the US National Library of Medicine MEDLINE Computer Search System:

> Following a MEDLINE search, Albrecht (1994, p. 52) reported that between 1966 and 1974 there were 40 references related to quality of life and between 1986 and 1994 there were over ten thousand. This information demonstrates an exponential rise in research in which quality of life was at least mentioned if not measured (Wood-Dauphinee, 1999, p. 355).

It should be noted that, among those research articles, some do provide a definition of the concept, but others do not, and some even attempt to measure the degree of QoL in various types of people, patients, population, etc., without proposing a conceptual definition. Whether or not a definition has been provided there has been, through the years, an increasing focus on QoL, that has resulted in a huge number of relevant publications in the scientific literature: "A Pubmed search of articles published from 1966 to 2005 identified 76,698 articles containing 'quality of life' as a Medical Subject Heading or as a title or abstract term. Since the mid-1960s, the number of publications on this subject has grown exponentially" (Moons et al., 2006, p. 891).

Furthermore, speaking about QoL has not been specific for medicine. As above mentioned, in the 1950s it was chiefly a notion of cultural and social criticism: The notion of quality of life vs. a materialistic perspective on human existence. The term "quality of life" was used to indicate the quality of existence or well-being and even the quality of being a human person, so that Lyndon B. Johnson's speech was followed by various attempts to advance QoL by focusing on social programs from education, to community development, housing, health, and welfare. In addition, QoL has become a relevant concept in different phases of the life-cycle, and it has been considered crucial to children, adolescents and the elderly. Through the years its importance has grown to such an extent that QoL has become a desired outcome of service delivery in an enormous variety of fields, from education to politics (Galloway et al., 2006).

Also the *environment* has emerged as another context where the concept of QoL became very important: Architectural design and the physical environment have an effect on the QoL of the elderly in particular (Barnes, 2002). Burger (2003) agrees that the environment affects QoL and personally seeks individuals' opinions prior to restoring urban ecosystems. In her study, individuals stated that maintaining natural habitat, removing pollution, and providing educational signs all improved their QoL.

Nowadays the expression "quality of life" is as well widely used in journalism, politics, sports, advertisements, governments, besides healthcare (Holmes, 2005). All this dissemination of the QoL's idea "has resulted in a plethora of definitions" (Holmes, 2005, p. 493), some of which we'll try to examine in our review.

Different Perspectives on QoL: Attempts at Defining the Concept and Measuring It

It should be noticed that the change in the concept of health, which has occurred during the second half of the 20th-century, has deeply affected and modified the idea of QoL, since they are so much related. The concept of health has undergone major changes, passing from the negative health measures like the "five D's" — death, disease, disability, discomfort, and dissatisfaction — research, towards the evaluation of more positive domains and features (Pais-Ribeiro, 2004). World Health Organization's (WHO) definitions of health and QoL are allowedly positively-oriented: Health is considered "A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHOQOL Group, 1995, p. 1403). And from this new perspective on health have stemmed new and more positive health measures aimed at assessing health and not disease. These new health measures have, in turn, affected the concept of QoL, which is defined by the WHO as:

> individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations and standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment (WHOQOL Group, 1995, p. 1403).

Notwithstanding these wide-ranging definitions provided by the WHO, Rosenberg's (1995) statement that "there is no generally agreed definition of QoL" (p. 1411) is still valid. As a matter of fact, trying to provide a conclusive and shared definition of the concept of Quality of Life and indicating how to best to measure it, are still true challenges.

Ravenek, Ravenek, Hitzig, and Wolfe (2012) state the conceptual and methodological ambiguity on how to define and measure QoL in general, and maintain that some definitions of this construct have been simplistic, while others tend to be complex, and to include an ample variety of factors to describe it.

After having examined the available literature, one is tempted to endorse the provocative statement expressed by Wulff (1999): "Scientists may use rating scales and visual analogue scales to measure pain, and they may even invent scoring systems quantifying types of handicaps, but when they talk about measuring quality of life, they have gone too far" (p. 549).

