## **ORIGINAL PAPER**

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# Structure of needs among persons with schizophrenia

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■ **Abstract** Background The importance of needs assessment for service development has been widely recognised. Several studies have focused on the associations between ratings of needs by patients and staff and have found clear differences, especially concerning the unmet needs. Methods The present study is part of a Nordic Multicentre study that investigates the life and care of outpatients with a schizophrenia group illness in all the Nordic countries. The aim of this paper is to study the patterns of needs as identified by patients and staff according to the Camberwell Assessment of Needs

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(CAN). Quality of life, level of functioning, and psychiatric symptoms were assessed. Results The sample includes 300 patients, 194 (65%) men and 106 (35%) women. The factor analysis identified five factors for patients and four factors for staff in the questionnaire on ratings of needs. In four of the five patient-related factors a meaningful interpretation was possible, and the factors were named skills, illness, coping, and substance abuse. The staff-related factors were named skills, impairment, symptom, and substance abuse. There were significant associations between the sum scores constructed from the factors and measures of functioning level and symptoms. Conclusions It seems that the sum factor reflecting secondary needs was the most important of the identified factors among both patient and staff ratings. The item-by-item comparisons in previous studies have emphasised differences between patient and staff ratings, but our analysis of the structure of needs also found similarities in the structures and in the associations between the identified sum scores and measures of symptoms, functioning level, and quality of life.

■ **Key words** schizophrenia – community – needs assessment – cross-sectional – quality of life

## Introduction

The importance of needs assessment for service development has been widely recognised [1]. Assessment of specific treatment needs and a wide range of other special needs is at the heart of choices among treatments at individual level, and planning at service level. To achieve a valid assessment of needs, a consensus is needed on what constitutes a need, and on when and how to address it. Need is a complex concept, and it has even been argued that a sound theory of needs is lacking [2]. Needs are dynamic in nature and are influenced by contextual factors. The evaluation of need also depends on who makes the assessment.

Bradshaw [3] presented a sociological perspective on the concept of need, identifying four different types of need: 1) normative need (need identified by experts), 2) perceived need (experienced need, "what people really want"), 3) expressed need (demand, a perceived need on which action is taken), and 4) comparative need (a need identified by considering people already receiving the service they are in need of). The WHO's Illness, Disability and Handicap (IDH) classification of consequences of disease and injury has also been applied to classify mental health needs into three levels. The primary needs are associated with psychopathology or impairment, the secondary needs are due to disabilities involving the restrictions on personal activities that may be directly caused by the impairment, and the tertiary needs deal with the social consequences of the illnesses, handicaps affecting an individual's interaction with the environment [4]. Psychiatric disorders are, thus, associated with a wide range of needs in the social and personal domains that are not as such covered by "need for care", although these domains are highly pertinent for people living with mental disorders.

Several studies [5–8] have identified clear differences between ratings of unmet needs by patients and staff using the Camberwell Assessment of Needs (CAN) [9]. Most of these have found significant differences especially concerning the unmet needs. Wiersma et al. compared the assessment of needs according to the objective measurement of Need for Care Assessment (NFCAS) and the subjective measurement of CAN [6]. The researchers found no meaningful associations between the two measures. Phelan et al. [9] have provided evidence of the validity of the CAN concerning its face, consensual, and content validity.

However, the lack of objective external criteria made it difficult to establish concurrent validity. Individual items were compared with the total Global Assessment of Functioning (GAF) disability rating, but the correlations they found were weak. Phelan et al. [9] found that there was a complex interaction between service provision, disability, and needs. An aggregated score of seven domains pertinent to GAF had a significant negative correlation with disability.

The present study is part of a Nordic Multicentre study investigating the life and care of schizophrenic outpatients in all the Nordic countries. The study was conducted in the centres that were originally involved in planning the whole project and, thus, the centres were selected on the basis of interest. There were altogether ten centres: in Denmark (Copenhagen NW, Roskilde and Aarhus), Sweden (Malmö NE, Malmö W, Umeå, Landskrona), Norway (Bodø), Finland (Turku) and Iceland (Reykjavik). The centres were municipalities with an urban and some also with a rural population. In addition, most of the cities had a university. The characteristics of the participating centres are described in two previous reports of the study [10, 11].

