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Background factors as determinants of satisfaction with care among first-episode psychosis patients

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■ **Abstract** *Objective* To evaluate the impact of demographic and psychosocial background factors and psychiatric and functional status before and at admission on the patients' satisfaction with care (PSC) among first-episode psychosis (FEP) patients. *Method* One year after entering the Parachute Project, 134 FEP patients completed a patient satisfaction questionnaire. The association with demographic and psychosocial background factors, together with psychiatric and functional status before and after admission, was analysed. *Results* Twenty-nine per cent of the variance of PSC was explained by factors such as educational level, social network, duration of untreated psychosis (DUP) and Global Assessment of Functioning (GAF) the year prior to onset. Negative symptoms and lack of hope at

admission were also predictors of PSC. The strongest predictor was DUP. *Conclusion* Affecting the public knowledge in psychiatric problems and psychiatric treatment, together with early intervention strategies aiming to decrease the prodromal and DUP period among FEP patients, can positively influence the patients' experience of given care. By increasing the knowledge of available psychiatric treatment, the sense of powerlessness might decrease among the affected persons, and the possibility of early help seeking might increase.

■ **Key words** patient satisfaction with care – first-episode psychosis – background factors – socio-demographic factors – determinants – schizophrenia

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Background

During the past decades, the role of the patient has changed from being one of a passive, dependent and uninformed object of treatment to that of an important source of information with whom the psychiatric staff should cooperate closely. The patients' satisfaction with care (PSC) is considered an important factor, and it does not always coincide with the priorities of the professionals [27].

PSC has mostly been used as an outcome measure of different treatment models. A common finding has been that a better treatment outcome is related to a higher level of satisfaction. However, the validity and reliability of the instruments measuring PSC have been questioned [26]. A frequent finding in the literature is that most people say they are satisfied with the care they have received [11, 26]. Nevertheless, some researchers state that PSC should be considered as a significant outcome variable in its own right [33]. Studies of the influence of socio-demographic variables (SDV) vary. Factors such as being older [5, 8, 11, 14, 22, 24, 31], female [5, 8, 11, 14, 22, 24, 31, 32], married [14] and having a lower level of education are

more prevalent amongst those who tend to be more satisfied [11, 14]. However, some studies have given another picture [31]. Additionally, members of racial minorities and [4, 19] psychotic patients tend to be less satisfied [12, 26]. A Swedish study of schizophrenia outpatients found that higher satisfaction was related to Swedish origin, independent living and no prior hospitalisation. A relationship was also found between PSC and psychopathology and psychosocial functioning [9].

Studies comparing satisfaction with care of “naive and experienced” patients, not only psychosis patients but the whole spectrum of psychiatric patients, have reported varying results. McIntyre [15, 22] found no differences between the groups, whereas Hansson et al. [15] reported that first-admission patients were more satisfied. As far as we know, there are only a few studies of PSC among first-episode psychotic (FEP) patients and [20, 23] only one of these, a British study, focused specifically on the influence of background variables on PSC. Patients born abroad were significantly more satisfied regardless of ethnicity [20].

The fact that patients in almost all studies tend to say that they are satisfied can be due to a narrow range of choices [26]. Having a skewed dependent variable with little variance may lead the researchers to focus on dimensions of satisfaction, rather than explaining its central aspects [11]. Discrepant results regarding PSC and age and gender tend to be reported in studies investigating either a unique type of organisational setting, i.e. females were significantly less satisfied when the service setting was military health agencies or a narrow range of diagnosed health problems, i.e. hypertension [24]. This inconsistency about SDV influence on PSC concerns health care in general and not only satisfaction with psychiatric care.