Thus, is the concept of QoL ineffable? Is the subsequent idea of measuring it utopian? Susan Holmes concludes her interesting article on QoL with some challenging, even provocative questions:

> Are our attempts to reduce a complex experience to something that is simple and amenable to measurement trying to turn it into something that we can never really understand? … Is describing the experience like trying to translate something for which there are no words? And, finally, if this is so, can we really define QoL or measure it or are we truly trying to measure the unmeasurable? (Holmes, 2005, p. 493).

All these hurdles in the field of QoL might leave those who want to reach a definition of this concept with a sense of discouragement. What is certain is that often, despite using the same expression – "QoL" – we do not mean the same concept (*happiness, subjective well-being, physical health, life satisfaction, living conditions,* etc.). This lack of consensus about the meaning of QoL has resulted in ambiguous definitions and, therefore, problems in its measurement along with the incapacity to define the components of this many-sided concept (Holmes, 2005). The challenge seems so awkward that someone has invited the scientific community to give up: Wolfensberger

(1994) wrote in a book on QoL a chapter whose title was: “Let’s hang up ‘quality of life‘ as a hopeless term” (p. 286).

QoL seems to be a vague, ambiguous and difficult concept to define, widely used, but with little consistency (Galloway et al., 2006). Along these lines, Holmes (2005) points out that, despite plenty of published literature, the concept of QoL is still elusive. Rapley (2003) argues that there are “serious ethical, conceptual and philosophical difficulties” (p. 81) involved in studying QoL, which researchers must take very seriously. And in a certain sense, as a consequence of this vagueness, it seems as though the realm of studies on QoL had been pulled apart for the weakness of scientific foundation in quality of life research (Wood-Dauphinee, 1999).

Nevertheless, providing a reliable definition and a subsequent reliable measurement of QoL is absolutely pivotal whenever outcomes of any kind of treatment have to be assessed: Whether a certain treatment has led to a certain degree of improvement, or not, will be the basis on which it is decided whether to prolong that type of treatment or not, to invest money on it or not, to continue administering it to other people or not, etc. (Barcaccia, 2013). This is one of the important reasons why a valid and reliable definition and measurement of QoL are needed. But will it ever be possible?

Another huge problem regards the fact that QoL is a *dynamic* condition, since it is modified by the developments, experiences and changes that occur in life. That's why trying to evaluate QoL can lead to errors, if assessments are conducted at different times in one's life, and that’s why measurements can sometimes be considered unreliable (Holmes, 2005). Hanestad (1990) had already went so far as to state that the qualities experienced may vary too quickly for them to be meaningful.

Holmes (2005), in her interesting article on QoL, does not provide her own definition of the concept, highlights the many traps one might fall into when attempting it, mentions the various possible definitions of the concept (well-being, happiness, health status, functional status, etc.) but also reports that there is now a certain general agreement regarding some aspects of QoL: Most researchers maintain that QoL is *subjective* and that it can only be understood from an individual perspective; QoL is *multidimensional* and comprises positive and negative features of life, depending in a complex way by “physical health, psychological state, level of independence, social relationships and their relationships to salient features of the environment” (WHOQOL Group, 1995, p. 347).

In fact, many authors, instead of providing a conceptual definition of QoL, use it as an indicator, or as a determinant.

Moons et al. (2006) again pinpoint the lack of consensus on the definition and measurement of quality of life. Nevertheless, they do provide their own conceptualisation of QoL, considering it as satisfaction with life, but in the sense of an indicator of QoL: *Life satisfaction* refers to a subjective evaluation of one's personal life. “Overall 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” (Moons et al., 2006, p. 891). The authors endorse this definition also on the strength of its being quite constant over time, even though it may fluctuate. They consider satisfaction with life an indicator that can well represent what QoL is, because, stemming from the field of “positive psychology”, it focuses on strengths and talents as opposed to shortcomings and weaknesses. Therefore it is not a perspective focused on health/illness, and, according to the authors, corresponds to overall QoL.

