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THE ROLE OF THE PERSON'S SELF - CONCEPT IN QUALITY OF LIFE RESEARCH ¹

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Abstract. The author of this paper considers the concept of health-related Quality of life (QOL) by paying special attention to the relevance of taking into account of one's own personal self-concept. An attempt was made to indicate to the importance of the unique way in which a person (patient) summarizes his own self-concept, i.e. the way he perceives and experiences him self in the context of the relationships with others and world in general. That is why the author suggest that in the careful QOL research it is essentially not possible to ignore or even to exclude a person's own subjective and unrepeatable values, feelings, experiences, attitudes, beliefs, and conceptions about himself as well about the various elements and/or sides of life, that differentiate particular person from all others. Some more general issues about QOL assessment are also included. The suggestion was made that the suitable QOL measurement has to include an idiographic and subjective approach - but only as an important complement to more nomothetic and objective one. It is argued that both approaches and measures should be used in QOL research, and that the quality of our dealing with this field of research can be increased in this way.

Key words: Quality of life, Self-concept, Idiographic approach, Subjective/Objective QOL measures

THE CONCEPT OF "QUALITY OF LIFE": A CURRENT STATE

Clinicians and clinical researchers in a number of health care areas have long sought to evaluate the patients' actual health status. However, it is only recently that they have become more interested in the possible impact of a variety of diseases on the quality of patients' lives, works, or their families. Thus, as a matter of fact, in the past two decades

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we can observe that the importance of assessing the patient's existing life quality is being increasingly realized all over the world.

As it has been noticed, the term and the concept of "Quality of Life" (hereinafter QOL) is a fashionable concern these days, both in the community and in the hospital, as well in the clinical research. In a word, it is now a medically accepted term. Unfortunately, it seems that there is little consensus about what constitutes health - related QOL, and how it could be measured in a suitable manner. According to Passchier (1992), quality of life can be defined in several ways, though the concept can basically be inferred from the answer to the question, "How have you been lately?". Among others, the concept is also seen as an important aspect of comprehensive diagnosis which covers, first, the basic components of health assessment, and then higher-order factor that are more difficult to define and assess (Mezzich, Schmolke 1995). Although no single definition of "Quality of life" is universally accepted, QOL is often defined as made up of the following health-related domains: physical health and degree of physical pain, social role functioning and interpersonal relationships, occupational activities and activities of daily living, economics and financial costs of illness, psychological well-being, happiness, goal attainment, and subjective perceptions of health and life satisfaction (Koran et al. 1996; Sainfort et al. 1996).

No matter how it is defined, health-related QOL is commonly recognized as an important measure of outcomes in patient management, cost-effectiveness evaluations, clinical trials, and treatment outcome studies-always implying a patient's functional status and positive sense of well-being. As Koran says: "Changes in signs and symptoms are insufficient measures of treatment outcome. As physicians, we hope also to increase our patients' quality of life "(Koran et al. 1996: 788).

THE MULTIDIMENSIONALITY OF QUALITY OF LIFE

It is widely acknowledged that a measure of QOL can be obtained from responses to questions about each important life dimension. In general, QOL is usually divided into physical, occupational, social, and psychological dimensions. Namely, these broad dimensions are commonly considered as the most important ones in a human life. It is reasonable to say that these health-related QOL dimensions and their various domains are inevitably inter-related, as well that there are expectable differences in the effects of mental and physical disorders on health-related QOL. Thus, for example, evidence exists that depression is associated with as much or greater limitation in multiple domains of daily functioning and well-being than that found for other common chronic medical conditions (Sherbourne, Wells, Judd 1996). Also, some findings indicate that the patients with obsessive-compulsive disorder described greater impairment in the mental health domains of QOL (social functioning, role limitations due to emotional problems, and mental health) and less impairment in the physical health domains (physical functioning, role limitations due to physical problems, and bodily pain) than the patients with diabetes, a chronic medical illness (Koran et al. 1996). Several other research findings unexpectedly suggest that these dimensions do not demonstrate parallel changes. For example, it has been shown that the activity and physical health of oesophageal cancer patients decline rapidly after surgery, while their emotional (psychological) state

improves (Passchier 1992). It seems also important to note here that attainment of a high life quality does not require experiencing all different aspects or levels of QOL; in fact, it can coexist with the presence of illness (Mezzich, Schmolke 1995).

According to the author's view, in addition to these four dimensions of QOL it is of special importance here to include the cognitive-experiential dimension as one of the basic personality references. In this sense, for example, Kendrick and Trimble (Trimble, Dodson 1994) have added a cognitive QOL dimension. Thus, these authors have developed a scale that allows the patient to identify specific QOL concerns after a semistructured interview. Their scale seeks to measure the important discrepancy between the patient's quality of life expectations and his/her current level of functioning. This discrepancy is seen as a major contributor to psychological distress in-patients with chronic illness. This important supplement of Kendrick and Trimble (1994) is in much accordance with the author's basic multidimensional approach to QOL research, in the sense that many different dimensions or aspects of patient's quality-of-life or well-being should be evaluated, involving a whole complex of interacting variables.

