

# Ten-Year Quality-of-Life Outcomes of Patients with Schizophrenia and Schizoaffective Disorders: The Relationship with Unmet Needs for Care

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## Abstract

**Purpose:** The present study examined the relationship between unmet needs and current as well as long-term quality of life (QOL) of patients with schizophrenia (SZ) and schizoaffective (SA) disorders. **Methods:** Ninety-five stable SZ/SA patients were evaluated using the Quality of Life Enjoyment and Life Satisfaction Questionnaire (Q-LES-Q), the Positive and Negative Syndrome Scale (PANSS), the Multidimensional Scale of Perceived Social Support (MSPSS), and the Coping Inventory for Stressful Situations (CISS). At the 10-year evaluation participants also completed the Camberwell Assessment of Need scale. Correlation and multivariate regression analyses were performed. **Results:** The number of unmet needs negatively correlated with Q-LES-Q domains; however, the predictive value for general quality of life did not reach significant levels controlling for MSPSS and CISS scores. Patterns of individual needs included assistance with psychological distress, daytime activities, welfare benefits, physical health, food, and intimate relationships, and emerged as significant predictors of current general QOL, even after controlling for PANSS, MSPSS, and CISS scores. Patients who had worsened and had dissatisfied courses of general QOL over time expressed many more unmet needs compared to those who were satisfied and had an improved course of QOL. Individual unmet needs concerning daytime activities, psychological distress, psychotic symptoms, information about treatment, company, and money were associated with worsened and dissatisfied general QOL outcomes. **Conclusions:** Unmet needs of SZ/SA patients show a strong relationship with prior long-term and current quality-of-life outcome. The pattern of individual unmet needs rather than the number of unmet needs had a greater predictive value for current subjective quality of life.

**Key Words:** Quality of Life, Schizophrenia, Schizoaffective Disorder, Unmet Needs

## Introduction

Although there is no universal operational definition of quality of life (QOL), most researchers agree that patients' statements regarding satisfaction with major life domains of daily functioning are relevant indicators of subjective QOL (1-10). In the past decades, remarkable attempts have been made to conceptualize health-related subjective QOL

constructs and related factors in severe mental health disorders, including schizophrenia (SZ) and schizoaffective (SA) disorders (7, 11-13). There is confirmed evidence that QOL impairment or deficit in SZ/SA disorders is associated with *illness-related factors* (e.g., depressive and negative symptoms) (1-3), antipsychotic-induced side effects (4-6), emotional and somatic distress (7, 8), anhedonia (9), and *psychosocial factors* such as coping styles, social support, and self-constructs (7, 10, 14, 15). These factors are integrated into the framework of the Distress/Protection Vulnerability Model, which postulates that: 1) QOL impairment is a core syndrome observed in severe mental disorders; 2) it is an outcome of the interaction between factors with distressing and putative protective effects; and, 3) satisfaction with QOL decreases if distressing factors outweigh protective factors, and increases if protective factors outweigh distressing factors (7, 16).

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### Clinical Implications

The main findings of this study extend previous works in this field and revealed that: 1) quality-of-life (QOL) outcomes demonstrate a strong relationship with different facets of unmet needs; 2) patterns of individual unmet needs have a greater predictive value on current subjective QOL deficits than number of illness and non-illness unmet needs; and, 3) individual unmet needs appear to be distinct from those associated with a worsening course of QOL in schizophrenia. These differences should be considered when evaluating QOL outcomes.

Since individual unmet needs appear to be quite sensitive to change over time (17), our research does not identify a causal link between needs and long-term QOL outcomes in schizophrenia and schizoaffective disorders. However, these findings may be useful for research and to improve the treatment of psychiatric patients. Specifically, given that needs show the strongest relationship with current and preceding long-term QOL outcomes, it can be concluded that unmet needs are important targets for treatments that aim to improve quality of life for individuals with schizophrenia and schizoaffective disorders.

Improving QOL is a key challenge when providing mental healthcare for people with severe mental illnesses. To accomplish this target, it is necessary to understand the particular relationship between mental health needs of patients and QOL outcomes over time. Currently, however, the interrelations between QOL deficit and mental healthcare needs are not fully understood. The relationship of unmet needs to QOL domains is especially relevant because of the variability of QOL across the course of SZ/SA disorders (13, 14). Few cross-sectional studies have indicated that poor subjective QOL was associated with high unmet needs among people with chronic SZ/SA disorders (17-25). In particular, unmet needs accounted for 20% of the variance for QOL, compared with 19% for clinical variables, and 7% for social variables of patients with severe mental illness (23). More specifically, a greater need for care and support in the areas of company, psychological distress, daytime activity and sexual expression was negatively associated with QOL levels controlling for the effect of symptomatology among 120 individuals with schizophrenia (18). The most frequently detected needs of 231 outpatients with schizophrenia who live in the community involved psychotic symptoms, house upkeep, food, and information (26).

The number of needs is associated with severity of psychopathology; in particular, with the disorganized and excited dimensions of the PANSS (27). When the complex longitudinal interrelations between baseline and 12-month outcome measures were evaluated using data from the European First Episode Schizophrenia Trial (n=498), four subtypes of patients with different courses of unmet needs were identified: three differed in their baseline levels of unmet needs and the fourth had a marked decrease in such needs (28, 29). Thus, although the association between QOL and unmet needs of SZ/SA disordered patients has been replicated in several studies, there is insufficient information about the association between unmet needs and long-term QOL outcomes.

