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Abstract: In this study, three male patients suffering from psychosis were interviewed about their experience of sexuality. The interviews were analysed according to thematic analysis. The mental illness had radically changed these men’s lives including their sexuality. They found sexuality important but mostly a need that was not sufficiently satisfied. Obstacles of forming sexual relationships were manifold and a social withdrawal, a harmed self-esteem, an uncertainty about who you are and what the other wants, a feeling of not being like others, a feeling of not being sufficiently masculine, a decreased drive, and not least, a tendency to turn away from reality came through. They also expressed a strong wish to get the opportunity to talk about sexuality in a meaningful and respectful way. Consequently, there seemed to have been a neglectance from the health care to address issues about sexuality. When it occurred, it was in a pedagogic way, often about side effects of medication - disregarding other crucial obstacles in forming sexual relationships. It is important to take all obstacles into consideration, otherwise a perchance well-intended intention to bring about a better sex life for this group could eventually completely miss the mark.

The field concerning patients diagnosed with psychosis and their thoughts about sexuality has not been deeply explored. Most studies in this area fall into the category of finding out what hinders this group to establish a decent functioning sex-life. The held idea is that a lot of patients with this diagnose stop to medicate because of side-effects including problems in the area of sexuality. There is, as far as known to the author, no Swedish study which explore this group’s own experience of sexuality. It is an important issue not least because sexuality is at the core of human life. A bit surprisingly, psychiatry, compared with other medical disciplines, has generated little data about sexuality of their patients (Friedman & Harrison, 1984). The various factors that eventually influence sexual relations among people with severe and chronic psychiatric disorders have been almost uninvestigated (Maurice, 2003). Even though the sexual needs appear to remain marginalized and neglected among this group, there is an increasing awareness that it is a justifiable concern for the mental health care (McCann, 2003).

In summary, findings in this area are partly contradictive. Some like Rozan, Tuchin and Kurland (1971) as well as Akhtar and Thomson (1980) conclude that the sexual functioning in the group of patients with schizophrenia differs from those not suffering from the illness both qualitatively and quantitatively. Some studies have reported that schizophrenic patients are
more likely, to have an autoerotic behaviour, i.e. masturbation, as their primary sexual activity. However, overall less sexual activity are reported compared to non-clinical groups. Furthermore, schizophrenic patients' sexual activity also drop earlier than normals which peaked around midthirties. This group’s sexual activity decrease progressively after adolescence (Nestros, Lehman, & Ban, 1981). Some studies have found that the relationships of people with schizophrenia are characterized by less intimacy and commitment than those in the general population (Brea & Wright, 2006). In contrast to this, some studies have found that the illness in itself does not diminish sexual desire or sexual activity, although psychotropic medication and hospitalization may limit both. A huge problem is alas the quality of sexual activity in this group, due to difficulties in forming relationships, poor judgement, lack of impulse control and high rates of comorbid addictions like alcohol and drugs (Kalichman, Sikkema, Kelly, & Bulto, 1995). One should also bear in mind that a psychosis often contains many bordering problems such as obsessions, strong negative emotions, cognitive difficulties, and not least a depressive symptomatology. An additional obstacle to express sexuality are experiences of abuse and childhood trauma that this group of men and women has encountered disproportionately more often compared to the general population (Jacobson, 1990). Due to the still prevailing societal stigma, people with mental illnesses lack some of the self-confidence and self-esteem that is needed to establish intimacy with others (Henley, 1994).

