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Quality of Life in Mentally Ill People

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1. Introduction

It is much easier to measure any of biological parameters than to describe any of them. Medical science is more „evidence based“ when can be expressed by parameters represented by amount of numbers describing functions in a body. Unfortunately, thanks to statistical approach to the medical science, philosophical or psychological dimensions disappear when considering the human life and its pathologies.

Quality of life seems to be a good example of controversy seen in medical science of nowadays. On one hand, quality of life in medicine seems to be too vague to be defined by conventional, measuring loving approach, and in this way it is postponed just as an additional parameter standing in a rest, on the other hand, quality of life represents integral feature which refers to complex evaluation of our therapy from patients point of view.

2. Quality of life – evolution in understanding the term

It is troublesome to define what is the quality of life. Everyone has individual and unique experience with every day life bringing both positive and negative aspects. Our evaluation of (our) quality of life is surely influenced by many individual aspects that can refer only to our experience. But can we generalize this individual experience to experience of the others? If so, what is relevant and what is irrelevant in evaluating one's life from external or expert position?

Although many difficulties, scientists tried to develop more precised concepts of understanding quality of life. These concepts have been influenced by evolution in understanding other important terms, such as health, disease and determinants of health.

The modern concept of the quality of life has been developed for more than 90 years. Soon after World War II, mainly material and economic conditions were considered to have an influence on the perceived quality of life. At that time, employment and good living conditions were the main prerequisite for having a good quality of life. Later, with the development of medicine and the society, new factors influencing the quality of life emerged, such as social, political, psychological, environmental and spiritual aspects, accompanied by the concept of new lifestyle demands.

In the 21st century, medicine (and psychiatry as well) is facing new challenges, different from those in previous centuries. The prevalence of non-communicable diseases, such as obesity, hypertension, diabetes mellitus, musculoskeletal disorders and other conditions,

reached the level of new pandemics replacing the earlier pandemics of infectious disease (tuberculosis, poliomyelitis etc.), having both economic and ethical impacts. Demographic changes in the population have postponed morbidity to an older age as people live longer now. This is related to comorbidities in the elderly, growing in number and exceeding the population of children and adolescents. Generally, the economic and social impacts of this demographic shift are expected to occur in most of the developed world.

The shifts in morbidity and mortality are well observed and recognized, with people dying at an older age and with more diseases. The most common cause of death are cardiovascular diseases followed by cancer. This situation is in the Czech Republic, too. As many of these conditions cannot be cured completely, they considerably influence the health-related quality of life the elderly patients. An approach to treatment with respect to the biopsychosocial concept of a human being may be an important way to improve the quality of life of the elderly and dying patients.

2.1 Human and human’s needs

Historically, the oldest concept was based on identifying first parameters of human satisfaction – human needs. First, material conditions were taken into account – living in poverty implied low quality of life and vice versa. This idea was close to policy makers who were interested in social and material indicators of well being.

Later, other conditions were studied – material, social, cultural, psychological and spiritual ones. The most complexed theory of human needs was presented by american psychologist Abraham Maslow. Maslow has ranged human needs into hierarchy according to their importace. First of importace are basic (or physiological) needs – they allow us to survive – and they are the first essential step to achieve *higher*, more developped needs. When these *lower* needs were fulfilled then it was an elementary precondition for a man to be satisfied – no shortcoming in considered need limited expected satisfaction. Graphically, hierarchy of human needs is represented as a pyramid where the more basic needs are situated at the bottom. (see fig. 1). Maslow theory of human needs promoted further thinking what is the quality of life and what are the influencing indicators of quality of life.

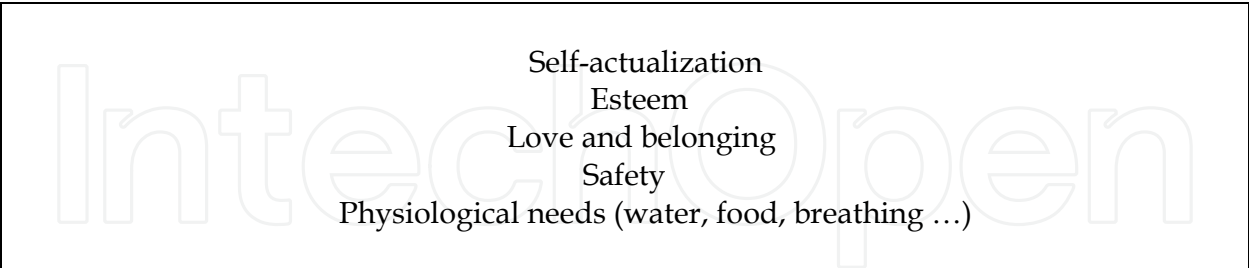


Fig. 1. Maslow’s hierarchy of needs

2.2 From spiritual and philosophical concepts to the concept of Health Related Quality of Life (HR-QoL)

Theory of human needs seemed to be essential when considering quality of life. It showed people need more than good functioning of all body systems – they need feel to live in safety, to be accepted by a community of other people, to feel good self-esteem, to have individual perspective reflecting one’s wishes and dreams. Later then, medical point of view has been accompanied by psychological, spiritual, social and spiritual dimensions

