

Specificity of quality of life assessment in people with mental disorders

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Summary

Quality of life is an integral element of a new perspective on health. Even though the definition and structure of the concept of quality of life are still being debated, researchers exploring the topic agree that it has both objective and subjective dimensions. When the quality of life of patients is examined somatically, the objectives formulated in the study procedure are usually easily achieved, particularly when the basic hypothesis is that good physical health generates a high quality of life. However, where mental diseases and dysfunctions are investigated, and the analysis involves a large number of variables constituting quality of life, the relationship is not so clear-cut. Consequently, in addition to methodological accuracy the researcher must put a major focus on the patients and their manifestations. The thesis stating that it is impossible to measure quality of life in this population, or worse still, that there is no need for such measurements, is indefensible, considering that people with mental disorders have the same right to a good life as healthy individuals, and achieving an improvement in their quality of life becomes an increasingly common target among anticipated therapeutic benefits. Looking at the issue from the perspective of findings obtained in multiple studies, it is evident that quality-of-life measurements are not easy, but a successful attempt may provide researchers with a source of valuable non-clinical data and even enhance their personal satisfaction.

Key words: quality of life, mental disorders, specificity of measurement

Introduction

Studies focused on quality of life (QoL) emerged in medicine along with the need to adopt a different outlook on the situation of patients and their issues, to encompass those spheres of life that had thus far been ignored in clinical evaluations. A perspective in which health is assessed exclusively on the basis of objective determinants is

usually inconsistent with the patient's own perception, because in addition to producing changes in the patient's state of health as such, the treatment process may also affect the patient's perceived quality of life [1]. Mental health is a fundamental human value and, at the same time, one of society's most important resources. Mental disorders and dysfunctions have the most adverse impact both on the subjective and objective dimensions of quality of life, as their consequences interfere with all spheres of life and activity of the patient [2]. In the domain of psychiatry, the results of QoL assessment are useful in situations requiring in-depth feedback on the efficacy of the applied methods of treatment and rehabilitation, when the patients' search for meaning in life becomes their specific need, helping them to reset their life goals or venture into new areas of activity. This approach is part of patient-centred medicine, focusing on patients' needs which have an inherent dimension of psychological experiences and are a subjective expression of the life process [3]. The humanistic nature of psychiatric contact – providing an opportunity to get to know the patient not only as an individual who exhibits deviations from the social norms held in a given community and consequently needs their adjustment in the interest of the general public, but also as a person who is dissatisfied with their life, and seeks moral and spiritual help – in some sense even predetermines the scope and direction of research on the quality of life in the population of people affected by mental disorders [4].

It can be argued that the measure of quality of life in people suffering from various mental disorders refers not only to the degree of fulfilment of their objective and beneficial life needs as seen from the point of view of the researcher and clinical practice, because it is frequently the case that the scope and degree of well-being perceived in this group of patients are ultimately determined by subjective factors that may not correlate at all with the objective aspects, but are nevertheless highly valued by the patient. They are not easy to identify, and limitations existing in this scope are due to the need to take into account a range of mental dysfunctions and their accompanying psychopathological symptoms as well as difficulties encountered by researchers attempting a critical assessment of the life situation of patients, which reflects their individual beliefs, expectations, and available health resources.

The main goal in QoL assessment among patients suffering from mental disorders should be to juxtapose elements of the patient's subjective experiences with their objective essence manifesting as the patient's dysfunctions. This strategy offers an opportunity to decode their underlying meaning for the patient, and to establish the priorities in therapy from the patient's perspective. This means that a parallel assessment should be attempted, involving objective 'external' criteria, with the stipulation that incorporating psychopathological manifestations into research tools should always be properly controlled, and various areas of life should be considered separately.

In the area of medicine, focusing attention on the relationship with the patient and the collaborative search for complex determinants underlying their illness is a characteristic feature of the psychosomatic approach, and is particularly close to psychiatry [5]. In fact, it is also a *sine qua non* for the correct conduct of quality-of-life research

in the populations where the socio-cultural and psychological context in which the illness is embedded carries a special importance.

