

Schizophrenia and Relationships: The Effect of Mental Illness on Sexuality

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Abstract

This paper seeks to investigate the impact of mental illness on the sexuality of patients with a schizophrenic disorder who live in the community in a long-term relationship with a partner. We conducted qualitative, in-depth interviews with five such patients who were in treatment at a psychiatric outpatient clinic, and three of their partners. The data were analyzed by thematic analysis and identified the following areas of concern: relationships outweigh sexuality; uncertainties about one's sexual capacity; the dwindling of sexual fantasies, feelings of desire, and satisfaction; and, a lack of communication and support in sexual matters. Both patients and partners reported feeling overlooked by psychiatric services as sexual beings. They also expressed dissatisfaction with a patient-therapist treatment model that excluded their partners. Our findings indicate that dysfunctional sexuality affects both patients suffering from severe mental illness and their partners. Patients and partners deplore the lack of opportunity to discuss questions related to their sexuality and long-term relationships with psychiatric clinicians. Sexual problems arising from, or exacerbated by, schizophrenia require supportive services, whether in the form of general, psychiatric, or couples therapy.

Key Words: Schizophrenia, Partners, Dysfunctional Sexuality, Need of Support, Couples Therapy

Introduction

Sexuality is a fundamental aspect of everyday life. Over the years, research has shown us the effect somatic diseases, substance abuse, and psychiatric disorders have on the human body and sexuality (1-5). Studies of patients with schizophrenia have generally focused on the dysfunctional effects of antipsychotic medications and their residual impact on sexuality (6-8). A controversial finding that has emerged holds that patients with schizophrenia tend to display less interest in sexuality (9, 10) and greater sexual incompetence than the general population (11), as well as dysfunctionality far beyond the levels found in a normal population (9, 12, 13).

Recent studies indicate that clinicians tend to be hesi-

tant in addressing sexual issues when treating people with a severe mental illness (14-16), despite knowing that the majority of patients with schizophrenia experience sexual dysfunctions as a side effect of antipsychotic medication (9, 17, 18). Furthermore, surveys confirm that people with schizophrenia identify the lack of counseling about personal and intimate relationships as a seriously unmet treatment need (16, 19, 20).

The sexual functioning of people with schizophrenia, the sexual issues they face in long-term relationships within the community and the situation concerning their sexual partners have gone almost entirely uninvestigated (21, 22), despite the fact that approximately 20 to 30% of patients with schizophrenia live with partners for many years (23, 24).

Studies in which informants with schizophrenia are allowed to speak freely about their sexuality are rare and mostly conducted on the premises of inpatient psychiatric institutions (25, 26). The present paper employed in-depth interviews with patients diagnosed with a schizophrenic disorder and living in the community, and interviews with their partners, to learn more about their sexual relationships and experience of intimacy.

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Submitted: September 28, 2010; Revised: February 7, 2011;
Accepted: April 4, 2011

Clinical Implications

We have found that people with psychotic illnesses wish to discuss issues relating to sex and relationships (25, 30). Many researchers have urged that psychiatric services treat issues of sexuality and increase training for clinicians in this area (6, 15, 31-34). To our knowledge, our investigation is the first one to show that although patients with a schizophrenic disease were in long-lasting intimate relationships, sexuality received almost no attention in the course of therapy provided them by psychiatric services. Earlier research has indicated that patients suffering from severe depression and their partners experience similar frustrations (4).

The first step in remedying the situation is to increase the awareness of mental health professionals in this regard, something that can be accomplished by more staff training in sexual matters and greater personal supervision of those providing treatment (22). The increasing documentation of unmet sexual needs should encourage psychiatric and other services who support severely mentally ill persons to develop greater competence in these matters than routine health-care staff possesses. Another possibility may be to refer patients with sexual problems for couples therapy or to other practitioners who offer treatment options that can positively effect levels of mental health. Supporting such couples at an early stage may help them keep their intimate relationships intact, which in turn may have a positive impact on the course of their mental illness.

Methods

Design

The data in this study came from in-depth interviews with patients and their partners at an outpatient psychiatric clinic. All patients who took part in the study had a diagnosis of schizophrenia and were in a relationship that had lasted more than one year with a partner with whom they lived in the community.

Furthermore, surveys confirm that people with schizophrenia identify the lack of counseling about personal and intimate relationships as a seriously unmet treatment need.

Eighteen male and female patients were invited to participate in the study. Five agreed, and agreed as well, to let the researchers interview their partners. Some patients declined to take part in the study because they were unwilling to burden their partners with the interview process. Those who participated gave their written informed consent prior to being interviewed. All participants were interviewed by the second author, who is experienced in sexology and psychiatric treatment.

