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Low satisfaction with sex life among people with severe mental illness living in a community

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ABSTRACT

Research on the sex lives of people with severe mental illness (SMI) most often focuses on dysfunction and the side-effects of medication. We wished to determine how people with SMI experience sex and assess satisfaction with it in a broader evaluation of quality of life. Data were gathered using mixed methods, including a reliable psychometric quality of life instrument, and in-depth interviews. Sex life showed the lowest rating of all quality of life domains, with men indicating lower satisfaction in this area than women. Low satisfaction also correlated with lower scores on the total quality of life index. Sexuality and intimate relations were generally experienced as out of reach or something of secondary importance that had to be controlled, according to many of those suffering from SMI. Programs such as patient disorder-specific or partner assisted interventions, to increase the possibility of sustaining a sex life might need to be added to existing recommendations for people with SMI living in a community.

1. Introduction

Sexuality is a fundamental aspect of everyday life, even for a person suffering from a somatic or psychiatric illness. Some researches have been done on different aspects of sexuality in people with severe mental illness (SMI), including the psychopathology of sexuality and sexual partnerships. However, such studies have mostly been quantitative in nature, focusing on the dysfunctional effects that antipsychotic medication have on sexuality (Wesby et al., 1996; Bobes et al., 2003; Baggaley, 2008); or, if qualitative, concerned with the impact of SMI on an existing relationship (Östman, 2008; Östman and Björkman, 2013). Clinicians tend to be reluctant to address sexual issues when treating people with SMI (Nnaji and Friedman, 2008), although it is known that a majority of such people experience a dysfunctional sex life (Macdonald et al., 2003; McCann, 2010a). People with SMI point to a lack of counseling on intimate relationships and sex as a serious unmet treatment need (Sullivan and Lukoff, 1990; Segraves, 1998; Bengtsson-Tops and Hansson, 1999). Patients with a clinical diagnosis of schizophrenia or other SMIs require a comprehensive medical assessment, followed by treatment of their health and social needs, including social isolation. They also require access to services such as occupational therapy and vocational rehabilitation in order to return to a state of social inclusion in society (NICE, 2009). However, assessments and recommendations on matters related to sex as part of the total recovery process often do not exist for them. Thus, examining satisfaction with these aspects of life is needed.

The reality of the sex lives of people with SMI living in the community is an under-researched area. Assessing satisfaction with sexual relations as part of other life domains might help us to better understand some of the circumstances under which these people must live. To the best of our knowledge, the everyday experiences of sexuality and sex life have not been studied by a qualitative approach with in-depth interviews of people with SMI, although it would be of importance for developing methods supporting the recovery process.

1.1. *Objectives of the study*

Our objective was to learn how people with SMI living in a community experience satisfaction with their sex lives in comparison to other life domains measured by the Manchester Short Assessment of Quality of Life (MANSA). An additional aim was to use in-depth interviews to illuminate the everyday sexuality and sex lives of this special needs population.

2. Methods

2.1. *Design*

This article is part of a larger examination of support and treatment facilities for people with SMI who live in a community (Nordström et al., 2009). It investigates

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the resources available and the experiences of individuals who use those resources. Our particular concern is with problems in the sex lives of those with SMI. We hope to contribute to research in the area of SMI and sexuality by assessing satisfaction with sex life as a component of the larger measure of quality of life. Mixed methodologies, including in-depth interviews, were used to obtain a comprehensive picture of the sex lives of people with SMI.

Psychiatric and social services staff members in two of 10 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. People who agreed and completed the survey phase were asked for permission to be contacted again at a later time for an in-depth interview concerning their everyday lives, including intimate relations and sexual activity.

All those who agreed to take part in the initial survey were provided with oral and written information about the study through a contact person known to them. Those who decided to participate were asked for written informed consent prior to the survey, and again before the in-depth interview. The data collection was done by independent researchers who were unaffiliated with the interviewee's psychiatric or social services providers. Each participant chose the time and place for the survey and the in-depth interview.

2.2. 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 2 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 6 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 initial survey. No information concerning the non-participants was available. The background characteristics of those who participated in the survey are shown in Table 1.

Thirty-seven of the 80 persons who participated (25 men and 12 women) agreed to be contacted again for an in-depth interview. Ten of those 37 subsequently declined to take part in the second phase and seven could not be reached, leaving 20 people (16 men and four women) for the in-depth interviews. Their mean age was 50 (range 33–82). All were currently in treatment in psychiatric outpatient services. Three were in a relationship with a partner, 11 lived on their own in an apartment or house, and nine resided in an assisted living facility. Fourteen of the 20 received help with activities of daily living from social services.

