QUALITY OF LIFE OF INDIVIDUALS WITH DISABILITIES -CONCEPTS AND CONCERNS

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ABSTRACT

INTRODUCTION: The number of people with disabilities has grown tremendously for the last 15 years in Bulgaria. Standardized quality of life instruments can be helpful in the development of public policies which target the needs of this population. The quality of life (QoL) paradigm is a challenging perspective for considering, planning and implementing changes within the area of disabilities. Moreover, an interview with a disabled person about her/his subjective health is a human care with a positive impact on the overall well-being of the individual. This paper aims at stimulating a debate on these topics by investigating the "QoL" and "disability" territories. Further, a study on QoL of individuals with disabilities is presented. The objectives of this study are: (1) to measure the QoL of a representative sample of 305 individuals with disabilities, who are patients from a general Territory Expert Medical Commission – TEMC (Territory Expert Medical Commission (popular abbreviation in Bulgarian language – TE/IK)) (St. Marina University Hospital, Varna) by using the WHO generic questionnaire (WHOQOL-BREF) - 26 questions; four-domains structure: Physical health, Psychological health, Social relationships, Environment (2). To define the influence of the four domains on QoL (3). To analyze the relationship between QoL and socio-demographic characteristics (4). To assess the influence of physical pain on QoL.

METHODS: A cross-sectional study was conducted in 2011 using a representative sample of the register of a general TEMC (n=305, >18 years old). Respondents were selected through the method of multi-stage random selection.

RESULTS: As a result of multiple-regression analyses it was found out that all the domains have influence on QoL but the most influential is the "Environment" domain (0.394), followed by "Physical health" domain (0.354), "Psychological health" domain (0.261) and "Social relationships" domain (0.169). The total multiple regression coefficient – R is 0.984 (R^2 =0.969). The patients who reported higher levels of pain – 95.80% - have lower QoL. No relations were found between socio-demographic characteristics of the patients and their QoL. Nowadays, the TEMC mission has to cover not only expert assessment and integration of persons with disabilities into society. The TEMC mission should also involve the improvement of QoL of the people with disabilities. A medico-social approach for handicap-assessment is proposed as a prerequisite for sustainable development of the public health policies concerning people with disabilities.

Keywords: quality of life, disability, WHOQOL-BREF

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INTRODUCTION

"Quality of life" is currently receiving a significant attention in public health and rehabilitation fields.

The creation of more effective legislative mechanism which guarantees the quality of life in the modern society (1) is a prerequisite for a sustainable development. The ambition of this paper is to initiate a discussion related to the above statement within the frame: "quality of life of individuals with disabilities".

Quality of Life (QoL) concept

Since the end of 20th century there has been a broadening in focus of the measurement of health, beyond traditional health indicators such as mortality and morbidity (2,3). The QoL-dimension has been described as "the missing measurement in health" (4). Nowadays, QoL assessment is an indispensable part of the care for the patients.

In 1996, the encyclopedic manual on measuring health (5) listed 21 health instruments. In 2015 the number of instruments described in the database of ProQolid managed by the MAPI Research Trust is 922 (6). There is no agreement on the universal summary measure for health assessment (7).

In this study we adopt the World Health Organization (WHO)-definition of individual-referenced QoL (8): Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, and level of independence, social relationships and their relationship to salient features of their environment.

This definition reflects the view that quality of life refers to a subjective evaluation which is embedded in a cultural, social and environmental context. Because this definition of quality of life focuses upon respondents' "perceived" quality of life it is not expected to provide a means of measuring in any detailed fashion symptoms, diseases or conditions, but rather the effects of disease and health interventions on quality of life. As such, quality of life cannot be equated simply with the terms "lifestyle", "life satisfaction", "mental state" or "well-being".

WHO's initiative to develop a quality of life assessment arises from a need for a genuinely international measure of quality of life and a commitment to the continued promotion of an holistic approach to health and health care. In parallel, the mechanistic model of medicine in Bulgaria, concerned only with the eradication of disease and symptoms, reinforces the need for the introduction of a humanistic element into health care and care for people with disabilities.

