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People living in community with a severe mental illness – utilization and satisfaction with care and support

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ABSTRACT

The object of this paper was to investigate the experiences of patients with severe mental illness (SMI) living in a community, including their utilization of care and treatment services. Psychiatric care and social services staff members were asked to make an inventory of those they served in two districts of Malmö, Sweden. Participants had to be over 18 years of age and unable to manage their daily lives without help from others. Almost all of the 80 participants (95%) were under psychiatric care. A majority (86%) was receiving dental treatment, and 61% were supported by social services. Fifty-four percent of the participants received somatic care on an ongoing basis. Although the majority reported the care given as sufficient, one-third of this SMI population considered the care and support they received to be insufficient. Satisfying those who are dissatisfied with the care they are being given would be a significant challenge for service providers, since the unsatisfied are shown to have more difficult lives.

INTRODUCTION

Despite the ambitious investments of society in de-institutionalization, several studies have shown that people with severe mental illness (SMI), as well as their relatives, continue to suffer from its impact. Indications of this comes from research documenting increased criminality, drug abuse, suicide, higher mortality, homelessness, isolation, lack of meaningful occupations and underutilization of social care and support systems in this population (Belfrage, 1994; Appleby, 1992; Wahlbeck et al., 2011; Scott, 1993; Beebe, 2010; Evert et al., 2003, Hansson et al., 2002). Admittedly, there has been a lack of consistency in how SMI has been defined (Slade et al., 1997). However, if one uses the WHO definition of SMI (WHO, 2001) as a psychiatric diagnosis according to the DSM or ICD, with a duration of more than two years and disability in functioning, the estimated prevalence of people with SMI are at least 0.7% of the worldwide adult population (Ruggeri et al., 2000).

In most developed countries the majority of people with SMI are treated by community mental health services and admitted to a hospital when necessary (Becker et al., 2001). Some people with SMI choose not to ask for help from the psychiatric or the social services systems available to them (Ambition and responsibility, SOU, 2006), either by preference, or because such services are in short supply or not regarded by them as satisfactory. As a result they may go without support or intervention.

Describing the everyday situation of people with SMI living in a community requires gathering the demographic, social, and functional characteristics of this population, as well as their demands and utilization of mental health care and social welfare services (Becker & Kilian, 2006). The role of community functioning in SMI thus necessitates the application of various instruments to

perform an assessment (Bellach et al., 2007). Moreover, it is necessary to measure the situation from the perspective of both the patient and the professionals.

Research on the everyday situation of people with SMI often considers the need for and utilization of psychiatric services. Use and satisfaction with other services of importance for someone with SMI, as social services in the community, and somatic and dental health, might be under-investigated.

This study used an interview supplemented by validated instruments to measure both subjective quality of life and what has been called helping alliance, in order to determine a broader range of support, care, and treatment services people with SMI utilized and their level of satisfaction with the care and support they received.

METHODS

Design

This paper is part of a larger study of support and treatment facilities for people with SMI who live in a community (Nordström et al., 2009). Psychiatric and social services staff members in two of ten districts in the municipality of Malmö, the third largest city in Sweden, were asked to jointly compile an inventory of the people with SMI whom they served, since register data of that population was not available. The first district had a population of 18,000 inhabitants, and the second 32,000. Those inventoried were contacted face-to-face and asked to participate in the proposed study. The objective was to learn what these patients thought their treatment needs were and how they utilized and experienced the services available to them.

Participants

To be included in the study, an individual had to be over 18 years of age, have an SMI, and reside in one of two districts in Malmö. In accordance with the WHO definition, we considered SMI as a diagnosis of psychiatric illness of more than two years duration that also involved a functional disability (WHO, 2001). Participants had to be unable to manage their everyday lives without help from others in consequence of their psychiatric functional disabilities. The assistance required could be either permanent or recurring, but had to continue for at least six months.

The staff compiling the inventory found 153 people who met the inclusion criteria. Forty-three people declined to take part in the study and 30 others could not be contacted by mail or phone, leaving 80 who agreed to participate in the survey. No information concerning the non-participants was available.

Instruments

Questionnaire

Information about the user's life circumstances, the support received from formal and informal caregivers, and satisfaction with such support was gathered by a questionnaire used in a Swedish survey investigating the life circumstances of people with a psychiatric disability (Nordström et al., 2009). The instrument contained 76 items organized in four domains: socio-demographic data and present living situation; support from formal organizations; support from informal organizations; and health and illnesses.