The aim of this paper is to study the structure of needs as identified by patients and staff according to the Camberwell Assessment of Needs (CAN). The needs identified by patients themselves are expressions of perceived needs, whereas the needs identified by the staff are expressions of normative needs. We hypothesise that the patterns of needs expressed by patients and staff reflect a varying structure of needs. Moreover, we further contrast the analysis of the structure of needs with the WHO's Illness, Disability and Handicap (IDH) classification of consequences of disease and injury to probe the feasibility of the classification as a model for categorising mental health needs, and to provide a framework for understanding the previously observed differences between ratings of needs by patients themselves and staff, or between "objective" and "subjective" ratings of needs. We also test for possible associations between the structure of needs, identified according to our analysis, and clinical symptom measures, level of functioning, quality of life, age, age at onset, and duration of illness.

Previous work on the needs ratings by the CAN [11, 12] has investigated needs as nominal, i. e. distinct constructs consisting of named categories with no implication of order. This earlier approach is, of course, meaningful if one compares item-by-item patient and key worker ratings of needs. Thus, met and unmet needs have been analysed separately, although an unmet need implies more need than a met need, lending support to the idea that CAN ratings can be studied as ordinal variables. The assessment of no needs, met and unmet needs is done by the interviewer in one session when he/she identifies a need for an intervention in a particular domain, and considers whether adequate treatment has been given or not. There is a risk of losing information if the factor analyses of met and unmet needs are conducted separately, as we were interested in studying whether there is an identifiable structure to the relationships among the domains in the needs assessed by the CAN. This means that we set out to seek whether the pattern of needs identified could be explained by a small number of underlying constructs, and whether these constructs resemble the IDH classification of needs.

## Subjects and methods

The study had a cross-sectional design with outpatients with schizophrenia in all the five Nordic countries participating. Inclusion criteria were: 1) a diagnosis of schizophrenia according to the ICD-10 (diagnoses set for clinical purposes by the psychiatrist in charge), 2) a minimum duration of 1 year since the diagnosis was made, 3) age between 20 and 55 years at the time of inclusion in the study, 4) at least one contact with the psychiatric outpatient services during the 12-month period preceding inclusion (day hospitals and psychiatric daycare units were regarded as outpatient facilities), and 5) non-institutional living situation (defined as less than 24-h staffing).

Patients who fulfilled the criteria were identified by means of local outpatient registers, and interviewed by a member of the research team. Informed written consent on the part of the patient was required. From each centre a representative sample of patients was recruited. The intention to include a minimum of 40 patients from each centre was not reached due to the restricted number of eligible patients or the unwillingness of patients to participate in the study. Altogether, 765 patients were approached and the final sample com-

prised 418 patients. The distribution of patients between the centres was as follows: Turku n=38, Copenhagen n=37, Roskilde n=20, Aarhus=43, Malmö NE n=76, Malmö W n=68, Umeå=33, Landskrona n=40, Bodø n=33 and Reykjavik n=30. Thus, the dropout rate was 55%, with a variation between the centres of 33–100%. No information was collected from patients declining participation because informed consent procedure prevented any detailed drop-out analysis. Patient needs ratings were available for all 418 patients, but the key worker assessments were not available from two centres (Malmö W and Umeå), and in addition, 17 key worker assessments were missing from the other centres. Altogether, 300 key worker assessments were available for the analyses. In this paper, we report the analyses of those CAN ratings that included assessments by both the staff and the patients, i.e. n=300.

#### Measures

The needs of the patients were assessed using the Camberwell Assessment of Needs (CAN) interview [9]. The CAN includes assessments of needs in 22 domains by the patient and key worker. Each domain comprises four sections. The first section in each domain establishes whether there is a need by asking about difficulties in that particular area. The needs are rated on a three-point scale: 0 = no serious problem (no need); 1 = no serious or moderate problem because of continuing intervention (met need); 2 = current serious problem irrespective of any ongoing intervention (unmet need). The second section asks about help received from friends, relatives and other informal carers. The third section asks about how much help the person is receiving, and how much help the person needs from professional services. A two-step scale, 0 = no and 1 = yes, is used to assess whether the patient is getting the right type of help for the problem. The research version 2 of the CAN instrument, translated into Swedish, Danish, Norwegian, and Finnish, was used. Professional help is defined here as formal help, and help from friends and next-of-kin as informal help.

Quality of life (QOL) was measured using the Lancashire Quality of Life Profile (LQOLP) [12]. The LQOLP assesses the objective life situation of the patient (objective quality of life: how things really are) and subjective life satisfaction (subjective quality of life: how do you feel about this?) in nine domains of life: work; leisure; religion; finances; living situation; safety; family relations; social relations; and health. The interview yields an overall perceived QOL score, and includes a global well-being item. In addition, the interviewer assesses the global QOL of the patient using a visual analogue scale (VAS). The interviewer makes a choice according to the specific instructions given in the LQOLP between the worst possible and the best possible quality of life. Objective life situation and personal characteristics are measured using categorical or continuous variables. Subjective QOL is rated using a seven-point Likert-type scale. The LQOLP has been found to be a reliable and valid measure of QOL among psychiatric patients [13]. Symptoms were rated using the Brief Psychiatric Rating Scale (BPRS) [14]. Psychosocial functioning was assessed using the Global Assessment of Functioning (GAF) scale [15]. A number of social and clinical background variables were also collected.