FEP patients are “naive” regarding their reception of psychiatric care. This means that their perception of received care is mainly influenced by their own pre-conception of such care. Their expectations about psychiatric care should therefore be congruent with those of the general public. Studies assessing the public view have reported that many standard psychiatric treatments were considered as more harmful than helpful, although most believed that the psychosis becomes worse without any help. Environmental factors were seen as more important than biological factors regarding the cause of the psychosis, and general practitioners were rated as more helpful than psychiatrists and psychologists [17, 18]. These collective expectations become a part of the unique patient’s pre-conception of psychiatric diseases and psychiatric care. They can be interpreted as representing to what extent the patient has confidence/trust in helping interventions and harbours hopes of recovery. Lack of confidence/trust in the professionals’ ability to help may influence the patients’ help-seeking pattern, lead to prolonged duration of untreated psychosis (DUP) and affect compliance and outcome in a negative way [3,

25]. Haley et al. [13] found that FEP patients appeared to have similar “health beliefs” to patients with a physical illness and that these beliefs differed from those of healthy controls. The two experimental groups had less confidence/trust in their own ability to cope with their situation and felt more dependent upon “powerful others” than the controls. It can be concluded that it is not only the kind of disease that matters but also the actual loss of health. Long DUP was related to a greater lack of autonomy and dependence upon “powerful others”.

Aims of the study

This study aims to analyse FEP PSC and its relationship with background factors such as demographic factors, as well as psychosocial, psychiatric and functional status before and at admission.

Materials and methods

The present study is a part of the Parachute Project, which represents an effort to provide “need-adapted treatment” [1] on a large-scale basis for FEP patients. The aims of the Parachute Project have been to optimise elements considered to contribute to a better outcome, such as psychosocial support for the individual and the family, lowest effective doses of neuroleptic medication, continuity of care, not mixing first-episode and chronic patients and reliance on small therapeutic units and less hospital care. Finally, the project aims to provide an opportunity to study prognosis and outcome with reference to clinical, psychological, social and biological variables. The methods and the materials have been described in a previous paper [6].

Seventeen clinics participated in the Parachute Project, seven in the Stockholm area and the others in the rest of the country. The catchment area consists of about 1.5 million inhabitants, representing one sixth of the population of Sweden. The inclusion criteria were as follows: seeking psychiatric help for psychotic symptoms for the first time, age 18–45 years and without dominating substance abuse or diagnosed brain disorder. During the years 1996 and 1997, 253 patients fulfilled the criteria, and 175 were included in the project [6].

■ Outcome variable

No standardised measures aiming to measure satisfaction with need-adapted care for FEP patients are available. Experienced clinicians and a statistician constructed the Patient Satisfaction Questionnaire (PSQ). None of the items were reversed due to the clinicians’ experience that psychotic patients, with cognitive and perceptual deficits in various degrees, might have problems understanding reversed questions. With other scales with reversed questions, this problem was usually solved by staff members who supported the patients. This staff support was not possible with the PSQ because this could have affected the patients’ ability to evaluate the care. The questions in the PSQ were based on the aims formulated for the Parachute Project [6]. The scale was discussed, constructed, modified together with experts, a modified Delphi Technique although the experts were not anonymous [16], and discussed with six young non-first-episode psychotic patients. After the scale was conducted, it was retrospectively validated in a qualitative study of eight patients [21]. The reliability of the PSQ in terms of internal consistency was tested using Cronbach’s alpha (0.9).

At the 1-year follow-up, every patient received the PSQ which consisted of 13 items. Twelve of the items were to be responded to using a five-point scale with answers ranging from 1 (not at all) to 5 (completely). A final item was an open-ended question to give the patient the opportunity to make comments. In this study 11 of the 12 items in the PSQ were used. One item, about satisfaction with the relatives' cooperation, was not included because some patients misunderstood it. The following variables were also used:

Demographic characteristics

Age, gender and country of origin.

Social characteristics

Educational level, married/cohabitant status, presence of children, social contacts [29], number of days at work the year before onset [29] and social network support; the latter was assessed during the first month using a four-point scale and dichotomised [6].

Symptoms and functional status

DUP was defined as the period between the first psychotic symptom and the first contact with psychiatry. DUP was estimated from interviews with the patients and the relatives/network at first week after admission.