In light of these data, we planned to evaluate whether there is a relationship between unmet needs for care and both the present and long-term QOL course (outcomes) among SZ/SA patients. This paper addresses the following research questions:

- 1) is there a substantial correlation between the number of illness and non-illness unmet needs and QOL domains?
- 2) what aspects of unmet needs (number of illness-related unmet needs, and non-illness related or personal unmet needs) have predictive value regarding the current general QOL level controlling for symptoms, perceived social support and coping styles?
- 3) how do patient subgroups with permanently worsened and dissatisfaction with the course of QOL across a 10-year period differ from patients who are permanently satisfied and have improved general QOL in terms of the present number and pattern of personal unmet needs?

This study sought answers to these questions by using data from the Sha'ar Menashe Longitudinal Quality of Life Study (initiated in 1998) (6, 7, 9, 13, 14, 30, 31).

### Method Study Design

This report is based on cross-sectional data with regard to subjective QOL and unmet needs of SZ/SA patients with defined 10-year QOL outcomes. All participants were asked to complete the Camberwell Assessment of Need scale (patient-rated short form; CANSAS-P) that was added to the set questionnaires for 10-year evaluation. A detailed description of the design, data collection, measures and cross-sectional QOL findings was reported elsewhere (7, 30, 31). Briefly, the initial sample was systematically selected from the hospital case register according to the following inclusion criteria: 1) fulfilment of *DSM-IV* criteria (32) for schizophrenia and schizoaffective disorder; 2) age 18–65; and, 3) inpatient status in closed, open or rehabilitation hospital departments of a

university hospital. Patients with mental retardation, organic brain disease, severe physical disorders (i.e., oncological disorders, stroke, epilepsy), drug/alcohol abuse, and those with low reading and writing comprehension skills were not enrolled. Patients that met the inclusion criteria were assessed prior to discharge from hospital (initial assessment), two and ten years later. The Sha'ar Menashe Internal Review Board and the Israel Ministry of Health approved the study. All participants provided written informed consent for participation in the study after receiving a comprehensive explanation of study procedures.

**Participants**

Of 108 outpatients who were assessed at the 10-year evaluation, 95 (88%) patients completed all 22 items of the CANSAS-P, while 13 patients (12%) left one or more items of the CANSAS-P unrated. The present report is based on a sample that included 95 subjects: 73 (76.8%) men, mean age 48.2±9.1 years (range: 30–69), 56 individuals (58.9%) were single, 20 (21.1%) were married, and the rest 19 (20.0%) were

divorced, separated or widowed. Mean extent of education was 10.4±2.3 years. Mean age of application for psychiatric care was 28.8±7.7 years, and mean duration of disorder was 25.1±9.2 years (range: 11–49). Among 95 patients in the sample, 55 (57.9%) presented with *DSM-IV* paranoid type of schizophrenia, 18 (18.9%) with residual type, 1 (1.1%) with disorganized type, 2 (2.1%) with undifferentiated type of schizophrenia, and 19 (20.0%) with schizoaffective disorder. Patients were treated with first-generation antipsychotic agents (FGAs, 51 patients), second-generation antipsychotics (SGAs, 21 patients), and with a combination of FGAs and SGAs (23 patients).

Over the 10-year period, four groups of patients with different general QOL outcomes were identified: 71 patients remained dissatisfied (n=60) or worsened (n=11) in general QOL, whereas 24 patients remained satisfied (n=9) or reported improvement (n=15) (14). Predictive values of disorder-related and psychosocial factors for ten-year QOL outcomes among 108 patients with schizophrenia and schizoaffective disorders were reported elsewhere (30, 31).

**Table 1** Characteristics of 95 Patients with Schizophrenia and Schizoaffective Disorders

| Dimensions                                   | Mean | SD   | Min | Max |
|--|------|------|-----|-----|
| Q-LES-Q domains (scores):                    |      |      |     |     |
| Physical health                              | 3.51 | 0.86 | 1.4 | 4.9 |
| Subjective feelings                          | 3.68 | 0.92 | 1   | 5   |
| Leisure time activities                      | 3.43 | 1.16 | 1   | 5   |
| Social relationships                         | 3.41 | 0.94 | 1.3 | 5   |
| General activities                           | 3.47 | 0.81 | 1.3 | 5   |
| Life satisfaction                            | 3.61 | 1.16 | 1   | 5   |
| Satisfaction with medicine                   | 3.69 | 1.14 | 1   | 5   |
| General quality of life (Q-LES-Q index)      | 3.53 | 0.75 | 1.5 | 4.9 |
| Total number of unmet needs (CANSAS-P)*      | 3.39 | 3.0  | 0   | 13  |
| - illness-related number of unmet needs      | 0.95 | 1.1  | 0   | 5   |
| - non-illness related number of unmet needs  | 2.44 | 2.0  | 0   | 9   |
| Symptom severity (PANSS total score)         | 77.1 | 17.3 | 38  | 161 |
| Perceived social support (MSPSS total score) | 55.6 | 18.5 | 12  | 84  |
| Coping abilities (CISS, scores):             |      |      |     |     |
| - task-oriented coping style                 | 55.1 | 17.2 | 4   | 80  |
| - emotion-oriented coping style              | 42.0 | 13.8 | 11  | 72  |
| - avoidance-oriented coping style            | 48.2 | 14.3 | 6   | 79  |

\*Mental illness-related (psychotic symptoms, psychological distress, treatment information, safety to self, safety to others, alcohol and drugs), and non-illness related needs (accommodation, food, looking after the home, self-care, daytime activities, physical health, company, intimate relationships, sexual expression, child care, basic education, telephone, transport, money, benefits).

