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The life situation of people with persistent mental illness visiting day centers – a comparative study

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Abstract

This study compared the life situation of visitors of day centers (DC) for people with mental illness (N=93) with a comparison group (N=82) in respect of sociodemographic and clinical characteristics, care consumption, well-being and everyday activities. The response rate was 49%, and those who declined are believed to be those with the most severe psychiatric disabilities. Most individuals were single (81%/78%) and few had children (12%/18%). The DC group had less education than the comparison group but had a friend more often. Although having their need for daily activities met, the DC group had greater unmet needs in respect of daily living in general. They less frequently reported having a psychosis and had fewer negative and more depressive symptoms. They got more housing support and general outpatient care, while the comparison group used specialized psychiatric care more frequently. The samples were equally satisfied with their care, health and well-being and found their everyday activities equally meaningful. The DC visitors formed a vulnerable group, by living single, having a low level of education and having unmet needs, and were at risk of not getting specialized psychiatric care.

Key words: Schizophrenia, activities of daily living, well-being, satisfaction with care, care utilization, needs.

Introduction

People who are psychiatrically disabled and depend on day centers (DCs) in order to get structure into their daily routines are rarely subject to research. Since they constitute a large group and substantial resources are spent on DCs this is unacceptable. Research so far indicates that, seen as a group, people with severe mental illness spend much of their time alone in their homes, quietly observing their environment, and going to the DC may be one of few reasons for leaving their homes (Bejerholm & Eklund, 2004). DCs may be organized in different ways, but have been described as being of mainly two types, either meeting-place oriented or work oriented (Tjörnstrand, Bejerholm & Eklund, 2010). In meeting-place oriented DCs, the participants may typically play games, eat and socialize, while work oriented DCs offered scheduled work for the participants, such as manufacturing and selling things, managing second hand stores or providing catering services (Tjörnstrand, et al., 2010). There are opportunities for both performing activities and socializing with others (Catty, Goddard, & Burns, 2005; Tjörnstrand, et al., 2010). In a review of studies on DCs attendees, Catty et al. (2007) concluded that controlled studies are totally lacking and that the existing research concerns descriptions of the target group (Catty & Burns, 2001; Shepherd & Richardson, 1979) and characterizations of DCs versus day hospitals (Catty, et al., 2005; Holloway, 1991). More knowledge regarding the needs of people who attend DCs, and how they perceive the support they get and their health, well-being and everyday activities, is required in order to be able to provide the best possible support. By more detailed information in these respects, it would be possible to differentiate and individualize the support, to fit people with certain backgrounds and needs. Therefore, the aim of the present study was to explore DC attendee’s life situation, including socio-demographic and clinical characteristics, satisfaction with care, perceived health and well-being, and everyday activities. A comparison group of non-attendees was used as a reference group.

Methods

This was a cross-sectional study of visitors at all DCs, meeting-place oriented as well as work oriented, in four municipalities in Southern Sweden and a comparison group selected at the psychiatric outpatient units for people with psychosis in the same municipalities. Many of the DC attendees also visited outpatient mental health services, but those who did were excluded from those eligible for the comparison group.

Selection procedure and participants

Attendees at the DCs were asked by the DC staff to participate. Those who agreed gave their written consent, and appointments were made for interviews, performed by experienced occupational therapists who received specific training for the project. The Regional Ethical Review Board of Lund University approved the study (reg. no. 303/2006).

In DCs as well as outpatient units, the inclusion criteria were that the subjects should have a mental illness which had persisted for at least two years and which hindered them from participating in employment and fulfilling important life goals. These criteria correspond to the definition of psychiatric disablement proposed by the Swedish Board of Health and Welfare (Swedish, Government, Official, & Reports, 2006). The participants were also required to be of working age, i.e. between 18-65 years of age. Additional criteria for the DC subjects were having been attending a DC for at least one month and at least four hours per week, and for the subjects from the outpatient clinics, another criterion was that they did not visit DCs on a regular basis (< four hours per week). In the DC group 195 persons were approached and 93 (48%) participated, and of 168 eligible outpatients, 82 (49%) participated.

Instruments

Sociodemographic and clinical characteristics

Sociodemographic information was gathered by means of a questionnaire devised specifically for this study. The following *sociodemographic variables* were targeted: sex, age, marital status, having children living at home, having friends, housing situation and educational level.