Overall quality of life

The Manchester Short Assessment of Quality of Life (MANSA), *measuring subjective quality of life*, was used to assess overall quality of life (Priebe et al., 1999). MANSA measures 11 life

domains, each of which is addressed by one item. It is administered as a structured interview and includes an individual's subjective rating of general life satisfaction and satisfaction with different domains of quality of life. These include work, finances, social relations, leisure, living situation, security, family relations, sexual relations, and physical and psychological health. Ratings are made on a scale ranging from one (worst) to seven (best). An overall subjective quality of life score may also be calculated. The MANSA has been translated into Swedish and was found to be psychometrically sound (Björkman & Svensson, 2005).

Helping Alliance Scale (HAS)

The relationship between user and contact person was assessed with the Helping Alliance Scale (Priebe & Gruyters, 1993), which has a patient (HAS-P) and a therapist (HAS-T) version. The patient version contains six questions. Five questions are self-rated on a scale from 0 (not at all) to 10 (completely) and ask about receiving the right treatment, feeling understood, feeling criticized, the contact person actively involved in treatment, trust in the contact person, and his/her professional competence. The sixth question "How do you feel immediately after a session with your contact person?" had two possible responses: "worse/unchanged" or "better". The contact person version had five self-rated questions to complete, also on a scale from 0 (not at all) to 10 (completely), about getting along with patient, understanding the patient and his/her views, looking forward to meeting the patient, being actively involved in the patient's treatment, and feeling able to help the patient and treat him/her effectively.

Statistical analysis

All domains of the questionnaire, with the exception of "support from informal organizations" (which excluded from statistical consideration since only five people had agreed to be supported this way), were chosen for analyses in this study.

Items measuring categorical psychosocial variables, care utilized, and satisfaction with care received from psychiatric, somatic, and social services providers were dichotomized into positive and negative values. MANSA, HAS-P, and HAS-T total mean values and the value for an item in MANSA measuring sexual relationships were used for the analysis. Statistical differences between groups were investigated using the chi-square test for categorical values and one-way analysis for continuous variables. The probability level required to demonstrate significance was set to not exceed 0.05. Statistical analyses were conducted using SPSS software.

Ethical considerations

All 123 persons which could be reached and met the inclusion criteria were provided with oral and written information about the study. Those who agreed to participate gave their written informed consent prior to the interview. The data collection from the person with SMI was done by a member of the research team who was experienced in the instruments used. If the person being interviewed requested it, their contact person from psychiatric care or social services supported the interviewee. In order to obtain a more comprehensive picture of the situation, data was gathered from both the participant and from that person's contact whenever appropriate. Each participant selected the time and place where the data collection took place. The researcher who analyzed the data had no affiliation with any of the service providers who supported the participants. The data gathering was done in accordance with the Helsinki Declaration. Permission for the study was obtained from the Regional Ethics Committee in Lund (Dnr 238/2007). There are no known conflicts of interest. The first author certifies responsibility.

RESULTS

User's life circumstances

The mean age of the participants was 47 years (range 19 to 81). Most of the participants (72%) were men, and 87% were single and living alone. Seventy-four percent lived in their own house or apartment, or in a rented place, while 26 % resided in an assisted living facility. The majority, 55% self-reported a diagnosis of schizophrenia, 26% reported an affective disorder and for 19% the diagnosis was unknown. Eighty-four percent of those interviewed were on medication prescribed by psychiatric services. 10 participants reported any use of alcohol or drugs more often than once a week, although no one agreed to have a substance use disorder. The participants' first contact with psychiatric services had taken place on average 18 years previously, (range 1 to 53 years). A little more than half of the participants were engaged in everyday occupations and 61% reported having seen a friend during week before. Half of the participant experienced dental problems, 35% reported *any additional* somatic illnesses, and 9% reported have been subjected to physical violence at some time in the past. Fifteen percent had been accused of a crime in the previous year.

Results from the MANSA Quality of Life Scale

When comparing satisfaction of the eleven life domains measured, we found that living accommodations (mean 5.5), personal security (mean 5.2), the people with whom one lives (mean 5.2), and family relationships (mean 5.0) were those areas that participants said gave them the greatest satisfaction. Sexual relations (mean 3.7) and finances (mean 3.9) were rated by participants as giving them the least satisfaction.