Participants

Of the five patients who comprised the study group, three were women. They had all been diagnosed with schizophrenia during adolescence or early adulthood, were all heterosexual, and ranged in age from 32 to 41. All of them had

had long-term (4 to 20 years) pharmacological treatment with various antipsychotic medications, had been psychiatric inpatients on at least one occasion, and were all unemployed.

The partners of only three of the patients' partners participated in the study. They were between 33 and 46 years of age and two of them were men. All three reported that they themselves were in psychiatric outpatient treatment for mood disorders, which they said was a result of their long-lasting relationship with the patient.

Main Questions

The interview began with two key questions about the patient's mental illness and how it affected different aspects of the couple's sexuality, including sexual fantasies and intercourse. An additional key question asked if the couple had ever felt a need for support from psychiatric services in sexual matters. Each main question was followed up by a series of related questions. The interview lasted between 45 and 60 minutes. It was recorded on tape with the participant's permission and later transcribed verbatim.

Analysis

The first author analyzed collected data using thematic methodology (27, 28). Preliminary categories were inductively generated from the words of the participants through "the constant comparison method" described by Lincoln and Guba (27). The initial categories were modified until themes had been identified that represented all aspects of the data.

The study was approved by the Research Ethics Committee of the Medical Faculty at Lund University.

Results

Relationships Outweigh Sexuality

All interviewees pointed out that an intimate relationship for them meant having good day-to-day lives with their partner. They valued an existence in which they complemented and helped each other with the activities of daily living. Patients and partners stressed the need to feel closeness, including experiences of hugging and kissing without necessarily having sexual expectations. Some patients said they longed for tenderness but not sexual activity, and said that love meant much more than sexual intercourse.

The patients' narratives told of bad or nonexistent sexual relationships, with some patients and partners having experienced no sexual intercourse at all. Some reported no sexual activity in their relationship for 8 months, 2 years, and even 7 years. Both patients and partners indicated that they had had a much healthier sex life before the onset of the illness. Some patients related with delight how they had experienced sexuality earlier and actively partook in it.

However, one couple told us the opposite. They both reported being able to achieve a much more comfortable sexual relationship as a positive effect of the illness, especially after changing antipsychotic medication.

Partners told us that the most difficult thing in their relationship was to show forbearance with the patient's illness and its consequences, even when the patient isolated herself or himself. Another difficult topic for them to handle was the reaction of some people in the community whose comments stigmatized both the patient and the partner.

Patients and partners said that their relationship had evolved from a sexual union to one of a very different kind. They spoke of themselves living together as siblings or friends.

Uncertainties about One's Capacity

The narratives of patients often included worries about being unable to lead a life in which healthy sexuality played a part. They wondered whether they still had the capacity for sexual activity and could give their partner satisfaction in a sexual relationship. They questioned how their partner would react to them physically, and expressed their own feelings of discomfort with the sexual act. Some found themselves unattractive due to weight they had gained as a side effect of their medication; they spoke of their inability to make themselves attractive by means of clothing or cosmetics. Narratives also articulated the insecurity that accompanies the feeling of being different from other people.

Patients often expressed their desire to behave more actively in sexual encounters. Failing to achieve this, they then wished for partners who were more active. If both partners

fell short, there was no sexual intercourse. Some patients told us they were sure their partner avoided having sex with them because of their severe mental illness and the effect it had on their everyday lives. Their partners conceded this was true, speaking of how hard it was to have any sexual feelings at all when everything in their world was upside down. Some partners confessed that they stayed in the relationship only because there was nobody else to take care of the patient.

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Sexual Fantasies, Feelings of Desire, and Satisfaction

The patients we interviewed experienced a failure to achieve satisfaction during sexual intercourse. Some longed for the ability to achieve orgasm. Others claimed that they were incapable of feeling anything at all: neither desire nor satisfaction, whether they were aroused or not. One patient, who had been sexually abused as a child, told of how those experiences had impacted her thoughts and behavior, leaving her with feelings of inappropriateness, dirtiness, and embarrassment about sexual matters. Patients occasionally stated that they no longer felt they were sexual beings. Some spoke of even having no interest in masturbation.

Partners said it was easier to masturbate for their sexual and physical needs, although it was not seen by them as a way of achieving sexual fulfillment. Some longed to find that satisfaction outside the present relationship. The issue of masturbation, as well as repugnance toward engaging in sexual activity with the patient, gave rise to bad feelings about their relationship in general.

With only one exception, all the patients and partners interviewed confirmed the negative side effects of antipsychotic medications on their everyday lives, including their sexuality. They spoke of lacking sexual desire and of dysfunctional sexuality during intercourse, citing problems with erections, orgasms, and attaining satisfaction.

