

Multi-Informant Perception of Quality of Life and Adaptation in Chronic Schizophrenia

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Abstract. The Quality of Life (QoL) in psychiatric patients is currently of great relevance. This study aims to examine, through a multi-informant approach, the QoL perception in schizophrenic patients, analyzing differences between the informants, as well as the relationship between negative symptoms and QoL. Participants were 32 schizophrenic patients, their caregivers (relatives or psychosocial educators; 25 and 3, respectively), and a team of four professionals of Outpatient Centers of Mental Health in Guipuzcoa, Spain. The assessment of patients' QoL was obtained with application of Satisfaction with Life Domains Scale and Karnofsky Performance Status Scale. Self-informant QoL was assessed with Seville Quality of Life Questionnaire and Social Adjustment Scale Self-reported. The negative symptoms were measured with the Brief Psychiatric Rating Scale and the Scale for Assessment of Negative Symptoms. Patients showed an average high life satisfaction. There were significant discrepancies among informants' reports, with the lowest evaluation given by the professional team and the highest by the patients. Evaluations made by caregivers and patients yielded similar results. These findings suggest that patients and their caregivers present a more optimistic perception of their QoL.

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The interest to study Quality of Life (QoL) in medicine has emerged in recent decades as a powerful concept, which reflects change within the health paradigm, analyzed now from a biopsychosocial approach (Voruganti, Helesgrave, Awad, & Seeman, 1998). QoL research refers to such theoretical concepts as well-being, happiness, and satisfaction (Gladis, Gosh, Dishuck, & Crits-Christoph, 1999). Therefore, is a multidimensional construct that includes not only objective components of community functioning, but also subjective assessment of well being (Kurtz & Tolman, 2011).

Measuring QoL can be regarded as an examination of objective and subjective characteristics of different areas of a schizophrenic patient's life (Packer, Husted, Cohen, & Tomlinson, 1997). The objective evaluation of QoL assesses areas such as marital status, educational level, finances, participation in daily activities, and social relationships (Narvaez, Twamley, McKibbin, Heaton, & Patterson, 2008).

The subjective evaluation of QoL is usually defined in terms of life satisfaction or wellbeing (Lehman, 1988). Thus, the assessment involves knowing and understanding the view that patients have regarding their

lives, whereas the evaluation of objective components emphasizes the need for identifying measures which would not be contaminated by mood or cognitive deficits of patients (Eack & Newhill, 2007).

However, not always there was a consensus in the conceptualization of QoL. A result was a division within QoL research that followed either biomedical or social criterion. Revisions of QoL concept definitions have helped to find a perspective on what is exactly meant by QoL, as well as to get to know how to use this concept within mental health research. Gladis et al. (1999) proposed two models that have guided the research in this area. The first focuses on individual satisfaction with the present life circumstances and is estimated through subjective evaluation (Diener, 1984). The second one concerns health, social and material wellbeing assessed by objective measures.

Lehman posits a multimodal dimension of the QoL construct, incorporating in it an assessment of perceived satisfaction with life, the patient's functional state, as well as the assessment of their needs, resources and opportunities (Lehman, 1997).

As a result, we propose a multimodal evaluation of QoL that includes the following measures: a) life satisfaction, b) psycho-social adaptation, and c) performance index, as well as such objective measures as: a) disability index, and b) assessment of clinical symptoms. Integrating distinct variables is an attempt to approach the concept of QoL from a holistic point of view.

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Patient's evaluation might be influenced by the lack of awareness of disease and the presence of cognitive impairment, mainly attention deficits and speed information processing (Ueoka et al., 2011). Stainfort, Becker, and Diamond, (1996), in their research on the perception of QoL with clinician and patient's assessments, found two possible sources of discrepancy. The first refers to what is important for each type of informant. The second point of discrepancy regards the disagreement related to the form of assessment of the domains.

Although some data point towards a concordance of perceptions between clinicians and patients (Becchi, Rucci, Placentino, Neri, & Girolamo, 2004; Wisniewski et al., 2009), a great deal of research shows a disagreement between the patients themselves and other informants in their evaluation of QoL. There exists empirical evidence that there is little correlation between the ratings made by patients and by health professionals in all domains except for the symptoms (Koivumaa-Honkanen et al., 1999; Salonkas et al., 2006; Stainfort et al., 1996).

