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The elderly and quality of life: current theories and measurements

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ABSTRACT. The rapid evolution of biomedical knowledge and techniques has resulted in new life expectations, nourishing hope not only of adding years to life, but also quality of life (QoL) to years. The aim of the present study was to review the national and international literature concerning QoL and the elderly, and to outline the conceptual developments of QoL that have guided the research and development of different measurement instruments used for the assessment of QoL among the elderly population. From the review it emerged that the questionnaires most used to assess QoL in the research on the elderly are: the Short Form 36 (SF36), the Short Form 12 (SF12), the EuroQol (EQ5D), Life-Quality-Gerontology Centre Scale (LGC-Scale), and Quality of Life-Alzheimer's Disease (QoL-AD).

Key words: *Quality of Life, elderly.*

RIASSUNTO. La rapida evoluzione delle conoscenze e delle tecniche biomediche ha permesso di aggiungere anni alla vita e, allo stesso tempo, di migliorare la Qualità della Vita (QdV) delle persone anziane.
Lo scopo del presente lavoro è quello di effettuare una revisione della letteratura internazionale e nazionale sulla QdV nella popolazione anziana; nello specifico si propone di individuare l'evoluzione teorica e concettuale del concetto di QdV in tale popolazione indicando, inoltre, gli strumenti maggiormente utilizzati per valutarla.
Dalla revisione bibliografica è emerso che gli strumenti prevalentemente utilizzati per la valutazione della QdV nella popolazione anziana sono il questionario sullo stato di salute Short Form 36 (SF36), e la versione ridotta denominata Short Form 12 (SF12), lo EuroQol (EQ5D), il Life-Quality-Gerontology Centre Scale (LGC-Scale), e il Quality of Life-Alzheimer's Disease (QoL-AD).

Parole chiave: Qualità di Vita, anziani.

Introduction

Over the past 20 years, the concept of QoL has progressively evolved due to profound changes in the social and economic context, represented by demographic imbalance, growth of secondary needs and development of social and occupational status (1).

In addition, the rapid evolution of biomedical knowledge and techniques has resulted in new life expectations, nourishing hope not only of adding years to life, but also quality of life to years. In this perspective, the "third- and fourth-age cohorts" have emerged as a new social reality, playing an integral and active part in society, and constituting a specific group with needs and issues that must be addressed. This relatively recent development has prompted new social research development, aimed to answer the elderly's essential needs and to better and more clearly define and satisfy the demand for a good QoL.

The aim of the present study was to make a review of both the national and international literature concerning QoL and the elderly. We consequently identify which theories are at the core of this field of research and which measurements should be used to assess QoL in the elderly.

Material and Methods

In order to outline the conceptual development of quality of life (QoL) and to understand which instruments are currently being used for the assessment of QoL among the elderly population, a bibliographic review was made on the PubMed database. The key words chosen were, respectively: quality of life conceptualization, elderly; and quality of life, older and elderly people. We reviewed English and Italian documents published in the period 1985-2006 relating to the development of QoL theories and definitions, evaluating a total of 135 articles. With regard to the instruments of QoL assessment, only the studies involving patients aged 65 years and older were taken into account. These studies were published between January 2000 and July 2006; 119 documents were added to the review.

Literature Analysis

From the literature, it transpired that over the years different definitions of QoL have been provided, and the most forceful and applicative of these have been summarized as: the level of real and perceived well-being versus the ideal and wished-for well-being in regard to a specific condition.

Schalock (2) claims that the large number and different definitions of QoL produced over the past two decades arose amid continual changes in perspective. Qol studies started from a medical and technical scientific concept, in order to reach an understanding of individual and social welfare emerging from the complex combination of such factors as values, perceptions and pragmatic environmental conditions.

From a conceptual and concrete point of view, research - motivated by the development of community-based services - focused on the measurement of the outcomes of individual lives within the community, by evaluating the emergence of sociological changes, which orientated the focus again on the individual, personal and subjective aspects involved in the concept of QoL.

Furthermore, Schalock underscores that the concept of QoL has acquired a whole dimension. QoL has been used as a sensitizing notion by highlighting the environment and providing a reference point and guidance with regard to the individual perspective; it has been used as a unifying theme, by providing a conceptual and pragmatic framework of QoL. In the last instance, the concept of QoL has been employed as a social construct, by enhancing the individual well-being and furthering a working collaboration in order to reach a pragmatic, community and societal change.

