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ORIGINAL PAPER

Subjectivity in the Perception and Measurement of Quality of Life: Conceptualization and Development of the Seville Questionnaire

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Abstract Quality of life (QoL) is a significant parameter in estimating the social and interpersonal impact of psychopathology, clinical course, and response to treatment in many mental illnesses, particularly schizophrenia. The clinician's assessment and patient's subjective report are essential ingredients of this process. We describe the development and structure of a QoL questionnaire based on the patient's subjective understanding of the problems. Ninety areas identified by four groups of experts resulted in a 126-item questionnaire administered to 279 patients with a DSM-IV diagnosis of schizophrenia. A factorial approach led to 59 total items and two final scales (favorable and unfavorable), with three factors each. The Seville QoL Questionnaire (SQLQ) results can be presented as individual scores for each scale, or a total for both. Its psychometric properties have proven quite acceptable in reliability and validity, comparing favorably with other scales. SQLQ may prove to be a useful addition to QoL-measuring instruments.

Keywords Quality of life · Schizophrenia · Clinical questionnaires · Subjectivity

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Introduction

The social repercussions of diseases such as schizophrenia have been the focus of attention of many clinicians and researchers, particularly those in the areas of social and cultural psychiatry, and of the social sciences in general. Quality of life (QoL) has emerged as a significant parameter in the estimation of the social and interpersonal impact of psychopathology, clinical course, and response to treatment [1]. The chronicity and the clinical relapses of schizophrenia, the declining cognitive performance and other deficits in affected individuals as they age, and the implications of such developments for care providers and caretakers make this field as important as the assessment of the genetic or neurobiological bases of the disease [2]. Furthermore, QoL in schizophrenia should be read also as the outcome of a variety of factors and interventions, from the use of neuroleptics to the level of understanding and acceptance by the patient's family [3]. Its impact on a variety of areas from the clinical to the social through health economics, and health planning is considerable [4, 5].

Quality of life has been mostly assessed clinically, that is, by observers of the patient's behavior [6, 7]. Yet, it is becoming clear that its true estimation must reflect the subjective perspective of the patient more substantially than judgments made by others. The context of his/her social and cultural surroundings, hopes, aspirations, and personal interests are of primary importance in such perspective. Subjective well-being may also be an important factor in the patient's adherence to treatment [8]. The critical examination of these aspects demonstrates that there is always a zone of uncertainty, uniqueness, and difficult-to-interpret behaviors, actions, or judgment of situations that belong to the specific purview of the patient [9, 10]. Quality of life, then, must be studied not only from an "etic" (outside observer's) perspective, to use an anthropological term, but also from an "emic" one, that is "from within" the patient him/herself [11]. It is also essential to evaluate the subjective effects of any therapeutic intervention (pharmacological or psychosocial) from the patient's vantage point, his/her resulting sense of well-being, and perceptions of health and comfortableness [12, 13].

Atypical antipsychotics, with good tolerability and greater clinical effects on negative symptoms and cognitive deficits of schizophrenia [14], are potentially good agents for the enhancement of the patient's quality of life; however, treatment results are usually measured with clinical, psychopathology-based instruments, rather than by assessing the patient's own genuinely subjective perception. Some previous works in this area have demonstrated that the correlation psychopathology-subjective well-being is not lineal [15], thus the importance of measuring the latter as part of the overall assessment of results of any therapeutic intervention, particularly antipsychotic medications. Yet, most of the scales used to measure the effect of psychotropic agents assess, again, psychopathological variations of the psychosis, not the quality of life of the patient.

Quality of Life Instruments

In the examination of instruments measuring QoL among psychiatric patients, several issues require careful and consistent consideration. They include validity and reliability, sensitivity to change, practicality, and subjectivity. Furthermore, inclusiveness of useful dimensions, comparability, adequacy to the study populations, appropriateness to different moments of the illness, and different age groups of probands must be demonstrated

[16, 17]. Last but not least, grammatical and stylistic characteristics of the statements deserve equally close scrutiny [18].