As regards the caregivers' perception of the QoL of their relatives research has revealed that it is usually less positive than the perception in the patients themselves (Glozman, 2004; Li, Lambert, & Lambert, 2007; Richieri et al., 2011).

To recap, our research objective is to study the QoL perception in a sample of chronic schizophrenic outpatients, as well as the perception regarding the patients in a sample consisting of their families / educators and professional staff who assist them. At the same time, this study aims to analyze the relationship between clinical symptoms and the QoL of patients.

We expected that perceived quality of life and adaptation in schizophrenic patients would be higher than the perception of their caregivers or families, and the clinical staff that treats them (H1). In addition, we predicted that the clinical symptoms, specifically negative ones, would negatively affect the patient's perceived adaptation and Quality of Life (H2).

Method

Participants

Three types of informants participated in the study: 32 patients, relatives or psychosocial educators (25 and 3 respectively; each educator evaluated more than one patient), and a team of four professionals evaluating each patient: a clinical psychologist, a psychiatric nurse, a psychiatrist, and an occupational therapist, all of them with above 10 years of experience in the treatment of psychotic disorders. This research was approved by the Ethics Committee.

The sample of patients included 20 males and 12 females. The patients were recruited from a Mental

Health Center. Participants had been diagnosed on the basis of criteria from (ICD-10) (World Health Organization, 1996) used for the diagnosis of schizophrenia. All of them were under psychopharmacological (mainly risperidone and olanzapine) treatment.

Procedure

All the instruments were self-administered in the group of patients. Following the multi-informant approach, two types of observers filled in the same measures: one relative or a caregiver of each patient and the professional team who jointly assessed each patient.

All patients were informed about the research objectives, voluntariness of participation, and confidentiality of data, as well as being asked to sign the informed consent. The same procedure was applied in regard to the caregivers. The instruments administration was carried out over three months, within the framework of therapeutic consultations.

Measures

Multi-informant evaluation of quality of life and adaptation: We evaluated two aspects of subjective perception of QoL (SQoL) with the multi-informant approach: satisfaction with life and adaptation (both physical and social).

Life satisfaction measure was *Satisfaction with Life Domains Scale* (SLDS) (Baker & Intagliata, 1982). The scale consists of 14 Likert-type items with facial expressions, with response range from 1 (very dissatisfied) to 7 (very satisfied). The data was obtained for few topics concerning various domains of perceived satisfaction with life, grouped into the following areas: material goods, social life, use of leisure time, and health.

For evaluating the perception of patients' adaptation, we used *Karnofsky Performance Status Scale* (KPS) (Karnofsky & Burchenal, 1949). The KPS scale allows patients to be classified as to their functional impairment. The scale includes a list of 11 categories describing the level of physical ability, autonomy, and self-sufficiency. Patients are asked to choose a category that they identify with. The lower the KPS score, the worse the survival for most serious illnesses.

Self-informant (patients only) evaluation the QoL and adaptation: Patients QoL and adaptation was additionally evaluated by two other self-administered questionnaires.

Seville Quality of Life Questionnaire (SQoLQ) (Giner et al., 1995; Ibañez et al., 1997) was designed to evaluate patients with severe mental disorders. It consists of 59 items, Likert-ranked from 1 (completely disagree) to 5 (complete agreement), and is divided into two subscales: favourable (e.g. "I like the way I am") and unfavourable (e.g. "I feel very tired) aspects.

The *Social Adaptation Self-evaluation Scale* (SASS) (Bosc, Dubini, & Polin, 1997; adapted by Bobes et al., 1999) is a self-applicable measure of social functioning so that higher scores correspond with better social functioning. The scale consists of 21 items that explore respondents' performance in five areas: work, family, leisure, social relationships, and motivation. Each item is assessed with a Likert-type scale ranging from 0 (worst functioning) to 4 (best performance). A global score is computed by summing up all the items, and ranges from 0 to 60. The results are interpreted on the basis of following cut-off points: a score lower than 25 indicate social maladjustment, a score between 25 and 52 is interpreted as normal adjustment or normal range, and a score higher than 55 shows pathological "super" social adaptation.