In the beginning, the literature had incorrectly assimilated the concept of QoL to that of health, not considering it was much greater and wider than its traditional interpretation. Not only does the concept of QoL encompass mental and physical health status, but it also differentiates ranges, such as aspirations, personal values, satisfaction in social relationships (3).

Later, QoL was thought of as the attainment index of confidence, self-esteem and likelihood of using intellective and physical attributes in achieving set goals (4); subsequently, as the degree of satisfaction regarding physical, psychological, social, relational, material and structural needs (5, 6). And to conclude, QoL was conceived as the personal feeling arising from the satisfaction or dissatisfaction within one's compass of life, subjectively perceived as a major issue (7, 8).

The '90s were crucial. They marked an important moment as far as the QoL conceptual development is concerned. The World Health Organization (WHO) defined QoL as "the individual's perception of his or her position in life, within the cultural context and value system he or she lives in, and in relation to his or her goals, expectations, parameters and social relations" (9).

In short, the WHO stated that life stretches along two dimensions: quantity and quality. If the length of life can be measured in terms of "average expectations," the relative importance of quantitative indicators is limited, especially in the most developed countries. Therefore, it is necessary to take into account a different pattern of indicators able to represent the qualitative dimension. In practical terms, QoL loses its universal conceptual value because, foremost, it becomes assessable on the basis of subjective perceptions, which cannot solely be analyzed in quantitative terms (10).

The change from quantitative operating definitions, such as the one created by Revicki (11) -which considers QoL as the index reflecting preferences for health states and allows the combination of improvements of morbidity and mortality rates within a single measure - to multidimensional definitions, such as the one developed by the WHO QoL Group (9, 12, 13, 14) -which proposes a broad-ranging concept encompassing a long time-frame that is affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to the salient features of their environment - was implemented gradually by changing the research, intervention interests and methodology.

The constant development of QoL as a concept greatly influenced the methodological development for its assessment. From the literature, four main principles have emerged that have guided the development of QoL measurement instruments.

The first guiding principle pertains to the importance of a multidimensional assessment, as is increasingly recognized in the literature (15, 16, 17, 18). Physical assessments alone are inadequate as indicators of QoL (19), as highlighted by the findings of a low correlation between self-rated QoL and functional capacities (20). By now it is widely recognized that the measurement of QoL should include the person's physical health, day-to-day functioning, psychological well-being, social relationships and environment.

The second guiding principle concerns the importance of the subjective assessment of QoL, applied by individuals themselves (15, 17, 18, 21, 22, 23). A number of studies have demonstrated that physicians' ratings of the QoL of patients with chronic illness are significantly different from patients' self-rated QoL (20, 24). By highlighting the discrepancy between exogenous and endogenous QoL assessments, these findings opened a discussion among the researchers on the effects of adjustable internal standards on self-perceived ratings of QoL (25,26). The discussions suggested that people's perceptions of their lives change depending on their expectations, with the latter formulated through experiences, underscoring the importance of including subjective ratings of QoL.

The third guiding principle emphasizes the importance of a relative assessment as a central factor in the overall assessment (22, 23, 27). The importance of various life circumstances, including relationships, abilities or disabilities, varies among individuals, and it is necessary that QoL instruments are sensitive to such differences.

The fourth and last guiding principle regards the importance of cultural relevance. The measurements need to be culturally sensitive (28, 29, 30, 31), emphasizing the critical nature of the direct translation process for an instrument, during which cultural idiosyncrasies and language idioms may not always be taken into proper account (32).

The Instruments and Their Development

Our bibliographic review reveals that, in over 39% of the studies, the questionnaire used to assess QoL is the Short Form 36 - SF36 (10) or its reduced version, the Short Form 12 - SF12 (33). These are generic questionnaires (questionnaires addressed to the overall population, irrespective of sex, age and illness) that investigate the patients' perceptions of their general health. Many present more than one dimension, usually discriminating the aspect linked to physical, emotional and social functioning. The goal of using these broad questionnaires is to assess the general health state rather than a specific condition. The questionnaires offer the possibility of comparing data coming from patients with different pathologies and conditions. However, these questionnaires run the risk of not focusing exactly on the issue of interest.