Psychiatric symptoms were assessed by means of the interview-based Brief Psychiatric Rating Scale (BPRS) (Overall, 1962), which consists of 18 items that are rated on a seven-point scale. A rating of one indicates absence of symptoms and seven indicates an extreme level. Good inter-observer and intra-observer reliability has been demonstrated, especially with specialized training (Andersen, et al., 1989) and a structured interview guide (Crippa, Sanches, Hallak, Loureiro, & Zuardi, 2001), which were measures considered for this study. A test of inter-rater reliability among the interviewers trained for the study resulted in alpha coefficients of 0.80 or more. Subscales of positive symptoms, negative symptoms, depressive symptoms and general psychopathology were used, for which the mean scores were calculated.

Global Assessment of Functioning (GAF) (Endicott, Spitzer, Fleiss, & Cohen, 1976) was employed to estimate *psychosocial functioning*. This provides a single rating on a 100-point scale, where 100 indicates not only the absence of pathology but also positive mental health. It has good inter-rater reliability (Tracy, Adler, Rotrosen, Edson, & Lavori, 1997) and good concurrent validity (Endicott, et al., 1976; Startup, Jackson, & Bendix, 2002). Inter-rater reliability was also assured for the present study, by an intra class correlation of 0.86.

Diagnosis was not available for the day care sample, since no medical records were kept. As a proxy for diagnosis, *self-reported diagnosis* was requested. Since all participants took part in mental health services, they had seen a psychiatrist and were likely to have an idea about their most recent psychiatric diagnosis. The self-reported diagnoses were then grouped by the second author, who is a M.D. specialized in psychiatry, in accordance with the ICD-10 (WHO, 1993). The diagnoses were further grouped into four larger categories: 1 – schizophrenia and other psychotic disorders (interval F20 and affective psychoses from F30), 2 – mood disorders (the remaining diagnoses from F30), 3 – anxiety, phobia and stress disorders (interval F40) and 4 – other diagnoses (intervals F00, F10, F50-90). In order to give a simple indicator of the validity of the self-reported diagnoses, a post-hoc comparison between the four diagnostic groups was made regarding symptom ratings according to BPRS. Statistically significant differences were found regarding positive symptoms (p=.001) and negative symptoms (p=.002), on which the group with schizophrenia and other psychoses scored the highest, and concerning depressive symptoms (p<.001), on which the group with reported mood disorders scored the highest. No difference between the diagnostic groups was found in respect of general psychopathology. Although a blunt test, the result provides some validity to the self-reported diagnoses.

Use of and satisfaction with care

Questions regarding the care received and the satisfaction with such care covered the areas of housing support, outpatient care other than mental health care, outpatient mental health care, inpatient mental health care, seeing a psychiatrist and getting psychotropic drugs. The participant was asked a) whether he or she had received the targeted type of care during the past six months and b) to give a satisfaction rating from 1=can’t be worse to 7=can’t be better.

Perceived health and well-being

As an estimate of *self-rated health*, the first item of the Short Form - Medical Outcomes Survey (SF-36) (Ware & Sherbourne, 1992) was used. It is considered a trustworthy brief estimate of self-rated health because of high correlations with more comprehensive measures of self-perceived health (Bjorner, et al., 1996; Streiner & Norman, 2004). Participants rate their health on a five-point scale from 1 (*excellent*) to 5 (*poor*).

The *self-esteem* scale used was that developed by Rosenberg (Rosenberg, 1965). It consists of 10 items to which the respondent answers “yes”, “no”, or “I do not know”, and has been shown to have acceptable internal consistency (Oliver, Huxley, Bridges, & Mohamad, 1996). A self-esteem average score that may vary between minus one (negative self-esteem) and plus one (positive self-esteem) is obtained.

Perceived social status was rated according to the MacArthur Scale of Subjective Social Status (MacArthur & MacArthur, 2007). In a pictorial format, it presents a “social ladder” and asks individuals to place an “X” on the rung on which they feel they stand. A ladder with 10 rungs was used, but there was also a space below the lowest rung, providing the possibility for 11 scale steps, 0-10, where the highest rating indicated the highest social status.

Everyday activities

Met and unmet *activity needs* were assessed by four items (feeding, home management, hygiene and regular daily activities) from the Swedish version of the Camberwell Assessment of Need (CAN), shown to have good inter-rater agreement (Hansson, Bjorkman, & Svensson, 1995) and to be reliable over time (Arvidsson, 2003). Each need is rated according to problem level, amount of help received from relatives and friends, amount of help received from social and health services, amount of help needed from social and health services, whether adequate help is received or not, and being generally satisfied with received help or not. The items were analyzed separately according to these aspects. Besides, an average problem level score, based on all four activity needs, was calculated, with a possible range of 0 (no problems) to 2 (severe problems).