Table 1
Background characteristics of participant with severe mental illness (SMI) ($n=80$).

Characteristics	*n*	%
Age (mean, range) 47, 19–81		
Gender ($n=79$)		
Men	57	72
Women	22	28
Marital status ($n=77$)		
Single	67	87
Married/cohabiting	10	13
Minor children in family		
Have children <18	28	41
Living with children <18	–5	–6
Living circumstances		
Own house or apartment	28	35
Rented living quarters	31	39
Assisted living in institution	21	26
Diagnosis (self-reported)		
Schizophrenia	44	55
Affective disorders	21	26
Diagnosis unknown	15	19
Medication		
On medication	72	90
On psychotropic medication	67	84
Education		
Primary school	27	34
College	34	42
University	19	24

2.3. Ethical considerations

The investigation concerned an area in which ethical issues are prominently involved. Since sexuality and sexual relations are intimate matters, they are often difficult to discuss with others. Moreover, people with SMI living in a community may constitute a marginal group in research studies, since they are known to be difficult to contact, and thus under-researched.

The collection of quantitative data from the person with SMI was done by a member of the research team experienced in the instruments used. If the person being interviewed for the quantitative data wished it, their contact person from psychiatric care or social services was invited to support them. The in-depth interviews were done without the presence of any staff members. The interviewers in this part of the study had considerable experience treating people with SMI and some familiarity in interviewing people about matters of sexuality.

The researcher who analyzed the data had no affiliation with anyone providing services to those interviewed. 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).

2.4. Instruments

2.4.1. Questionnaire

Information about the life circumstances of each interviewee, the support received from formal and informal caregivers, and satisfaction with the support given was collected by a questionnaire. It was based on an instrument used in a Swedish survey investigating the life circumstances of people with a psychiatric disability that 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 (Nordström et al., 2009).

2.4.2. Satisfaction with sex life and overall quality of life

The Manchester Short Assessment of Quality of Life (MANSA) was used to assess satisfaction with sexual relations (Priebe et al., 1999). The MANSA is administered as a structured interview containing 16 items (four objective and 12 subjective), and it evaluates satisfaction with 12 domains of quality of life. Sex life constitutes one of 12 life domains in the assessment, each of which is addressed by one item. In addition to sex life, these include work, finances, social relations, leisure, living situation, those with whom one lives, security, family relations, and physical health and psychological well-being, and the individual's subjective rating of general life satisfaction. Ratings are made on a seven-point scale ranging from very bad (1) to excellent (7). An overall subjective quality of life score can also be calculated. The MANSA has been translated into Swedish and has been found to be psychometrically sound (Björkman and Svensson, 2005).

2.4.3. In-depth interview

The interview guide used was constructed by a multi-disciplinary group composed of individuals experienced in the treatment of people with SMI, and from findings in earlier studies of people with SMI and their sexuality done by our research group (Östman, 2008; Östman and Björkman, 2013). The proposed interview questions were validated in collaboration with a service user research advisory group.

The interviews took place 2–3 weeks after the survey was completed. It was conducted in Swedish and began with a question concerning the interviewee's experiences of living with SMI. Subsequent questions related to the interviewee's living and work situation, relationships, and sex life. This study focuses only on the questions concerning relationships and sex life. The questions inquired about those who provided support in sexual matters; experience of sex life and what was valued in sexual relations; and factors considered important for an active sex life. Each question was followed up by related questions in the same area. The interview lasted between 40 and 65 min. It was recorded and later transcribed verbatim by the same researcher who had conducted the interview.

2.5. Statistical analysis

In the analysis, participants were categorized into two groups based on how they rated their satisfaction with sex life. Those with ratings from 1 to 4 constituted a low satisfaction group, and those with ratings from 5 to 7 formed a high satisfaction group. Individuals with mixed satisfaction were included in the low satisfaction group in accordance with general practice in this type of assessment (Fugl-Meyer et al., 1991). The other MANSA quality of life domains were only used for descriptive purposes. The overall rating of quality of life was applied as one of the health-related factors in further analyses. Items measuring categorical psychosocial variables, care received, and satisfaction with care given by psychiatric,