There are huge differences between women and men among this group. Women have overall a better social functioning, they have sexual relations, are married, and raise children more often compared to men in this group (McGlashan & Bardenstein, 1990). The other side of that is that women with schizophrenia compared to those demographically comparable women without any mental illness are at a high risk to experience negative or harming sexuality. Women with schizophrenia run a higher risk being victims of sexual assault, they are more engaged in sex-exchange behaviour, they also have more lifetime sexual partners, and they are less satisfied with their sex life. Consequently, a common pattern is that women generally have problems within close relationships and are exploited, while men become isolated (Miller & Finnerty, 1996). Subsequently, the complaints among the women focus on the quality of past and present relationships and among the men the complaints focus upon isolation (Bhui, Puffet, & Herriot, 1995). Many studies in this area comes under the epithet risk-avoidance research, as an aftermath of a focus on HIV. Moreover, females in this group have also an increased tendency to expose themselves to unprotected sex with high risk partners (Buckley, Robben, Friedman, & Hyde, 1999). In this paradigm, sexual behavior becomes a symptom to be cured (Pinderhughes, Barrabee, & Reyna, 1972). Parallel to this many clinicians believe that individuals in this group are asexual (Buckley et al., 1999).

The deinstitutionalization in the 90s changed the social arena for this group of patients. Earlier, institutionalization decreased the sexual activity by discouraging and even prohibiting sexual relationships. Living in the community, increase the opportunities for sexual encounters (Nicholson, Geller, & Fisher, 1996). Patients have described a feeling of having been abandoned by the psychiatric care, due to that no support or treatment initiative has focused on questions about sexuality. There is thus a need to increase awareness about these issues among those who work in mental health care and questions concerning sexuality have to come to the fore (Östman, 2008). One can then according to several authors (Dincin, 1995; Bhui & Puffet, 1994; Lukoff et al., 1986) overcome or minimise these concerns through educational and cognitive interventions such as explicit sex therapy, role playing, modeling, practical assistance with social skills; this to overcome sexual dysfunction and to enhance intimacy skills.
According to Kelly and Conley (2004), the sexual functioning in this group, as an aspect to take into consideration in the care, has not been recognised enough. Earlier, an idea existed which prevented a constructive attitude. This attitude consisted of a belief that sexual activity could contribute to the development of schizophrenia (Pinderhughes et al., 1972). Clinicians often therefore hesitate to ask the patients of potential sexual problems. However, patients are most eager to talk about these issues if the clinician raises them (Wasow, 1980) and this group has a great need of counselling about intimate relationships (Bengtsson-Tops & Hansson, 1999). Furthermore, 75 percent of those suffering from a severe mental illness thought that it would be beneficial to discuss sexual issues (Lewis & Scott, 1997). A lot of studies are primarily built on quantitative data describing sexuality in the group of schizophrenics. It could be supposed that for many in this group it is a challenge to articulate themselves concerning sexuality. Findings point to that this group lack a basic vocabulary to discuss sexuality, and they also seemed to have many misunderstandings of sexual anatomy and physiology (Rozensky & Berman, 1984). The educational efforts made to remedy this deficiency has been successful in the short term, but without reinforcement, the acquired knowledge and abilities diminishes over time (Kalichman et al., 1995). Moreover, to study this patient group’s experience of sexuality is surrounded with obstacles. The reluctance to talk about sexuality and especially with this particular group seems to be difficult (Pinderhughes et al., 1972).

Another aspect is the impact of antipsychotic medication on sexuality, and it is known that medication causes sexual dysfunction as a side effect for a majority in this group. Several studies focus this dilemma starting with the report of Shader and DiMascio from 1968. Researchers in clinical field have an interest in trying to find strategies to handle those sexual dysfunctions which contribute to the low compliance with antipsychotic medicine. Like in all these issues you can not certainly establish the order in what things follow, what causes what. Most studies report that antipsychotic medicine causes problems with libido, arousal, and orgasm (Sullivan & Lukoff, 1990). However, there are also findings, that even before the onset of illness, there exists a diminished interest to form sexual relationships among those who later on develop the disease (Rowlands, 1995). Few studies concern the second-generation antipsychotics, however, they are supposed to cause less sexual dysfunction than the first generation antipsychotics (Kelly & Conley, 2004). Furthermore, it is quite frequent with prescription of other psychotropic drugs parallel with antipsychotics, for example antidepressant that also has documented side effects on the libido (Balon, 2006).