Multidimensional structure of the QoL concept

It has been 30 years since Schipper [6] introduced the concept of health-related quality of life (HRQoL) into modern clinical medicine, defining it as a ‘functional effect of an illness and its consequent therapy upon a patient’. Since that time, the number of publications on this topic indexed in the National Library of Medicine database has increased 22 times, and if all studies on quality of life are included – more than 230 times. If ‘QoL & psychiatry’ are selected as keywords in a database search, the first retrieved publication is the paper by Rosenberg (1995) [7] outlining his concept for prospective quality-of-life research. At the time of the paper’s publication, the author argued that the main precondition for successful studies involved adopting a naturalistic hermeneutical QoL framework in which philosophical reflection on the concepts of health and illness would be combined with the psychometric validity of the measurement tools and criteria used.

Importantly, the author aptly pointed out that quality of life required multidimensional evaluation. This aspect, he claimed, should always be incorporated into the study, being the only approach with a capacity to accurately decode the complex concept of quality of life [7]. The definition of quality of life proposed by the World Health Organisation (WHO) in 1997 placed the individuals’ perception 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, thus making a direct reference to the definition of health as a model of physical, mental and social well-being. The WHO thus highlighted the individual perspective in the assessment of human life and health, which is important from the point of view of every person, and also its subjective character [8]. Similarly, the WHO established that at its core mental health was ‘a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community’ [9]. It would be difficult, it seems, to adopt a contemporary definition of health that does not take into account all the components included in the WHO’s ‘triad’, or accept the results of any QoL assessment not referring to these domains. However, this does not mean that the concept of ‘universal and positive well-being’ in mental health is not being challenged. Galderisi et al. [10] claim that despite moving away from a biomedical model of mental health, which they still regard as progress, the definition formulated by the WHO identifies and affirms only positive feelings and positive mental health factors. Consequently, the authors put forth a new concept of mental health, based on a model of a dynamic state of internal equilibrium. In the new framework, within the postulated health norm, the individual is granted the right to experience a full spectrum of emotions – including fear, anger, sadness and grief – and to use their abilities to also cope with adverse life events [10].

Is this an attempt to move away from the Epicurean theory of happiness and eudaimonia, and back to the views of Hippocrates? It seems that the question can be answered in the affirmative. The concept is close to the new perspective on health. It sets the desired direction for exploring the concept of mental health, and makes an attempt to conceptualise it. At least some of the definitions of quality of life proposed in the literature are suitable for implementation into psychiatric research.

In a synthetic approach, Jarema et al. [11] explore quality of life as ‘the patients’ subjective perception of life satisfaction in the context of their own needs and abilities’. Gill and Feinstein [12] view quality of life from the perspective of the extent to which a person’s life reflects the aspects that they find satisfying or important. It would be difficult to formulate more concise definitions of quality of life which, at the same time, fit into the psychiatric context of the patient’s cognition. In its initial phase, research on the quality of life of people with mental disorders was geared primarily towards objective determinants, such as the severity of symptoms, length of hospitalisation, or the course of remissions. The underlying assumption was that especially chronically ill patients were unable to assess their life in a reliable manner [13]. At the same time, it was falsely claimed that measuring QoL was essentially superfluous because psychiatric evaluation largely addresses the sphere of patients’ internal experiences, including those related to their subjective attitude towards their life situation, which in fact corresponds in scope to the concept of quality of life [14]. Over time, however, a growing interest in the patient’s subjective feelings, which may affect the process of treatment and rehabilitation, has brought about a shift towards the holistic nature of the concept of quality of life, so that the patient’s perspective began to be incorporated into QoL research. This tendency can be attributed to the realisation that for many patients affected by mental disorders the concept of recovery is based on the ability to maintain control over their lives rather than the somewhat fuzzy notion of returning to their pre-disease state of functioning [15].

At present, there is no doubt that QoL assessment is an expression of the patient’s individual experience of the disease. Therefore, when constructing disease-specific QoL rating scales, it is so important to select appropriate areas to include in QoL measurement. When conducting quality-of-life research in the field of medical sciences, it is advisable to adopt a multidimensional structure for the QoL construct, and compare it against the clinical norm, the social norm, and the individual norm [16]. This perspective is embraced by many authors who postulate a broad context for measuring the available dimensions of quality of life, including its individual spheres (domains), such as the World Health Organization Quality of Life Assessment (WHOQOL-100) questionnaire, which analyses six areas of human life and assigns them a specific rank value [17], or the Quality of Life Self-Assessment Inventory (QLSAI) scale, used for example to plan the therapeutic process in patients with schizophrenia [18].