intersecting in one term – quality of life. Despite diversity in some of aspects mentioned above, simplified concept of health related quality of life showed its importance. Health related concepts of quality of life seemed to be much better understood and much better accepted by health care professionals, especially when evaluating outcomes of therapy or any other intervention, with special attention to therapy which seems to be expensive or troublesome (typically in oncology or intensive care). The Karnofsky Performance Scale (measured by the decimal Karnofsky score, where 100% represents ideal or perfect health status and 0% represents death, see fig. 2) is used in oncology to evaluate patient’s fitness before starting and during oncological treatment, or the APACHE II. evaluation system (Acute Physiological and Chronic Health Evaluation System, with total score from 0 to 71, where higher score means more serious condition with higher risk of death) used to evaluate patient’s fitness in intensive care could be good examples. (see fig. 3)

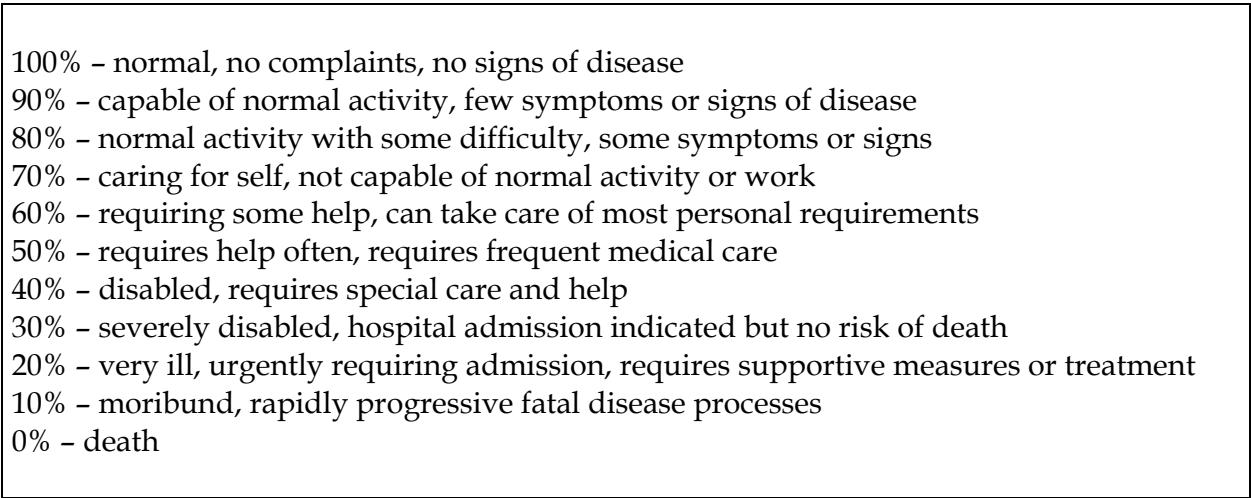


Fig. 2. The Karnofsky Performance Scale

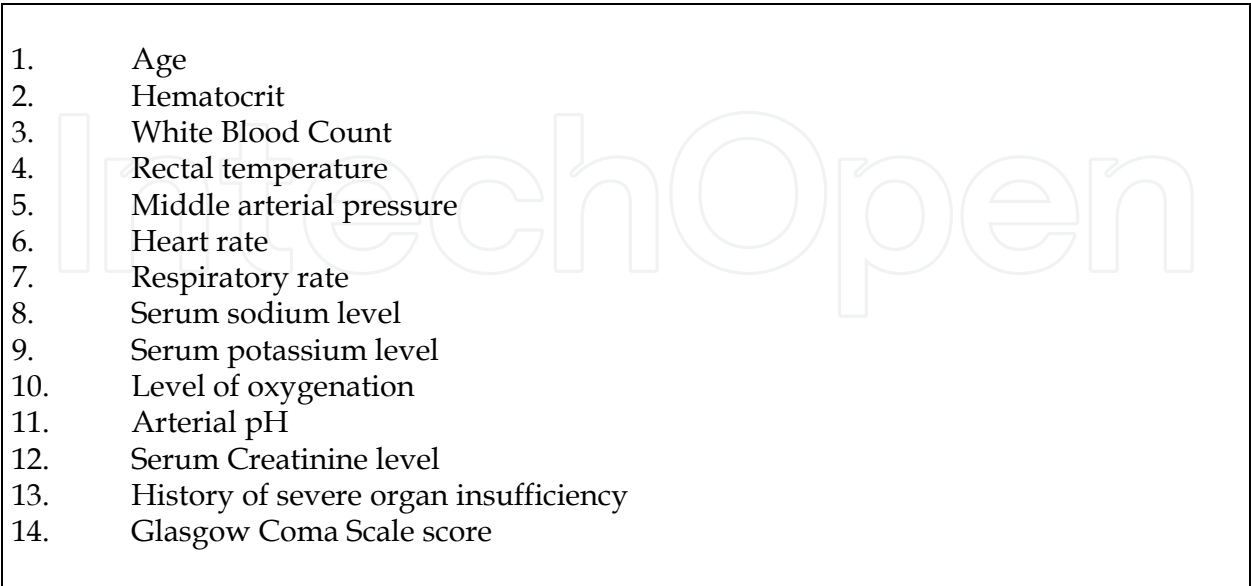


Fig. 3. The APACHE II. evaluation system - issues (calculator for obtaining the total score is needed)

2.3 Multidimensional concept of quality of life – more than just medical approach

Multidimensional concepts are the most developed and the most complexed concepts dealing with quality of life. These concepts combine traditional material and health-related approach with further dimensions, such as spirituality, self esteem, well-being, autonomy and competences, or acceptance by community and usefulness of an individual in community. They reflect global fitness of an individual when living in everyday society. Thence, eclectic approach is typical in multidimensional concepts of quality of life. WHO Model of quality of life could be an example of such concept (see chapter below). Despite its intended complexity, they can't define entirely what quality of life is in general. Any interpretation of one's quality of life or any comparison of quality of life among individuals will cause methodological difficulties.

3. How to evaluate quality of life?

As mentioned above, quality of life is a complex category comprising many aspects: physical and mental condition, social networks, and environmental, educational, economic and cultural aspects of an individual. The quality of life is highly subjective and its evaluation is problematic. It can be evaluated on different levels – individual level, group level (e.g. group of patients with a disease) or population level.