Method

Participants

The participants were diagnosed (according to ICD-10) by professionals in the health care system with schizophrenia, unspecified psychosis, and cycloid psychosis, thus variations under the broader heading psychosis. At the time of data collection they all had ongoing treatment in the psychiatric care. They were all men and lived in the western part of Sweden. They were 23, 38, and 41 years old. One was presently living in a relationship, one had had a few relationships, and the third reported very few experiences of sexuality in relationships.

Interviews

The study has a qualitative approach where the material was gathered from three semi-structured interviews. I partly followed an interview-guide that I had formulated according to
my preconception of the area, and of my reading of former studies in the field. The interview dealt with the participants’ thoughts about sexuality, and their experiences of sexuality. In the interviews, I had to improvise fairly often to facilitate their speech; my ambition was that the participants should talk freely and open-ended about their thoughts and feelings about sexuality.

**Procedure**

First I contacted those colleagues that I knew worked with the group in question, and I asked them to inform those who they thought would like to participate in the study. The colleagues were asked to inform possible participants about the study, about 15-20 patients were asked to participate in the study. A letter of information was prepared to be given to the patients. Those who were interested were asked to contact me for an interview. It was stressed that it was totally voluntary to participate. No incitement to participate was offered. Five contacted me, two changed their mind and cancelled the interview. Three participants showed up and the interviews lasted from 50 minutes to 1.15 h. The interviews were conducted in Swedish, transcribed and then translated into English. Before starting the interview I informed them of the preconditions and had their consent to follow through with the interview. After the study’s completion they were promised to have a copy each. No one was manifestly psychotic at the time for the interview, a consent in that situation would have been unethical. One interview was conducted at the Department of psychology at the University of Gothenburg, the other two interviews at the psychiatric care where the patients were recruited.

**Analysis**

The material were analysed according to thematic analysis, which is an analytic method frequently used within psychology (Roulston, 2001). Its main objective is to discern themes and patterns within a material; i.e. a structured method to identify and analyse themes within data. It is a method that can be applied within different theoretical frameworks and epistemological approaches, and is a fairly flexible method used to report experiences, meanings, and the reality of the participants (Braun & Clarke, 2006). The discerned themes capture something substantial in relation to the area covered, it contains some level of patterned meaning or response within the data set. In other words it captures something valid and important in relation to the research question. How important the prevalence of each theme is within the data set depends on the question asked and can not be regulated beforehand. The analysis was done in an inductive or bottom-up way. This form of thematic analysis is data driven and not driven of a theoretical interest. The themes are strongly linked to the data themselves (Braun & Clarke, 2006). However, depending on the area there was also a minor expansion in to interpretation on a latent level, a smaller excursion to a reflection of the themes, their broader meanings, and implications.

The analysis in this study could be described in the following different steps. After transcription the material was read closely and carefully, all possible themes and patterns, large and small, regardless of substance and importance were noted and identified without trying to fit the data into a pre-existing framework. The different codes were organized and structured into subthemes. The data were then reviewed too see whether these themes fitted the data, the themes were then adjusted accordingly. A preliminary naming of the different themes were then made, some names were subsequently modified by a closer examination of the material. The material was then sorted under the different themes. The material that either fell outside the study's interest or was too unclear to be of usage was at the time being sorted
under an additional category and reviewed then repeated times to ensure that nothing was dismissed which could be relevant. The subthemes were then organized in two major groups, becoming main themes capturing the whole material. Following this descriptive analysis, the themes and sub-themes were conceptualized in more psychological terms to see if it provided a deeper understanding of the transcripts. Lastly, the transcripts were reviewed to find the examples that illustrated the essence of each theme.

**Aim**

The aim of this study was to examine what male patients suffering from psychosis told about their experience of sexuality, and to explore the variety of opinions about sexuality in general as well as experiences of their own sexuality.

**Results**

An overview of the themes that emerged from the interviews are shown below (table 1.), thirteen sub-themes were divided in two main themes.