Assessment of clinical symptoms: It was performed with two measures and was provided by the professional team.

The *Brief Psychiatric Rating Scale* (BPRS) (Overall & Gorham, 1962) provides information about the patient's symptoms. We used the 18-item version evaluating the symptom's severity on a 5-point Likert scale and where the value of 0 equals no symptoms and 4 equals the presence of symptoms in extreme degree. The BPRS address negative and positive symptoms. The total score ranges from 0 to 72.

The *Scale for Assessment of Negative Symptoms* (SANS) (Andreasen & Olsen, 1982) was developed as a description of negative symptoms in schizophrenia. This scale includes assessment of specific and global symptoms.

Disability was assessed as a percentage (for descriptive purposes) by an external medical council with International Classification of Functioning, Disability and Health (Querejeta, 2004). This generic scale evaluates the severity on five levels ranging from: no problem (0–4%), minor or scarce problem (5–24%), medium or moderate problem (25–49%), serious or extreme problem (50–95%), and complete or total problem (96–100%).

Statistical Analyses

First, we present descriptive statistics for the sample of patients related to their socio-demographic characteristics, clinical symptoms, and self-reported QoL as measured by SQoLQ and SASS. Further, the H1 concerning the SLDS and KPS score differences between the three types of informants (the patients, their families or educators, as well as those made by the team of professionals) was tested by statistical analysis of Kruskal-Wallis ANOVA, followed by post hoc U Mann-Whitney test. Finally, to test the H2 concerning the relationship between the clinical symptoms (BPRS and SANS) and QoL (both multi-informant and

self-informant only measures), we ran non-parametrical Spearman correlation analysis.

Results

Table 1 presents main characteristics of the patients. The average time of evolution of the disease was of 17.6 years ($SD = 9.71$). Sixty two percent of the sample was male. Ninety seven percent was assessed as disabled and were receiving a monthly annuity from the state. Regarding the external classification, the majority of our sample shows more than 50% of handicap with a maximum score of 68. Thirty seven percent were found to be professionally active in companies with protective employment policies.

The sample exhibited negative symptoms that were within the expected characteristics spectrum for this type of disorder. With a mean score of 10.60 ($SD = 3.02$) in the SANS scale; BPRS mean score of 5.97, ($SD = 2.77$). The BPRS positive clusters mean value was 5.20 ($SD = 3.98$).

As concerns to the self-reported QoL and adaptation in patients, measured with the SQoLQ and SASS, the results show patients' high to moderate life satisfaction and social adaptation. The scores for favorable aspects index of SQoLS pointed to a moderate perception of QoL ($M = 2.17$, $SD = .75$). The unfavorable aspects index scores exhibited the same pattern with mean score of 1.35 ($SD = .66$), thus, evidencing a low perception of these negative aspects of the QoL. Finally, the SASS scores ($M = 41.76$, $SD = 15.0$) showed that the group exhibited a moderate level of psychosocial adjustment, with 24% of the sample exhibiting lack of social adjustment, 48% normal adjustment, and 27.6% placing themselves on a "super" social adaptation level. Mean scores for SQoLQ and SASS scales are presented in Table 3 (together with correlations between clinical symptoms and QoL).

Multi-informant QoL and adaptation: ANOVA. The Kruskal-Wallis ANOVA results for life satisfaction measured with SLDS (total score) showed significant differences between different informants groups $\chi^2(2) = 14.97$, $p < .001$. Post hoc U Mann-Whitney test demonstrated that professional team, $M = 54.34$ assessed the patients' QoL significantly lower than the patients themselves, $M = 68.19$; $U = 227.5$, $Z = -3.82$, $p < .001$ and relatives / educators, $M = 63.12$; $U = 339.5$, $Z = -2.32$, $p = .020$.