Two different methodological approaches can be used – qualitative and quantitative approach.

3.1 Qualitative approach in research of quality of life

Qualitative approach in research of quality of life requires more intense contact with individuals evaluating quality of life. This approach seems to be less exact for further statistical analysis because of using less standardized procedures even though it can reveal many important, individually specific aspects of quality of life.

The most common techniques of qualitative research of quality of life are inspection, interview, focus groups, content analysis of texts or documents.

3.2 Quantitative approach in research of quality of life

Quantitative approach in research of quality of life refers to measuring different aspects and parameters of quality of life. It uses more standardized procedures which can be perceived as more exact and more accessible to statistical analysis of data. Nevertheless, there is a risk of neglecting some of individually specific aspects of quality of life and thence of misleading.

When studying the quality of life, questionnaires are most frequently used. Nowadays, there are hundreds of questionnaires available that can be found in the ProQolid database of psychometric instruments. This database comprises, among others, tools for assessing the quality of life, divided according to the research aim into generic instruments (used for the whole populations, both healthy and ill), disease-specific instruments (related to certain diseases, such as HIV or cancer) and target-population instruments (related to target populations, such as children or senior citizens).

The most common techniques of quantitative research of quality of life are questionnaires, studying of medical records, statistical surveys, structured inspection.

Questionnaires of quality of life are a very popular tool – they are easy to be used in clinical practice, despite having limits (reduction of information, statistical testing of hypotheses, problems with generalization of results and interpretation of summarized results).

ProQolid database (Patient Reported Outcome Quality of Life Instruments Database) is collecting many of questionnaires used in research of quality of life – they are divided into generic instruments, disease-specific instruments and instruments used for targeted population.

Generic instruments can be used for any group of patients or healthy individuals. They can be used for a population research of quality of life as well. Their disadvantage can be perceived in lower sensitivity in detection of any of strong influencing phenomenon (such as a disease). Some examples of generic instruments in ProQolid database are attached below:

AQoL Assessment of Quality of Life
CSQ Client Satisfaction Questionnaire
EQ-5D Euroqol EQ-5D
GQoL Global Quality of Life Scale
HAQ Health Assessment Questionnaire
PedQL tm Pediatric Quality of Life Inventory™
PLC Quality of Life Profile for the Chronically Ill
PQoL Perceived Quality of Life scale
QL-Index Spitzer's Quality of Life Index
QALYs Quality Adjusted Life Years
QLI Ferrans and Powers Quality of Life Index
QLQ-E Quality of Life Questionnaire-Evans
QLSI Quality of Life Systemic Inventory
QODD Quality of Dying and Death
QOLI Quality of Life Inventory®
QOLS Flanagan's Quality of Life Scale
QUEST Quality of End-of-life care and Satisfaction with Treatment scale
QWB Quality of Well Being scale
QWB-SA Quality of Well-Being scale Self-Administered
SAS-SR Social Adjustment Scale - Self Report
SEIQoL Schedule for the Evaluation of Individual Quality of Life
SF 12 SF-12® Health Survey and SF-12v2™ Health Survey
SF 36 SF-36® Health Survey and SF-36v2™ Health Survey
SQLP Subjective Quality of Life Profile
SWED-QUAL Swedish Health-Related Quality of Life Survey
TAAQoL TNO-AZL TNO-AZL Questionnaire for Adult's Health-related Quality of Life
TACQoL TNO-AZL TNO AZL Children's Quality of Life
TAPQoL TNO-AZL TNO-AZL Preschool children Quality of Life questionnaire
TEAQV Tableau d'Evaluation Assistée de la Qualité de Vie
TedQL Quality of Life measure for children aged 3-8 years
WANQ Wyke's Assessment of Need Questionnaire
WHOQoL World Health Organization Quality of Life assessment instrument
WLQ Work Limitations Questionnaire
YQoL tm Youth Quality of Life Instrument

According to ProQolid Database

Fig. 4. Generic Instruments – Examples (ProQolid Database)

Disease-specific instruments are used for group of patients suffering from studied disease. They monitor impacts of a disease on patient’s common life. Some examples of disease-specific instruments in ProQolid database are attached bellow:

Q-LES-Q	Quality of Life Enjoyment and Satisfaction Questionnaire
PTQL	Pictorial Thai Quality of Life
QLQ-IR/QLQ-SR	Oregon Quality of Life Questionnaire Interviewer Rating version / Respondent Self-Report version
W-QLI	Wisconsin Quality of Life Index
ACQLI	Alzheimer's Carer's Quality of Life Instrument
ADRQL	Alzheimer's Disease-Related Quality of Life
QoL-AD	Quality of Life in Alzheimer’s Disease
QUALID	Quality of Life in Late-Stage Dementia Scale
CBS	Cornell-Brown Scale for Quality of Life in Dementia
D-QoL	Dementia Quality of Life Instrument
DEMQoL	Measurement of health-related quality of life for people with dementia
QOLAS	Quality of Life Assessment Schedule
QLDS	Quality of Life in Depression Scale
SLQQ	Sexual Life Quality Questionnaire
ILSS	Independent Living Skills Survey
LQOLP	Lancashire Quality of Life Profile
QLQ/CEQ	Quality of Life Questionnaire or Client Experiences Questionnaire
QLS	Quality of Life Scale
ONYCHO	Onychomycosis Quality of Life questionnaire
APQLQ	Angina Pectoris Quality of Life Questionnaire
MILQ	Multidimensional Index of Life Quality
CHAL	Quality of Life Questionnaire for Arterial hypertension
MINICHAL	Short form of Quality of Life Questionnaire for Arterial hypertension
MacNew	MacNew Heart Disease Health-related Quality of Life Questionnaire
LVQoL	Low Vision Quality-of-Life Questionnaire
GlauQoL	Glaucoma Quality of Life Questionnaire
NEI-RQL-42	National Eye Institute - Refractive Error Quality of Life Instrument – 42

According to ProQolid Database

Fig. 5. Disease-Specific Instruments – Examples (ProQolid Database)

Instruments for targeted population are used for studying quality of life of specific population, such as children, adolescents, adult men, war veterans etc. They depict characteristic feature of such population. Some examples of instruments for targeted population in ProQolid database are attached bellow:

Children (SCLQI -Children's Dermatology Life Quality Index, COHQoL - Child Oral Health Quality of Life Questionnaire apod).
Adolescents (JAQQ -Juvenile Arthritis Quality of Life Questionnaire, Stoma-QOL -Stoma-QOL)
Caregivers (PSQI -Pittsburgh Sleep Quality Index, MCSI - Multidimensional Caregiver Strain Index)
Terminally ill patients (HQLI - Hospice Quality of Life Index apod.)
Adult men (N-QoL Nocturia Quality of Life Questionnaire, PC-QoL Prostate Cancer Quality of Life scale)

According to ProQolid Database

Fig. 6. Targeted Population Instruments – Examples (ProQolid Database)

3.3 WHO model of quality of life

The WHO has been trying to define and evaluate the quality of life since its first definition of health in 1946. From that time on, health-related aspects of the quality of life have prevailed. For its assessment, numerous methodological tools were developed: the performance status, APACHE scoring system, quality of life indices (with the Karnofsky score being the best known), self-rated quality of life scales, quality of life questionnaires (with the EuroQol, SQUALA or WHOQOL questionnaires being the most widely used), individual interviews or focus groups. Any of the above-mentioned tools for measuring the quality of life can be used at different levels: an individual level – evaluating the quality of life in individuals, a group level – assessing the quality of life in groups of patients or people, and a population level – measuring the quality of life in populations of patients suffering from certain diseases or undergoing some therapeutic modalities.