Treatment and support

Our results showed that almost all participants (95%) were receiving psychiatric treatment, a majority (86%) was being treated by a dentist, and 61% received help with activities of daily living from social services. Fifty-four percent of all participants were receiving somatic care.

Of those participants in the study receiving care from psychiatric services, almost all were out-patients. The most common support provided by psychiatric services was medication (87%), followed by advice, psychosocial interventions, and psychotherapy. Forty-eight percent of those interviewed had a contact pattern of once a week; 34 % were seen once each month. Most often those who sought care were treated by a psychiatrist (67%) or a nurse (53%). Of those patients who came in contact with psychiatric services, 77% said they were satisfied with the support they received. The 23% who stated they were dissatisfied with psychiatric services wished to receive more effective medications, more psychotherapy, or both.

A majority (61%) received some support from social services, 85% of these on either a daily basis or several times a week. However, 22% of those receiving support of some kind from social services considered it insufficient and asked for more practical help with daily living instead.

Dissatisfaction with treatment and support received

Thirty-six percent of all those participating in the study expressed dissatisfaction with the care given by psychiatric, somatic, dental care, or social services. Nineteen percent were dissatisfied with the assistance they received from a single caregiver, 13% with that from two caregivers, and 4% with the help provided by three caregivers.

Those dissatisfied with their care showed a significantly lower total mean score on MANSA compared to other who were satisfied with the help they received (4.44 vs. 4.88, $t = -2.320$, $p = .024$). No other significant correlation was found in the total group between those satisfied and dissatisfied with help received in all areas measured.

Dissatisfaction with psychiatric treatment and support

The 23% of the participants who found their psychiatric care inadequate exhibited significantly worse mental and somatic health than those who were satisfied with their care, $\chi^2 = 13.79$; $p < .001$ vs. $\chi^2 = 4.35$; $p = .037$. Furthermore, they showed a lower total mean on MANSA, $t = -3.62$; $p = .001$, as well as experiencing more unsatisfactory sexual relationships, $\chi^2 = 8.18$; $p = .004$. Dissatisfied psychiatric patients also experienced HAS-P vis-à-vis their contact person as less valuable, $t = -2.62$; $p = .011$.

Dissatisfaction with somatic care, dental treatment, and support from social services

Twenty-five percent of those receiving somatic care and 16% of those receiving dental treatment expressed dissatisfaction. Those who considered their somatic care unsatisfactory also experienced unsatisfactory sexual relationships more frequently, $\chi^2 = 8.18$; $p = .046$, while people rating their dental care as inadequate were older, $t = -2.08$; $p = .042$, had worse somatic health, $\chi^2 = 4.33$; $p = .038$, and showed a reduced total mean on MANSA, $t = -3.71$; $p < .001$. There were no differences found in any of the aspects analyzed if the person experienced the support received from social services as unsatisfactory.

Dissatisfaction according to age of user or developmental stage of illness

When comparing users of different age groups, one group containing people up to 35 years of age (11 individuals, 15%) and the other with people 36 years of age or more (65 individuals, 85%), we

found only one significant difference among all aspects measured. Taken the number of years since first contact with psychiatric services as a measurement of the developmental stage of illness showed a difference between the age groups of 8.54 years vs. 22.31 years, $t = -3.49$; $p = .001$. No other significant differences were shown according to the users' diagnosis, life circumstances measured, developmental stage of illness or dissatisfaction with any formal help given.

DISCUSSION

Studies comparing satisfaction with different treatment models in psychiatric services have shown greater satisfaction with assistance provided by community mental health teams as compared to standard care (Malone et al., 2010). However, no studies have been found to focus on satisfaction with care received from different service providers by people with SMI living in a community.

Our study found significant disruption and impairment of an individual's ability to lead a healthy meaningful life in a community when suffering from SMI. For men, who constituted the majority of participants in our study, we concluded, in accordance with earlier studies (Hansson et al., 2002, Wheeler, 2007), that most of them lived alone, were neither married nor in a close relationship, had no daily occupation, and experienced a more unsatisfactory quality of life. The study also showed that people with SMI and psychiatric functional disabilities living in a community may require not only psychiatric care, but somatic, dental, and social services as well. In such a diversified service delivery context, all of them of considerable value for the individual affected, the user's experience of those interventions needs to be assessed from the perspective of each specialized service.