Table 2 also contains the mean scores for satisfaction with specific life domains for each of the three types of informant. The evaluations of three informants groups differed significantly in reference to material goods, $\chi^2(2) = 9.200$, $p = .010$. For this dimension, the differences were statistically significant for professionals' evaluations $M = 4.48$ in comparison to

Table 1. Socio-demographic characteristics and clinical symptoms in the patients

	Male (N = 20)	Female (N = 12)	Total (N = 32)
Frequency (%)	62.5	37.5	
Age M (SD)	40.35 (11.24)	39.5 (7.98)	40.03 (10.01)
Marital Status (N)			
Single	15	11	26
Married	1	1	2
Separated / Divorced	2	–	2
Professional Status (N)			
active	8 (40%)	4 (34%)	12 (37%)
Disease evolution	18.58 (10.65)	15.82 (8.01)	17 (9.71)
Disability			
0 – 4%	10.5	9.1	10
25 – 49%	31.6	36.4	33.3
50 – 95%	57.9	54.5	56.7
SANS			
Total	10.31 (3.25)	11.09 (2.66)	10.60 (3.02)
Affective Flattening	2.05 (.91)	2.54 (1.25)	2.73 (.82)
Alogia	1.89 (.94)	1.82 (1.25)	1.87 (1.04)
Apathy	1.89 (1.05)	2.27 (.79)	2.03 (.96)
Anhedonia	2.58 (.90)	2.54 (.82)	2.57 (.86)
Attention	1.72 (.75)	1.82 (1.08)	1.76 (.87)
BPRS (Positive Cluster)	5.42 (3.89)	4.82 (4.28)	5.20 (3.98)
BPRS (Negative Cluster)	6.26 (2.51)	5.45 (3.24)	5.97 (2.77)

Note: Some data are missing.

Table 2. Kruskal-Wallis ANOVA: SLDS and KPS of the patient, the relative/ educator, and the professional team (N = 96)

	Patient		Relative / Educator		Professional Team		χ^2	df	p	Pairwise comparisons
	M	SD	M	SD	M	SD				
SLDS	68.19	15.13	63.12	15.82	54.34	9.22	14.97	2	<.001	<i>p, r, > pro</i>
Material Aspects	4.91	1.14	5.19	.957	4.48	.732	9.20	2	.010	<i>p, r, > pro</i>
Social Aspects	4.62	1.19	4.07	1.44	3.26	.98	16.91	2	<.001	<i>p, r, > pro</i>
Use of the time and Leisure	4.64	1.321	3.87	1.179	3.48	.807	13.28	2	<.001	<i>p > r, pro</i>
Health	4.37	1.66	3.44	1.24	2.91	1.20	15.99	2	<.001	<i>p > r, pro</i>
KPS	74.06	16.04	68.75	13.85	53.12	14.01	25.61	2	<.001	<i>p, r, > pro</i>

Note: Satisfaction with Life Domains Scale (SLDS); Karnofsky Performance Status Scale (KPS); *p* = patients; *r* = relatives / educators; *pro* = professionals.

and relatives / educators', $M = 5.19, U = 293.5, Z = -2.95, p = .003$, as well as patients' assessment, $M = 4.91, U = 352.5, Z = -2.16, p = .031$.

The assessment of satisfaction with social life also significantly differed between the informants, $\chi^2(2) = 16.91, p < .001$, with again professionals evaluating the patients QoL as lower in comparison to the other to informants (patients: $U = 201.0, Z = -4.18, p < .001$; relatives / educators: $U = 341.5, Z = -2.30, p = .022$). With regard

to the use of leisure time, the patient group scored the highest in this domain of life satisfaction (patient $M = 4.64$, family / educator: $M = 3.87$; professional team: $M = 3.48$), and these differences were significant between patients and both professional staff, $U = 245.5, Z = -3.59, p < .001$, and their relatives / educators, $U = 337.0, Z = -2.36, p = .018$.

In relation to satisfaction with health, the Kruskal-Wallis ANOVA results revealed statistically significant

differences, $\chi^2(2) = 15.99, p < .001$, being again significantly higher the evaluation of patients (vs for relatives / educators: $U = 327.5, Z = -2.54, p = .011$; vs professionals: $U = 237.0, Z = -3.76, p < .001$).