Kane (2001) is more concerned with the issue of measuring reliably QoL, as a useful tool in assessing health services outcomes, even when acknowledging all the difficulties inherent to this task: “While focusing attention

on the centrality of quality of life (QoL) in assessing the effectiveness of health care is a laudable goal, it may also be viewed as a Promethean act of hubris …. There is no unanimously agreed upon definition of quality of life" (Kane, 2001, p. 1079).

The author, in his article on the problems related to the measurement of QoL, in fact does not provide a specific definition of the concept, even though he encourages clinicians and researchers to expand their definition of clinical success and also considers other issues that affect a person's life – provided they are restrict to domains that can reasonably be influenced by health care, thus leading to a perspective of Health-related Quality of Life. Among the main problems in providing a reliable definition of the concept, the author admits that, on one level, QoL is an immensely personal concept: "No stranger can determine what represents QoL for me or what aspects of that construct are most important to me" (Kane, 2001, p. 1079), thus resulting an extremely subjective concept. On the other hand, he highlights the importance of making efforts in understanding and defining it, since this can result in policy tools that employ a common metric to facilitate comparisons: If QoL is considered only as a subjective feature, then it will never be possible to conduct research comparing different kinds of patients, of different age, etc.

Felce and Perry do provide a definition of QoL: "an overall general wellbeing that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional wellbeing together with the extent of personal development and purposeful activity, all weighted by a personal set of values" (Felce & Perry, 1995, p. 51). These three elements are considered by the authors as being in dynamic interaction with each other, so that modifications in some objective aspect of life may affect satisfaction or one's personal values. Correspondingly, modifications in *values* may change satisfaction and deliver change in some objective aspect of life. And similarly, a modification in one's sense of satisfaction may lead to reevaluation of values and lifestyle (see Pallini, Bove, & Laghi, 2011). So, these three features influence each other, but can also change as a consequence of some external influence, such as genetic, social, material inheritance, age and maturation, developmental history, employment, peer influences, and other social, economic, and political variables. Thus, according to the authors, all the three features which compose QoL must be assessed in order to evaluate people's quality of life, because the knowledge of just one among three elements cannot predict the level of the other two.

Problems in reaching a shared definition of QoL are also portrayed by Farquhar who argues that "Definitions of quality of life are as numerous and inconsistent as the methods of assessing it" (Farquhar, 1995, p. 1439). The author also notes that an attentive analysis of medical and nursing papers mentioning "quality of life" in their titles often shows professionals' limited perceptions of the QoL concept, and also points out that many studies have avoided in the first place to define what they intend to measure. Farquhar' study has contributed to the understanding of QoL, even though the research regarded a specific population – the elderly – by offering a clearer understanding of the concept, through a qualitative analysis. The findings, in particular, question the validity of the operationalisation of QoL merely in terms of physical health measures and functional ability, because they show that social contacts emerge as an essential facet of a good quality of life. It follows that, as far as the elderly are concerned, measures of QoL should also include measures of social contacts and activities, emotional wellbeing, life satisfaction, adequacy of material circumstances, suitability of the environment, besides physical health and functional ability.

Costanza et al. (2007) propose their own integrative definition of QoL: QoL is the extent to which objective *human needs* are fulfilled in relation to personal or group perceptions of subjective well-being. Human needs are basic

needs for subsistence, reproduction, security, affection, understanding, participation, leisure, spirituality, creativity/emotional expression, identity, freedom. 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 fulfillment 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. It is of common knowledge that many different fields of study are interested in QoL. Therefore the descriptions provided of the various dimensions vary a lot, depending on the different perspectives.