There are some shortcomings in our method of selecting the participants in this study. Only people utilizing psychiatric or social services took part in the inventory. Furthermore, asking those

with SMI living in a community to participate in a study has been shown to lower the rate of participation without individuals giving any specific reason for their decision (Beebe, 2010). Our data collection method, which proceeded from the perspective of people living in the community and not from a clinical psychiatric service perspective, eliminated the possibility of comparing the thoughts of participants using a standardized measure of functional level from a clinician's perspective. Unfortunately, ethical considerations prevented us from obtaining comparable measures from the significant others of participants.

Our findings indicate that a majority of people with SMI experience the care and support they receive as suitable and adequate. However, the one-third of the same population who considered their care inadequate represents a challenge for service deliveries. We recognize that these findings may contain some bias, since people participating in this kind of survey, where they are supported by their contact person in the interview situation, may feel obliged to satisfy the contact persons with the answers they give, since those contacts represent the services under investigation by the inquiry. Thus, some participants may have overestimated their satisfaction with the care they received. On the other hand, the support their contact person provided was not directed toward answering items on the instruments, but was more in the nature of psychological support, which might have increased the possibility of gathering data. We can also presume that users dissatisfied with the care they have been given may be more likely to avoid participating in surveys measuring satisfaction with care received. Nevertheless, our results are an encouraging indication that many people with SMI feel themselves well cared for or, when asked, report their experiences with the existing service delivery system as positive.

We also found that people dissatisfied with the care and support they received commonly experienced a decreased quality of life according to MANSA. The interpretation of this may go in

either direction, since it is difficult to distinguish cause from effect here. However, our findings suggest that dissatisfied individuals may lead more difficult lives. People who were dissatisfied with their psychiatric care also showed poorer self-assessed mental and somatic health, as well as reduced satisfaction with sexual relationships. The latter was especially evident in people who experienced their somatic care as inadequate. These results have been confirmed in recent research, which has found an absence of sexual relationships in people with SMI, in consequence of which they report feelings of loneliness (Wheeler, 2007; Östman, “Low satisfaction with sex life among people with severe mental illness living in a community”, unpublished paper). Researchers and clinicians have previously focused on the shortcomings of interventions supporting individuals with SMI in sexual matters (Bhugra, 2000). Programs that provide support to people with schizophrenia still fail to address matters of sexual relationships (Lehman et al., 2004, National Collaborating Center for Mental Health, 2002). Our findings of somatic ill health among our participants are findings replicated in previous research that has shown people with SMI overrepresented in assessments of somatic ill health, as compared with the general population (Bouza et al., 2010). Moreover, psychiatric patients who have problems with their dental health and the dental care they receive tend to be older and suffer from worse somatic health (Person et al., 2009).

Our findings of a correlation between frustration with psychiatric services and an inadequate relationship with one’s contact person might suggest the value of encouraging treatment relationships to develop into positive bonding, as shown in earlier studies of psychotherapy and other psychosocial interventions in psychiatric services (Norcross, 2008, 2011).

CONCLUSION

People with SMI and psychiatric functional disabilities living in a community have access to not only psychiatric services, but somatic, dental care, and social services as well. The majority of people with SMI in our population indicate that the care and support they receive is adequate and appropriate. Satisfying the minority of those who say they are dissatisfied with the care they receive is a challenge to service providers, but one which, if met, might result in a significant improvement in the quality of life of those individuals affected.

REFERENCES

Statens offentliga utredningar. (2006). *Ambition och ansvar: Nationell strategi för utveckling av samhällets insatser till personer med psykiska sjukdomar och funktionshinder. Slutbetänkande av nationell psykiatrisamordning*. [Ambition and responsibility; National strategy for Severely mentally ill people in Sweden]Stockholm:SOU.

Appleby, L. (1992) Suicide in psychiatric patients, risk and prevention. *British Journal of Psychiatry*, 161,749–758.

Becker, T. & Kilian, R. (2006) Psychiatric services for people with severe mental illness across Western Europe: What can be generalized from current knowledge about differences Provision, costs and outcome of mental health care? *Acta Psychiatrica Scandinavica*, 113,(suppl 429), 9–16.

Becker, T. & Vasques-Barquero, J. (2001) The European perspective of psychiatry reform. *Acta Psychiatrica Scandinavica*, 104 , (suppl 410), 8–14.

Beebe, L. (2010) What community living problems do persons with schizophrenia report during periods of stability? *Perspectives in Psychiatric Care*, 46, 48–55.