<table>
<thead>
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<th>Table 1. Themes and subthemes</th>
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**A harmed sexuality**
- 1.1 Phantasy replaces reality
- 1.2 Uncertainties
- 1.3 Difficulties in understanding the other
- 1.4 A wish to be like others
- 1.5 Uncertain about one’s masculinity
- 1.6 Satisfying the other
- 1.7 Loneliness
- 1.8 Lost desire

**The importance of sexuality**
- 2.1 An unfulfilled need
- 2.2 Satisfying myself
- 2.3 Hopes and expectations
- 2.4 The fear of approaching
- 2.5 Difficult to talk about

1. **A harmed sexuality**

Something that the informants agreed upon was that their mental disease had radically changed their lives including their sexuality. This was in a negative way by feeling for instance less drive, partially due to medication, social withdrawal, lower self-esteem about their ability to conquer what an ordinary man normally should be. Other aspects that were related to their illness also affected sexuality. The imagination sometimes prevailed and reality came into the background. An uncertainty about who you were and what the other wanted also complicated as well as a feeling of not being like others, not being able to fulfill the other’s expectations, and not being sufficiently masculine. Furthermore, an involuntary isolation as a result of the disease was an obstacle to form relationships.
1.1 Phantasy replaces reality

It is interesting and crucial to see how the characteristic of the schizophrenic – not sharing the same reality - was reflected in the informants way of speaking about sexuality. It thus happened that phantasy partially replaced reality. Phantasy took the place which originally was given reality; reality which otherwise had the property to correct and adjust the inner psychical life.

“It was just fantasies about her, I was thinking if she could come home to me, and then we could be with each other. Sometimes I talked to her, I liked her character and so, it was fairly innocent things. But she did not talk back, she said nothing really.”

There was an obsession about specific women, a preoccupation out of proportion - if one can use such an expression when talking about love - which by definition is disproportionate. However, the informants described an excessive emotional investment in someone they had only fleetingly met. In that situation they were completely at the mercy of their own imagination, it made the reality of their lives draped in their desires and preconceptions. This turning away from reality also harmonized with a lack of experience of earlier sexual encounters and love relationship, where reality could come in as a corrective. The phantasies increase, when you are alone, as the saying goes.

“I courted her at a distance, I never knew where she lived, I did not know anything about her. I was really in love, but it became insane, completely insane. I cried because I had an unfortunate infatuation.”

1.2 Uncertainties

Overall, a disorientation was expressed by the informants, regarding what a relationship meant, what it could mean, what expectations the other one had, and also uncertainty about what they themselves wanted. These general human problems were magnified out of the uncertainty about themselves, life, and the others’ expectations and needs.

“Because I have not found the right one, or found the right way.”

In a sexual encounter, the individual has to rely on it’s own fantasies and personal world, it’s individuality, and idiosyncratic world. The three men could not rely on and be comfortable with that in a natural way, they could not assume that their inner world would lead them in the right direction trusting that everything will end up right.

“I can not, I do not know what to do and then there will be anxiety, a bit tense.”

1.3 Difficulties in understanding the other

The difference between reality and fantasy was not always clear-cut when it came to love. For everyone a part of love includes and requires that this border becomes blurred but here it was sometimes that much in the foreground that it hindered the realization of a relationship.
“I found it difficult to interpret their intentions, there were small promises that I might get a chance, but I might have been too optimistic. There was a girl that just swept my feet away. I really wanted her, after that I was crazy about her for two years. I thought of her for two years, before I finally could get her out of my mind.”

There were a lot of misunderstandings of the other, of the intentions shown, what others wanted. Sometimes these misunderstandings bordered to insanity. They had an idea how it should be, and then the other abruptly and obviously proved to be a real person and not an imagination.

“You have an idea how it should be, but in reality it is in a different way, one's partner might be in a certain way, so I just have to adjust to the other one too.”

The men also expressed difficulties in identifying what others wanted and what they craved. Their own fantasies seemed to have been given priority since experiences with others had been sparse.

