

The Quality of Life in the Contexts Health and Illness

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INTRODUCTION

Quality of life represents a category that is recently very frequent, often as a subject of research or an interpretative starting point for a range of problems. Quality of life is a term which is used in many disciplines and it has got into medicine, psychology and pedagogy through economy and sociology, when by researching, for example a life level, it has been shown that qualitative criteria are more decisive than quantitative ones.

Quality of life is an interdisciplinary term, thus it is very convenient everywhere we deal with human problems in a wider aspect. Quality of life researching, in a way, enriches and extends health researches, which have been recently the centre of attention in social medicine and in quickly developing health psychology and pedagogy. Health category has become one of central conception of materials and programs of World Health Organisation; while in health research attention was paid also to subjective variables, it was better to interpret them within quality of life. Certain disadvantage in quality of life researching is a wide conception of this term and often different understanding by diverse specialists; on the other hand it is a term, which is adequately perceived also by the public and it is easy to work with in practice.

We do not want to deal with the theory here; the reader can find it further in the book. We only want to give notice that we do not research the quality of life only in patients, but quality of life is a very favourable term also in investigation of “normal” individuals or society groups. Basically we always pursue maintenance or increase of quality of life, when we are aiming at the human personality and at those its components that we are able to successfully develop in a certain situation as these issues are being offered by contemporary positive psychology.

The presented publication shows plenty of knowledge that can be divided into reports usable in the clinic sphere (especially in ontological patients) or in the domain of personality and social load situations (such as unemployment, age) and furthermore the research of quality of life in the school system. Theoretical questions are solved here and research results from different observations of the quality of life domain are presented as well. We assume that, in the conception of the whole publication, authors' effort to show individual aspects of quality of life research is evident and, in the diversity of approaches, conceptions and results, ambiguity, interdisciplinarity and wide field of usable possibilities of the quality of life examination are also shown.

The impulse for publication of this collective monograph was a seminar meeting held on 25th April 2008 in Brno with the same title **QUALITY OF LIFE IN THE CONTEXTS OF HEALTH AND ILLNESS**; we are offering this publication as a starting point for further discussion about this interesting and important issue.

Brno, October 2008

Oliva Řehulková, Evžen Řehulka

HEALTH - RELATED QUALITY OF LIFE PARADOXES (HRQL)

Jiří MAREŠ, Jana MAREŠOVÁ

Introduction

Contemporary medical science does not only contemplate offering health care to the ill and **prolonging** human life or saving it (no matter whether towards its beginning or its end) It begins to devote more and more time to thinking about the **quality** of the months and years added, as advanced scientific knowledge, increasingly sophisticated technologies, revolutionary treatment and surgery procedures and new medicaments allow to save human lives even in the cases that would have been deemed fatal a few years ago. It is little to be wondered that ethical aspects of health care and nursing are being discussed on a wider scale and recommendation *guidelines* are being set up.

On the other side, health care institutions more frequently meet complaints (either justified or not justified) about the poor quality of their care made by patients and their families. There have also been legal suits and law courts investigate whether, while providing care, health care workers neglected or did not neglect their duties.

Arising problems are also viewed from a different perspective now. The dominating professional-centred approach is now supplemented with patients' opinions and adjusted by the patients themselves and their families, and ,in case of small children, by their parents. Concrete objective health care results yielded are, as a standard procedure implemented in developed countries, combined with the patients' subjective views on the quality of the health care provided, and, especially , on the **after-treatment quality of life**.

Generally speaking, we can say that health-related quality of life concerns mainly **professional health care** and becomes an important **result indicator** of provided **care** (Wilson, Cleary, 1995).

In a document by the American Ministry of Health (Guidance, 2006), methods examining health-related quality of life are ranked among the methods used by the **patient** to refer about the health intervention impacts known and are known as *patient-reported outcomes measures*. They report for example about positive treatment effects or about its side effects, which often hold unpleasant consequences for the patient. Three of the document's main arguments supporting the necessity to ask patients rather than health care workers are:

- some clinical research outcomes in new medicament testing are only known to the patient

- it is desirable to know patient’s opinion on total treatment effectivity
- systematical and standardized procedures in assessing patients’ views can bring precious information likely to be lost if verification is based only on doctor-conducted clinical interview

Extensive research into health-related quality of life has not only offered a vast number of useful theories, many research and diagnostics instruments and valuable clinical data, but also some surprising discoveries – paradoxical findings.