Physical Adaptation. There were also significant between-group differences in the perception of physical adaptation measured with KPS, $\chi^2(2) = 25.61, p < .001$. As it was in the case of SLDS, these statistically significant differences were found for professionals $M = 53.12$ when compared both with patients, $M = 72.06; U = 170.0, Z = -4.67, p < .001$, and family / educators, $M = 68.75; U = 223.0, Z = -3.95, p < .001$. In sum, the lowest scores on both scales were the evaluations made by the professional team, whereas the highest ones correspond the patients' self-perception (see Figures 1 and 2).

Finally, the correlation between the total scores for those scales, considering all participants as a total sample, was $Rho(96) = .37, p < .001$, which would confirm a degree of moderate consistency in the assessment of the patient's QoL in general terms and by all respondents.

Clinical symptoms and multi-informant QoL. The correlation analysis (KPS and SLDS scale) indicated

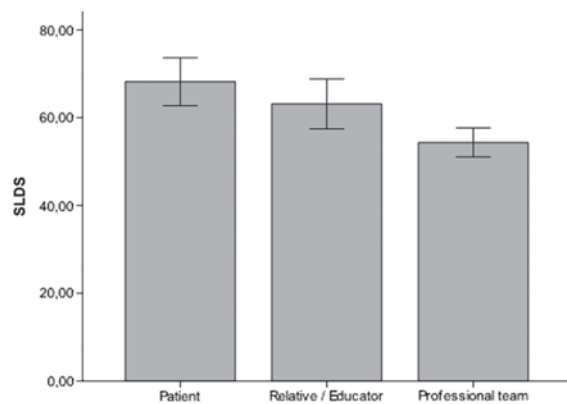


Figure 1. Means and standard errors (CI 95%) in satisfaction with life: patients, relatives / educators, and professionals.

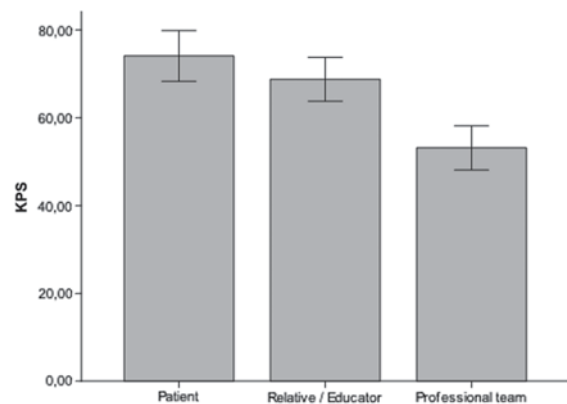


Figure 2. Means and standard errors (CI 95%) in physical adjustment: patients, relatives / educators, and professionals.

that in overall low deterioration was associated with higher QoL (see Table 3). Among patients, the higher was the QoL in material aspects, the lower global score in clinical symptoms, SANS: $Rho(30) = -.41, p < .05$, and specifically in the dimension of apathy, $Rho(30) = -.39, p < .05$. Yet, the more perceived QoL with their social life, the higher score in positive symptoms had the patients, BPRS: $Rho(30) = .36, p < .05$. As regards QoL related to the use of leisure and time, there was a negative significant relationship with anhedonia, $Rho(30) = -.40, p < .05$.

Among relatives or educators and professionals, higher performance was associated with less attention deficit in SANS scale, $r: Rho(30) = -.54, p < .05$; pro: $Rho(30) = -.53, p < .05$, but only with less clinical symptoms in overall among professionals, SANS: $Rho(30) = -.40, p < .05$. Paradoxically, among professionals better QoL in material aspects was associated with more anhedonia (and the correlation was positive for attention deficit). Similarly, professionals' perception of QoL in the use of leisure and time had a positive relationship with alogia and BPRS negative symptoms. Relative and educators in turn reported higher QoL in SLDS, the higher affective flattening they perceived in the patients. Nevertheless, these latter effects did not reach statistical significance.

Finally, the assessment of patients' QoL and adaptation measure with SQoLQ and with SASS did not show any statistically significant correlations with the clinical symptoms.

Discussion

This study was aimed at examining the complexity of the perception of QoL through the use of both subjective (SLDS) and objective (SQoLQ) measures and from a multi-informant approach. There were significant discrepancies among informants' reports. The evaluations made by caregivers and patients yielded similar results. Finally, the assessment provided by the professional team shows in overall a relationship between the increased clinical symptoms and poorer perception of QoL, indicating the importance of deficits caused by this kind of disease.