In order to get a picture of the *meaningfulness* the participants perceived in their everyday activities, the following questions were asked: “In general, would you say that you do things in everyday life that are meaningful; – to yourself? – to others in your near environment? – in a wider context of which you are part?” Each of these three aspects was rated on a five-point scale from 1=not at all to 5=very much. These questions have been used and found to be relevant in previous research (Bigelius, Eklund, & Erlandsson, 2009).

Data analyses

Since the data was of categorical or ordinal nature, non-parametric statistics were used. The participants’ situation with respect to the studied variables was analyzed by descriptive statistics, and differences between the day care and the comparison group were analyzed by the chi-squared test (for categorical variables) or the Mann-Whitney U-test (for ordinal variables). The p-value was set at $p<.05$ and the software used was the SPSS 14.0.

Results

Sociodemographic and clinical characteristics

The DC attendees were on average 46 years old and 59% were males. Only a few were married/ living with someone (19%) or had children (12%). Sixty-four percent lived in an own apartment or house without support. No statistically significant differences were found in relation to the comparison group in these respects. A vast majority in the DC group, 88%, reported having at least one close friend. This was significantly more ($p=.010$) than in the comparison group, where 59% reported that they had a close friend. Moreover, the DC group reported a lower education level than the comparison group ($p<.001$). Very few (7%) in the DC group had a university degree, compared to 32% in the other group.

The BPRS indicated few psychiatric symptoms, around a rating of two, in both groups, and the most severe symptoms were of a depressive character. The statistically significant differences found indicated more severe general psychopathology in the DC group (p=.019) and more negative symptoms in the comparison group (p=.020). The level of psychosocial functioning was in the range of 55-60 in both groups, which corresponds to moderate difficulties.

Schizophrenia and other psychoses were the most common self-reported diagnostic category in both groups. Still, there was a strong statistically significant difference—only 44% of the DC group reported having schizophrenia or some other psychosis, as opposed to 82% in the comparison group. By contrast, 22% in the DC group, and only 5% in the comparison group, reported a mood disorder.

Use of and satisfaction with care

The most common types of care in the DC group were the receiving of psychotropic medication (79%) and seeing a psychiatrist (72%). There was a statistically significant difference (p<.001) in relation to the comparison group, where 98% received psychotropic medication and 99% saw a psychiatrist. Furthermore, outpatient care, other than mental health care, was more common in the DC group, (p<.001), as was housing support (p=.043). Inpatient care was rare in both groups, and there was no statistically significant difference in this respect. Neither were there any differences with respect to satisfaction with care in any of the assessed areas, all ratings varying between 5.2 and 5.8 on the seven-point scale used.

Health and well-being

Self-rated health and social status were in both groups rated slightly worse than the midpoints of the scales, while perceived self-esteem was rated somewhat better than the midpoint. There was no statistically significant difference between the groups on any of these variables.

Everyday activities

The problem level of the four activity needs was significantly greater among those in the DC group, whose average score was 1.5 on the two-point scale while that of the comparison group was 1 (p<.001). There were several statistically significant differences between the groups regarding the need area of regular daily activities. Significantly more serious problems were identified in the DC group (p<.001). Moreover, in that group the staff more often played the main role in meeting the needs (p<.001) and the need for support was stronger (p<.001). The DC group was also more often satisfied with the help received (p<.015), although the groups got equally adequate help. Regarding feeding and hygiene, no statistically significant differences were found. Neither were there any differences between the groups regarding perceived meaningfulness in daily activities. The ratings were around or above the response scale’s midpoint, and the highest rating in both groups was on the item ”meaningful to yourself”.

Discussion

In line with previous research on similar groups (Eklund, Hansson, & Ahlqvist, 2004; Eklund, Hansson, & Bejerholm, 2001), and as per the comparison group, most of the attendees were single and few had children. However, they reported having a friend more often than the comparison group. This is possibly a result of visiting the DC and making contacts there, but may also indicate that those with more friends were more likely to attend DCs. The DC visitors also had a considerably lower level of education. This may be important information when aiming to provide individually matched activities to the attendees and indicates that the DCs should provide some kind of supported education in order to fill out educational gaps amongst visitors. But on the other hand the finding could mean that the non-visitors avoided the DCs because these could not meet the demands of persons with higher education, implying that the DCs should also offer more intellectually stimulating activities. In truth, adding both supported education and more intellectually stimulation activities to the supply may be warranted, and DCs should thus provide a wide range of activities with varying demands (Tjörnstrand, et al., 2011).