**Table 2 Spearman’s Correlation Coefficients between the Number of Unmet Needs and Q-LES-Q Domain Scores**

| Quality of Life                                     | Illness-Related Unmet Needs | Non-Illness Related Unmet Needs | Total              |
|---|-----------------------------|---------------------------------|--------------------|
| Physical health                                     | -0.37 <sup>‡</sup>          | -0.33 <sup>‡</sup>              | -0.39 <sup>‡</sup> |
| Subjective feelings                                 | -0.44 <sup>‡</sup>          | -0.35 <sup>‡</sup>              | -0.44 <sup>‡</sup> |
| Leisure time activities                             | -0.45 <sup>‡</sup>          | -0.29 <sup>†</sup>              | -0.38 <sup>‡</sup> |
| Social relationships                                | -0.35 <sup>‡</sup>          | -0.30 <sup>†</sup>              | -0.37 <sup>‡</sup> |
| General activities                                  | -0.52 <sup>‡</sup>          | -0.46 <sup>‡</sup>              | -0.55 <sup>‡</sup> |
| Life satisfaction                                   | -0.29 <sup>†</sup>          | -0.21 <sup>*</sup>              | -0.26 <sup>†</sup> |
| Satisfaction with medicine                          | -0.45 <sup>‡</sup>          | -0.40 <sup>‡</sup>              | -0.46 <sup>‡</sup> |
| General quality of life (Q-LES-Q <sub>index</sub> ) | -0.55 <sup>‡</sup>          | -0.44 <sup>‡</sup>              | -0.55 <sup>‡</sup> |

\*p<0.05, †p<0.01, ‡p<0.001

### Assessments

Diagnosis was based on a face-to-face interview, medical records, and consensus between two senior psychiatrists.

Quality of Life Enjoyment and Life Satisfaction Questionnaire (Q-LES-Q) (33), a self-report instrument, was used to assess subjective quality of life. Responses are scored on a 1- to 5-point scale (1=“not at all or never” to 5=“frequently or all the time”), with higher scores indicating better enjoyment and satisfaction with specific life domains. Mean scores of seven domains and the general quality of life (measured with Q-LES-Q<sub>index</sub>) are presented as an average of the scores of the items. Internal consistency of these seven domains as measured by Cronbach’s  $\alpha$  coefficient ranged from 0.82 to 0.91.

Needs were assessed using the Camberwell Assessment of Need scale (34), patient-rated short form (CANSAS-P) (19, 35). The CANSAS-P assesses needs over the past month in 22 health and social items. The need rating for each item is 0=“no need” (no problems at all in the domain), 1=“met need” (no or moderate problems in the domain because of help received), or 2=“unmet need” (a serious problem, regardless of help provided). CANSAS-P relates to two groups of unmet needs (21): *mental illness-related* (psychotic symptoms, psychological distress, treatment information, safety to self, safety to others, alcohol and drugs), and *non-illness related needs* (accommodation, food, looking after the home, self-care, daytime activities, physical health, company, intimate relationships, sexual expression, child care, basic education, telephone, transport, money, benefits). The CANSAS-P exhibited comparable detection of needs with its predecessor, better identification of domains that are problematic for patients to respond to, good test-retest reliability, especially for unmet needs, and generally positive evaluations by patients

(36). For this sample, Cronbach’s  $\alpha$  coefficient was 0.83.

Severity of psychopathology was assessed using the 30-item Positive and Negative Syndrome Scale (PANSS), divided into positive, negative and general psychopathology subscales (37).

The Multidimensional Scale of Perceived Social Support (MSPSS) (38) was used as a measure of a social support. The MSPSS is a psychometric instrument used to assess emotional support and the degree of satisfaction with perceived social support from family, friends and significant others. For the present sample, MSPSS demonstrated high reliability (Cronbach’s  $\alpha=0.89$ ).

Coping was measured using the Coping Inventory for Stressful Situations (CISS) (39). This is a 48-item inventory assessing ways in which people react to various difficult, stressful, or upsetting situations. Responses are scored on a 5-point scale ranging from “not at all” to “very much.” Three basic coping styles are evaluated (each by 16 items): task-oriented, emotion-oriented and avoidance-oriented coping. For the present sample, internal consistency of the CISS dimensions was high (Cronbach’s coefficient  $\alpha=0.88, 0.86,$  and  $0.93,$  respectively).

### Statistical Analysis

Average scores of general and domain-specific Q-LES-Q and individual CANSAS-P needs, as well as the number of unmet needs, were used for statistical analyses.

First, Spearman’s correlation coefficients of the number of unmet needs with QOL domain scores, PANSS, MSPSS, and CISS scores were evaluated.