Ruta, Camfield, and Donaldson (2007) consider the problem of a working definition of QoL from their socio-economic point of view. They consider Sen's definition of QoL: "QoL … is not merely a matter of what a person achieves, but also of what options the person has had the opportunity to choose from" (p. 69). The authors subsequently propose a new definition in which QoL 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" (Ruta et al., 2007, p. 402). By introducing this notion of an expected or desired capability in the definition of QoL, subjectivity is given a total supremacy, in the sense that only the single human being, living his/her life can actually evaluate its quality. In their interesting paper, the authors describe also some of the causal determinants of QoL, like income, social relationships, religious and spiritual beliefs, political participation and life events.

Dijkers (2007) is one of the authors who endorses the idea of QoL as Life Satisfaction. He highlights the ubiquity of the term "quality of life" and even levels harsh words to those who take advantage of QoL, just because it is fashionable and lucrative and can further one's career in the medical and nursing fields. "Unfortunately, when it comes to research, many investigators do not bother to consider whether QoL is a construct they need to measure, and if so, what they mean with it. It appears that typically they grab off the shelf the first instrument they see with 'QoL' on the label or that is reputed to measure QoL" (Dijkers, 2007, p. 153). Naturally, this harsh judgment should be considered in the context of a wider perspective: It is in fact well established that the motivational patterns implied in the choice of studies of nursing students are typically pro-social (Amann Gainotti & Pallini, 2006).

Along the lines of Moons et al. (2006), even though less "unshakable" in his position, Dijkers provides a definition of QoL, but admits of being among the ones who hold a particular point of view on QoL's definition, with no other reason than personal preference: The author believes Life Satisfaction as most deserving of the name QoL, however, he does not corroborate this definition with any "evidence" proving the validity and reliability of this perspective. Although having a predilection for this particular meaning of QoL, Dijkers (2007) believes that the conceptualisation and operationalisation of QoL deserve more in-depth analysis and discussion.

Wood-Dauphinee (1999) correctly points out that QoL might be seen as "representing the widest range of human experience" (p. 355); she admits that theoretical work on the concept of QoL has lagged behind instruments development and validation. From our perspective, this is truly surprising: Measures have mushroomed, but with a complete lack of clarity on what they were intended to measure. The author leans explicitly towards the term health-related quality of life (HRQL), a term which more specifically refers to the impact of disease and treatment on the lives of patients (Lin, Lin, & Fan, 2012; Barcaccia, 2013). Wood-Dauphinee does not provide an ultimate definition of the concept – the author acknowledges that there is disagreement on a single definition – but pinpoints the consensus on a concept which takes into account levels of physical, mental, social, and role functioning, and

includes abilities, relationships, perceptions, life satisfaction, and well-being, patients' satisfaction with treatment and its outcome, future prospects and the overall value a person attaches to living.

Malkina-Pykh and Pykh (2008) do define QoL as a measure of how positively or negatively we perceive our lives, a measure of *well-being*; this measure is influenced by three main domains: built environment QoL, social environment QoL and economic environment QoL. The built QoL is where one lives: house, surroundings, available facilities, infrastructure (electricity supplies, telephone lines, running water and sewerage systems, etc). The social environment QoL involves friends, family, entertainment, health and education level. The economic environment QoL concerns money, how money is spent, employment/unemployment. But the authors add that, by definition, QoL is a subjective concept, dependent on cultural perspectives and *values*. Values, the features of our world that we believe are crucial, good from an ethical point of view or personally desirable, stem from our personal perspectives (Pallini et al., 2011). Age, gender, socio-economic status, education, health, religion, occupation, etc, all contribute to form our perspectives, and make us different one from the other. So these differences in personal experience and condition in life shape our beliefs and values about what is crucial, good, or desirable. Eventually these values determine also which conditions of life constitute a QoL problem (Malkina-Pykh & Pykh, 2008).

Levasseur, St-Cyr Tribble, and Desrosiers (2009) rightly note that "intervening to enhance QoL definitively requires starting from the person's perception and fully considering his/her expectations" (2009, p. 91). We also endorse a "subjective" model that takes into account the importance of personal values in determining one's QoL: In our opinion one has to go beyond objective measures of health, and take into account people's personal perspectives and values. Although these variables are by definition personal and subjective, they should be assessed in a scientifically valid and reliable way, so that comparisons across populations/groups are made possible.