This review study **objectives** can be summarized into three points: 1. to investigate in detail the term *health-related quality of life* and its clinical use, 2. to characterize the term *paradox* 3. to describe and explain the five paradoxes discovered while exploring the quality of life that is related to health.

Term Definition

It is not easy to define the general category called *quality of life*, as it did not originate as a scientific term. It gradually spread into use in many branches of science and started to acquire specific nuances.

The term *quality of life*, applied throughout health care generally and in individual branches of medical science specifically, is labelled **HRQL** - *health-related quality of life*. It could be said that HRQL coverage is more *narrow* than in case of *quality of life* (Spilker, Revicky, 1996; Epstein, Stinson, Stevens, 2005) and that is why it is more suitable for use while considering wider contexts in providing health care (Strand, Russell, 1997).

However, theoretical defining of the term is not unified. There are numerous approaches to how to define this term. We drew inspiration from an overview chart created by researchers centred around E. Davis (2006), as the table struggles to give definition cores. We added more information as seen in Table 1, which was created by us.

Tab. 1 Diverse definitions of health-related quality of life, especially in children and adolescents. (modified according to Davis et al., 2006, p. 315; Mareš, Marešová, 2006, p. 30-31).

Definition Core	Definition Example	Authors
Overall being (total existence)	Overall being (total existence) of an individual or a group including various positive health aspects	Lindström, Kohler (1991) *)
Functioning	It includes somatic functioning, emotional and social functioning, as well as role functioning	Varni, Burwinkle, Seid et al., (2003)
	Multidimensional construct covering three main domains: somatic functioning, psychological and social functioning	Speith, Harris (1996); Bouman, Koot, van Gils et al. (1999)
Functioning and its subjective assessment	It is usually defined as an individual’s subjective quality functioning assessment and satisfaction or distress linked to it	Graham, Stevenson, Flynn (1997)
	Multidimensional term including a broad area of functional state, psychological and social well-being as well as perceived health and symptoms related to a disease and its treatment	Aaronson et al. (1991) *)

Disease impact; objective and subjective assessment of its influence	Objective and subjective impairment effects on somatic, psychological and social aspects of quality of life affected by an individual's disease and its treatment	Strand, Russell, (1997) *)
Disease impact and its subjective evaluation	Functional effects of a disease and its subsequent treatment on the patient as seen by patients themselves	(Schipper, Clinch, Olweny, 1996) *)
	Patient's subjectively perceived impact of his or her illness on their everyday life, somatic functioning, psychological and social functioning and well being	(Reflection paper, 2005) *)
Functioning and well-being	Multidimensional construct including somatical, emotional, psychical, social and behavioural components of well-being and functioning as perceived by patients and/or individual patient feelings related to health	Ravens-Seiberer, Gosch, Abel, et al. (2001)
State of health	An individual's state of health as a continuum with increasing complexity of patients' outcomes; it can be assessed on five levels: biological/physiological factors, symptoms, functioning, perceived overall health and total well-being or quality of life	Wilson, Cleary, (1995) *)
State of health and perceived feelings about the state of health	It is a combination of state of health and affective reactions to problems with health	Vogels, Verrips, Verloove-Vanhorick et al. (1998); Fekkes, Theuissen, Brugman et al. (2000); Rosenfeld, Goldsmith, Tetlus et al. (1997)
A component of health	A component of overall quality of life primarily determined by an individual's health and can be affected by clinical interventions	Mishoe, Baker, Poole et al. (1998); Juniper (1997)
Value assigned to life	The value assigned to life during its course as modified by impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment or policy	Feeny, Furlong, Boyle et al. (1995); Patrick, Erickson (1993); Furlong et al. (2005) *)
Life satisfaction	The level of personal satisfaction with the life aspects that can be influenced by disease impact and its treatment	(Brouwer, Maillé, Rovers et al., 2005) *)

Explanatory notes:

*) Quotations marked with an asterisk were supplied to the original Davis et al. overview by us.

Just taking a short glance at Table 1 suggests that authors usually perceive HRQL as the influence of a disease on an individual's functioning, on various aspects of their lives, on their state of health, on health and components of life as assessed by the individuals themselves.