The Brief Psychiatric Rating Scale (BPRS) [30] was used to measure severity and type of symptoms. It consists of 24 items, which are rated on a seven-point scale on the basis of an interview. A score of 1 indicates no symptoms, and a score of 7 indicates severe symptoms. Constructed scores for positive, negative and depressive symptoms were used. The highest score of one of the included items in every sub-scale was used.

Symptom severity in combination with social functioning was assessed with the Global Assessment of Functioning (GAF) scale [10], the highest score, the year before admission and the actual score at baseline.

Axis I Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV diagnoses [2] were established using a Structural Clinical Interview for DSM-IV conducted by a psychiatrist. The baseline diagnoses were revised at the 12-month assessment and used in this study. They were classified as schizophrenia syndromes and other psychoses.

Experience and expectation variables

History of psychiatric illness or substance abuse within the family was obtained at the 1-month follow-up. This included whether relatives had been treated for psychiatric illness or substance abuse as well as if the patient had received previous psychiatric treatment for a non-psychotic diagnosis.

Hopelessness/helplessness was assessed at baseline by an extra item that was added to the BPRS.

Participants and non-participants

One hundred and thirty-four patients out of 175 completed the PSQ. The non-participants were younger (mean age 26.0, SD 6) than the participants (mean age 29.0, SD 7) (p 0.007). They also had less days at work the year prior to admission (50 vs 75%, p 0.002), and fewer of them had a social network capable of cooperation (40 vs 63%, $\chi^2 = df$ 1, p 0.01).

Statistical analysis

Data were analysed using the SPSS statistical package version 11.0 [28]. Correlation test, t test and analysis of variance (ANOVA) were performed to study associations between PSC and demographic, historical, functional and expectation/experience variables. Block-wise multivariate linear regression analyses were performed to assess the contribution of these variables in explaining PSC.

Results

The means of the items included in the study are presented in Table 1.

At year 1, the average patient satisfaction was 3.9 (SD 0.8).

Demographics and social characteristics

As shown in Table 2, the mean age of the participants was 29 years, and most were male, Swedish and single. Few participants had children. In addition, many patients did not have a social network capable of cooperation, and only 43% had weekly contact with friends. Sixty-four per cent had a secondary education, with 14% having completed university studies. Finally, most

Table 1 Means (SD) of the PSQ items

	Mean	SD
Are you satisfied with how quickly you were offered help when you initially contacted psychiatric services?	3.9	1.3
Are you satisfied with the help you received during the first week?	3.5	1.4
Are you satisfied with the continuity, i.e. the extent to which you have been able to see the same persons in the psychiatric team?	4.3	0.9
Are you satisfied with the time that has been given to you by the staff?	4.3	0.9
Are you satisfied with the concern and understanding the psychiatric staff have shown for your situation?	4	1
Are you satisfied with the influence you have had on your care?	3.9	1.1
Are you satisfied with how quickly you were offered help when you needed it? (concerns the first year except the first week)	4.1	1
Have the sessions with the psychiatric staff been helpful?	3.7	1.1
Was the care offered in the evening and at night adapted to your needs?	3.8	1.1
If you have been taking medicine, has the medicine been of help to you?	3.5	1.1
If you have been taking medicine, are you satisfied with the information you have received regarding effects and side-effects?	3.4	1.2

Five-point scale (1=not at all, 5=completely)

Table 2 Demographics and social characteristics

	Mean	SD
	Number	%
Age	29	7
Female gender	65	48.5
Born in foreign country	23	17
Married/cohabitant	42	29
Presence of children	42	32
Network capable of cooperation	83	63
Contact with friends		
No contact	1	1
Seldom	19	14
Once a month	23	18
2–3 times a month	31	24
Every week	57	43
Education		
Compulsory school attendance	29	22
Upper secondary school	85	64
University	18	14
Number of days at work the year before onset		
No work	9	7
Work 25% of the year	14	11
Work 50% of the year	17	13
Work 75% of the year	15	11
Work all year	76	58

Number of cases varies slightly between the tested variables

(58%) of the participants were in full-time employment the year before onset, and 7% were unemployed.