Because the relationships between objective and subjective indicators of quality of life are neither simple nor direct, available models of QoL and research tools addressed to them analyse at least some additional areas of quality of life, such as the Lancashire

Quality of Life Profile (LQOLP) questionnaire derived from the Lehman interview on quality of life, developed for people with schizophrenia, which is also used in the assessment of quality of life of people suffering from other severe diseases and mental disorders [19, 20]. The tool is used to assess the impact of treatment methods on the quality of life of patients, diagnose their health needs in community psychiatric care, and in its modified version, which now includes ten domains, directs particular attention to the definition of quality of life from the perspective of the patients themselves (autonomy, coping, self-esteem) [21-24].

Multiple studies have shown that mental illness itself, being the source of a range of tensions and negative emotions, predictively impairs the quality of life, and the patients' psychological deficits may cause them more discomfort than would be expected from the loss of function or reduced performance [25]. An additional problem producing a negative impact on the quality of life of patients with mental illnesses is the belief, still deeply entrenched in the social consciousness, that they are mentally incompetent and unpredictable, or even pose a constant threat to people around them. Such opinions are widely held especially towards schizophrenia patients. This stigmatising stereotype often means that the emotional burden associated with a mental disorder may persist long after the primary symptoms have resolved [26].

It must also be noted that the patient's assessment of QoL depends on their current mental state, personality traits, system of values, and a number of other variables. What is more, the way these different aspects are reflected in the assessment may differ significantly from one stage of the disease to another. Measurement errors may take place when the acquired data pool is incomplete or the data are insufficiently precise, which, as practice shows, often results from differences in patient status, and their varying willingness to cooperate. This situation should prompt the researcher to repeat the assessment, e.g. during a period of remission of symptoms, attempt to apply a different diagnostic tool, or request that a complementary measurement is performed by the clinician or the patient's caregiver.

The authors of the study argue that in view of major limitations on the part of the patient, external QoL evaluation should not be viewed as a complementary measure but rather a mandatory component, especially when, for example, this approach is strongly suggested by the results of cognitive performance measurement. Barbe et al. [27] argue that in cases where patients are unable to participate in a quality of life survey by themselves, for example because of advanced Alzheimer's disease, an assessment by the patient's caregiver can be used to improve the patient's quality of life.

Methodological problems and specific nature of QoL measurement in mental illnesses

In view of the diverse nature of different aspects, criteria and variables considered in the assessment of quality of life, conducting such studies is far from easy, and in individuals with severe mental disorders it may become a real challenge. Problems

confronted by the researcher include potential difficulties at the stage of designing the research procedure, during its implementation, and subsequent evaluation of results. A number of methodological questions arise already at the stage of preliminary conceptualisation of the study, when a literature review yields a wide range of available measurement tools, and there is no certainty as to the importance and comparability of results obtained by applying different instruments. A crucial element for the entire quality of life assessment process is the selection of an appropriate QoL assessment tool, which should be characterised by appropriate reliability and validity and, in the case of questionnaires, also a high coefficient of internal consistency (Cronbach's α). The usefulness of measurement scales is greater if they can be applied in all cultural, ethnic and linguistic groups [28].

The Quality of Life Group of the European Organisation for Research and Treatment of Cancer (EORTC) has formulated a 'methodological model' for research into quality of life, which organises the issues of standardisation and validation of research tools, and is therefore intended to facilitate research [29]. Since the selection of diagnostic instruments is the researcher's privilege, but also a responsibility, it seems appropriate to recapitulate their classification as well as the basic principles relating to the operationalisation of variables. *Generic scales* for the evaluation of quality of life are used when, in the most general terms, the researcher is looking for possible relationships between QoL and the basic areas of patient's functioning. In contrast, targeted instruments (*disease-specific scales*) should be adopted where the researcher expects deep insights into the mutual relations and determinants of quality of life, especially in relation to a specific group of disorders or a selected disease entity. In such cases, the researcher's attention focuses either on a specific sphere of the patient's life or on the effects of illness on the patient. Mixed questionnaires contain both elements that are characteristic of the generic form and specific elements targeting a specific type of dysfunction.