## Statistical analysis

The SAS System for Windows software package, version 8.02, was used to compute the statistical analyses. Exploratory factor analysis with promax rotation was used to study structure of needs. The sample correlation matrix used in factor analysis was computed using polychoric correlations, because the needs were measured on an ordinal scale. For further analysis, the sum scores were constructed by summing the items (no need = 0, met need = 1 or unmet need = 2) of the factor divided by the total number of items in that factor. The associations between these sum scores and a symptom measure (BPRS), perceived and interviewer-assessed QOL according to the LQOLP, a measure of functioning level (GAF), age, age at first admission and duration of illness were calculated using Spearman rank-order correlations. Duration of illness was measured using age at first admission

as the starting point for the illness. The differences in the sum scores between centres and subtypes of schizophrenia were evaluated using the Kruskal-Wallis test, and the differences between the sexes using the Mann-Whitney U test. P-values less than 0.05 were considered statistically significant.

## Results

The sample included 300 patients, 194 men (65%) and 106 women (35%). The mean age at first admission was 24 years (SD 7.0), at the time of the interview 38 years (SD 8.8), and at the time of termination of education 19 years (SD 5.2). Of the patients, 49 % had been given a diagnosis of paranoid schizophrenia. The other diagnostic subgroups were rather small, as simple schizophrenia had a prevalence of 9%, both hebephrenia and undifferentiated schizophrenia had a prevalence of 8%, and other schizophrenias altogether accounted for 16%. The majority of the patients were not married (78%), were living alone (56%), and had no children (78%). The mean GAF score of the patients was 49 (SD 14.3) and the mean BPRS score 33 (SD 9.7). Details of the sample and psychiatric treatment system have been given elsewhere [10, 11].

The factor analysis identified five factors among CAN needs ratings by patients (Table 1) and four factors among CAN needs ratings by staff (Table 2) with an eigenvalue greater than one. There were some differences between the patient and staff ratings as to which items loaded on these factors in our analyses, and this is reflected in how we named these factors. The patient-related factors were named skills, illness, coping, and substance abuse. Only two items had the greatest loadings on the fifth factor and no meaningful interpretation of this factor was available, so factor five was excluded from further analyses. The staff-related factors were named skills, impairment, symptom and substance abuse. The skills factor identified, in both patient and staff ratings, was the most prominent factor discovered in the analysis.

There were significant associations between the sum scores constructed from the identified factors and measures of functioning level and symptoms (see Tables 3 and 4). The duration of illness was not significantly correlated with any of the sum scores in either patient or staff ratings of needs. We found no association between the subtype of schizophrenia and any of the sum scores whether rated by patients or staff. There were no significant differences between the sexes regarding the sum scores in the factor analysis of patients.

Regarding the staff ratings, there was a significant difference in the skills sum score between men [mean 0.43 (SD 0.41), median 0.40] and women [mean 0.25 (SD 0.33), median 0.10] (Mann-Whitney U test, p < 0.001), and a significant difference in the substance abuse sum score between men [mean 0.26 (SD 0.32), median 0.20] and women [mean 0.20 (SD 0.33), median 0.00] (Mann-Whitney U test, p = 0.02). The staff ratings in CAN also varied significantly among the centres concerning im-

**Table 1** Factor loadings after Promax rotation for patient ratings of needs according to CAN in factor analysis

Item	Skills	Illness	Coping	Substance abuse	NI
Food problem	0.86	0.01	-0.03	-0.21	0.11
Home problem	0.70	0.09	0.05	-0.04	-0.07
Accommodation problem	0.64	-0.01	-0.23	-0.05	0.38
Self-care problem	0.62	-0.02	0.19	0.14	-0.26
Transport problem	0.47	0.28	-0.20	-0.02	-0.44
Money problem	0.45	-0.22	0.13	0.36	0.21
Company problem	0.36	0.34	0.08	0.05	0.15
Psychological problems	0.15	0.73	0.03	0.10	-0.04
Safety of self problem	-0.17	0.67	0.37	-0.01	0.06
Psychotic symptoms problem	0.13	0.59	0.00	-0.09	-0.23
Sexual expression problem	-0.03	0.59	-0.13	-0.04	0.09
Intimate relations problem	0.01	0.49	-0.08	0.08	0.45
Information problem	-0.04	0.11	0.64	-0.35	0.06
Telephone problem	0.05	-0.17	0.60	0.12	-0.23
Benefits problem	0.08	-0.02	0.58	-0.10	0.05
Safety of others problem	-0.12	0.12	0.34	0.11	-0.00
Drugs problem	0.04	-0.09	-0.01	0.73	0.00
Childcare problem	-0.29	0.14	-0.24	0.63	-0.03
Alcohol problem	0.03	0.14	0.09	0.40	0.19
Day-activities problem	0.28	0.24	0.31	0.32	0.10
Education problem	0.11	0.04	0.02	0.05	0.51
Physical health problem	0.03	0.19	0.14	-0.02	-0.24
Eigenvalue	4.54	1.66	1.42	1.28	1.12

