

The Quality of Life in the Contexts Health and Illness

*Oliva ŘEHULKOVÁ, Evžen ŘEHULKA
Marek BLATNÝ
Jiří MAREŠ
et al.*

BRNO 2008

**Publication represents work completed
within the projects
focusing on problems of health and quality of life**

GA AV ČR IAA7025403

Paradigm of health and quality of life: methodological, personality and ontogenetic aspects

MSM00216224721

School and Health in 21st Century

GAČR 406-07-1384

Quality of life in children surviving cancer: A developmental approach

GAČR 406-06-0035

Quality of life in children and adolescents

The publication is supported by GA AV ČR IAA7025403 Paradigm of health and quality of life: methodological, personality and ontogenetic aspects and MSM00216224721 School and Health in the 21st Century

Book viewers: Prof. PhDr. Mojmír Svoboda, CSc.
Doc. PhDr. František Baumgartner, CSc.

Publisher: MSD
Printing: MSD
Brno 2008
PC layout and typography: JarDa

ISBN: 978-80-7392-073-9

CONTENT

INTRODUCTION

Oliva ŘEHULKOVÁ, Evžen ŘEHULKA.....5

HEALTH - RELATED QUALITY OF LIFE PARADOXES (HRQL)

Jiří MAREŠ, Jana MAREŠOVÁ.....6

QUALITY OF LIFE ISSUES - BASED ON PREVIOUS RESEARCH RESULTS

Oliva ŘEHULKOVÁ, Evžen ŘEHULKA.....16

QUALITY OF LIFE VIEWED IN TERMS OF EMPIRICAL DATA

Jitka ŠIMÍČKOVÁ-ČÍŽKOVÁ, Bohumil VAŠINA.....31

EFFECTS OF CHILDHOOD MALIGNANCY TREATMENT ON QUALITY OF LIFE: PRELIMINARY RESULTS OF THE QOLOP PROJECT

Marek BLATNÝ, Tomáš KEPÁK, Irena VLČKOVÁ, Martin JELÍNEK, Petra NAVRÁTILOVÁ, Milan PILÁT, Šárka KÁROVÁ, Alena SLEZÁČKOVÁ, Hana HRSTKOVÁ, Jaroslav ŠTĚRBA.....37

QUALITY OF LIFE OF CANCER CHILDREN CAREGIVERS

Helena VAĎUROVÁ.....42

A MEANING OF A GAME SPECIALIST WORK WITH A KINESIOLOGY THERAPEUTICS SPECIALIZATION BY ONCOLOGY SICK CHILDREN

Marie BLAHUTKOVÁ, Jana DLOUHÁ.....49

AN INFLUENCE OF EDUCATIONAL PROCESS IN HOSPITAL PRIMARY SCHOOLS ON SICK CHILDREN'S QUALITY OF LIFE

Jana DLOUHÁ, Marie BLAHUTKOVÁ.....56

LEISURE TIME OF CHILDREN IN HOSPITAL AND QUALITY OF LIFE

Jana DLOUHÁ, Marie BLAHUTKOVÁ.....72

QUALITY OF SCHOOL LIFE FROM THE STUDENTS' PERSPECTIVE - RESEARCH THESIS

Věra VOJTOVÁ.....78

PSYCHOTRAUMATIZING OF PUPILS, STUDENTS AND TEACHERS AT CZECH SCHOOLS

Rudolf KOHOUTEK, Eva FILÍPKOVÁ.....90

QUALITY OF LIFE OF THE LONG-TERM UNEMPLOYED

Božena BUCHTOVÁ.....97

**THE TASK OF SPIRITUALITY IN LIFE QUALITY AND LIFE SATISFACTION
IN YOUNG PEOPLE**

Irena OCETKOVÁ.....114

QUALITY OF LIFE IN THE OLD AGE

Vladimír SMĚKAL, Hana HOBZOVÁ.....120

ABSTRACTS.....130

BIBLIOGRAPHY.....137

LIST OF AUTHORS.....153

SUBJECT INDEX.....155

NAME INDEX.....158

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).