Levasseur, Desrosiers, and St-Cyr Tribble (2008), in a study designed to evaluate Quality-of-Life predictors for older adults with physical disabilities, have provided a definition of QoL as the sum of cognitive and emotional reactions that an individual experiences associated with his/her achievements, in the context of his/her culture and values, taking into account his/her goals, expectations, standards, and concerns. QoL is affected by health condition, activity, participation, personal factors, and by their relationship to salient features in their environment. The findings of this study show that satisfaction with participation in social roles (more than participation in itself) and obstacles in the physical environment are the best predictors of QoL.

Levasseur et al. (2009), in another study, conclude by highlighting the importance of multidimensional components of human functioning, and of an interdisciplinary team approach to improving QoL of the elderly. This study analysed, using a qualitative design, the perceptions and lived experience of older adults about their quality of life. Personal factors, such as health, inner life and behavioral abilities, emerged as crucial for QoL; also being occupied, doing activities, good health habits were found important in determining the level of QoL.

Some other authors tried, also, to measure to what extent the relationship between health and QoL is replicated when health is measured objectively. Blane, Netuveli, and Montgomery (2008) used objective measures of health and their change over time in the elderly, along with measures of QoL as assessed with CASP-19. According to the results, functional limitations, as falls or urinary incontinence, etc., could be responsible for the reduction in the QoL of the elderly. The authors believe that objective health is related to QoL in this population mainly through *functional limitations* (Blane et al., 2008). Nevertheless, this paper does not seem to provide a definition of the concept, a trend that is not rare in the scientific literature (Meeberg, 1993). On the one hand, there have been

many different attempts at defining QoL, according to different disciplines, fields of study and research, using either definitions of the concept, or indicating domains, determinants and indicators. But on the other hand, there is also an opposite tendency, that is not to define the concept at all; this happens mainly within the medical literature (Taillefer, Dupuis, Roberge, & LeMay, 2003). As a matter of fact, many publications on QoL have mainly focused on measures and psychometrics, rather than on theoretical and conceptual issues (Moons et al., 2006).

Pais-Ribeiro (2004) reminds us that, in fact, many articles addressing QoL do not define the concept at all. He also maintains that "QoL is recognised as a vague and ethereal entity, something that many people talk about, but which nobody knows very clearly what to do about" (Pais-Ribeiro, 2004, p. 121), so that there is not a single definition of QoL considered appropriate both for practice and research which has become a common standard.

In 1994, Gill and Feinstein stated that a conceptual definition of QoL was included only in 15% of published articles regarding these issues (Gill & Feinstein, 1994). Taillefer et al. (2003), in a systematic review carried out in 2003, noted that 16 out of 68 health-related QoL models evaluated did not provide a definition of QoL. This common failure to define what is being measured or, alternatively, to cite definitions used elsewhere without stating a preference, adds considerably to the sense of conceptual confusion. Often researchers and clinicians will evade issues of definition by focusing on "approaches" or skipping forward to discuss "measures" which imply a type of definition. Some authors do not even try to propose their own definition of QoL and they just choose "internationally widely used" instruments to assess it, seemingly to avoid the well-known difficulties in the definition of this concept.