Empirical research participating authors do not devote their time to discussing

its theoretical basis and various ways how to define it, as we found out for ourselves in empirical research works on quality of life in Czech and Slovak juvenile patients (Mareš, Marešová, 2006).

Taking into account the facts given, the renowned research worker M. Rapley (2003, p. 140) recommends using the definition formulated by the American Disease Prevention and Treatment Centre. Further, he calls attention to the fact that HRQL as a scientific category is suitable for use not only on the individual level, but also for groups of people and even for whole populations.

HRQL includes the aspects of the total quality of life which can be clearly related to being health influenced, both by somatical health and mental health. It is perceived somatic and mental health, including further factors of influence like health hazards and conditions, functional state, social support and socioeconomic status. On the community level, HRQL includes resources, conditions, health policy and practical procedures that influence a population's perceived health and its functional state (Centers, 2000).

HRQL in Clinical Branches

Health-related quality of life is a significant component of medical and nursing care and its apt quality indicator. This fact is utilized both in clinical experiments (Fayers, Hays, 2007), and in clinical practice.

Russak, Croft, Furst et al. prepared a basic thesis review for clinical applications (2003, p. 575- 577).

HRQL importance for clinical experiments:

- Data on patients' quality of life collected from the questionnaires filled in by patients in clinical experiments can show changes in their state of health as effectively as a physical or clinical examination.
- Health-related quality of life data discriminate better active therapy effects from placebo effect than using joint costs.
- Methods used for finding about health-related quality of life should be included in the set of methods used for assessing clinical experiments.

HRQL importance for clinical practice:

- Methods used for finding about a patient's health-related quality of life bring information important both for the doctor and for the patient
- Multidimensional questionnaires finding about a patient's health-related quality of life yield further information not available from traditional questionnaires.
- Data outcomes brought by the methods investigating a patient's health-related quality of life represent significant predictors of a patient's functional state, health care costs, work absence and premature mortality.
- Methods finding about a patient's health-related quality of life are reliable and valid for group diagnostics of patients.
- Methods finding about a patient's health-related quality of life can help improve the health care documentation for the care provided to the patient.

Jenkinson et al. (1993) explicitly notes the following possibilities:

- Methods finding about a patient's health-related quality of life allow for quality monitoring of the care provided to the patient.
- They improve the doctor-patient interaction.
- Generic methods allow for comparing treatment effectivity in different diseases; in other words, they help compare quality of life improvements while being used in various patient groups and so help in deciding about treatment focus priorities.

Paradox as a Term

People intuitively understand paradox as a term. They perceive it as something that contradicts their common sense. In ancient Greece and Rome, paradoxes were logical tricks of mind – carefully thought out statements leading to contradictions. Later on, a paradox was a controversy between two statements, which were both based on factual or logical proofs; nevertheless, as a whole, they could not be valid both at the same time.

The term *paradox* in our study will be used to describe an unexpected or peculiar antagonism in that part of quality of life which is related to health and five of these antagonisms shall be presented here.

HRQL Paradoxes

The paradox hidden in the title. The term definition (health-related quality of life) both in original works and their Czech translations^{1*)} says unambiguously that it is related to the health of an individual, a group or a population. As a matter of fact, it is a well-established description, which is, however, not very accurate, as far as the dominating research subject is concerned. As a rule, authors are interested in the quality of life in people suffering from some kind of a disease (Veenhoven, 2000; Mareš, Marešová, 2005). In other words, HRQL measures are predominantly the measures of *negative* health (Veenhoven, 2000).

European medical institutions also hold this opinion when they state that HRQL represents a *patient's* subjective perception of their *illness* and its treatment influence on their everyday life, somatic, psychological and social functioning and their well-being (Reflection paper, 2005). The official definition by the American Ministry of Health and other institutions dealing with quality of life clinical research states: HRQL is a term covering many area – it is multidomained. It expresses a patient's overall perception of how the *illness* and its treatment influence their health. It depicts a patient's functioning at least on three levels – somatic, psychological (including emotional and cognitive one) and social. (Guidance, 2006, p.31).

One of the exceptions truly accentuating the category of health is the definition by Lindström and Kohler (1991), which understands HRQL as total being (overall existence) of an individual or a group, including numerous positive health aspects.