By operationalising the variables, an attempt can be made to determine which aspects of the patient's quality of life are covered by a particular research problem, which variables may be predictive and accessible to observation, and furthermore how measurements are done or what instrument should be used to obtain answers to research questions using selected indicators. In this approach, the operationalisation of variables is a process of giving theoretical meaning to appropriate empirical constructs [30]. Finally, it is useful to clearly indicate whether QoL assessment refers to the global quality of life or its integral areas. In the latter case, patients have an opportunity to perform constituent assessments of each domain, based on a hierarchy of values that are important for them.

The overall QoL index is usually an averaged representation of its individual spheres, and less commonly an assessment resulting from a direct question about quality of life, as is the case, for example, in the WHOQOL-BREF questionnaire.

Carr and Higginson [31] claim that many of the QoL measurement tools in use fail to focus individually on the patient or group of patients, and impose standard-

ised quality of life models, ultimately describing the patient's overall health rather than their quality of life. Looking for tools to measure QoL/HRQoL in patients with problem gambling, Bonfils et al. [32] conducted a systematic review of this field, including original reports published between 1950 and November 2018 and indexed in medical databases. The review included both randomised controlled and non-comparative trials, as well as epidemiological studies. The authors identified seven types of instruments covering twenty-six areas of patients' life, grouped in the following categories: social relationships, activity, physical condition, mental condition, financial problems, medical care, and life satisfaction. Because of their generic nature, the measurement instruments used in the study were found to be insufficiently specific for exploring problem gambling, and were not fully (or not at all) validated in terms of psychometric properties. According to the researchers, these characteristics mean that their application in QoL studies in this population should be regarded as limited [32]. Doubts as to the reliability of obtained study results may arise not only when, instead of a multi-faceted assessment of QoL in people affected by mental disorders, one seeks to evaluate just one parameter conventionally referred to as 'quality of life', but also when findings obtained by evaluating patients' subjective well-being (SWB) are equated with a comprehensive assessment of their quality of life, which inevitably leads to difficulties when attempting to compare empirical data acquired by various researchers. The risks of measurement error associated with the adoption of a static concept of quality of life and an atomistic perspective in QoL research, without assigning 'weights' to the individual spheres of the patient's life, were aptly pointed out by Hunt [33] already back in 1997. It appears that synthetic measures can be effectively employed in epidemiological studies where the QoL measurement, despite being objective and clinically relevant, focuses on quantitative factors. This aspect should be considered, for example, when formulating predictions as to the efficacy of performed interventions and implemented therapeutic programmes [34].

The specific nature of QoL assessment in patients with mental illnesses requires – in addition to adopting a certain theoretical concept of quality of life – an analysis of various areas of the patient's life, including the availability of resources, level of functioning, outlook on life's possibilities and sense of meaning in life, as well as social needs, which often forces the researcher into using several QoL measurement tools. Connel et al. [35] identified seven domains predictive for the quality of life of people with mental health problems, including well-being and ill-being; relationships and a sense of belonging; activity; self-perception; autonomy, hope and hopelessness; and physical health. According to the authors, the order does not appear to be random, and people may experience substantial improvements in their quality of life without registering on the positive end of the quality of life scale. In addition, the researchers postulate that a full spectrum of negative and positive aspects of each domain should be included in any measure of the quality of life [35]. Haraldstad et al. [36] reviewed a total of 163 articles relating to quality of life indexed by the world's largest bibliographic databases, which were published during a period of just one week in 2016. The publications under

review were based on 55 different questionnaires dedicated to measuring quality of life, both generic and disease-specific. The most commonly used general instruments were the Short Form-36 (SF-36), European Quality of Life-5 Dimensions (EQ-5D), EORTC QLQ C-30, WHOQOL-BREF, and SF-12. It is significant to note that none of the studies gave the subjects an opportunity to list additional elements that are important for their quality of life. Only one study included this possibility as an option. It is also worth emphasising that many of the interventions described in the reviewed studies did not aim directly to improve QoL, which was a secondary endpoint of the studies. This may show that researchers investigating quality of life are interested both in medical outcomes and the impact of treatment on patients' lives [36].