NI no interpretation available

**Table 2** Factor loadings after Promax rotation for staff ratings of needs according to CAN in factor analysis

Item	Skills factor	Impairment factor	Symptom factor	Substance abuse
Home problem	0.83	-0.09	0.11	0.06
Food problem	0.75	-0.05	0.14	0.02
Self-care problem	0.73	0.05	-0.01	0.00
Accommodation problem	0.39	0.12	0.04	0.29
Transport problem	0.33	0.00	0.22	-0.27
Benefits problem	-0.01	0.64	-0.20	0.25
Intimate relations problem	-0.04	0.63	0.24	-0.08
Information problem	-0.06	0.58	0.09	-0.18
Sexual expression problem	-0.15	0.57	0.33	0.03
Education problem	0.12	0.50	-0.19	-0.11
Telephone problem	0.04	0.38	-0.04	0.21
Day-activities problem	0.24	0.35	0.34	0.16
Psychological problems	0.26	-0.12	0.66	0.17
Safety of self problem	-0.22	-0.02	0.63	0.18
Psychotic symptoms problem	0.27	0.07	0.51	0.07
Company problem	0.31	0.33	0.40	-0.24
Physical health problem	0.10	-0.03	0.25	-0.02
Drugs problem	0.05	-0.09	-0.05	0.71
Alcohol problem	0.12	-0.10	0.14	0.57
Safety of others problem	0.04	-0.08	0.30	0.52
Childcare problem	-0.36	0.15	0.22	0.49
Money problem	0.32	0.34	-0.33	0.35
Eigenvalue	4.97	1.59	1.52	1.39

**Table 3** Sum scores and their Spearman rank-correlations with measures of functioning level and symptoms: patient ratings of needs according to CAN

	n	Skills	Illness	Coping	Substance abuse	NI
GAF score	300	-0.37***	-0.30***	-0.09	-0.19***	NA
BPRS score	300	0.45***	0.36***	0.08	0.24***	NA
Age	300	0.02	-0.13*	-0.03	-0.11	NA
Age at first admission	292	-0.05	-0.02	0.08	-0.03	NA
Duration of illness	292	0.07	-0.10	-0.03	-0.07	NA
Perceived QOL	300	-0.34***	-0.26***	-0.15**	-0.28***	NA
Interviewer QOL	293	-0.40***	-0.21***	-0.15**	-0.25***	NA

<sup>\*</sup> statistically significant at level p < 0.05; \*\* statistically significant at level p < 0.01; \*\*\* statistically significant at level p < 0.001

NA not available; NI no interpretation available

**Table 4** Sum scores and their Spearman rank-correlations with measures of functioning level and symptoms: staff ratings of needs according to CAN

	n	Skills	Impairment	Symptom	Substance abuse
GAF score	300	-0.39***	-0.25***	-0.44***	-0.21***
BPRS score	300	0.42***	0.28***	0.50***	0.10
Age	300	0.01	-0.08	0.01	0.08
Age at first admission	292	-0.15**	0.05	-0.07	0.06
Duration of illness	292	0.09	-0.11	0.05	0.05
Perceived QOL	300	-0.15**	-0.26***	-0.25***	-0.24***
Interviewer QOL	293	-0.39***	-0.28***	-0.34***	-0.21***

<sup>\*\*</sup> statistically significant at level p < 0.01; \*\*\* statistically significant at level p < 0.001

pairment and symptom sum score (Kruskal-Wallis test, p < 0.001). All the patients' sum scores varied significantly among the centres (Kruskal-Wallis test, p < 0.001).