“It has been a bit difficult for me to understand their sexuality, what they like and so, the thing is, I do not talk so much about this with others, and I'm not talking so much with my partner either, so it is difficult, yes.”

To have an idea about what people commonly think and feel obviously demands knowledge of others, which was sometimes like a blank slate.

“I do not know what it is to be normal, I do not know how sexuality is for other people, I guess the majority is very active and meet a lot of partners.”

1.4 A wish to be like others

There was a strong urge to be like others, and the men talked about themselves as “being in the margin”, and as not belonging to an ordinary human context.

“It feels like a setback when others talk about their love-life, I get a bit excluded, but I laugh with them and join the talk, and pretend that I am not excluded. No one knows that I do not have any experience.”

The men expressed a longing for normality in its own right. It seemed as that they had an idea that one wants to conquer the normality on the basis that one is excluded from it. There was also a feeling of exclusion by not having any sexual experience, then obviously the solution to the exclusion was to gain the required experience.

“It was a pity that I never hit it off with a girl, I would like to become a full man, normal, but I have no good contact with girls.”
The “project” was also uncertain not just because lack of experience but also by a freight to be perceived as being abnormal. Their attitude towards abnormality and others’ sexual orientations and preferences was relatively open-minded, in contrast to a harsher attitude to their own sexuality and identity.

“It is clearly okay with all kinds of sexuality, it would not be excluded, it's all about love, it's just that, you do not need to like or accept everything.”

Clearly, however, was that they also wanted to highlight that they did not belong to any minority group. This attitude was used, possibly in order to guarantee themselves a place among the non-deviant, to secure a place among the normal, i.e. the heterosexuals.

“I think I am pretty normal in comparison with others, perhaps.”

However, there was also some expressions of ambiguity concerning gender identity, which perhaps was a consequence of experiences from having been in a psychotic state. To be in a psychotic state could result in a general lack of clarity in who you are, who the other person is and where the lines between reality and fantasy are.

“I like girls, but sometimes I get scared that I like guys too much, but I do not, I work mostly with men, then maybe I like to talk mostly with men, and I forget that there are girls. Girls are really softer and kinder, that suits me, they could make me whole, the case is just to find one.”

1.5 Uncertain about one’s masculinity

Psychosis could also be described as a failure in establishing manhood, since autonomy, power, strength, and success often are attributed to being a man. These informants tended to do the same.

“There are so different definitions of what it means being a male, sometimes I think, I'm too wimpy then it comes to things, some guys are very dominant, they have very masculine jobs. Then I wonder if I have what it takes.”

Consequently the image of manhood is not compatible with being sick and not self-supporting. Due to the hunger for love, the men tried to find out what the women wanted, and then they wanted to become that desirable object, they would like to be what the other wanted. This is in a way, traditionally, a more non-masculin and vulnerable position, which also made their search for love more strenuous. It is clear that the one informant that did not solve it in this way was also more satisfied with his love life. Two of the men had no experience of being confirmed as a unique valuable partner by previous satisfactory love relationships. They described the disease as a clear rupture in their sexual life, as well as in their overall life. This rupture happened so early in life that it seemed as these men had no already conquered sense of masculinity to return to. A concern that often came to the fore was to be sufficient, even though this is a human issue it was accentuated for these men by a sense of exclusion due to the illness. Another hindrance that was mentioned was an experience of an inability to give, and therefore not wanting to engage in relationships.
“That was while I was sick, I felt that I could not give her what she wanted, the emotions and the attention and the time.”

In two of the men’s experience the idea of the woman, based on these men's loneliness and lavish fantasy, took fantasmatic and frightening proportions. Specifically, there was a fear of not being a real man. As a shelter they held on to “typical” ideas of what it means to be a manly man.

“I would like to feel more like them, the manly men, but I feel like a man anyway. They have something I do not have though.”

1.6 Satisfying the other

A recurrent concern was the wish to satisfy the woman they were together with or fantasizing to have, and the insecurity and worry of not fulfilling that mission.