The SF36 is a broad questionnaire consisting of 36 items divided into 8-scales that examine the different aspects of the person's health state: physical activity, physical health, physical pain, general health, vitality, social activities/role and emotional state, mental health and health state modifications. The final score (it is possible to score each scale individually) ranges from 0 to 100, in which a higher score corresponds to a better QoL. SF36 is a tool that measures the positive states of health, so as to be suitable to assess healthy, ill, and disabled populations.

The SF12 consists of 12 items (extracted from SF36), which include 2 brief indexes of the assessment of QoL: the "Physical Component Summary" and the "Mental Component summary." The limited number of items makes this questionnaire less accurate compared to the SF36. It assigns each subject to a particular level, but this factor acts like a buffer when the sample is large. Its short length makes it especially suitable for use in addition to other questionnaires, which focus on a special domain or a determined pathology, or to be completed through phone or computer.

Another generic questionnaire used in research on the elderly population is the EQ5D (34). This measurement tool comprises only 5 items and investigates independence, personal care, day-to-day life, pain and anxiety/depression. The EQ5D gives one final score, in which a higher score corresponds to a better QoL. Its brevity makes it convenient for use along with other questionnaires.

As previously stated, generic questionnaires may be used alone or together with specific tools to assess QoL. The latter can be addressed to a domain, a specific pathology, a specific age or a symptom. Compared to generic instruments, these specific measurement tools are more sensitive to the clinical approach but they do not allow for comparisons among different pathologies and/or ages.

Findings from the present review indicate that there is not one specific prevalent measurement tool used in the elderly population, but that each clinician or researcher administers the instrument he or she considers most suitable, depending on the dominant pathology in the group of patients being evaluated.

Among the most used measurement tools are the Life-Quality-Gerontology Centre Scale (LGC Scale) (35) and the Quality of Life-Alzheimer's Disease (QoLAD) (36, 37).

The LGC Scale is a specific instrument used to assess QoL in the elderly population, consisting of 49 items. It was derived from the analysis of the items from other instruments, such as the Neugarten's Life Satisfaction Index A (LSIA) (38), Lawton's Philadelphia Geriatric Centre Morale Scale (38) and Rubenowitz's Life Quality Scale (38).

QoLAD is a questionnaire created to assess the QoL of Alzheimer's patients and their caregivers. The language used in the formulation of the questions is very simple, and the items specifically investigate family relations and friendships, economic status, physical health, mood and a global evaluation of QoL. The completion of QoLAD takes about 5 minutes. The caregivers answer the questions referring to their patient's QoL, while the latter respond in reference to their own situation. QoLAD consists of 13 items and there are 4-level answers with a final score, ranging from 13 to 52 points, in which the best QoL corresponds to the highest score.

Discussion

Over the last 20 years, many books have been published on QoL and its assessment; many Internet Web sites have been created on this topic and the number of scientific publications on the subject has increased.

The most followed approach on the evaluation/measurement of QoL is Positivism and Natural History. QoL, as any other concept, must be measurable and standardizable and lead back to normative data. As a consequence there has been a proliferation of theories that have investigated and classified the aspects within real life in order to identify the main components of QoL, so as to make it as objective and measurable as possible, by asking one or more questions.

Most instruments for assessing QoL, especially those devoted to the elderly population, have been developed considering good healthy functioning as an index of a high QoL. The items on the questionnaires mentioned above focus prevalently on physical health, the impact a determined illness (or pattern of symptoms) has on the day-to-day activities, and the impact of the medication dosage.

If it is commonly recognized that QoL is a multidimensional concept, then why do we confine ourselves to assessing only the physical health domain as far as the elderly are concerned? Several researchers (39, 40) have emphasized that the elderly consider important the same things as other ages do in regard to QoL. Physical health is just one of the determinants in assessing QoL, which goes along with and impacts family relationships, quality of friendship, social contacts, economic independence, mobility, psychological well-being, spirituality, ability to enjoy spare time and planning for the future (41).