Second, illness and non-illness unmet needs were used as potential explanatory variables in regressions with the average Q-LES-Q<sub>index</sub> as the dependent variable. The models

**Table 3** Summary of Multiple Regressions to Predict General QOL Scores from Number of Unmet Needs Controlling for Severity of Symptoms, Perceived Social Support and Coping Styles Among 95 Patients with Schizophrenia and Schizoaffective Disorder (A Dependent Variable: Q-LES-Q<sub>index</sub>)

| Model | Independent Variables                | $\beta$ | Partial R <sup>2</sup> (%) | F   | p      | Significance                                    |
|-------|--------------------------------------|---------|----------------------------|-----|--------|---|
| 1     | Illness unmet needs (number)         | -0.39   | 10.5                       | 3.7 | <0.001 | R <sup>2</sup> =0.32, Adj. R <sup>2</sup> =0.28 |
|       | Non-illness unmet needs (number)     | -0.23   | 3.6                        | 2.2 | 0.033  | F=8.2, p<0.001                                  |
|       | PANSS positive subscale              | -0.03   | 0.0                        | 0.3 | n.s.   |   |
|       | PANSS negative subscale              | -0.05   | 0.0                        | 0.5 | n.s.   |   |
|       | PANSS general psychopathology        | 0.13    | 1.1                        | 1.2 | n.s.   |   |
| 2     | Illness unmet needs (number)         | -0.32   | 6.8                        | 3.1 | 0.002  | R <sup>2</sup> =0.44, Adj. R <sup>2</sup> =0.39 |
|       | Non-illness unmet needs (number)     | -0.11   | 0.7                        | 1.0 | n.s.   | F=10.6, p<0.001                                 |
|       | Perceived social support (MSPSS)     | 0.39    | 12.2                       | 4.2 | <0.001 |   |
| 3     | Illness unmet needs (number)         | -0.19   | 2.0                        | 1.9 | n.s.   | R <sup>2</sup> =0.57, Adj. R <sup>2</sup> =0.52 |
|       | Non-illness unmet needs (number)     | -0.01   | 0.0                        | 0.1 | n.s.   | F=11.2, p<0.001                                 |
|       | Perceived social support (MSPSS)     | 0.29    | 4.8                        | 2.9 | 0.005  |   |
|       | Emotion-oriented coping style (CISS) | -0.25   | 4.3                        | 2.7 | 0.008  |   |
|       | Task-oriented coping style (CISS)    | 0.38    | 7.3                        | 3.6 | <0.001 |   |

$\beta$  is a standardized regression coefficient. Partial R<sup>2</sup> reflects the percentage of variation in the Q-LES-Q<sub>index</sub> explained by each independent variable adjusted to the effects of rest independent variables. Models 2 and 3: non-significant PANSS subscales are not presented. PANSS=the Positive and Negative Syndrome Scale; MSPSS=the Multidimensional Scale of Perceived Social Support; CISS=the Coping Inventory for Stressful Situations; n.s.=non-significant.

were refitted controlling for severity of symptoms (PANSS subscale scores), PANSS subscale scores + perceived social support (MSPSS total score), and PANSS subscale scores + MSPSS + three CISS coping styles (models 1–3).

Third, in order to determine the cross-sectional association between individual types of needs and general QOL deficit, raw scores of CANSAS-P items (independent variables) and Q-LES-Q<sub>index</sub> (dependent variable) were used for regression analysis. This multiple regression analysis was carried out with stepwise backward selection procedure in order to reduce the number of CANSAS-P items to a much smaller number of significant predictors. The obtained set of independent variables was also refitted controlling for PANSS, MSPSS and CISS scores (models 4 and 5).

Fourth, an analysis of variance (ANOVA) with Tukey-Kramer multiple-comparison test was applied in order to compare patient groups with worsened, permanently dissatisfied, satisfied and improved QOL outcomes over the follow-up period with regard to the present unmet needs.

Mean values with standard deviation (SD) are presented. Differences in the frequency of categorical variables were

examined with the  $\chi^2$  test. For all analyses, the level of statistical significance was defined as p<0.05. Statistical analyses were performed using the Number Cruncher Statistical Systems (40).

## Results

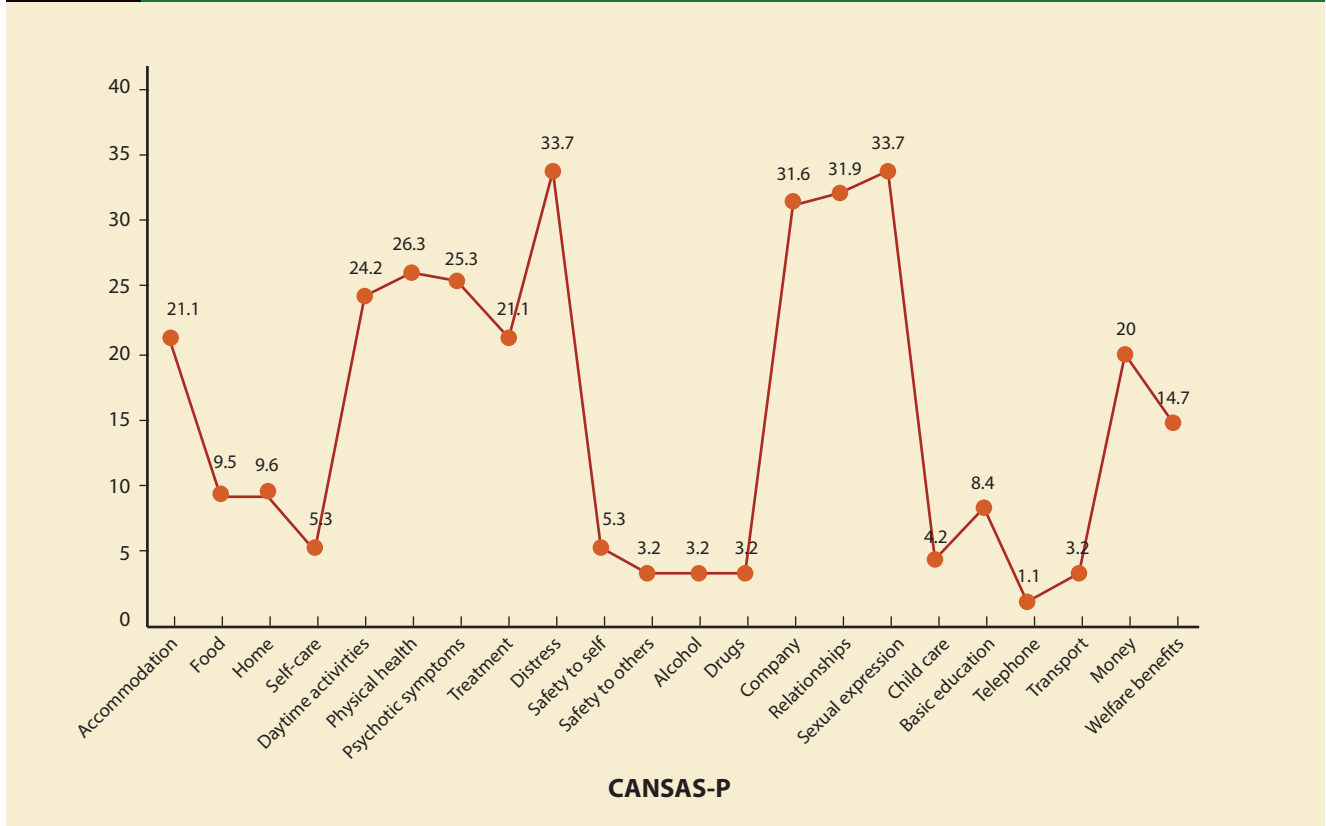
Table 1 describes quality of life, the total number of needs and clinical data for the 95 patients. Since differences between patients with SZ and SA disorders in mean scores of both the Q-LES-Q dimensions and the CANSAS-P items did not reach significant levels (all p>0.05), SZ and SA disordered patients were combined for the following analyses.