The WHO model of the quality of life and WHO questionnaires are highly appreciated for their complex and practical approach to the quality of life. The WHO model describes the quality of life as a very heterogeneous, specific, individual and sophisticated category which can only be understood in its complexity. The WHO formed working groups for developing psychometric instruments measuring the quality of life and this painstaking research and work aimed at designing questionnaires lasted for more than 15 years before these could be used in practice.

The WHO questionnaires have good psychometric characteristics and are highly recommended for research into the quality of life.

Traditionally, research into the quality of life has been the domain of somatic medicine (the quality of life in patients with HIV, cancer, rheumatological conditions, after transplantations or undergoing some therapeutic modalities). However, the first studies concerned with the quality of life in psychiatric patients, such as those with mood disorders or schizophrenia, have been carried out in many countries all over the world. Unfortunately, research into the quality of life of the elderly patients with psychiatric morbidity in institutional care is rare up to now.

Some of the WHO Quality of life questionnaires are listed bellow:

- WHOQoL 100- 100-items WHO questionnaire of quality of life – general population
- WHOQoL BREF-26-items WHO questionnaire of quality of life – general population
- WHOQoL OLD – 33-items WHO questionnaire of quality of life – suitable for seniors
- WHOQoL-HIV-WHO questionnaire of quality of life for patients with HIV positivity
- WHOQoL Children – WHO questionnaire of quality of life for children population
- DIS-QoL – WHO questionnaire of quality of life for people with disabilities

Fig. 7. WHO Quality of Life Questionnaires – Examples

4. Quality of life in psychiatric disorders

4.1 Organic disorders

Dementia is one of the most common psychiatric condition in senior population. Its prevalence estimation is about 5% of population at the age of 65, with further exponential increase in association with age. Etiology of dementia is represented by more than 60 various cause, the most common is atrophic – degenerative cluster (dementia of Alzheimer’s type, Lewy body disease, frontotemporal dementia, subcortical dementia etc.) followed by cluster of symptomatic dementia (vascular dementia and other symptomatic dementia).

According to research, patients with dementia generally experience worse quality of life compared to seniors without dementia (Hoe et al, 2006). Seniors with dementia living in community tend to retain higher autonomy compared to seniors hospitalized because of any of mental disorders (Hoe et al., 2009, Spector and Orrel, 2006).

In Czech republic, we have designed a unique, cross sectional study. We have chosen Kromeriz region to compare quality of life of seniors living in community without dementia, then of seniors without dementia hospitalized in geriatric wards because of somatic disease and finally of seniors with dementia hospitalized in inpatient psychogeriatric ward. The last group of seniors had significantly the worst quality of life, compared to formel groups of seniors. Seniors who were hospitalized in psychogeriatric ward experienced significantly the highest risk of social exclusion, loneliness, refusal of patient families, loss of autonomy with dependence on health care professionals in performing activities of daily living and last, these seniors had the highest risk of long term hospitalization. Mentally ill seniors hospitalized in psychogeriatric ward were at highest risk of developing major depression and further acceleration of dementia (cognitive decline and decline in non-cognitive symptoms). Positive correlation between decline in cognitive functions (measured by Mini-Mental state examination, MMSE) and lowered quality of life in seniors was found (see fig. 8). Deterioration in functioning (represented by activities of daily living, ADL) and worsening of the quality of life in seniors with dementia correlates significantly (see fig. 9). Guardianship in relation to quality of life in seniors was studied by Jurickova (Jurickova et al, 2011).

As for gender in our research, women formed more vulnerable group of seniors compared to men (Luzny, 2009).