A way to understand the QoL of the elderly is to create measurements that are able to investigate all the domains mentioned above, taking into account the interactions and the subjective weight reported by the single characteristics (42). Every individual has a unique perspective on what is important in his or her own QoL. It is the meaning given to each event recognized as significant that will cause -or not- an improvement in the perception of QoL.

An abstract approach that attempts to go beyond the limits of all the questionnaires cited above is trying not to use only pre-formulated questions on a health model but to develop new measures of QoL. These new measures consider themes that the patient deems relevant, by adding his/her values and preferences (38).

Examples of questionnaires created using this approach are those proposed by Elizabeth Juniper: the Asthma Quality of Life Questionnaire (AQLQ) (43) and the Pediatric Asthma Quality of Life Questionnaire (PAQLQ) (44). Both of these measurements are specific in assessing the impact of asthma on the perception of QoL. The first one consists of 32 items and is designed for adults; the second one has 3 items and is specific for children 7 to 17 years of age. A characteristic form of such instruments is that a part of the instrument is interactive: patients are asked which activities they prefer doing (choosing among a pre-defined list and/or adding other new choices) and answer using pre-formulated options only about these ones.

The questionnaires developed by Prof. Robert A. Cummins (45) from the School of Psychology (Deakin University) and Prof. Ivan Brown (46) from the University of Toronto coincide with this theory. Both place emphasis on the patient's subjectivity and point of view as far as the questionnaire's construction is concerned.

The abstract approach that guides the creation of these instruments identifies some life ranges applicable to every person's life. It bases itself on the assumption that the relationship between the individual's perception of the importance given to these domains and the individual's perception of the satisfaction felt in the same areas is the most complete and effective way to assess QoL (47, 48. Brown states that something that is of no interest is never going to be a reason for satisfaction, and so it is not going to add quality to life. On an applicative level, this theoretical point of view recognizes questionnaires in which, for the score referring to the QoL perceived by the patient, the satisfaction experienced in a specific domain will be "thought" through the importance assigned to the domain in question. The subject will give a double answer to each item, i.e. about the way he/she is able to do a determined activity and how important it is for him/her to do that specific action (49, 50, 51, 52).

Conclusion

In conducting an analysis of the society and health system, the definition of QoL assumes value only if measurable with valid and concrete quantitative and qualitative indicators, traceable to scales of identified and structured values. These start from variables effectively designating individual characteristics of the common population or specific group (53).

Regarding the third- and fourth-age population, it is necessary to proceed in identifying the general factors outlining the global profile of QoL. Then within the global profile we can look for the most meaningful indicators for its quantification in the elderly population.

In the past, the QoL quantification approach has consistently caused confusion about the development of evaluation systems to measure the effectiveness of measurement techniques of health status and QoL itself. However, currently we know that it is not only "normative data" that give useful and accurate information on QoL: the elderly's point of view could be different from that of an expert's and that difference should be taken into account when creating measurements.

The manifoldness of the factors influencing QoL might suggest that analysis may not be carried out with linear statistical and epidemiological methodology (54).

The preliminary outcomes of a research study conducted in 2002, highlight the possibility and utility of developing dynamic profiles of qualitative and quantitative assessment of QoL, through the analysis of complex systems and the use of models. The shift is to start from ideal values, as defined by the scientific community in regard to the general population and specific sub-populations, and to compare them with the real values, measurable objectively by the same principles, in the sample of the population observed.

The use of different methodologies, based on subjective factors, allows the analysis of the QoL wished for and perceived by the population. Then it is possible to correlate the four levels of QoL in grids of reference so as to define the relationship and outline the specific social conditions that represent the direction, thereby redirecting the planning and organization of the social and health services.

In the wake of these transformations, the WHO is currently working on a project (WHOQoL-OLD Project) to develop an instrument that measures the QoL of the elderly in a way that is internationally applicable (55).The purpose of a cross-cultural validation of the Active Ageing concept was successively added to the instrument. In 2002, the WHO () defined Active Ageing as a theoretical and pragmatic paradigm in which the elderly are active members in a society where the different ages are integrated; the elderly have their own specific and irreplaceable value and productively contribute to the improvement and development of the community (56, 57). The challenge proposed by Active Ageing has been to redirect research, moving the focus away from illness towards the promotion of an active presence and integration of the elderly in society.

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