From a medical point of view, QoL assessment has been used to justify or refute different forms of medical treatment, resolve disputes concerning different therapeutic approaches, and provide a basis for allocating to those treatments judged to be more effective (9). From a public health standpoint, standardized quality of life instruments can be helpful in the development of public policies which target the needs of the vulnerable populations. The quality of life paradigm is a challenging perspective for considering, planning and implementing changes within the area of disabilities. Moreover, an interview with a disabled person about her/his subjective health is a human care with a positive impact on the overall well-being of individuals with disabilities (10,11). Herewith, the instrument to assess QoL of patients from a general Territory Expert Medical Commission (TEMC) that has been chosen is a generic summary measure - WHOQOL-BREF, e.g., a measure not designed to relate to any particular health condition but rather intended to measure health as a holistic, generic quality affected by any disease or combination of diseases. Generic instruments are intended to be used without modification across all diseases and conditions as well as across all medical interventions. The patients in this study are often polymorbid which is another reason to use a generic questionnaire.

Disability concept

Since 2001, WHO has been demonstrating a broader, more modern view of the concepts of "health" and "disability" through the acknowledgement that every human being may experience some degree of disability in their life through a change in health or in the environment. Disability is a universal human experience, sometimes permanent, sometimes transient. It is not something restricted to a small part of the population (12).

The number of people with disabilities has grown tremendously for the last 20 years. It is estimated that there are over 1 billion disabled persons worldwide, with approximately 200 million of them experiencing very significant difficulties (13). This growth has been driven both by the increasing life expectancy and by an exposure to factors such

as traffic accidents, stress, drug misuse etc. Due to these and other factors, it is estimated that an individual born in a country where the mean life expectancy is 70 years of age will spend, on average, 11 years of his/her life with some form of disability (13). In 2001, persons with disabilities were estimated to account for 2.2% of the Bulgarian population (14), whereas in 2013 they represented nearly 2.6% of the population. Even though the number of disabled may be overestimated due to inclusion of pensioners in TEMC assessment since 2000, the number of people with disabilities is growing as ageing of the population is one of the biggest challenges facing Bulgaria. According to International Labor Organization in 2020 the number of people over the age of 60 will be 28% of the Bulgarian population (15). It is essential to make a terminology clarification in a Bulgarian context. As a result of cultural or institutional differences and developments, the term "person with disability" is often used interchangeably with the terms "handicap", "invalid", and person with "permanently diminished working capacity" or "pensioner with a disease".

Quality of Life of People with Disabilities

The quality of life paradigm challenges the traditional approaches towards people with disabilities. WHO looks beyond the idea of a purely medical or biological conceptualization of dysfunction, taking into account the other critical aspects of a disability. The use of QoL-instrument allows assessing the impact of the environment and other contextual factors on the functioning of an individual with disability to be considered, analyzed, and recorded. The interest in QoL appears from the trends toward greater attention to the personal needs and wishes of the individuals within health and social services and getting better results with fewer resources.

In Bulgaria, social integration of people with disabilities is closely related with their TEMC examination. The expert decision (ED) by TEMC is a legal document which gives rights to the person with a disability for a social rehabilitation. Possibilities for community integration including job opportunities, chances for extra-qualifications etc. are based also on the ED by TEMC. The choice of a general TEMC for a "laboratory" of the presented research is based on these facts. Moreover, the system of disability assessment has been in transition for years.

This paper **AIMS** at stimulating a debate on these topics, by investigating the "quality of life" and "disability" territories. Herewith, the study on quality of life of individuals with disabilities is presented. The **OBJECTIVES** of this study are (1) to measure the quality of life of a representative sample of 305 individuals with disabilities, who are patients from a general TEMC (St Marina University Hospital, Varna) by using the WHO generic questionnaire (WHOQOL-BREF) - 26 questions (2). To define the influence of the four domains on QoL (3). To analyze the relationship between QoL and socio-demographic characteristics. (4) To assess the influence of pain on QoL.