Symptoms, functional status and experience/expectation

A large proportion (43%) had a DUP of more than 1 month, with 18% having a DUP of more than 1 year before onset. The mean highest GAF in the year before onset was 68, with a reduction to 32 at baseline. The BPRS positive, negative and depressive symptoms at baseline ranged between 3.1 and 4.8. Forty per cent were diagnosed with a schizophrenia syndrome, whereas 60% had other psychotic disorders (Table 3).

Forty-eight per cent of the patients had a relative/relatives treated for a psychiatric illness or substance abuse, and 29% of the patients had had previous psychiatric contact. Patients scored an average of 3.2 regarding hopelessness [5, 8, 11, 14, 26, 27, 33].

Associations between demographic, historical, functional and expectation/experience variables and PSC

PSC was positively correlated with number of days at work the year before onset ($r=0.14$, $p<0.05$) but negatively correlated with the highest GAF scores the year before onset ($r=-0.20$, $p<0.01$), DUP ($F(2,102)=7.8$, $p<0.001$), baseline scores of hopelessness ($r=-0.24$, $p<$

Table 3 History of symptoms, functional status and experience/expectation

Before onset	Number	%
DUP		
<1 month	60	57
1–12 months	26	25
>12 months	19	18
	Mean	SD
Highest GAF during the year before onset	68	15
At baseline		
GAF	32	9
Symptoms, BPRS (1–7)		
Positive symptoms	4.8	1.6
Negative symptoms	3.1	1.8
Depressive symptoms	4.5	1.7
	Number	%
Diagnoses		
Schizophrenia syndromes	53	40
Other psychosis	81	60
Relative treated for psychiatric illness or substance abuse	64	48
Previous contact with psychiatry	38	29
	Mean	SD
Helplessness and hopelessness (1–7)	3.2	2.1

Number of cases varies slightly between the tested variables

Table 4 Historical and baseline predictors of satisfaction with care among first-episode psychosis patients

Independent variables	Satisfaction with care, Beta _{stand}
Demographic variables	
Age ^a	−0.06
Female gender ^b	−0.001
Born in foreign country ^b	−0.19
R ² change	(0.003)
Social variables	
Married/cohabitant ^b	0.21
Presence of children ^b	0.15
Network capable of cooperation ^b	0.10
Weekly contact with friends ^b	−0.27**
Educational level ^a	0.20*
Number of days at work the year before onset ^a	0.10
R ² change	(0.08)
Clinical characteristics, baseline	
Revised baseline diagnosis Schizophrenia syndrome ^b	−0.005
GAF past year ^a	−0.32*
GAF baseline ^a	−0.07
BPRS-positive ^a	−0.07
BPRS-negative ^a	−0.24*
BPRS-depressive ^a	−0.10
Duration of untreated psychosis (DUP) ^a	−0.42***
R ² change	(0.18)
Experience/expectation variables	
Relative treated for psychiatric illness or substance abuse ^b	0.08
Previous contact with psychiatry ^b	−0.06
Helplessness and hopelessness ^a	−0.24*
R ² change	(0.03)
Total R ²	(0.293)

^a Continuous variables

^b Category variables

* $p<0.05$; ** $p<0.01$; *** $p<0.001$

0.01) and BPRS-negative symptoms ($r=-0.22$, $p<0.05$). No other variables were associated with PSC.

■ Predictors of PSC

As shown in Table 4, background characteristics did not independently predict PSC. Together, these variables accounted for less than 1% of the variance.

Contact with friends was significantly related to less satisfaction with care. In addition, higher level of education was independently associated with PSC. Together, social variables explained 8% of the variation.

High GAF scores the year prior to onset, longer DUP and negative symptoms at baseline independently predicted low PSC. Together, clinical characteristics explained 18% of the variation.

Patients with high hopelessness scores were more likely to report less PSC. Together, experience/expectation variables accounted for 3% of the variation.