The following are the most important diagnostic tools for assessing the quality of life of people with mental illness and disorders (Table 1).

Table 1. Diagnostic tools for assessing quality of life most commonly used in mental diseases and disorders

Tool name	Acronym	Authors, year created	Tool type/disease unit	No of domains	No of items	Mode of administration	Testing time (min)
World Health Organization Quality of Life questionnaire	WHOQoL-100	WHOQOL Group, 1998 [37]	Generic	6	100	Self-report or administered by researcher	30
	WHOQoL-BREF	Skevington, Lofly, O'Connell, 2004 [38]	Generic	4	26	Self-report or administered by researcher	10-15
EUROHIS-QOL 8 – item index	EUROHIS-QOL 8	Schmidt, Mühlan, Power, 2005 [39]	Generic	4	8	Self-report	Several minutes
	SF-36	Ware, Sherbourne, 1992 [40]	Generic	8	36	Self-report	10-15
Short-Form Health Survey	SF-12	Ware, Kosinski, Keller, 1996 [41]	Generic	8	12	Self-report	Several minutes
	IMHQOL	Long, 2004-2020 [42]	Generic	15	78	Self-report	30
Internet Mental Health Quality of Life scale	EQ-5D	The EuroQol Group [43]	Generic	5	5	Self-report	Several minutes
	Q-LES-Q	Endicott, Nee, Harrison et al, 1993 [44]	Designed to be generic (commonly used for affective and anxiety disorders)	8	93	Self-report	40-45
European Quality of Life-5 Dimensions questionnaire	Q-LES-Q SF (Short Form)			8	16	Self-report	10

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Lancashire Quality of Life Profile	LQoLP	Oliver, 1991 [45]; Oliver, Huxley, Priebe et al., 1997 [46]	Severe and chronic mental illness	9 (10)- van Nieuwenhuizen, Schene, Koeter et al., 2001 [24]	105 (133) van Nieuwenhuizen, Schene, Koeter et al., 2001 [24]	Structured self-report interview conducted by researcher	45-60
Lancashire Quality of Life Profile, European version	LQoLP-EU	Gaite, Vázquez-Barquero, Arizabalaga et al., 2000 [47]	Severe and chronic mental illness	9	105	Structured self-report interview conducted by researcher	45-60
Lehman's Quality of Life Interview	QoLI	Lehman, Ward, Linn, 1982 [48]	Severe and chronic mental illness	8(9)- either with or without the religion domain	143	Semi-structured self-report interview conducted by researcher	45
Dementia Specific Quality of Life Instrument	QUALIDEM	Ettema, Dröes, de Lange et al. 2007 [49]	Dementia	9 (mild to severe dementia) 6 (very severe dementia)	37 (mild to severe dementia) 6 (very severe dementia)	Self-report completed by patient, researcher or proxy	ND
Dementia Quality of Life Instrument	D-QoL	Brod, Stewart, Sands et al. 1999 [50]	Dementia (suitable for use in patients with mild to moderate dementia)	5	29 (30) (an optional question about the overall quality of life)	Self-report completed by patient, researcher or proxy	ND
Quality of Life in Bipolar Disorder scale	QoL-BD	Michalak, Murray, Crest 2010 [51]	Bipolar disorder	12	56	Self-report	25
	BREF QoL-BD			12	12	Self-report	Several minutes
Satisfaction with Antipsychotic Medication scale	SWAAM scale	Rofail, Gray, Gournay, 2005 [52]	Schizophrenia Bipolar disorder	5	33	Self-report completed by patient, researcher or proxy	ND