According to the World Health Organization [19], QoL scales in schizophrenia must include the evaluation of areas such as the decision-making process related to therapeutic options, a measure of the patient's autonomy, self-respect and respect by others, including health professionals. Similarly, these scales should allow longitudinal studies of the natural course of the psychosis, the evaluation of individual and group-based treatment programs, the negative effects of the illness on the patient's way of life, and the analyses of cost-benefit margins [20]. It follows that QoL instruments should be longitudinally self-administered, with a baseline assessment followed by their systematic use through different stages of the treatment.

Bibliographic data banks have reported at least seven most frequently used scales. Among those generated on the basis of specific instruments, the Quality of Life Interview [21], the Satisfaction with Life Scale [22], the Quality of Life List [23], the Quality of Life Scale [24], the Quality of Life Scale-100 [25], are frequently mentioned. Scales arrived at through generic instruments include the SF-36 Medical Outcomes Survey-Short Form [26], and the Psychological General Well-being Index [27].

The Seville Quality of Life Questionnaire (SQLQ)

Conceptualization and Developmental Steps

The above considerations led to the conceptualization and development of the Seville Quality of Life Questionnaire by a Spanish research group, over a period of 6 years [28–30]. Our basic assumption was that QoL must be understood on the basis of the subjective impact of any occurrence, in a given patient, at a given moment since it is, in fact, a cognitive and affective evaluation of the situation as perceived by the patient himself/herself. An instrument aimed at a thorough and objective assessment of QoL must include, as much as possible, the totality of problems, and the most significant events experienced by the patient.

The selection of areas to be explored by and included in the questionnaire was made by a team of clinicians familiar with the functional status, and the psychological condition of schizophrenic patients. The point of departure was that, if subjective criteria in the perception of QoL (understanding "subjective" both, in affective and cognitive terms), were to be the nucleus of the instrument, those areas evaluated in normal persons may not be necessarily useful for, or applicable to, the schizophrenic patient; rather, there may be other facets of the patient's life that he/she may consider important to define his/her own QoL. It was necessary, therefore, to evaluate: (a) areas that can be significantly modified by the occurrence of schizophrenia; (b) to what extent the patients consider that their psychopathology-induced changes may affect QoL; and (c) the perception that the patient has about the repercussions of side effects of any treatment on his/her everyday life.

Thus, the limitations and restrictions on different aspects of everyday life, reported by the patients, were assessed first. It was established that if the patients complain, it is because whatever is happening to them is affecting their QoL. What could be called "psychopathology of everyday life" variables such as fear, anxiety, sadness, or agitation are clearly present in the schizophrenic patient, and may affect his/her QoL, as much as the secondary effects of the treatments, co-occurring problems with medications or alternative medicines, or the use/abuse of other substances.

Ninety areas were identified as a result of these initial analyses and discussions. Such areas ranged from basic needs (eating, sleeping, drinking) to secondary effects of neuroleptics (tremor, impotence, dryness of mouth, etc.), through aspects that can be viewed as satisfactory or relevant by the patient, even if relatives and care providers may consider them as "psychopathological." Each area included several statements whose pertinence and clarity were individually assessed by the research group. Thus, an original 126-item SQLQ was administered to a sample of 279 patients with a DSM-IV-based diagnosis of schizophrenia [28]. It used a Likert Scale modality that included five options, from "totally in agreement" to "totally in disagreement." The selected items were analyzed separately, and resulted in two blocks of data: one referring to positive, satisfactory, or agreeable aspects of QoL, and the other reflecting negative, disagreeable, or unsatisfactory perspectives. A factorial approach led to two final fields or scales in the SQLQ: Favorable (F), and Unfavorable (U). A reduction in the number of explored areas followed, and the original 90 were consolidated into a total of ten dimensions.