Communication and Need for Support in Sexual Matters

We found that patients and partners do not regularly communicate with each other about issues related to their sexual relationship. However, patients have said that they do speak with close friends and relatives about their sex life and their feelings of dysfunctionality. Both patients and partners

indicated that they tried to raise the problem with psychiatric services during regular treatment sessions without any response on the part of clinicians. They report that even when they are residing at inpatient psychiatric wards, issues concerning their sexuality are avoided. Both patients and partners clearly expressed the desire to speak with someone about these matters because they realize their sexual problems influence their mental health and their lives as a whole.

Both patients and partners wished for access to treatment regimes in both inpatient and outpatient psychiatric settings where clinicians would speak forthrightly with them about their sexuality, and not simply be content to diagnose dysfunctional patterns. Partners especially said they would welcome integrating both individuals in the treatment plans *as a couple*, because their lives were already so intertwined with each another, and in one way or another they were both living with the illness.

To our knowledge, our investigation is the first one to show that although patients with a schizophrenic disease were in long-lasting intimate relationships, sexuality received almost no attention in the course of therapy provided them by psychiatric services.

Discussion

Our study has shown that the complications resulting from dysfunctional sexuality not only affect the person with schizophrenia but also his/her sexual partner. Data from our study accord with earlier research (29), indicating that the impaired relationship between patients and partners as a consequence of schizophrenic illness may evidently influence the partner's desire and ability to engage sexually with the patient.

Partners spoke of how trying it can be to remain in a long-term sexual relationship with a person diagnosed with schizophrenia, and how the illness may bring about the end of the sexual relationship. We also learned that patients and their partners received little support from psychiatric services, particularly with regard to non-drug related issues, when dealing with sexuality and long-term relationships, as has been noted by earlier research (4, 26).

Earlier studies (13) confirm our findings that both patients and partners experienced a decrease or cessation of sexual fantasies and erotic dreams as an effect of schizophrenic illness. However, we also received reports of erotic dreams and sexual fantasies, mostly from partners, and these were often focused on situations outside the relationship with the patient.

The connection between the doubts expressed by our schizophrenic interviewees over their sexual competence, their worries about whether they were considered adequate sexual partners and the fear of being worthless is found in other studies (11).

In an earlier research investigation (4), we tried to discern the factors influencing the sexuality of both patient and partner where the patient had been diagnosed with severe depression and was in need of inpatient care. We found similar effects as in the present study with regard to sexuality and relationships between patient and partner, but the interplay differed from that shown in the present study. Patients with a diagnosis of depression actively (and often aggressively) turned their backs on their partners, leaving the partner "turned off" sexually. Some partners adopted a wait-and-see attitude, leaving it up to the patient to take the initiative in sexual matters. In the cases of patients diagnosed with schizophrenia, however, the partner was the one expected to initiate sexual activity.

The Attitude of Mental Health Medical Personnel

We have found that people with psychotic illnesses wish to discuss issues relating to sex and relationships (25, 30). Many researchers have urged that psychiatric services treat issues of sexuality and increase training for clinicians in this area (6, 15, 31-34). To our knowledge, our investigation is the first one to show that although patients with a schizophrenic disease were in long-lasting intimate relationships, sexuality received almost no attention in the course of therapy provided them by psychiatric services. Earlier research has indicated that patients suffering from severe depression and their partners experience similar frustrations (4).

The first step in remedying the situation is to increase the awareness of mental health professionals in this regard, something that can be accomplished by more staff training in sexual matters and greater personal supervision of those providing treatment (22). The increasing documentation of unmet sexual needs should encourage psychiatric and other services who support severely mentally ill persons to develop greater competence in these matters than routine healthcare staff possesses. Another possibility may be to refer patients with sexual problems for couples therapy or to other practitioners who offer treatment options that can positively effect levels of mental health. Supporting such couples at an early stage may help them keep their intimate relationships intact, which in turn may have a positive impact on the course of their mental illness.

As with most qualitative research, concerns regarding the generalization of data are secondary to the understanding afforded by an in-depth glimpse into the experience of

each participant. Furthermore, our results are not recommended for application beyond groups of clinically stable outpatients in long-term relationships.

Supporting such couples at an early stage may help them keep their intimate relationships intact, which in turn may have a positive impact on the course of their mental illness.

Although the sample in this study was very small, the method chosen sought to give a voice to patients and partners in a way seldom afforded earlier. As one participating partner declared, “Maybe both our sexuality is more intertwined with the schizophrenia than we may ever express or admit.”

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