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Schizophrenia Quality of Life scale	SQLS	Wilkinson, Hesdon, Wild et al., 2000 [53]	Schizophrenia	3	30	Self-report	5-10
Quality of Life scale	QLS	Heinrichs, Hanlon, Carpenter, 1984 [54]	Schizophrenia	4	21	Semi-structured self-report interview, completed by researcher	40-45
Quality of Life in Schizophrenia	QLiS	Franz, Fritz, Gallhofer et al., 2012 [55]	Schizophrenia	12	52 (plus two optional items related to work)	Self-report	ND
	QLiS-SF (Short Form)	Senin, Franz, Deuschle et al., 2017 [56]		3	13	Self-report	ND
Health-Related Quality of Life in Eating Disorders	HeRQoLED	Las Hayas, Quintana, Padierna et al., 2006 [57]	Eating disorders	8	50	Self-report	25-30
Eating Disorders Quality of Life Instrument	EDQoL	Engel, Wittrock, Crosby et al., 2006 [58]	Eating disorders	4	25	Self-report	10-15
Quality of Life in Depression Scale	QLDS	Hunt, McKenna, 1992 [59] Tuynman-Qua, de Jonghe, McKenna, 1997 [60]	Depression	8	34	Self-report	10-15
SmithKline Beecham Quality of Life scale	SBQoL	Stoker, Dunbar, Beaumont, 1992 [61]	Depression and anxiety disorders	10	28	Self-report	45

ND – no data

As mentioned above, the correlations and interrelationships between QoL and the objective state of affairs are far from being obvious and may assume various forms. The 'dissatisfaction dilemma' applies to patients who, despite clear indicators of their good life situation, remain dissatisfied and rate their quality of life as low, for example patients with depressive disorders. The so-called 'paradox of satisfaction' takes place when patients are in an objectively unfavourable position, yet perceive their quality of life as high. The condition may occur in patients with hypomania and mania, or it may be an expression of various types of defence mechanisms developed by patients in response to the onset of disease. People who view their lives as happy and of high quality will experience 'justifiable satisfaction'. In contrast, a group of patients who are 'justifiably dissatisfied' will rate their quality of life as low, in line with their life situation [62]. Some authors highlight that even though the primary goal of treatment, particularly in patients with chronic disorders, is to improve their quality of life by eliminating tangible effects of their condition, some patients benchmark their expectations against their past experience of health and disease, and consistently rate themselves as having high quality of life despite limitations 'objectively' existing in their lives. The value of this relationship is claimed to depend on the point along the disease trajectory at which QoL is measured, as well as other variables such as age, sex, relations with the environment, or belonging to a particular social group, sexuality or disability [63].

Cummins [64, 65] presents a different view, rooted in the theory of subjective well-being (SWB) homeostasis. According to this framework, objective circumstances have relatively little influence on an individual's overall well-being, which is regulated homeostatically and varies within a narrow range of adopted genetic values. Objections are occasionally raised with regard to the results of QoL assessment in patients with mental disorders, which claim the absence of procedural diligence. Such situations may also relate to the failure to consider the impact of a specific affective state of the patient on measurement results, or the continuation of assessment despite identifying particular cognitive function disorders which should prompt a decision to exclude the patient concerned from further study participation. Yang et al. [66] argue that the researchers' knowledge of standardised tools for collecting data on health resources and quality of life in patients with cognitive disorders and dementia still seems to be limited.

Different data have been reported in a systematic review of the subject literature on the QoL assessment in patients experiencing subjective cognitive impairment (SCI), indicating a lower level of quality of life in this group of patients, regardless of the methodology applied for the assessment [67]. Katschnig [68] points out that the patient's subjective assessment may become distorted as a result of the so-called 'affective fallacy', 'cognitive fallacy' or 'reality distortion fallacy'. Affective fallacy is considered to be the most conspicuous type, showing the highest prevalence in the course of study. For example, depressed patients because of their low mood tend to see their quality of life as worse than it might appear to an independent observer, while manic patients typically rate their life very highly. In this context, the author

asks rhetorically whether, since the patient's own view seems necessary to assess their quality of life, and the view is subjective, it is sufficient for the assessment of QoL in people with mental disorders. As already highlighted, the affirmative answer is not so straightforward, at least with regard to patients in the acute phase of their illness. In such cases, it is advisable to measure QoL during a period of relative stability of symptoms or supplement the data obtained from the patient by performing a clinical assessment, as is the case in patients with schizophrenia [69-71].