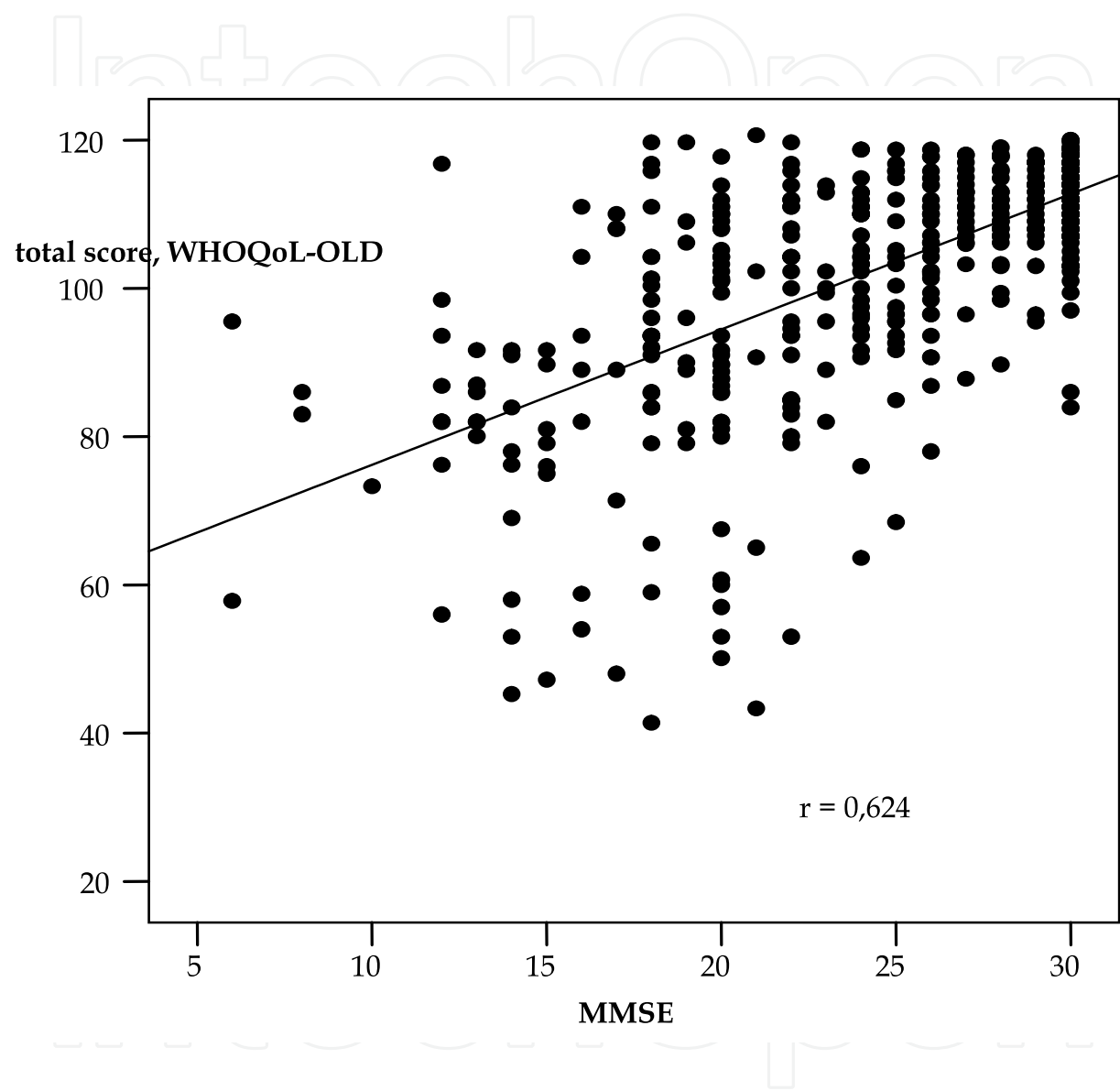


Fig. 8. Correlation between decline in cognitive functions and lowered quality of life in seniors with dementia