^{1*)} Quality of Life: as related to health (Sláma, 2005), from health point of view (Křivohlavý, 2002), influenced by health (Hnilicová, 2005), health-conditional (Kalová, Petr, 2004; Bukertová, 2006), concerning health (Vaďurová, 2006), related to health (Džuka, 2004; Mareš, Marešová, 2005; Sláma, 2005).

Health Impairment Positive Effect Paradox. Research studies have shown that ill people state the same or even a higher quality of life than healthy people. One of the first researchers to identify this phenomena was Cassileth et al. He found that five patient groups suffering from a chronic disease (arthritis, diabetes, oncological diseases, kidney failure and dermatological disorders) were unexpectedly *not* different in the perceived quality of life from the surrounding healthy population. His study outcomes suggested that psychological adaptation in chronic patients to living with their disease is extraordinarily efficient and, in fact, independent from the type of the chronic disease (Cassileth, Lusk, Strouse et al., 1984).

Similar findings were observed by Albrecht and Devlieger (1999) in patients suffering from spinal chord impairments, cerebral palsy, orthopedical impairments, multiple sclerosis, HIV/AIDS, chronic obstructive lung disease, diabetes and chronic pain. They asked themselves a question – why do many people seriously ill or with a long-term health impairment claim that their quality of life is good or excellent, when most *outside observers* would consider their everyday life hard and certainly not desirable? To describe the discrepancy between the objective proofs of a serious diagnosis and its grave impacts as seen by the outside observers, including health care professionals on one side and by the subjective high rating of quality of life by those with serious diseases on the other side, Albrecht and Devlieger chose the term *disability paradox*. Although there were partial objections to the term (for example Koch, 2000; Albrecht and Devlieger, 2000), it was coined.

Nowadays it is used not only in people with a *disability*, but it is also used in people with a serious disease. Let us mention a recent study in women after a myocardial infarction. Their indicators were lower in the somatic domain and they were less satisfied with their state of health, but their quality of life was no different from the psychological and social domains observed in healthy women population (Norekvål, Wahl, Fridlung (2007).

The above mentioned discrepancy of the positive effects of a disease can be, according to Albrecht and Devlieger, explained by the theory of balance. Many people who are seriously ill are able to balance the somatic, psychical and spiritual components of their life. They are also helped by the positive influence of the surrounding environment, no matter whether the environment is natural or social. On the other hand, seriously ill people who claim that quality of their life is bad, are not able to create such balance and/or they are not helped by the environment.(Albrecht, Devlieger, 1999).

So far, our comparisons were based on ill people and healthy people commenting on their quality of life. The question is: what is the situation like if we compare how the ill individual views himself or herself and their doctor's point of view? In some cases, we find out that objectively ill people (aware of their illness) feel quite all right. Old people after femur neck fractures belong to the group stating palpable improvement in quality of life, although objective examinations showed they should be having problems. The authors hold the opinion that this finding shows how important *subjective factors* are in assessing therapy quality and their influence on HRQL assessment. A successful therapy that can be objectively documented is not primary and decisive for a patient-stated improved quality of life (HRQL), whereas subjective assessment is (Papadopoulos et al. , 2007).

Successful Treatment Difficulty Paradox. An objectively cured individual sometimes encounters various difficulties as 'going back to normal' is not easy and can mean complications. Wilson et al. (Wilson, Bladin, Salin, 2004) observed epileptic patients after a surgery (temporal lobectomy), which removes the cause for epileptic attacks. She found out that the outcome is a paradox situation: the cured patients did not view this fact as a purely positive event and they mentioned problems that complicates their everyday life they had been adapted to. The problems overview is seen in Table 2.

Tab. 2 Clinical demonstrations of the 'burden of normality' (modified according to Wilson et al., 2004, p.19)

Psychological Aspects	Behavioral Aspects	Emotional Aspects	Social Aspects
Missing one's illness Growing expectations by the patients themselves and by their environment, too Trying to catch up with the 'time lost'	Celebrating new freedom Excessive activity: in body movements and sports, at work and social one, too Increase in sexual activities Inclination to higher alcohol and drug consumption Sleep deprivation Disobeying medical advice given by the doctor after the surgery	Mood improvement and feeling of being cured Deeper anxiety states Depressive states with psychotic spells Higher probability of post-surgery treatment in psychiatric wards	Changes in family relationships and in established ways of family life Inclinations to rebel against excessive mothering Higher inclinations towards divorce Difficulties in finding new job perspectives Difficulties in adopting new social skills necessary for 'new life'

Table 2 shows that patients are likely to have problems at least in four areas: psychological, behavioral, emotional and social one. As a result, they miss the time when they were ill, which is totally incomprehensible for the people around them.