“The important thing for me is that I feel appreciated, that my partner thinks it is satisfactory.”

There was a worry not being able to perform. There was also an uncertainty about what sex should contain, and what was important for a woman.

“I know how to do it, how to have sex, but then there's good and bad sex. Then I can imagine, we've known each other for quite some time, I have heard stuff about her sex life and then you get cold feet, I would not be able to perform.”

The men also described that when the woman had a lot of experience, and themselves less experience, the claim and requirement was increasing, leading forward to an increased insecurity, and subsequently the whole enterprise got scary. Uncertainty about being able to fulfill the woman’s expectations, was leading to anxiety about the performance.

“She has more to compare with if she has been with other men.”

More crassly and prosaic, there also existed an anxiety of not getting erection, and not being physically sufficient. Due to various factors, including medication, there were experiences of failure.

“It was bad experiences, I could not satisfy them, they were disappointed, I felt bad about that.”

Such experiences lead forward to an unsecurity about future possible sexual relations.

“That I should not get an erection, that worries me, I think that it will resolve itself, but you never know.”

1.7 Loneliness
These men reported a self-inflicted loneliness during the illness, and described how hard it was to regain the social life afterwards. However, even before the sickness they described feelings of loneliness.

“I have had very little contact with girls, I have always been shy, that's clear, I have had the chance to spend the night with a girl on two occasions, but then, it has become complicated. It has not been successful.”

Because of this loneliness they did not find someone to talk to about personal issues, such as sexuality.

“I guess there is someone that is close that I can talk to about it, probably, but I have not so many close friends, I do not know.”

There was a frustration and disappointment due to feelings of loneliness, and feelings that what they longed for may not be possible for them to get. Overall, there was a great loneliness in two of the informants’ life, solitude on many levels, not least, the solitude of being in a world that was not shared by others; a private world. One informant felt something was missing even when he was in a relationship.

“I've had a few sexual relationships but I've never felt that I had someone that it was for real with.”

When they talked about loneliness, the desire for a relationship came to the foreground, and the longing for sexuality dropped to the background.

“It is clear that I want to have sex with her, that's an objective as well, but I feel I want a love relationship with her, which then develops into something more, that is how I feel.”

All of the men had experiences of isolation, specifically during the worst outburst of illness. They described it as paranoia and they found it hard to be where others were.

“I did not get out in the same way, I met hardly any people in the beginning when I was sick, the first 6 months, I met almost no one.”

More aggravating was, that they did not recover what they lost during that period, and they found themselves very lonely. Due to this, the social situations where one can meet a partner decreased.

“Sometimes I think I recovered some of what I lost, but many of those phobias still remain, to dwell among a lot of people where it is messy and cluttered, and perhaps make contact, to create new contacts takes energy. I have not really the stamina anymore.”

There were also worries about not handling the social skills, and there was a fear that if they would talk about what occupied them they would be seen as boring. Two of them feared that they seemed too moody and pensative for girls to like.
“I'm a little worried that I seem depressed and like that, I will try to be happy, maybe she thinks I'm too ruminating, they might think I'm religious, it's not good”

1.8 Lost desire

The men described a desire that had been lost because of various reasons, such as an overall tiredness, a numbness, and an impaired self-confidence

“I feel less sexually aroused nowadays, I think that is because my self-confidence and hope have deteriorated.”

The fatigue also affected the chances of being there when it happened, and they thought that the forming of relationships often took place late at night.

“I like to fantasize about women but so little happens these days, I want to go out and meet people and girls, but I get too tired, I go to bed early, everything happens just so late in the evenings and weekends, before 9-10 pm no one is out and, I go to bed at that time. It makes it harder for me, I am not there when it happens.”

One reason to a lost desire was that medication had affected sexuality in a negative way. They reported that they felt less overall, a general tiredness, dullness, and numbness both psychologically and physically.

“I do not think I had much pleasure in anything at all then, but it all came back later when I wanted to meet someone. I can not remember exactly when it was, but there was a change in my desire and willingness, surely it was.”