Bellack, A., Green, M., Cook, J. Fenton, W., Harvey, P., Heaton, R., Wykes, T. (2007) Assessment of community functioning in people with schizophrenia and other severe mental illnesses:a white paper based on a NIMH-sponsored workshop. *Schizophrenia Bulletin*, 33, 805–822.

Belfrage, H. (1994) Criminality and mortality among a cohort of former mental patients in Sweden. *Nordic Journal of Psychiatry*, 48, 343–347.

Bhugra, D. (2000) Literature update: a critical review. *Sexual Relationship and Therapy*, 15, 193–9.

Björkman, T. & Svensson, B. (2005) Quality of life in people with severe mental illness. Reliability and validity of the Manchester Short Assessment of Quality of Life (MANSA). *Nordic Journal of Psychiatry*, 59, 302–306.

Bouza, C., López-Cuadrado, T., Amate, J. (2010) Hospital admissions due to physical disease in people with schizophrenia: a national population based study. *General Hospital Psychiatry*, 32, 156–163.

Evert, H., Harvey, C., Trauer, T., Herrman, H. (2003) The relationship between social networks and occupational and self-care functioning in people with psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 38, 180–188.

Hansson, L., Middelboe, T., Sorgaard, K., Bengtsson-Tops, A, Bjarnason, O., Merinder, L., Vinding, H. (2002) Living situation, subjective quality of life and social network among individuals with schizophrenia living in community settings. *Acta Psychiatrica Scandinavica*, 106, 343–350.

Lehman, A., Lieberman, J., Dixon, L. McGlashan, T., Miller, A., Perkins, D., & Kreyenbuhl, J.

(2004) Practice guideline for the treatment of patients with schizophrenia, second edition.

American Journal of Psychiatry, 161, 1–56.

Malone, D., Marriot, S., Newton-Howes, G., et al. (2010) Community mental health teams

(CMHTs) for people with severe mental illnesses and disordered personality. *Cochrane Database of Systematic Reviews*, (3).

National Collaborating Center for Mental Health. (2002). : *Schizophrenia: Core Interventions for the treatment of schizophrenia in primary and secondary Care*. London: National Institute for Clinical Excellence.

Norcross, J. C. (Ed.). (2011) *Psychotherapy relationships that work* (2nd ed.). New York: Oxford University Press.

Norcross, J. C., Hogan, T. P., & Koocher, G. P. (2008) *Clinician's guide to evidence-based practices: Mental health and the addictions*. New York: Oxford University Press.

Nordström, M., Skärsäter, I., Björkman, T., Wijk, H. (2009) The life circumstances of persons with a psychiatric disability: a survey in a region in southern Sweden. *Journal of Psychiatric and Mental Health Nursing*, 16, 738–748.

Persson, K., Axtelius, B., Söderfeldt, B. & Östman, M . (2009) Association of perceived quality of life and oral health among psychiatric outpatients. *Psychiatric Services*, 60, 1552-1554.

Priebe, S. & Gruyters, T. (1993) The role of the helping alliance in psychiatric community care. A prospective study. *Journal of Nervous Mental Disorders*, 181, 552–557.

Priebe, S., Huxley, P., Knight, S., & Evans, S. (1999). Application and results of the Manchester Short Assessment of Quality of Life (MANSA). *International Journal of Social Psychiatry*, 45, 7–12.

Ruggeri, M., Leese, M., Thornicroft, G, Bisoffi, G., & Tansella M. (2000). Definition and prevalence of severe and persistent mental illness. *British Journal of Psychiatry*, 177, 149–155.

Scott, J. (1993) Homelessness and mental illness. *British Journal of Psychiatry*, 162, 314–324.

Slade, M., Powell, R. & Strathdee, G. Current Approaches to identifying the severely mentally ill. *Social Psychiatry and Psychiatric Epidemiology*, 32, 177-184.

Wahlbeck, K., Westman, J., Nordentoft, M. Gissler, M. ,& Laursen, T. (2011) Outcomes of Nordic mental health systems: life expectancy of patients with mental disorders. *British Journal of Psychiatry*, 199, 453–458.

World Health Organization (WHO). (2001) *International Classification of Functioning, Disability, and Health*. Geneva: WHO.

Wheeler, A. (2007) Sociodemographic, functional and clinical correlates in outpatients with schizophrenia: comparison with affective disorder. *Australian and New Zealand Journal of Psychiatry*, 41, 809–818.

Östman, M. (2013). *Low satisfaction with sex life among people with severe mental illness living in a community*. Manuscript submitted for publication.