In that light, one might venture the opinion that when the quality of life of patients is examined somatically, the objectives formulated in the study procedure are usually easily achieved, particularly when the basic hypothesis states that good physical health generates a high quality of life. Even then, however, nothing relieves the researcher of the obligation to evaluate the patient at least for symptoms of depression and anxiety, and investigate their possible impact on QoL. This is particularly relevant given the knowledge that somatic and psychiatric disorders frequently coexist, especially if the former are chronic in nature. However, where mental diseases and dysfunctions are investigated, and the analysis involves a large number of variables constituting the quality of life, the relationship is not so clear-cut. Consequently, in addition to methodological accuracy the researcher must put a major focus on the patients and their manifestations, which often have a very complex nature and causes. The specific nature of QoL assessment in patients with mental disorders also involves the need to provide the patient with a sense of emotional connection in the relationship with the researcher. This is done by establishing contact on the level of psychological experiences available to the patient, even when the patient's own activity in this area is markedly limited. Meetings with patients affected by mental disorders are always extremely private in nature, and always require extraordinary tact and patience, and occasionally even a fair amount of intuition when taking actions. Patients with mild and moderate mental health issues often experience a sense of helplessness, powerlessness, and confusion about the mental care system, which, as they claim, is general and 'universal' in nature rather than geared to meeting their individual health needs [72]. There are still not enough studies determining factors with a QoL impact in patients with depressive disorders in which quality of life issues are less commonly considered as a study problem, and instead depression is addressed as an important constituent of quality of life in the course of other diseases, leading to it being evaluated as a feature of patient functioning with a particular disorder [73]. There is now considerable evidence that QoL improvement should be recognised as an important goal in the treatment of schizophrenia, as this group of patients is especially strongly exposed to the loss of mental resilience, low self-esteem, and feelings of hopelessness about their life situation, yet until recently the possibility of such measurements was questioned, mainly because of the presence of cognitive limitations [74, 75].

Kilbourne et al. [76] see the need for a comprehensive revision of the approach to mental health problems. The starting point – and the reference point – should be adopting qualitative (rather than quantitative) measures and standards of care which, if implemented, may improve the overall culture of the psychiatric care system.

Conclusions

Mental illness is in itself a source of tensions and negative emotions. Consequently, it predictively generates a lower quality of life in affected patients. The starting point for quality-of-life research in the population of people with mental disorders should be to adopt a holistic concept of health, so that mental health is recognised as a value that helps people maintain – and even achieve – physical and social well-being. What this means in practice is that a number of phenomena, problems and factors constituting human health and life must be taken into account in the assessment. An important aspect in the procedure of QoL assessment is providing the patient with a sense of emotional connection in the relationship with the researcher. This is done by establishing contact on the level of psychological experiences available to the patient, even when the patient's own activity in this area is markedly limited. While recognising the 'ordinary' nature of patients' illness, their individuality and the uniqueness of their life situation should be emphasised, and they should be gradually included in the process of taking control over their health. Every encounter with a mentally ill person is always extremely private in character, and requires from the researcher extreme tact and patience, and even a certain amount of intuition in the researcher's actions, rather than merely methodological accuracy and compliance with clinical standards, though reliability in this respect should not be compromised, either. QoL measurement in people with mental disorders should not be incidental or carried out with the aid of research tools that are not appropriate for a particular clinical situation at hand. Also, quality of life should not be equated with 'subjective well-being', when after a brief psychopharmacological intervention a 'quality of life change' is claimed to be observed. In the practice of psychiatric QoL assessment, one should also take into account the fact that the patient's critical attitude towards their illness is frequently impaired. Consequently, a patient who – in objective terms – is in a difficult life situation, rates his or her quality of life highly (the so-called 'satisfaction paradox' or 'disability paradox'), and clinical situations where this relationship is exactly the reverse. In situations involving significant (e.g. cognitive) limitations on the part of the patient, external QoL evaluation should not be viewed as a complementary measure but rather a mandatory component. Looking at the issue from the perspective of findings obtained in multiple studies investigating the quality of life in patients with mental dysfunctions, it is clear that such measurements are not easy, but a successful attempt may provide researchers with a source of valuable non-clinical data and even enhance their personal satisfaction.

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