Next, four Delphi groups (conformed by psychiatrists practicing in general hospitals, university professors of psychiatry, clinical psychologists, and a mix of clinicians, educators, and administrators) proceeded to adjudicate items to each of the areas or dimensions. Items were placed together on the basis of level of agreement between the four groups of experts. An analysis of concurrence of classification [29] was conducted to confirm that the agreement between the four groups of experts was not a random occurrence; hence, good assignment reliability was attained. The results reached a Kappa de Cohen value of high congruence ($\kappa = 0.81$). Eighty-four items achieved 100 percent of adjudication agreement. These items were then applied to 236 clinically stable patients with different types of schizophrenia, diagnosed according to DSM-IV. The scores thus obtained were the subject of a principal components factorial analysis with Varimax rotation. As a result, the final version of the SQLQ included 59 items, 13 of which were grouped in the Favorable or F scale, and 46 in the Unfavorable or U scale.

Description of the SQLQ

SQLQ is, thus, a self-evaluating instrument in which the patient answers each question utilizing a Likert scale of five levels. Its factorial structure contains a series of relatively independent factors. It is a binary scale that reaches its maximum potential when the two basic components are analyzed, and result in two total scores for each individual patient. The Favorable (F) scale consists of three factors: Life Satisfaction (F1), Harmony (F2), and Self-esteem (F3), all of them directly related to a "good" QoL in schizophrenic patients. The Unfavorable (U) scale includes also three factors, Inhibition (U1), Lack of Understanding (U2), and Irritability (U3), all reflecting problems that alter the QoL of the schizophrenic patient, but which not necessarily entail clinical psychopathology or "symptoms." In turn, the Inhibition factor (U1) has the sub-factors automatism, lack of internal control, difficulty of cognitive expression, loss of energy, and difficulty for emotional expression. The factor Lack of Understanding (U2) is constituted by two subfactors: fear of loss of control, and lack of cognitive comprehension. The Irritability factor (U3) is composed of contained hostility, and awkwardness (Table 1).

SQLQ results can be presented on the basis of the total score resulting from the two scales, or reflect the individual scores of the F and U scales; in the latter case, a score 5/1 would represent a maximum F score [5], and a minimal U score [1], respectively: it would reflect a significantly high quality of life, with eventual psychopathological problems having none or just a minimal impact. Conversely, scoring 1/5 would represent a patient

Table 1 Factorial structure of the Seville Quality Of Life Questionnaire

Scales					
Favorable			Unfavorable		
Factors					
Life Satisfaction (F1)	Harmony (F2)	Self-Esteem (F3)	Inhibition (U1)	Lack of Understanding (U2)	Irritability (U3)
			Subfactors		
			Automatism	Fear of loss of control	Contained hostility
			Lack of internal control	Lack of cognitive comprehension	Awkwardness
			Difficult cognitive expression		
			Loss of energy		
			Difficult emotional expression		

who estimates his/her quality of life as extremely unfavorable or negative, and considers aspects prototypical of a good quality of life, as not present.

This dichotomous scoring allows a more adequate classification of the study subjects. It is evident that when the U scale score is clearly higher than the F score, the quality of life is poor, and vice versa. When the scores are similar in both scales, the estimation of QoL may be unclear or ambiguous. We have found, however, that an U scale score of three or higher, identifies the subject in the group with worse quality of life, independent from a high score in the F scale. Even if the individual does well in some aspects, his/her perspective is going to be mostly reflected in the U score which, then, can be considered as reflecting the negative impact of pervasive psychopathology. On the contrary, when the U factors do not reach a high score, F factors, even if not too high, may lead to the estimation of an acceptable QoL, even in the presence of some psychopathology. The perception of one's QoL seems to be decisively colored by the subjective experience of the psychopathological manifestations, not the symptoms themselves.

Psychometric Properties

Research on QoL in schizophrenic patients, must test the psychometric quality (reliability and validity) of the instruments used, the need to reduce their size in order to reach a better applicability, the possibility of a transcultural comparative evaluation, the interpretation of existing data, as well as their value in the context of treatment and development of specialized services [31, 32].