With respect to clinical factors, there were a few differences between the groups. Negative symptoms were less pronounced and self-reported mood disorder more common in the DC group. Moreover, self-reported schizophrenia and other psychoses, as well as the use of psychotropic medication, was more common in the comparison group. Thus, a psychiatric disability, which is the common denominator for people who visit DCs (Tjörnstrand, et al., 2010), is not necessarily linked to a self-perceived diagnosis of schizophrenia or other psychosis.

There was an interesting difference in the pattern of the use of care in the two groups. The DC group used general outpatient care, such as primary health care, more often than the comparison group, which used more outpatient mental health care. Fewer persons in the DC group visited a psychiatrist and fewer used psychotropic medicine than in the comparison group. Thus, there might be a risk that these get less specialized mental health care. As regards the level of satisfaction with care, similar levels of satisfaction were expressed in the two groups. High levels of satisfaction were found, in line with previous research (Eklund, Ornsberg, Ekstrom, Jansson, & Kjellin, 2008; Hansson & Höglund, 1995). No differences at all were found regarding the participants’ health and well-being. This is also similar to previous research, comparing DC visitors and other psychiatric groups on well-being variables (Eklund, et al., 2004).

Daily activities, which formed the condition that was known to differ between the groups on a formal basis, were investigated in relation to needs and perceived meaningfulness. Both groups perceived meaning when engaged in their everyday activities, which is in line with recent qualitative research, which included both types of participants (Argentzell, Håkansson, & Eklund, 2010; Leufstadius, Erlandsson, Björkman, & Eklund, 2008). Not surprisingly, the DC group was in need of more support with respect to regular daily activities. Both groups received equally adequate help in this regard, but the DC group was more satisfied. In this respect, the comparison group was disadvantaged. Focusing on activity in the DC group, the findings suggest that they found meaning in their everyday activities and that their need for regular daily activities was satisfied. However, they still had more unmet activity needs than the comparison group within the areas of feeding, housing and self-care, despite the fact that the DC group more often received housing support. This raises questions regarding the boundaries of a setting and whether support should be extended to clients' homes.

The participation rate was quite low, just below 50%, but comparable to that of other similar samples (Bengtsson-Tops, et al., 2005). Because of the frailty and vulnerability of the target group, it is difficult to attain participation rates above 50-60% in studies that go beyond clinical routines. Analyses of attrition in a similar sample have indicated that the non-participants were somewhat more likely to be females and to be marginally younger, but not to differ from the participants regarding diagnosis (Eklund et al., 2004). Both the BPRS ratings of psychiatric symptoms and the GAF rating of psychosocial functioning indicated mild to moderate psychopathology. This suggests that those who declined to participate were those with the most severe psychiatric disability. Although this systematic attrition should reasonably have affected both samples similarly, it should be borne in mind that the results of the study may not be representative of the most disabled individuals. Moreover, due to the way in which DCs in Sweden are organized, it was not possible to get a psychiatrist's assessment of the participants' diagnoses. Therefore, self-reported diagnosis was used as a proxy. There might be a risk that some of the diagnoses reported by the DC group in the present study, such as depression or anxiety, were overused as explanations since the term also denotes a subjective, recognizable feeling, and the samples might be more diagnostically similar than the findings indicated.

Conclusion

The DC visitors formed a specifically vulnerable group in terms of living single, having a low level of education, and having unmet needs pertaining to activities of daily life, despite visiting a DC. They also appeared to be more at risk of not receiving specialized psychiatric care than the comparison group. When planning for support and care for this group, these circumstances should be considered. Supported education, adding intellectually stimulating activities, providing home-based support in managing self-care and home duties and assistance in seeking psychiatric care are just a few recommendations. This study also identified a risk in the comparison group, namely that of being less satisfied with help in respect of regular daily activities. People who visit DCs form a large and resource-consuming group and effective support is important from both humanitarian and economic perspectives. As one of few studies on the target group, this study contributed with some unique findings regarding how they perceived their everyday activities. However, considering the low response rate, interpretations must be made with caution and recommendations be seen as preliminary. The activity aspect should be further investigated in future studies. When more is known regarding the target group’s engagement in the DCs, and which types of activities they experience as being meaningful and health promoting, interventions that aim at improving the care and support to the target group may be developed and evaluated.

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