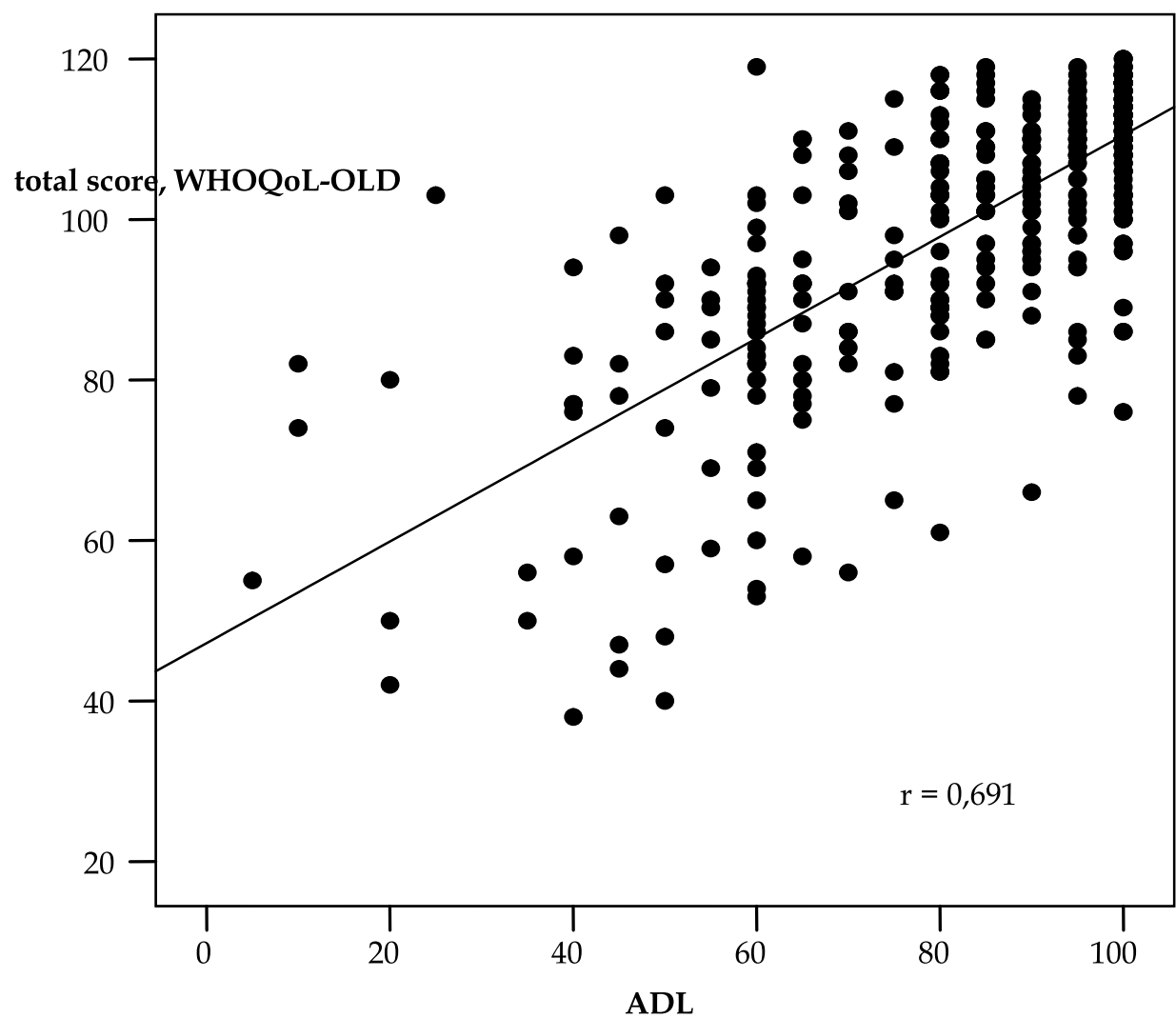


Fig. 9. Correlation between deterioration in functioning (activities of daily living, ADL) and quality of life (total score WHOQoL OLD) in seniors with dementia

4.2 Substance abuse disorders

Psychoactive substances attracted human attention from all times through history. Prevalence of experience with psychoactive substance in general adult population ranges from 25% of population as for smoking to 90% of population as for experience with drinking alcohol. 33% of population has lifetime experience of at least one illegal drug (Semple et al, 2005).

Abuse disorders cause many of social, economic and health related problems - unemployment, homelessness, divorces and high rate of criminality are on top of the problems. Researchers showed significantly worse quality of life of patients with substance abuse disorders compared to healthy control groups. On contrary, treatment of substance abuse disorders improved level of social functioning of addicted patients with secondary increase in perceived quality of life of these patients. Social and psychological conditions influencing quality of life in substance addicted patients were studied by Czech researcher Donkova (Donkova, 2009).

4.3 Schizophrenias

Schizophrenia is severe long-lasting psychiatric disorder changing thinking, perception or altering behaviour towards the others in acute phase of this disorder, in chronic phase of disorder, self-esteem, self-confidence, functioning in community or autonomy is usually altered too. Treating schizophrenia usually requires life-long adherence in therapy, what cause problems and leads to relapse of a disease (Staring et al, 2009). Schizophrenia is typical psychiatric disorder which is stigmatizing an individua and worsening his or her positron in community. All aspects mentionned above are worsening quality of life in patients with schizophrenia (Chromy, 1995).

4.4 Affective disorders

Affective disorders include broad spectrum of disorders characterized by pathological mood. Depression is one of the most common conditions in this cathegory (unipolar, bipolar or recurrent type). Anhedonia is worsening quality of life of depressed patients, together with apathy, abulia and dyssomnia (Ay-Woan et al, 2006). Positive correlation between depressivity in seniors (measured by Geratric Depression Scale, GDS) and low quality of their lives was found by Luzny (Luzny, 2009) – see fig. 10.