The reliability of the SQLQ was based on the analysis of its internal consistency (Tables 2 and 3). The F scale showed a reliability higher than 0.70, while the U scale was even higher than 0.80. Furthermore, the testing of the questionnaire in different studies [30, 33, 34] has confirmed its validity, not only because it allowed differentiation between groups of patients assessed by other diagnostic means (such as a clinical interview), but also because it appears to be quite congruent with current clinical tenets about schizophrenia, i.e., that those patients with episodic clinical course and progressive occurrence of

Table 2 Reliability coefficients for the Favorable (F) Scale

Alfa of Cronbach = 0.85
Equal Length Spearman-Brown = 0.81
Unequal-Length Spearman-Brown = 0.81
Guttman Split-Half = 0.81
Alfa for Part I = 0.76
Alfa for Part II = 0.75
Correlation between forms = 0.68

cognitive deficits, find increasingly difficult to use adequate expressiveness, present a higher level of awkwardness, and a clear correlation between worsening cognitive performance, and lowering of quality of life. The concomitant social isolation and further behavioral regression are predictable consequences [35].

Conceptual validity of the questionnaire was obtained by correlating the total scores of the F and U scales with the total score of Lehman et al.'s [21] QoL Interview (QLI) scale, one of the most validated instruments in this field of inquiry with schizophrenic patients. Correlation values reached 0.50 ($P < 0.001$) for the F scale, and -0.35 ($P < 0.001$) for the U scale, both indicating good validity. Likewise, the multitrait-multimethod matrix approach was used to examine convergent and divergent validity: in addition to the SQLQ, the QLI, and Kay et al.'s [36] Positive and Negative Symptoms Scale (PANSS) were used. Convergent validity of the SQLQ with QLI was confirmed ($r = 0.54$ and $r = 0.35$), whereas the discriminating validity was high for SQLQ's F scale ($r = 0.04$ and $r = 0.17$), but low ($r = 0.33$ and $r = 0.41$) for the U scale (Table 4). This suggests that, somehow, the U scale may still include some "psychopathology" load.

To determine the relationship between QoL level with the subjective experiencing of psychopathology and the disability level, 222 schizophrenic inpatients (29.9%) and outpatients (70.1%) from five cities in Spain, were evaluated using the SQLQ [37]. Levels were significantly associated with lower scores on eight of nine unfavorable SQLQ factors: lack of cognitive awareness, loss of energy, lack of internal control, difficulty in emotional expression, difficulty in cognitive expression, fear of losing control, contained hostility, and automatism; and with higher scores on the three favorable SQLQ factors: vital satisfaction, self-esteem, and harmony. Mostly satisfied patients showed significantly lower global,

Table 3 Reliability coefficients for the Unfavorable (U) Scale

• Alfa of Cronbach = 0.94
• Equal Length Spearman-Brown = 0.91
• Unequal-Lenght Spearman-Brown = 0.91
• Guttman Split-half = 0.91
Alfa for part I = 0.88
Alfa for part II = 0.88
• Correlation between forms = 0.84

Table 4 Multitrait-multimethod matrix

	QLI-global	PANSS-P	PANSS-N
SQLQ-F total	0.50 ($P < 0.001$)	-0.04 ($P = 0.515$)	-0.17 ($P = 0.011$)
SQLQ-U total	-0.35 ($P < 0.001$)	0.33 ($P < 0.001$)	0.41 ($P < 0.001$)

work, family, and social disability levels. It was clear that a better QoL was strongly associated with a lesser subjective experience of psychopathology and disability levels.

The satisfaction of individual needs, and the level of disability have a significant impact on the schizophrenic patient's QoL. Studies to evaluate such correlations utilizing the SQLQ and the Disability Diagnostic Scale (WHO-DDS), developed in 1988 in a Spanish sample, showed a moderate disability level, with significant negative correlations between QoL and the level of disability [38, 39]. Correlation analyses were low or moderate, determining only 14.2% of the variance. This justifies the need to incorporate the patient's point of view in the multiaxial diagnostic process, in order to reach better therapeutic planning. Not surprisingly, actively employed subjects and/or those with a clinical course leading to an almost complete remission, presented significant lower levels of disability than the other subgroups.