## Discussion

We found both similarities and differences in the structure of needs ratings by the CAN in this community sample of schizophrenia patients. There was conspicuous agreement between patients and staff on the most powerful factor ("skills" factor, eigenvalues above 4.5) identified in our analysis. There were only two domains of needs that loaded on the skills factor among the patient ratings that did not load on the skills factor among the staff ratings. The company problem loaded on the "symptom" and the money problem on the "substance abuse" factor. Interestingly, in an analysis of the same sample, there was no great disagreement between the staff and patients in their assessments of met or unmet needs concerning these two domains, but there was disagreement regarding, for example, the benefits and telephone domains [16].

There was, however, some variation in the structure of needs between patient and staff ratings, as the number of factors identified in the analysis differed between patient and staff ratings despite the fact that no meaningful interpretation was available for the fifth factor of the patient ratings. It seems that the skills factor, reflecting secondary needs, was the most important of the identified factors. Moreover, some of the items that

loaded on the impairment factor for staff ratings loaded on the coping factor for patient ratings. Thus, patients and staff may differ in how they view the importance of certain needs. There were also similarities between patient and staff ratings as the skills and substance abuse sum scores correlated in a similar fashion with the GAF and BPRS measures. On the other hand, the correlation between perceived QOL and the skills sum score was at a higher level in the patient ratings than in the staff ratings.

The associations identified among patient and staff ratings regarding correlations between sum scores and the various measures used resemble each other. It seems that the item-by-item comparisons conducted in previous studies place the emphasis on differences in the ratings of needs between patients and staff, whereas a structural analysis also identifies similarities in the structures and the associations between the sum scores and various other measures. According to our analysis, the patients prioritise needs related to "illness" above needs related to "coping", whereas the staff prioritises needs related to "impairment" above needs related to "symptoms".

As there were significant and meaningful correlations between the sum scores constructed from the identified factors and the BPRS score, the GAF score, and QOL among both patient ratings and staff ratings, we conclude that we found evidence of the concurrent validity of the CAN. The illness and skills factors in the patient ratings and the skills and impairment factors in the staff ratings correlated negatively in a statistically significant manner, with the GAF being at about the level of

-0.40, which is in keeping with the findings by Phelan et al. [9].

Using the WHO classification cited above, it seems that the assessment of needs by the CAN in a community sample of schizophrenia patients tends to emphasise the secondary needs. This is no surprise as the patients were no longer in an acute phase of the illness and they were also receiving psychiatric treatment. However, the structure identified in the ratings especially of patients is fairly in line with the WHO classification [4]. The first factor reflects secondary needs, the second primary needs, and the third factor "coping" reflects the patient's interaction with his/her environment, although, for instance, needs related to "company problem" loaded on the illness factor in patient ratings. Among the staff ratings, no singular factor accounts for the tertiary, social needs, and, for example, "company problem" loaded on the "symptom" factor.

Furthermore, the illness and skills sum scores of the patient ratings were significantly associated with the ratings of perceived QOL, although the negative correlations were from low to moderate in size. This supports the notion that the patients' perception of their QOL is influenced by their illness-related needs. The staff ratings correlated weakly with perceived QOL, but there was a moderate association between the interviewer ratings of QOL and the skills and symptom factors. It might be expected that the staff ratings of needs, representing normative needs, are, indeed, closely associated with interviewer ratings of QOL, while patient ratings of needs are closely associated with perceived QOL, representing perceived needs.

The staff ratings differed according to sex, as men had more substance abuse-related needs. There was no such difference in the patient ratings, indicating a possible problem of insight among the male patients concerning use of substances. Substance abuse has been found to be common in patients with schizophrenia, especially among young men [17, 18]. Patients with schizophrenia who abuse substances have been found to have a poorer prognosis in respect to symptoms and functional ability [17, 18]. In addition, the abuse impedes the treatment adherence of patients with schizophrenia [19]. In our sample, however, the correlations between substance abuse and the GAF and the BPRS, if statistically significant, were modest in size among both patient and staff ratings of needs. Men also had more needs concerning the skills factor. This is also in line with previous findings, as Salokangas et al. [20] found that women had a better daily functioning level, more close interpersonal relationships, and more experience of employment than men. Men with schizophrenia living outside their families have been found to be at risk of poor outcome [21]. This further indicates that the level of skills necessary for daily living is more likely to be lower for men than for women.

In our series, there was a clear predominance of men although schizophrenia is not so much more prevalent among men. There is, thus, a selection bias that is obviously due to men remaining within rehabilitative services for longer periods than women. Men tend to develop schizophrenia at a younger age, and may have a more deteriorating course than women with schizophrenia [22,23]. Therefore, it is possible that some of the observed differences in the needs ratings by the patients and the staff may actually be biased by the sex distribution of our sample. However, the advantage of this sample is its large size and the comprehensive assessment of many dimensions of the patients' lives and treatment received.

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