### General and Domain-Specific Quality of Life

#### Number of Unmet Needs

The mean number of met and unmet needs identified per patient was 7.29±4.8; among them unmet needs was 3.39±2.9. From the correlation matrix shown in Table 2, we see that the number of illness and non-illness unmet

**Figure 1** Profile of Unmet Needs of 95 Patients with Schizophrenia and Schizoaffective Disorder



needs negatively correlated with current QOL domain scores ( $r$  ranged from  $-0.21, p < 0.05$  to  $-0.55, p < 0.001$ ). The number of unmet needs positively correlated with PANSS total score ( $r = 0.30, p < 0.01$ ) and emotion-oriented coping style ( $r = 0.38, p < 0.001$ ), was negatively associated with task-oriented coping style ( $r = -0.37, p < 0.001$ ) and perceived social support ( $r = -0.42, p < 0.001$ ), and was not associated with avoidance-oriented coping style ( $r = -0.17, p > 0.05$ ).

To estimate the contribution of the number of unmet needs to the prediction of the general QOL score (dependent variable), a series of stepwise regression analyses was conducted (see Table 3). In the first model, the number of both illness and non-illness unmet needs together with the PANSS subscale scores accounted for 32% of the variance in perceived QOL index scores (14.1% were explained by unmet needs alone). In the second model, illness unmet needs and social support accounted for 6.8% and 12.2%, respectively, of the variance, while the number of non-illness unmet needs lost predictive value. Finally, the third model that best fit the data explained 57% of the variance, but the number of both illness and non-illness unmet needs lost their predictive values. In the latter, 16.4% of QOL variance was explained by social support (4.8%) and coping styles (11.6%). Predictive values of the PANSS subscale scores did not reach significant levels in these models.

### Individual Unmet Needs

The most common areas of unmet needs were psychological distress (33.7%) and psychotic symptoms (25.3%), sexual expression (33.7%), intimate relationships (31.9%), company (31.6%), physical health (26.3%), daytime activities (24.2%), information on condition and treatment (21.1%), accommodations (21.1%), and money (20%) (see Figure 1).

Table 4 summarizes multiple regression analyses to predict Q-LES-Q<sub>index</sub> scores from CANSAS-P individual needs. Regression model 4 revealed five negative predictors (welfare benefits, information on condition and treatment, daytime activities, physical health and psychological distress), while two positive predictors (food and intimate relationships) negatively associated with QOL deficit. This regression model explained 49% of the variance in general subjective QOL. Six predictors remained significant (except information on condition and treatment) when the confounding effect of symptom severity, perceived social support and coping styles was controlled (model 5). In addition, emotion-oriented coping style negatively correlated with task-oriented coping style, and perceived social support positively associated with general QOL deficit. Other CANSAS-P items, PANSS scores, and avoidance-oriented coping style did not reach significant levels in predicting general QOL.

**Table 4** Summary of Multiple Regressions to Predict General QOL Scores from Specific CANSAS-P Needs Controlling for Severity of Symptoms, Perceived Social Support and Coping Styles Among 95 Patients with Schizophrenia and Schizoaffective Disorder (A Dependent Variable: Q-LES-Q<sub>index</sub>)