METHODS

The WHOQOL-BREF Instrument

WHO's initiative to develop a quality of life assessment arises from a need for a genuinely international measure of quality of life and a commitment to the continued promotion of a holistic approach to health and health care (16). The recognition of the multi-dimensional nature of quality of life is reflected in the WHOOOL-100 structure. The WHO-QOL-100 allows detailed assessment of each individual facet relating to quality of life. In certain instances however, the WHOQOL-100 may be too lengthy for practical use. The WHOQOL-BREF Field Trial Version (26 questions) has therefore been developed to provide a short form quality of life assessment that looks at Domain level profiles, using data from the pilot WHOQOL assessment and all available data from the Field Trial Version of the WHO-QOL-100 (17). The Bulgarian version has been created and validated as WHOQOL-100-bg (18,19). The WHOQOL-BREF is a health profile which uses summating rating scales. The WHOQOL-BREF is therefore based on a four domain structure:

- 1. Domain- Physical health (Facets incorporated within domains: Activities of daily living; Dependence on medicinal substances and medical aids; Energy and fatigue; Mobility; Pain and discomfort; Sleep and rest; Work Capacity).
- Domain- Psychological health (Facets: Bodily image and appearance; Negative feelings; Positive feelings; Self-esteem; Spirituality/Religion/

Personal beliefs; Thinking, learning, memory and concentration).

- 3. Domain- Social relationships (Facets: Personal relationships; Social support; Sexual activity).
- 4. Domain- Environment (Facets: Financial resources; Freedom, physical safety and security; Health and social care: accessibility and quality; Home environment; Opportunities for acquiring new information and skills; Participation in and opportunities for recreation/leisure activities; Physical environment(pollution/noise/ traffic/climate); Transport).

The WHOQOL-BREF (Field Trial Version) produces a quality of life profile. It is possible to derive four domain scores. There are also two items that are examined separately: question 1 asks about an individual's overall perception of quality of life and question 2 asks about an individual's overall perception of their health. The four domain scores denote an individual's perception of quality of life in each particular domain. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain is used to calculate the domain score. A time frame of two weeks is indicated in the assessment. The reliability and validity of the questionnaire has been tested extensively including: the internal consistency (Cronbach alpha), and hypothesis testing (criterion groups), criterion validity, through concurrent and discriminant validity, and test-retest reliability (20).

The WHOQOL-BREF should be self-administered if respondents have sufficient ability: otherwise, interviewer-assisted or interview-administered forms should be used. Standardized instructions, given on the second page of the WHOQOL-BREF example assessment, should be read out to respondents in instances where the assessment is interviewer-administered.

The generic WHOQOL-BREF has been used in numerous studies all over the world (21-25). The Department of General Medicine, Medical University – Varna also has an experience using it in several research projects (26).

The use of WHOQOL-BREF version is preferable for the following reasons:

 WHOQOL-BREF version reflects the holistic approach in medicine and public health (it incorporates with equal importance somatic, psychological and social components);

- WHOQOL-BREF version takes at about 10-15 min. to be filled in;
- WHOQOL-BREF version is very clear and exact (high face validity)
- WHOQOL-BREF version the calculation of the data is simplified and easy;
- WHOQOL-BREF version gives the opportunity to compare patients with different disabilities and diseases;
- WHOQOL-BREF version is adapted to the Bulgaria culture (adapted in 1999).