Koller, Klinkhammer-Schalke, and Lorenz, (2005) do not provide a conceptual definition of QoL, believing it to be counterproductive to get caught up in endless discussions on what quality of life (QoL) is and whether it can be assessed. They believe it is much more important to focus on whatever it is in QoL studies that can ameliorate clinical practice: "Survival of the QoL concept within the medical community will depend on its contributions to a better understanding of patients and to improving patient care" (Koller et al., 2005, p. 186). The authors believe the definitions of QoL based on WHO's perspective as being too encompassing and idealizing and, consequently, totally impractical from a clinical point of view. How can a doctor treat the patient's social relationships, for example? So the authors focus much more on the importance of distinguishing between acceptable QoL and unacceptable symptom burden; in particular, they underline the importance of detecting precise threshold values in order to assess a person's quality of life. They report that a typical remark often expressed by QoL skeptics is: "We are aware of these questionnaires, but they did not change anything" (Koller et al., 2005, p. 186). Indeed, QoL scores usually are meaningless to clinicians. Authors consider, for instance, how easy it is to detect high blood pressure and, conversely, how difficult it is to evaluate what a certain score in a QoL questionnaire means. That's why, they maintain, thresholds are necessary to allow such evaluations, and detect whether an individual's QoL is good / bad, low / high, *acceptable / unacceptable*. With this process, raw data gain meaning and may elicit corresponding interventions and treatments, while theoretical discussions on concepts are considered useless by the authors, who do not even provide their own conceptualisation of QoL.

Some other authors have instead relied upon the WHO's perspective: Fassino et al. (2002) have endorsed WHO's definition of health, which does not simply stress the absence of disease, but considers as well the presence of physical, mental and social well-being, so that medical interventions must be meant not only to prolong life, but also to assure its quality. From the authors' point of view, three domains are crucial in the multifaceted concept of QoL – psychological, functional and existential – and all of them must be evaluated together with the health status to reach a thorough understanding of the elderly's QoL. More specifically, they highlight that the functional

status is important in determining QoL, but also that it is a dimension more strictly related to the health status. For this reason *psychological* and *existential* aspects can enrich the definition of QoL and it is worthwhile assessing them. Therefore it appears that the "QoL oriented" therapeutic strategy should take into account more complex geriatric interventions, including also psychological ones. The authors underline that, unfortunately, despite the importance of the psychological dimension, only 5.4% of their sample was receiving psychological help. Thus, there is a strong need for multidisciplinary medical teams, who hold a perspective on QoL which goes beyond the mere measurement of objective physical conditions. We support this perspective, also considering that it is possible to evaluate in a scientifically valid and reliable way the psychological dimensions of QoL.

Other authors as well have held an encompassing perspective on QoL, in this case regarding elderly cancer patients: "The management of older cancer patients is better performed by an interdisciplinary team which would consider a holistic approach, looking not exclusively at the diagnosis of cancer, but also at other issues that are relevant to the general health status of the patient" (Bernabei, Venturiero, Tarsitani, & Gambassi 2000, p. 45).

Grant and Sun (2010) highlight the importance of an accurate assessment of QoL in oncology settings, particularly when the disease is incurable. They start from a multidimensional definition of QoL to describe, then, the various QoL measures that have been developed over the years, specifically those used to assess QoL at the end of life (EoL). They don't provide an original conceptualisation of QoL but consider it as multidimensional and including three different levels of measurement: overall QoL, QoL domains and individual items. They also specify that this definition "includes a focus on illness and is limited to the subjective assessment of the impact of disease and its treatment across the physical, psychological, social and somatic dimensions of functioning and well-being" (Grant & Sun, 2010, p. 27).

Spirituality (O'Connell & Skevington, 2005; WHOQOL SRPB Group, 2006) and *relationship* dimensions are also considered as two relevant factors of QoL at the end of life. How important QoL assessment is in oncology and, in general, in clinical practice, is also highlighted by Varricchio and Ferrans (2010). They address the value of QoL assessment for the practicing clinician in order to improve care and outcomes for patients, even though they do not attempt to provide an original formulation of QoL. They pinpoint the importance of evaluating QoL, since it can improve the quality of care: Scientific biomedical treatments are nowadays available for oncological patients but, sometimes, their psychosocial problems are not addressed at all, and this failure can negatively affect the effectiveness of health care, thus compromising, in some way, the health of oncological patients (Varricchio & Ferrans, 2010).