Unlike other studies, where the informants were the patients themselves, we found moderate to high QoL perception among the patients. The empirical evidence indicates that, as a general rule, patients who suffer from schizophrenia present QoL levels well below the values reported by patients with other mental and physical pathology (Heider et al., 2007; Pinikahana, Happel, Hope, & Keks, 2002). In our study, these scores were obtained with generic and specific measures, which may caused both by the process of adaptation to their living conditions that they have to face with,

Table 3. Spearman correlations: negative symptoms and quality of life

	KPS			SLDS			Material aspects			Social aspects			Use of leisure and time		
	p	r	pro	p	r	pro	p	r	pro	p	r	pro	p	r	pro
BPRS Positive Symptoms	-.07	.02	-.16	.27	-.05	-.10	-.17	-.13	-.05	.36*	-.06	.05	.15	-.01	.03
BPRS Negative Symptoms	-.07	-.25	-.02	-.21	.16	.01	-.16	.05	.11	-.11	.15	.15	-.08	.05	.31+
SANS Total	.01	-.08	-.40*	-.18	.21	-.15	-.41*	.05	-.01	-.12	.26	-.12	-.22	.19	.04
Affective Flattening	.04	.09	-.28	-.28	.32+	-.29	-.23	.20	-.09	-.29	.20	-.26	-.10	.31	-.18
Alogia	-.10	.08	-.25	.21	-.05	-.08	-.15	.05	-.19	.30+	.13	-.00	.11	.02	.34+
Apathy	-.19	-.15	-.27	-.29	.17	-.27	-.39*	-.06	-.26	-.26	.12	-.17	-.26	.09	-.14
Anhedonia	.25	.10	-.08	-.28	-.10	-.01	-.16	-.15	.33+	-.23	-.07	-.14	-.40*	-.03	-.03
Attention	.10	-.54**	-.53**	-.05	.26	.04	-.22	.16	.20	-.12	.29	.21	-.00	.14	.01

Note: Karmofsky Performance Status Scale (KPS) is from Karnofsky and Burchenal (1949); Satisfaction with Life Domains Scale (SLDS) is from Baker and Intagliata (1982); p = patients; r = relatives / educators; pro = professionals.

* $p < .05$; ** $p < .01$; + $p < .10$.

as well as by the lack of disease awareness and the possible deterioration in their ability to give judgments.

What is more, the application of multi-informant assessment has enabled us to compare the perception of QoL by the patients themselves, by their families (if they live with them) or by their educators (when they live in protected flats), and by the professional staff. The findings of this study show differences between the informants, both in the overall index and in the satisfaction with life domains. The professional team gives more negative evaluation in both cases. We can hypothesize such findings might reflect their more realistic perception with respect to the patients' abilities.

The patients exhibit a more positive perception of their QoL, reporting higher life satisfaction and physical performance compared to the clinical staff, whereas only higher life satisfaction in the use of leisure and time as well as health domain compared to their relatives and caregivers.

The evaluations of life satisfaction reported by the family and the educators fall between those given by the patients and these provided by the professional staff. The same occurs with regard to physical performance. The clinicians were less optimistic in their assessment than the patients and their relatives.

In relation to the dimension of use of free time, more positive assessments provided by patients could be understood in the following way: some behavior, both related to socialization and leisure, is perceived by the patients as normal, while is not commonly recognized and evaluated by the clinicians as socially adaptive.

Finally, as far as health dimension is concerned, the patients assess their satisfaction with this domain significantly better than do the rest of informants. We can infer that such finding has a strong link with the patients' lack of disease conscience. Many of them exhibited both psychological and physical co morbidity, and therefore their perception of QoL in health domain could be biased.

In light of the factors listed above, it would be interesting to further examine the quality of life in schizophrenic patients. Future research could lead to a change in the therapeutic approach for patients and their families, aiming at establishing more positive objectives. Guidelines for action and planning of social rehabilitation therapy of these patients could help in improving their quality of life.

We considered as a limitation of this study the lack of a measure of insight as this would help us to verify the presence of bias evaluating the satisfaction with the health.

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