Positive Posttraumatic Effect Paradox. Going through a very serious disease can improve an individual's life truly significantly in comparison with the time when they were healthy. As it can be seen here, a serious life event does not only have to bring negative impact. Positive impact on the individual can be observed immediately or after some time and he or she can rate their quality of life higher than in the time before the illness or trauma.

There are several descriptions and theories dealing with this paradox in more detail, for instance *perceived benefit* (Calhoun and Tedeschi, 1991, McMillen, Fisher, 1998), *flourishing* (Ryff and Singer, 1998), *positive illusion* (Tailor, Brown, 1988), *adversarial growth* (Linley, Joseph, 2004), *stress-related growth* (Park, Cohen, Murch, 1996) or *posttraumatic growth* (Tedeschi, Calhoun, 1996, Calhoun, Tedeschi, 2006). Most authors in the recent review monography (Calhoun, Tedeschi, 2006) tend to use the last term in the listing.

Literature defines posttraumatic growth as a significant positive change in an individual's cognitive and emotional life, which can also be manifested outwardly by changes in the individual's behaviour. By the growth here we mean such a change that takes the individual above their original level of adaptation, psychological functioning and life perception (Tedeschi, Park, Calhoun, 1998, p. 3). Moreover, by growth we mean both the process and its outcomes, which can manifest months, years or even decades later.

Posttraumatic growth is probably the result of an individual's attempts for a psychological survival; it can coexist with residual distress caused by the trauma (Tedeschi, Calhoun, 2004, p.5). In other words, the existence of posttraumatic growth does not mean that an individual's pain or other distress disappear. As a rule, it is not accompanied by changes in the individual's view on the crisis, loss or trauma itself as on something desirable. Serious life events themselves are not considered favourable, necessary or welcome – only the certain good originating from them takes a positive form (Tedeschi, Calhoun, 2004, p.6-7).

Hobfoll et al. (2007) suggests that the **real** posttraumatic growth should be defined not only as a cognitive process or an intellectual exercise leading to event reframing, but also as salutogenesis taking form of an *active development*. Individuals put into practice their ideas about the event benefits or make their illusions concrete via an action. So, it is not sufficient if looking for a new sense in a trauma is only cognitive. If no complementary action or deeds follow, it can result in negative consequences. People are more likely to take a concrete action after a crisis in health.

Petty events or common illnesses are not enough to start changes for better. The set of unfavourable factors must represent a serious threat to the individual's life up to date to make a positive change possible (Tedeschi, Calhoun, 2004; Janoff-Bulman, 2006). The key element in defining whether the change has actually taken place is a destruction or wrecking of their life up to the event; people talk about what their life was like 'before' and 'after'. If posttraumatic growth is to take place, the individual must be put under severe distress. It is possible to speak about a 'minimum dosage' here. On the other hand, if the dose is too high, it will not aid growth as it , among many other things, disturbs cognitive mechanisms necessary for an individual to process the event (Calhoun, Tedeschi, 2006). Based on what is said above, growth happens if trauma impact on the individual remains within a certain optimum scope.

Adult research states that posttraumatic growth is not universal experience and does not influence all people who were subject to a traumatic event. Posttraumatic growth prevalence seems to have two peaks – at 30-40 % and at 60-80 % of the population in research. Occurrence depends on (excluding trauma types, personality diversities and social environment) the diagnostics method used, and thus on the growth defining domains and on the limit which was set as a marker of a change for better.

Ethnic Minority Health Paradox. Based on common assumptions, the state of health is determined by four main factors – biological factor (genetically influenced; immunity), by individual styles of life (healthy or unhealthy life style), by the environment (health-supporting or harmful) and by the health care access and its quality. In the last twenty years, there has been growing empirical evidence of sociocultural influences as well.