Study design:

The presented study is part of a PhD-research project on "Legal consciousness for legalization of euthanasia and QoL of polimorbid patients with permanently diminished working capacity" (main investigator: P. Mancheva MD, PhD; Protocol/permission from 13.10.2011 by Ethical Commission MU-Varna). This cross-sectional study was conducted in 2011 using a representative sample from the register of a general TEMC/St. Marina University Hospital, Varna (n=305, >18 years old, 144 female/161 male). The patients are polymorbid and have acknowledged disability (above 50 %). Respondents were selected through the method of three-stage random selection: first selecting the living area - Varna region (town of Varna and villages according to the Administrative-Territory Map of Bulgaria). Then the TEMC was chosen - TEMC/St Marina University Hospital, which operates in the same region. The third stage was to select randomly respondents from the register of the concrete TEMC. The number of the respondents was determined by the preliminary review of all the patients from the register - 2 058 people with disabilities. The list of the respondents was defined according to the planned visit of the patient to TEMC within the period October-November 2011, which is 15% of all the registered patients, and is the number of people needed to be interviewed in order to get results that reflect the target population with acceptable accuracy.

Inclusion criteria:

Acknowledged disability (above 50%) and the respondents have to be from the register of a general TEMC/St. Marina University Hospital.

Exclusion criteria: Children; Patients without acknowledged disability; Patients with temporary acknowledged disability.

The patients were invited to participate in the study during their regular visit to TEMC. The respondents were informed that their participation is voluntary and their eventual unwillingness to participate will not influence their patient status. Moreover, the data obtained will be used only for research purposes. The filling of the questionnaire took between 10 and 15 minutes. An interviewer was at the disposal of the respondents if they had questions concerning the questionnaire and the study.

The statistical analysis was performed with SPSS v.17.0 for Windows. Hypotheses were tested using χ^2 -criteria (for the descriptive profile data) and

Student's t-test (for the differences in domains). A multiple-regression analyses has been used in order to assess the influence of every QoL-domain on the total QoL-score (R=0.984, $R^2=0.969$).

RESULTS

Here we report our findings from WHOQOL-BREF - survey which was a part of a wider research project in the area of disabilities. Respondents' rate – 98.71% (one person did not turn the questionnaire because of 'exitus letalis', and two others refused to participate). No missing data is reported. The characteristics of the sample can be seen on Table 1.

The results of QoL assessment are diverse as has been expected. The data is summarized in Table 2.

	-		
Characteristic		Frequency	Percentages
Gender			
	Female	144	47.20%
	Male	161	52.80%
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Age			
	Mean	60±10 years	
	Minimal age	24 years	
	Maximal age	81 years	3 60%
	Up to 40 years	11	51.00%
	41 – 60 years	155	45 40%
	Above 60 years	138	43.4070
Education			
	Primary	39	12.80%
	Secondary	145	47.50%
	Semi-higher/voc. training	49	16.10%
	Higher	72	23.60%
Employment			
	Unemployed	151	50.80%
	Pensioner	78	26.30%
	Employed	68	22.90%
Religion			
	Christian arthodox	225	73.80%
	A dyantiat	16	5.20%
	Mathadista	10	7.20%
	Protestants	<u>22</u> A	1.30%
	r iotestallis Muslima	4 20	9.80%
	Atheiste	5U Q	2.60%
	Atheists	ð	

Table 1. Characteristics of the study sample (n=305)

QoL - profile

Quality of life of individuals with disabilities - concepts and concerns

sumple (n=505)				
QoL		Score		
QoL profile	Mean	67.15±13.29		
	Minimum	38.00		
	Maximum	100.00		
	Very low	1/0.30%		
	Low	137/44.90%		
	Middle	127/41.60%		
	High	40/13.10%		

Table 2.	QoL of people with disabilities from the	e study
	<i>sample (n=305)</i>	

The influence of every domain on the whole QoL profile

The influence of every domain of the of the four-domain factor structure on the QoL profile were assessed using multiple regression analysis (Table 3).

The analyses show that the influence of every domain upon the QoL is significant (p<0.001). The total multiple regression coefficient of all the QoL predictors – R is 0.984 and R² is 0.969. The most powerful is the domain "Environment" (β =0.394), followed by "Physical health" (β =0.354), "Psychological health" (β =0.261) and finally "Social relationships" β =0.169. Here can been found difference with the conclusions of the WHOQOL – validation study in 1999 with psychiatric patients (schizophrenia and depression). This study proves the equal influence of the four domains. The difference could be explained with specificities of the psychiatric pathology, and with the multi-morbidity of the patients who participated in the current study. der, age and employment have nosignificant influence on QoL of the people with disabilities. The same can be stated for education and QoL.