THE PERSON'S SELF - CONCEPT AND QOL RESEARCH

Throughout the text the central attention is paid to the importance of incorporating the patient's subjective self-related experiences, idiosyncratic values and needs, and his/her personal point of view into the overall measurement of his/her health-related QOL. Briefly, the author's intention is to indicate that in QOL research we have also to include a person's own self-viewing and self-evaluation, not just the other's viewing and evaluation of him/her

The basic assumption of the paper is that taking into consideration not only the clinicians', caregivers', or family members' rating but also the patient's own viewing and assessment of his/her health-related QOL, as well as his/her rating the importance of its elements or dimensions may provide a more valid picture of one's own life quality. It implies the principal research interest in the following key question: "If a person (patient) is asked to summarize his own overall appreciation of himself and his life, what would he say? ". That is why the author suggests that in the careful QOL research it is essentially not possible to ignore or even to exclude a person's own subjective and unrepeatable values, feelings, experiences, attitudes, beliefs, and conceptions about himself as about the various elements and sides (light and dark) of life, that differentiate particular person from all others.

Thus, although each medical and psychiatric disorder has its own set of QOL issues and research designs vary considerably depending on the specific patients groups, also including the cross-cultural aspects of QOL, it seems that this kind of personal self-report (of the patent's sense of self, of self-identity, of sense of mastery after medical and therapeutic treatment, etc.) may indeed contain valuable and subtle information about patients' life quality, and can be used in QOL assessment. If it is so, then questions or items related to QOL have to be developed not only by the experts, but also in close relationships with the patients, who are the subject of the existing QOL assessments. In this way – besides by including a global rating of QOL and allowing the patient to add information not included in the measuring instrument, as it has been suggested in the work

of Koran et al. (1996) -- the validity and the quality of health-related-quality-of-life measurements can be increased.

From this point of view, an appropriate QOL assessment needs to include a complex and central personality structure of the phenomenal or conscious self-concept (or just self), which refers to some subjective entity closely related to the personal sense of identity, as the factor of importance in evaluating the patient's QOL. Thus, for instance, the happy person, when asked, is likely to report satisfaction with self- i.e., 'selfacceptance', or 'self-esteem'; he/she is also likely to report favourable sentiments toward a variety of other things or ideas that are significant for him/her -- such as other people, work, or 'God'. By contrast, 'dissatisfaction with self' would appear to be just one manifestation of a general state of misery that may focus on various objects. It is because a person's unique and individual self is indispensable constituent of personality, comprising both personal and idiosyncratic experience of oneself in the context of the relationships with one's own body, with others, and the world in general (Zlatanović 1994). This is one's own descriptive attributes or behavioural characteristics as seen from one's personal perspective. These characteristics may range from rather specific to quite broad. Thus, the personal self-concept includes not only physical, behavioural and internal characteristics, but also such aspects as gender identity, racial/ethnic identity, socio-economic class identity, age identity, and a sense of self-continuity as being the same individual through time (see Corsini 1987). The self-concept is also described as the most crucial component of the 'personal system' which is the most resistant to change, and more time is required for change. Moreover, if the self-concept is changed, there is a higher probability that other hierarchical components in the system (roles, behaviours, values, and attitudes) will change (see Ziller 1976).

Therefore, in the area of QOL research we must keep in wind that every person/subject has his own self-being, and his own personal world, the content of which is highly individualistic, consisting of unrepeatable reality of personal experiences and meanings. It is of particular importance, then, to understand the patient's personal and unique standpoint as the individual human being - the mind-in-particular. That we can, first and foremost, perceive from the particular patient's personal self-data, which always refer to the one-and-only-one-person. In doing so, in closer contact with patient, in the course of good-enough interviewing, we are in better position to understand and to assess his/her health-related QOL. That is the reason of the author's arguing that we cannot speak completely enough of this topic without any reference to the concept of self or self-concept, and self-conception variables.

THE NEED FOR COMPLEMENTARY APPROACHES TO THE OOL RESEARCH

This paper considers the role of the person's self-concept in QOL research, but it inevitably also includes some more general issues about QOL assessment in variety of disease states. It tries to present some preliminary ideas for one more balanced, although idiographic and understanding in its base, approach to the research in QOL area, with the proposal for more comprehensive assessment model for the purpose to give, at least, modest contribution to further developments in this field of research. It is hoped that they will stimulate further discussion of this subject.

In this context, most of the numerous instruments for assessing QOL that are used in mental health rely on a single respondent -- either the patient or the clinician is queried, but rarely both. Related to this, Sainfort et al. (1996) suggest that assessment areas that are most important to clinicians in judging QOL might be very different from those judged important by patients. Even among patients there are likely to be major differences about the relative importance of different QOL domains. Thus, for instance, ability to work might be most important to one patient, while a sense of physical health and the concomitant absence of medication side effects might be most important to another. That is why the author, in accordance with some recent authors, argues that personal values and the patient's preferences are important in monitoring the quality of medical care outcomes, and that it is important to assess both the patient's and the provider's perspectives.