In the last years, several new ways of gathering data on QoL have been implemented. Hacker (2010) discusses the impact of the technology explosion for researchers and clinicians: Telephone, computers and web/internet-based technologies have undoubtedly improved the quality of data collection but the problem of too many definitions and instruments still remains. The author reminds us that "over 600 instruments are currently available to assess QoL" (Hacker, 2010, p. 47) and that "no gold standard exist for defining QoL" (Hacker, 2010, p. 48) even though, from her perspective, there are two important points of theoretical agreement: "1) the individual is the most suitable judge of his/her own QoL; and 2) QoL is multidimensional, encompassing all aspects of a person's life" (Hacker, 2010, p. 47).

Koller and Lorenz (2002) do not provide a theoretical conceptualisation and refuse both Wulff's skepticism (1999) and WHO'S "romantic" perspective on QoL. They propose a pragmatic view on QoL, which is considered by the authors to be: assessed in disease; based on self-perception and self-report in 3 domains – somatic, psychological,

social; including health-related and therapy-related expectations and coping; influenced by psychosocial variables such as negative affect.

Another difficulty in providing reliable conceptual definitions, thus scientifically grounded and offering comparable values between subjects, stems from the importance of subjective interpretation of events: A good QoL is generally considered, if casting just a cursory glance, as being connected to good health. That's why, if people have disabilities, they cannot be seen as being in good health, thus cannot be considered as having a good QoL. But, as pointed out by Albrecht and Devlieger (1999), research evidence shows a much more complex picture: People's perceptions of their health, well-being and life satisfaction often diverge from objective measures of health status and level of disability.

Along these lines, Xavier, Ferraz, Marc, Escosteguy, and Moriguchi (2003) have highlighted that QoL depends on the interpretation the person gives to facts and events: “Quality of life is increasingly acknowledged as an assessment strongly dependent on the person’s subjectivity” (Xavier et al., 2003, p. 31). This perspective is very much “cognitivist”, i.e., focussing on the idea that people are not affected by events themselves, but by the interpretations and evaluations they give to what happens to them. One very important proof of how personal, idiographic evaluations of life do affect one's QoL, is the so-called disability paradox: How come some people “with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these people seem to live an undesirable daily existence?” (Albrecht & Devlieger, 1999, p. 977). This leads our perspective on QoL well beyond the assessment of physical health. The literature also shows for example that family members (partners, caregivers) of oncological patients can be highly distressed by the diagnosis of their dear one (Segrin, Badger, Dorros, Meek, & Lopez, 2007) and, in some cases, their QoL is worse than that of the patients (Barcaccia, Mismetti, & Saliani, 2010; Mismetti & Barcaccia, 2011).

Sometimes, QoL has been described as a composition of many different features. Campbell and Converse (1972), in a study designed to monitor the QoL of American life with a national sample, identified 12 main domains of life: community, education, family life, friendships, health, housing, marriage, nation, neighbourhood, self, standard of living, and work. Flanagan, in a study which began in 1972, designed to identify the major factors affecting the QoL of adult Americans, identified 15 domains: material comforts; health and personal safety; relationships with relatives; having and rearing children; close relationships with spouse or sexual partner; close friends; helping and encouraging others; participating in government and local affairs; learning, attending school, improving understanding; understanding yourself and knowing your assets and limitations; work that is interesting, rewarding, worthwhile; expressing yourself in a creative manner; socialising with others; reading, listening to music, or watching sports, other entertainment; participation in active recreation. To be noted, in both studies, health is only one of the domains of general QoL.

Banister and Bowling (2004) have explored what QoL is focussing on the perceptions of elderly people about their own QoL. The authors neither define the concept *a priori,* nor impose a framework for its analysis, but try to use the elderly's self-assessment in terms of their own priorities, needs and requirements. The authors indicate six main constituents of QoL for the elderly: 1. Peoples' standards of social comparison and expectations of life; 2. A sense of optimism and belief that “all will be well in the end”; 3. Having good health and physical functioning; 4. Engaging in a large number of social activities and feeling supported; 5. Living in a neighbourhood with good community facilities and services (including transport); 6. Feeling safe in one’s neighbourhood.