In summary, the model accounted for 29% of the variance in PSC.

Discussion

In the present study demographic and psychosocial background factors and psychiatric and functional status before and at admission explained 29% of the variation of PSC among FEP patients. Persons with higher education were more satisfied, which could be due to the fact that they were initiated in mental health issues, a factor previously identified as being related to an increasing confidence/trust in psychiatric health care [17, 18].

In this study longer DUP pre-admission was related to lower scores of PSC. The presence of psychotic symptoms might have affected the patients' pre-conception in a negative way. Loss of health affects the patients' "health beliefs", leading to less confidence/trust in their own power and an increased sense of dependence on powerful others. This has been shown to be related to prolonged DUP [13]. It was somewhat unexpected that a low GAF score the year before onset was related to higher PSC. The period of low GAF before the psychotic symptoms started consisted probably of a combination of a decline in function level together with various degrees of prodromal symptoms such as anxiety and depression. Before the psychotic symptoms started, the patients' insight in the developing problem was not muddled by the psychosis itself. Those patients seem to have been more prone to accept and be satisfied with offered care than those with a longer period of psychotic symptoms. However those with a greater sense of hopelessness at admission seem to already have lost their hope for help and cure and were therefore less satisfied. A high level of negative symptoms at admission has usually been devel-

oping over time, and the patient has often experienced a progressive loss of executive function, which is known to be a factor complicating the compliance and alliance with the patient. It has, in a way, already "built in" a negative pre-conception in the negative symptoms. The experience of greater hopelessness, longer DUP and higher level of negative symptoms might lead to a negative self-generating process and will most likely have less impact if it is stopped early.

The patients' belief in treatment has been reported to be a predictor of outcome among paranoid schizophrenic patients [3]. This belief can be another way of expressing confidence/trust and hope. Our finding that hopelessness was strongly related might be regarded as support for the conclusion that lack of hope and confidence/trust initially leads to lower PSC, which in the end can lead to poorer outcome.

The weakness of the present study was that the PSQ was not tested for validity and reliability before it was administered. Retrospectively a qualitative study showed concordance between the results of an interview concerning experience of care and the PSQ [21]. However the risk that a new constructed scale might fail to measure patient satisfaction cannot be excluded. The Parachute Project is a multicentre project with a naturalistic design, and it was not possible to control for a number of external factors that may have affected the results. Additionally the possible effect of the non-participant rate, 23%, cannot be ignored. Previous research has indicated that younger persons show a greater tendency to drop out [7], which was also the case in this study. Younger people also tend to be less satisfied, which partly can explain the high average of the results of PSC [5, 8, 11, 14, 22, 24, 31]. The non-participants also had fewer days of employment and less capable network, which can indicate that they had more disadvantages from their psychotic illness than the participant group. The included variables explained 29% of the variance, and nothing could be said about the other 71%. Twenty-nine per cent is a rather low number of explained variance, but as the variables measured were connected to the time before any care was given, it can be considered a surprisingly high number despite this. The possible impact of the rather low number of participants cannot be excluded.

The strength of this study is the epidemiological design of the Parachute Project, the wide range of collected data, the homogeneity of the patients and the pre-decided continuity due to the 5-year follow-up. The patient group and the care given were highly homogenous and thus less affected by variation [24]. The question arises as to whether this reflects more valid results because the impact of background variables on PSC was less contaminated by other heterogeneous, and perhaps unexpected or unknown, variables than in a sample containing not only FEP patients. This might explain why the results differ from those of previous studies, which have shown that age and gender are the

strongest correlates to satisfaction [5, 8, 11, 14, 22, 24, 31, 32].

Conclusion

Affecting the public knowledge in psychiatric problems and psychiatric treatment, together with early intervention strategies aiming to decrease the prodromal and DUP period among FEP patients, can positively influence the patients' experience of given care. By increasing the knowledge of available psychiatric treatment, there is a possibility that the sense of powerlessness will decrease among the affected persons, which might result in earlier help seeking.

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