| Model | Independent Variables                  | β     | Partial R <sup>2</sup> (%) | F    | p      | Significance              |
|-------|--|-------|----------------------------|------|--------|---------------------------|
| 4     | Welfare benefits                       | -0.28 | 13.8                       | 13.7 | <0.001 | Adj. R <sup>2</sup> =0.49 |
|       | Treatment*                             | -0.22 | 8.5                        | 8.0  | 0.006  | F=14.0, p<0.001           |
|       | Daytime activities                     | -0.29 | 10.6                       | 10.2 | 0.002  |                           |
|       | Food                                   | 0.27  | 9.9                        | 9.4  | 0.003  |                           |
|       | Intimate relationships                 | 0.18  | 5.8                        | 5.3  | 0.023  |                           |
|       | Physical health                        | -0.18 | 5.7                        | 5.2  | 0.025  |                           |
|       | Psychological distress                 | -0.38 | 17.0                       | 17.6 | <0.001 |                           |
| 5     | Welfare benefits                       | -0.14 | 5.7                        | 4.3  | 0.041  | Adj. R <sup>2</sup> =0.66 |
|       | Treatment*                             | -0.07 | 1.2                        | 0.8  | n.s.   | F=14.0, p<0.001           |
|       | Daytime activities                     | -0.19 | 6.5                        | 4.9  | 0.029  |                           |
|       | Food                                   | 0.24  | 11.2                       | 8.9  | 0.003  |                           |
|       | Intimate relationships                 | 0.22  | 10.9                       | 8.7  | 0.004  |                           |
|       | Physical health                        | -0.17 | 7.6                        | 5.8  | 0.018  |                           |
|       | Psychological distress                 | -0.26 | 11.8                       | 9.4  | 0.003  |                           |
|       | Perceived social support (MSPSS)       | 0.25  | 10.8                       | 8.5  | 0.004  |                           |
|       | Task-oriented coping style (CISS)      | 0.25  | 9.7                        | 7.6  | 0.007  |                           |
|       | Emotion-oriented coping style (CISS)   | -0.23 | 11.4                       | 9.1  | 0.003  |                           |
|       | Avoidance-oriented coping style (CISS) | 0.01  | 0.01                       | 0.0  | n.s.   |                           |
|       | Symptom severity (PANSS)               | -0.10 | 2.8                        | 2.0  | n.s.   |                           |

\*Information on condition and treatment. β is a standardized regression coefficient. Partial R<sup>2</sup> reflects the percentage of variation in the Q-LES-Q<sub>index</sub> explained by each independent variable adjusted to the effects of rest independent variables. PANSS=the Positive and Negative Syndrome Scale; MSPSS=the Multidimensional Scale of Perceived Social Support; CISS=the Coping Inventory for Stressful Situations.

## Long-Term General Quality-of-Life Outcomes

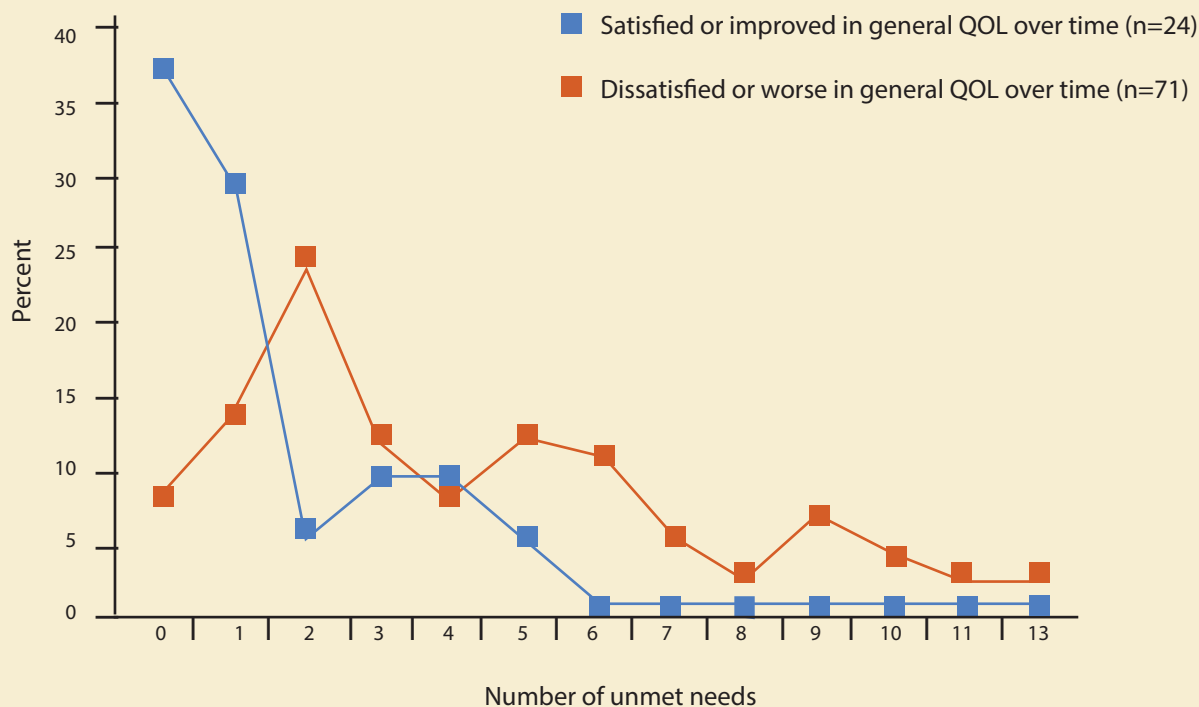
### Number of Unmet Needs

Figure 2 presents the distribution of patients who were dissatisfied or who had worsened versus those who were satisfied or improved in general QOL outcomes by number of unmet needs. Patients who had permanently worsened (5.7±3.7) and were dissatisfied (3.6±2.7) with general quality of life over time had a significantly higher number of unmet needs than patients who were permanently satisfied (2.1±2.8) and improved (1.7±2.2) over the study period (F=5.2, df=3,95, p=0.002).