Discussion

The linkages between perception of reality, psychopathology, and evaluation of QoL complement the merely clinical, symptomatic and descriptive evaluation of symptoms obtained through the traditional clinical interview [40]. Furthermore, the value of QoL measures resides not in the direct clinical interpretation of clinical course, but in the changes that may take place over time [41]. The finding of unfavorable aspects in the perception of QoL by the patients themselves opens new perspectives in the understanding of the disease, as it puts the psychopathology face to face with the patient's subjectivity [42]. Self-perceived areas such as difficulty of emotional expression, cognitive apprehension, or poor internal control may express more clearly the essential aspects of the patient's experience, sometimes masked by the formal psychopathological evaluation.

Considering SQLQ as a binary instrument with a superior classificatory and discriminatory potency than its separate scales, Seoane [43] suggested using Osgood et al.'s [44] Semantic Distance Index, subtracting the U scale scores from the F scale scores. He called this the "authentic" QoL score (PCV, acronym in Spanish). This author considers PCV, a more complete and richer measurement of the scale's content than the separate scoring for the F and U scales. In addition, this approach has a broader scope on the basis of its two-factor structure and, therefore, discriminates the subjects' QoL with a higher amplitude. Seoane further proposes a dimensional approach relating the F and U scales, in such a way that both measurements would be present in the same space rather than in separate ones. Each dimension captures the two aspects (favorable and unfavorable) and results in three dyads: satisfaction/inhibition, harmony/misunderstanding, and self-esteem/irritability. The distance between the two points in a given space represents the psychological distance perceived by the subject between both aspects of his/her QoL—too small or excessively long distances may suggest and identify problematic QoL styles. The analysis of the matrix of distortion of the PCV is a system of differentiation of different styles of quality of life. The pursuit of this line of reflection and analysis requires extensive, but undoubtedly promising, clinical research.

Additional studies could include the assessment of more specific target symptoms for different antipsychotics being used and compared while applying the SQLQ, with a concomitant search of differences between the sub-samples. The persistence of negative symptoms, for instance, can be interpreted as either a residual clinical expression, or a reflection of a greater level of resistance to the therapeutic effects of the antipsychotics. On the basis of these results, future studies could analyze changes observed both in QoL as

well as in the actual clinical symptomatology (PANSS), utilizing last observation clinical flow (LOCF) techniques. Furthermore, evaluations can be conducted of a variance analysis with contrast of techniques to detect differences between the mean values in each visit (at 3, 6, and 9 months, for instance), and the basal value as intra-subject variable. Last but not least, cross-cultural comparisons would ascertain not only clinical commonalities among schizophrenic patients in different parts of the world, but also the impact of cultural variables in the experience and assessment of QoL [31, 45, 46].

Conclusions

The measurement of QoL constitutes a useful approach to the evaluation of the schizophrenic patient, only if it primarily incorporates the patient's subjective perspective. This was the basic premise for the development of the Seville Quality of Life Questionnaire.[1] One of the most frequent objections to this postulate is the belief that the patient's perspective is distorted and "unreal," and therefore his/her self-assessment is considered "biased." Quality of life in any type of patient is an equation based not only on the way the patient experiences the illness, but also on his/her personal and experiential background. The above does not mean that the actual psychopathology does not influence the patient's QoL. What the studies with SQLQ appear to demonstrate is that the patient's subjective views about what QoL means to him or her, are a valuable addition to the instrumental assessment of the morbid process and its clinical course. Indeed, disability and QoL are two outcomes that are inversely related, yet essential for the comprehensive diagnosis of a schizophrenic patient.

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[1] The English text of the SQLQ is available on request from the senior author.

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