Religion is a significant factor and influences QoL of the patients ($\chi 2=27.56$; p<0.05) (Fig. 1).



Fig. 1. QoL, education and religion

Interestingly, the atheists show the highest levels of QoL, while the Methodists the lowest levels of QoL.

3.4. The influence of pain on QoL-profile of the disabled individuals.

The influence of "physical pain" was additionally analyzed as far as often goes along with a person with disability. The question was: To what extent

Predicting variable	Unstandardized coefficient B	Standardized coefficient β	t	р
Physical health	0.957	0.354	26.495	< 0.001
Psychological health	1.012	0.261	16.731	< 0.001
Social relationships	0.890	0.169	13.040	< 0.001
Environmnent	1.041	0.394	31.579	< 0.001

Table 3. The influence of the four domains on the QoL profile (multiple regression analysis)

3.3.Socio-Demographic factors – influence on the QoL

The QoL of the respondents vary between the low and middle level. There are also patients who declared high scores of QoL (χ 2=24.06; p<0.01). Gen-

do you feel that physical pain prevents you from doing what you need to do? The answer shows statistical significance of the influence of "physical pain" on QoL of the patients (χ^2 =129.67; p<0.001) (Fig. 2).



The respondents who reported higher levels of pain – 95.80% - reported lower QoL.

DISCUSSION AND CONCLUSION

Bulgaria had and is still experiencing the results from the societal changes which started in 1989, and the burden of health consequences after the transition appear to be one of the highest in Eastern Europe. The profound changes in social security, higher education and health care systems have been accompanied by phenomena previously not experienced, namely poverty, unemployment, demographic crisis and a general reduction in the quality of life. These processes led to erosion of the social capital, human relations and mutual trust – all these factors that keep a society and the individual healthy (27). All these facts determined the growing number of people who approach the system of TEMC in order to receive additional money and social benefits.

One of the objectives of this study was to evaluate the influence of the four domains on QoL by using multiple linear regression. The pivotal "role" of the domain "environment", followed by "psychological health" is a proof that the social and health care system need to be reformed towards effectiveness and efficiency. Political analysis and actions for change in the health and social services structure is required in order to guarantee the human rights of the people with disabilities. A further research is needed regarding the international experience in that area.

In this study, gender, age, employment and education were factors that do not affect QoL of the study population. Religion is a factor that influences QoL, the atheists are with the highest QoL. The influence of "physical pain" on QoL of the patients is very high. To sum up, after the analysis the following conclusions could be made: the QoL of people with disabilities is influenced mostly by social support and the level of pain. The reasons for these results are complex but one thing is definite – there is place for improvement in the whole TEMC system.

The medical model and the social model are the two main approaches for classifying and measuring disability (12). In the medical model, disability is viewed as a problem of the individual, directly caused by disease, trauma, or other health conditions, for which professional help is needed. From the perspective of the social model, disability is primarily attributable to characteristics of society that exclude participation by individuals affected by disease, injury, and so on. How disability is measured depends on the needs and the viewpoint of those doing the measuring. In the medical model, disability is measured primarily by health professionals and in terms of disorder and functional level, while in the social model it is measured primarily by self-report and in terms of the characteristics of the person's environment. These two models can be considered complementary to each other and should both be considered when measuring disability (i.e., the biopsychosocial model). It challenges us as professionals and as community members, to be responsible for the vulnerable people in the society.

WHOQOL-100 and the WHOQOL-BREF have proved to be useful in health policy research and have already become an important aspect of the routine auditing of health and social services. Policies that address health inequalities can be more broadly evaluated if QoL is systematically measured in the community. In Bulgaria, this is particularly important for evaluating policy impact and implications for people with disabilities.

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Quality of life of individuals with disabilities - concepts and concerns

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