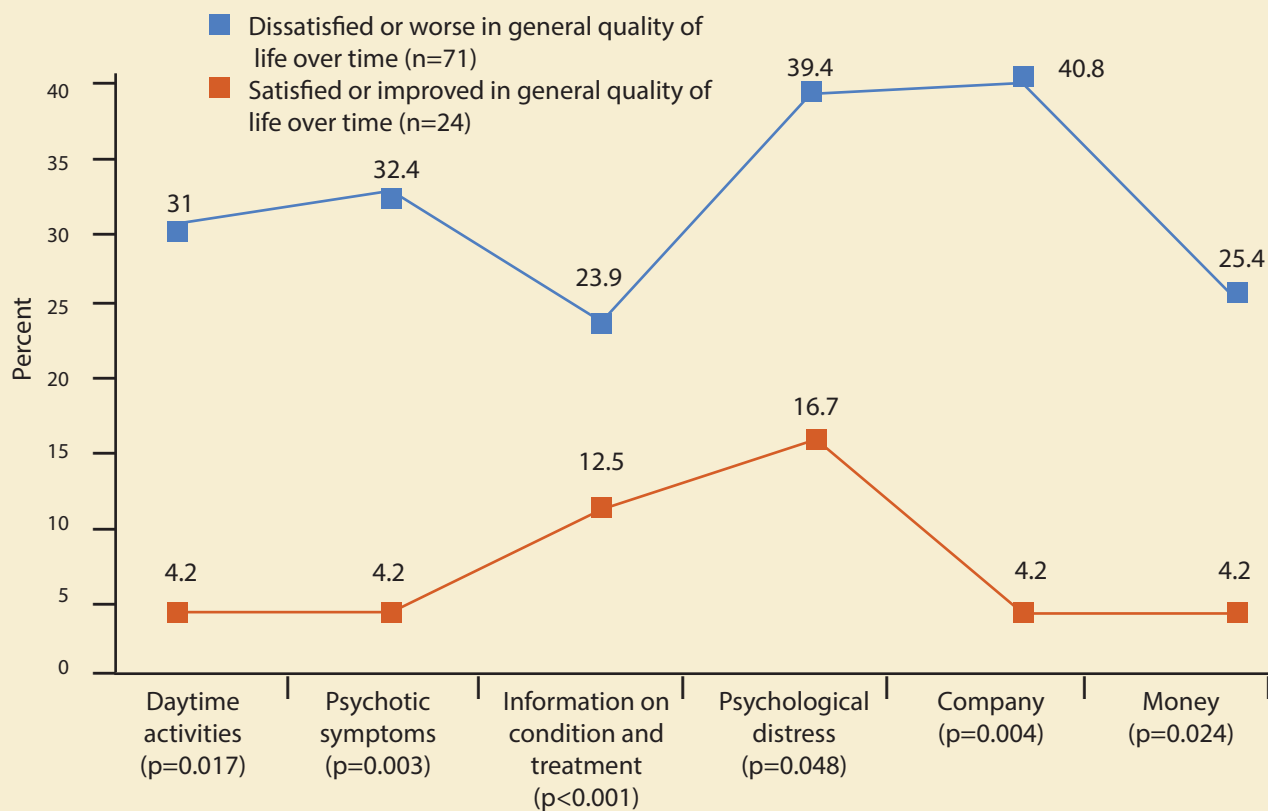
### Individual Unmet Needs

Figure 3 shows a higher frequency (24–41%) of patients with six unmet needs among patients with dissatisfied or worsened QOL outcomes compared to those who were satisfied or who revealed improvement (4–17%) in general QOL over time (df=2): daytime activities (χ<sup>2</sup>=8.1, p=0.017), psychotic symptoms (χ<sup>2</sup>=12.0, p=0.003), information on condition and treatment (χ<sup>2</sup>=17.5, p<0.001), psychological distress (χ<sup>2</sup>=6.1, p=0.048), company (χ<sup>2</sup>=11.2, p=0.004), and money (χ<sup>2</sup>=7.4, p=0.024). Differences in other healthy needs did not associate with the course of quality of life over time (all p's >0.05).

**Figure 2** Distribution of Patients with Different Course of General Quality of Life over Time by Number of Unmet Needs



**Figure 3** Frequency of Patients with Unmet Needs by Course of General Quality of Life over 10-Year Period





## Discussion

The assumption in this study was that there is a significant association of patient-rated unmet needs of care with both current QOL and long-term QOL outcomes in a sample of patients with SZ/SA disorders. To explore this assumed correlation, multiple regression analyses were conducted.

Results from this study show that—consistent with previous studies (34, 43, 44)—the mean number of needs in the present study was  $7.29 \pm 4.8$ . Descriptive findings suggest that the areas with the highest proportion of unmet needs (from 20% to 34%) were psychological distress and psychotic symptoms, sexual expression, intimate relationships, company, physical health, daytime activities, information on condition and treatment, accommodations, and money. These findings seem in line with previous studies of patients with schizophrenia and related disorders (26, 41, 42). Overall, our patients were significantly less satisfied with general and domain-specific QOL compared with healthy subjects at the initial assessment (7) and after the 10-year period (14). The 10-year QOL outcomes were characterized as satisfied, improved, dissatisfied and worsened (14, 31).