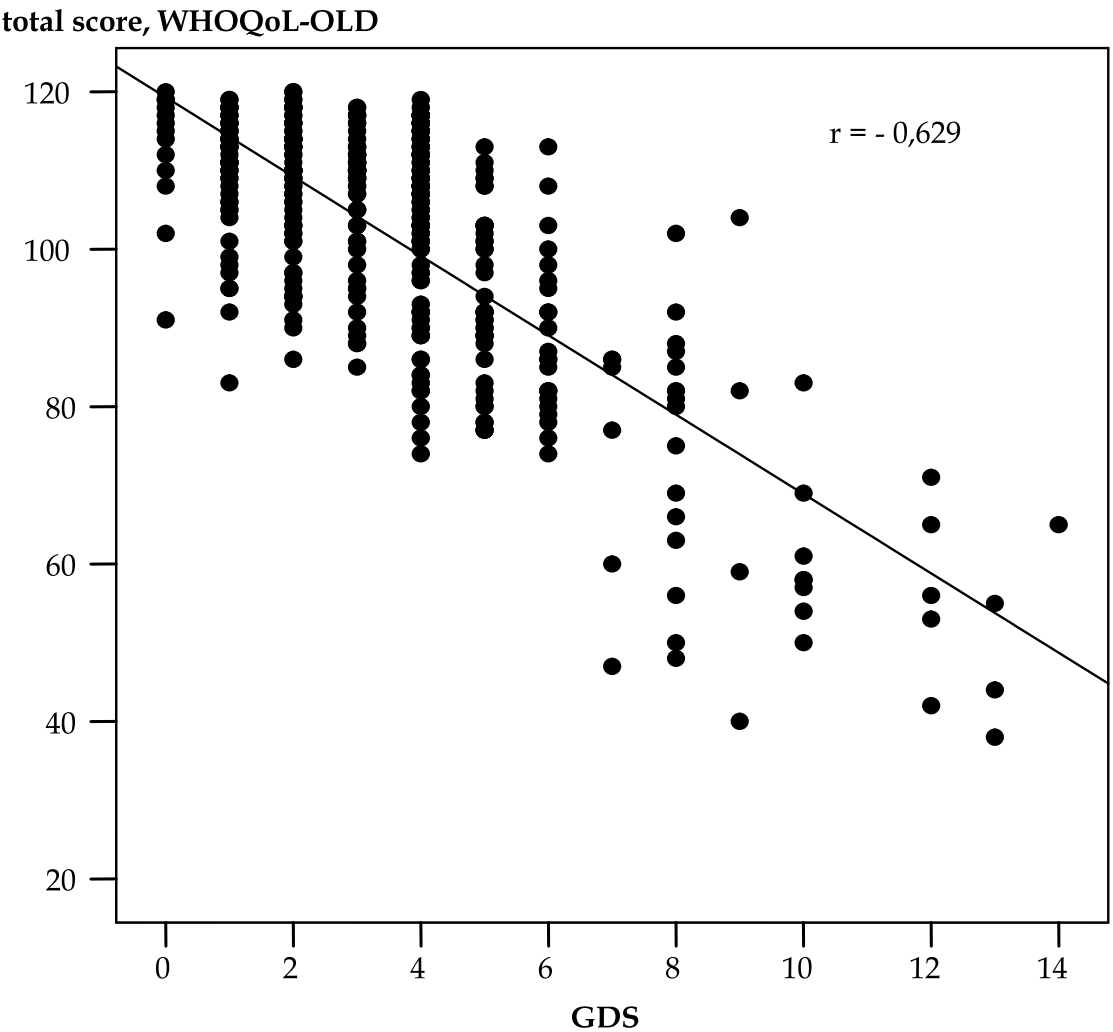


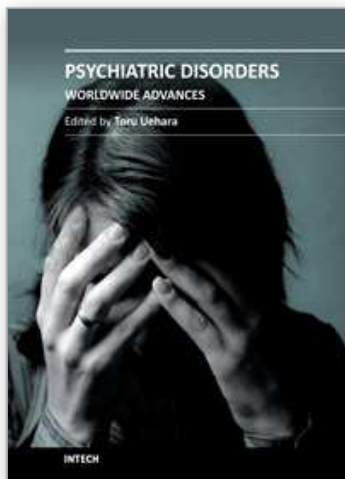
Fig. 10. Correlation between depressivity ald quality of life in seniors

4.5 Anxiety and stress-related disorders

Stress-Related disorders are one of the most common conditions in psychiatry. In developed countries, the prevalence of this cluster of mental disorders in general population is about 8.9% (Semple et al, 2005). Although these disorders, formerly called neuroses, don't alter seriously essential parts of human psyche, they affect satisfaction with life and lead to worsening of quality of life (low self-confidence, low self-esteem, feelings of exhaustion, feelings of worsening in labour and daily life activities). Beard et al. have studied health related quality of life across the anxiety disorders and have described such correlations (Beard et al, 2010).

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A psychiatric disorder is defined as any complex condition that involves the impairment of cognitive, emotional, or behavioral functioning. Aside from knowing the physical organic factors, its causal pathology has remained a mystery. Regarding recent advances in psychiatry and neurosciences, psychiatric disorders have been closely associated with socio-cultural, psychological, biochemical, epigenetic or neural-networking factors. A need for diverse approaches or support strategies is present, which should serve as common knowledge, empathetic views or useful skills for specialists in the field. This book contains multifarious and powerful papers from all over the world, addressing themes such as the neurosciences, psychosocial interventions, medical factors, possible vulnerability and traumatic events. Doubtlessly, this book will be fruitful for future development and collaboration in “world psychiatry”.

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