Another interesting attempt to investigate what QoL means for patients has been recently described by Fagerlind, Ring, Brulde, Feltelius, and Lindblad (2010). The authors wanted to identify how patients with a specific disease, namely rheumatoid arthritis, understand and appraise the concepts of health and QoL, through semi-structured interviews. Patients often show different perspectives and interpretations of apparently univocal concepts; their understanding of concepts such as being healthy and being able to function normally is " both individual and diverse" (Fagerlind et al., 2010, p. 109).

One of the key issues, in our perspective, is that of acceptance. "Accepting" comprises two different levels: one related to "external" events and one to "internal" states (Barcaccia, 2008; Saliani, Barcaccia, & Mancini, 2011). External events could be, for instance, the loss of one's physical health. Internal events can be, in this case, the negative thoughts and emotions related to that event (Hayes, Luoma, Bond, Masuda, & Lillis, 2006; Barcaccia & Petrocchi, 2011). The acceptance or not (or the different degrees of it) of both external aversive events and internal negative states, could have a key-role in future definitions of QoL.

As it has been shown above, QoL can be defined in a theoretical fashion as a concept, it can be defined through its indicators, domains, determinants, its definition can be considered by some authors useless or much more important than the identification of reliable measures.

Conclusions

QoL appears as an ambiguous and elusive concept, widely used in all fields of knowledge and human existence. Therefore, it would be of great importance to improve our understanding of this very popular construct. In order to analyse its use in the scientific literature, we selected a series of articles regarding quality of life, presented a brief history of the dissemination of this concept, highlighted the problems involved in describing clearly the construct, considered whether a conceptual definition was provided or not, and evaluated different conceptualisations of it.

Only a minority of these studies contained an original conceptual definition of QoL. Many more were either not defining the concept at all or endorsing WHO's definition or someone's else perspective, or using it as an indicator of physical health, material well-being, etc., or defined the concept simply through the description of the domains involved.

Overall, however, the importance of subjectivity in the definition of what QoL really is, seems to be a key aspect. We argue that this subjective dimension could be the starting point for a more thorough understanding of QoL. As the ancient philosopher Epictetus stated "What disturbs men's minds is not events but their judgments on events" (Prior, 1991, p. 211). The assessment of psychological, spiritual, social variables, as well as other variables not strictly related to physical health, should be an important part of how Quality of Life is evaluated in the future.

Most of all, our findings show the necessity for researchers and scholars to promote a clearer definition of the concept. So far, what is available is still unsatisfying, and risks leading us astray, especially considering the ethical consequences that different perspectives on Quality of Life can and do have.

Notes

1) American President from 1963 to 1969.

Notes

2) “We are rich and we are powerful, but that is not enough. We must turn our wealth and our power to a larger purpose. Even the greatest of past civilizations existed on the exploitation of the many. This nation, this people, this generation, has man's first opportunity to create its Great Society. It can be a society of success without squalor, beauty without barrenness, works of genius without the wretchedness of poverty. We can open the doors of learning, of fruitful labor and rewarding leisure – not just to the privileged few, but we can open them to everyone. These goals cannot be measured by the size of our bank balance. They can only be measured in the quality of the lives that our people lead. Millions of Americans have achieved prosperity, and they have found prosperity alone is just not enough. They need a chance to seek knowledge and to touch beauty – to rejoice in achievement and in the closeness of family and community, and this is not an easy goal. It means insuring the beauty of our fields and our streams and the air that we breathe. It means the education of the highest quality for every child in the land. It means making sure that machines liberate men instead of replacing them. It means reshaping and rebuilding our cities to make them safe, and make them a decent place to live. Yes, it means all of these things and more – much more”. (Text of Johnson's Address at Rally in the Garden, 1964).

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