Since SZ and SA disordered patients had similar ratings on Q-LES-Q and CANSAS-P items, we combined these subgroups for analyses. We addressed three specific questions:

*The first research question* addressed a substantial correlation between the number of illness and non-illness unmet needs and QOL domains. The present study showed that the number of illness and non-illness unmet needs had a strong negative correlation with all domains of Q-LES-Q ( $r$  ranged from  $-0.21$  to  $-0.55$ ), which extends previous work involving cross-sectional data (18-21, 24, 25).

*The second research question* addressed the needs for care as predictors that accounted for variability of the present general quality of life. In order to answer this question, multiple regression analysis was carried out with the number of illness and non-illness needs, and individual needs (CANSAS-P items) controlling for symptoms, perceived social support and coping styles (PANSS, MSPSS, CISS scores, respectively). The obtained regression models suggest that:

a) although the number of illness and non-illness unmet needs showed significant predictive value regarding general quality of life, they lost significance after controlling for perceived social support and coping styles. This finding suggests that perceived social support and coping styles may moderate the correlation between the number of unmet needs and general QOL.

b) individual needs such as lack of assistance with psychological distress, daytime activities, welfare benefits, and physical health emerged as significant negative predictors, while food and intimate relationships emerged as significant positive predictors of satisfaction with general quality of life.

Regression analysis indicated that these individual unmet needs are important contributors to the quality-of-life outcomes of SZ/SA disordered patients, even after controlling for symptoms, social support and coping styles. This suggestion seems in line with findings that showed consistent relationships of MSPSS and CISS scores with quality of life of individuals with schizophrenia (7, 31) and their need for care (17, 18, 28).

*The third research question* addressed the possible association of the present unmet needs with the preceding course of general quality of life over a 10-year period. In order to answer this question, patient groups with worsened, dissatisfied, satisfied and improved QOL outcomes over time were compared with respect to their present unmet needs, in terms of both number and individual needs. This study revealed that patients who had permanently worsened and had a dissatisfied course of general quality of life over time expressed many more unmet needs than those who were permanently satisfied and had an improved course of QOL. Among individual unmet needs, daytime activities, psychological distress, psychotic symptoms, information on treatment, company, and money were associated with worsened and dissatisfied long-term general quality-of-life outcomes.

Although unmet needs appear to be an important factor in the quality-of-life outcomes in SZ/SA disorders, the relationship between them is not defined as causal. However, Slade et al. (45) concluded that changes in patient-rated unmet needs may cause changes in quality of life. They asked 101 individuals who received adult mental health services to complete six monthly questionnaires, including quality of life measured with the Manchester Short Assessment of Quality of Life and unmet needs using CANSAS. Random effects regression models indicated an impact on current quality of life for average levels of unmet needs ( $\beta = -0.23$ ), but meeting unmet needs had only a negligible effect ( $\beta = -0.04$ ) on QOL. This suggests that unmet needs do not cause changes in QOL and that the relationship between the two may be associated with other factors that cause both (46). The relationship between satisfaction with QOL among patients with SZ/SA and unmet needs may be understood in the framework of the Distress/Protection Vulnerability model (7, 47). Primary factors such as harm avoidance, high levels of neuroticism, poor coping skills, elevated emotional distress, emotion-oriented coping, and weak self-constructs (16, 47-49) might lower the vulnerability threshold and, consequently, result in severe QOL impairment. In this conceptual model, unmet needs might be defined as a factor with harmful effect on satisfaction with general and domain-specific QOL. The present findings support the view that the relationship between unmet needs and QOL outcomes is influenced by confounding factors such as perceived social support and coping styles.

Future research should investigate whether changes in the QOL deficit over a long-term period are associated with current needs.

The present study has a number of limitations that need to be recognized and addressed in future studies. First, it is important to note that acutely psychotic patients were unable or refused to participate in the study. Patients with mental retardation, organic brain disease, severe physical disorders (i.e., oncological disorders, stroke, epilepsy), drug/alcohol abuse, and those with low reading and writing comprehension skills were not enrolled. Consequently, exclusion of these patient groups affects the generalizability of our study. Second, it should be recognized that the results of the present study might apply only to adult (30–69 years old) individuals with chronic schizophrenia and schizoaffective disorders (illness duration: 11–49 years) who tend to be more treatment compliant and more cooperative patients. The third limitation is common for most studies using self-report methodology for investigating mental health needs and QOL in severely ill psychiatric patients. Next, analysis of some life events such as traumas, severe life events, relapses, rehospitalizations, suicides, etc. observed for a long-term course of disorder was not within the scope of the present study. Finally, the cross-sectional design of this study cannot establish the direction of causality among the variables assessed. Despite these limitations, results suggest that future studies should examine the relationship of unmet needs with the quality-of-life deficit among younger (prodromal, first-episode) patients with severe mental disorders.

Taken together, the main findings of this study extend previous works in this field and revealed that: 1) quality-of-life outcomes demonstrate a strong relationship with different facets of unmet needs; 2) patterns of individual unmet needs have a greater predictive value on current subjective QOL deficits than number of illness and non-illness unmet needs; and, 3) individual unmet needs appear to be distinct from those associated with a worsening course of QOL in schizophrenia. These differences should be considered when evaluating QOL outcomes.

Since individual unmet needs appear to be quite sensitive to change over time (17), our research does not identify a causal link between needs and long-term QOL outcomes in SZ/SA disorders. However, these findings may be useful for research and to improve the treatment of psychiatric patients. Specifically, given that needs show the strongest relationship with current and preceding long-term QOL outcomes, it can be concluded that unmet needs are important targets for treatments that aim to improve quality of life for individuals with SZ/SA disorders.

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