In line with the above mentioned, it can be noted that while the assessment of OOL can be approached quantitatively, its scope and intricacy make it particularly pertinent to idiographic formulations (Mezzich, Schmoleke 1995). Additionally, as some researchers in this area have noticed (Malm et. al. 1981), it is the challenge to describe and assess our patients' pattern of existence, because a wide range of factors, together with subjective experience, contribute to their overall quality of life. Therefore, the full range of factors must be assessed in order to have a comprehensive view of our patients. It is the author's opinion that these researchers are right when in their comprehensive approach to QOL evaluation of the schizophrenic patients consider the patient's existential situation as the outcome criterion, and when they state as follows: "Existence is more than symptoms and behavior; more than happiness; more than adjustment, role performance, and social skills; more than admissions, relapses, days in hospital, and burden on the family. These are parts of existence, but they are not all". And farther: "Quality of life has many aspects, and each of us values them differently - hence an important part of therapeutic planning should be to find out which features of quality of life are particularly important to the patient and to the natural raters, that is, the persons who in real life make judgements that can have a significant impact on the patient" (Malm et al.: 478,1981).

If it is true that QOL is a personal and subjective value, then the patients' individual values, personal experiences and perceptions, as well their particular patterns of existence must be also incorporated in to the QOL study and quantitatively expressed if it is to be more completely measured. In the terms of this paper, the main point is that in order to complement more nomothetic and objective standard measures, health-related QOL has to be also treated from the inside out, from the subjective point of view - that means, from the experiential, existential position of the patient. For, too much 'detachment' and 'objectivity' can impoverish our ways of understanding and evaluating someone's life quality. Therefore, one more personalized, or idiographic dealing with QOL is also needed.

Related to this, the author supports the following two remarks that, in essence, are not contradictory to the ideas presented in this paper. One is that of Malm *et al.* (1981) who notice that there are two fundamental drawbacks to defining QOL in purely subjective terms: it ignores mental abnormality by a tacit assumption that happiness and dissatisfaction are never pathological, and it may lead to failure to distinguish the privileged from the disadvantaged. The other one emphasizes that there are specific methodological issues which render the measurement of QOL in psychiatric disorders difficult, such as the "affective fallacy" - the important fact that affective psychiatric

disorders way distort the perception of one's own quality of life. It is therefore argued that in psychiatry, more than in other disciplines, in addition to subjective measures, also objective measures have to be used to assess a person's life quality (Katschnig 1976).

In concluding this paper it should be pointed out again that all the above mentioned does not imply the author's intention to diminish research value of the objective QOL measures. It only implies that in this field of research it is needed to be flexible and comprehensive enough, having in wind the multidimensional nature of quality-of-life, with its complexity of the set of indicators involved, and to include both objective and subjective measures, as well as both basic and higher-order indicators of QOL assessment. Therefore, the main purpose of this paper was to stress and/or recommend such an complementary approach to the health-related QOL research, in order to make sure that same elusive but important subjective areas of a person's QOL outlined above are not overlooked.

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ULOGA POJMA O SEBI OSOBE U ISTRAŽIVANJU KVALITETA ŽIVOTA

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Autor ovog rada razmatra koncept kvaliteta života u vezi sa zdravljem, posvećujući posebnu pažnju važnosti uzimanja u razmatranje ličnog pojma o sebi (self-koncepta) pojedinaca. Učinjen je pokušaj da se ukaže na važnost jedinstvenog načina na koji osoba (pacijent) sažima svoj sopstveni pojam o sebi, tj. načina na koji ona opaža i doživljava sebe u kontekstu odnosa sa drugima i sa svetom uopšte. Zbog toga, autor ukazuje da u pažljivom istraživanju kvaliteta života suštinski nije moguće zanemariti ili čak isključiti sopstvene subjektivne i neponovljive vrednosti, osećanja, doživljaje, stavove, uverenja i poimanja osobe o sebi samoj i o raznim elementima i/ ili stranama

života koji je razlikuju od svih drugih osoba. Obuhvaćena su takođe neka opštija pitanja procenjivanja kvaliteta života. Tako, data je sugestija da podesno merenje kvaliteta života mora uključiti idiografski i subjektivni pristup - ali samo kao važnu dopunu nomotetskom i objektivnom pristupu. U radu se tvrdi da bi oba pristupa i mere trebalo da se koriste u istraživanju kvaliteta života, kao i da se na ovaj način može poboljšati kvalitet našeg bavljenja ovom oblašću istraživanja.

Ključne reči: Kvalitet života, Pojam o sebi (Self-koncept), Idiografski pristup, Subjektivne/Objektivne mere