The men had problems in performing while at medication. They described how they became more or less impotent when falling sick and receiving medication. In addition, the effects of the disease, became even worse when this area of life also was lost during the periods of illness.

“When I am sick I am not sufficient so to speak, can not perform, and my partner feels bad about that. She misses it. But I have no drive, the medication makes it hard to function. Then it takes a while before it will start again after stopping medication. It does not work when I take medication.”

However, the illness in itself also caused problems with sexuality, hallucinations for example could at times exclude all other interests, also sexuality. They also described how the medication made them put on weight, which added some further uncertainty in approaching a partner. Lastly, deteriorated ability to erection caused a sense of failure and embarrassment, and prevented them to explore a relationship further as well as being comfortable with one’s own sexuality.
“I do not know if it's my fault, the desire has been around. /.../ I had no bodily response, it was just meat.”

It was also accentuated that it was not due to the fact that the attraction was not there.

“I can not blame it on the girls, they were nice, they were normal girls.”

In this theme a number of aspects were in the foreground and predominating. Sexuality requires trust; of your body, of your desire, and of the other one. The men described that the trust was spoiled, damaged, and ruined. There seemed to be a paradox in which these men had ended up in, as they had through periods not shared the same reality as others. Consequently, the isolation caused feelings of not belonging to others, and in that way they had not access to others' points of reference balancing their own. Recurring was that the imagination came to the fore, and there was thus a reduced possibility of creating a good and rewarding reality. There existed an inner drama that did not reach the outside world. In addition, they often were exploited because they were starved of human contact and love. This starvation tarnished their judgment, which in turn led to ending up in destructive situations. They talked about missing an important period in their lives due to the fact that the onset of the illness coincided with the period when most people are making their first sexual experiences. However, during that time they were limited by the disease, and missed this opportunity.

2. The importance of sexuality

Sexuality was an issue that was important to them, which they often thought about even if they did not talk with anyone else about it. The hope remained to find someone, and to be able to initiate a rewarding relationship. No one had really thought thoroughly about what it meant to have children, regarding pregnancy as a result of sex. They meant that things had to work out and be sorted before they were ready for being parents. The material also revealed that health-care had not noticed sexuality as an important area for the patients to talk about. They expressed that sexuality was an area that was difficult to talk about. The two men that did not have a regular sex-life thought about this more or less constantly, and their expectations were loaded with magic. Consequently, they expressed a lot of thoughts, dreams, and imagination about sexuality, mostly alas tinged with a negative feeling. A number of things came to the fore; they found sexuality important but often a need that was not sufficiently satisfied. There was a longing for something to happen that very rarely actually did happen. Other obstacles were an inability to initiate romantic relationships, and a fear to make themselves vulnerable to anyone else.

2.1 An unfulfilled need

They talked about sexuality as something central, as a natural part of life, something desirable but also something that had become conflict-laden. It was loaded with magical beliefs about what it would mean.

“Those who feel sexual I think have a richer life, they experience the days as brighter and the nights as not so dark, those who have that life. Everyone needs body contact. It is important to touch, I get hugs from my mom and it helps, of course, but it's not sexual.”
The longing for sexual experiences was alive, and they had hopes that these fantasies would come true. The man who had no sexual experience felt odd about that. However, he expressed a strong belief that he would find someone that would understand him and be attracted to him.

“Being close to someone would mean a lot of positive things, surely you will get more energy and become clearer in the head, more energy to get off to work in the morning, everything like that, it's things you imagine, maybe it will happen to me too, it will surely happen to me too, then it has to be that both like each other, otherwise it will not lead to hugs and the sexual things.”

The sexual part had been both a pain and a joy. They also expressed mixed feelings towards the fact that it had become too important, not least based on a lack of a regular sex life.

“I might have been looking for it too much, it has occupied much of my life and my thinking, all around sexual relationships, since I was little.”

When they thought of sexuality, they tended to see what was missing, they focused on a need that was not saturated, but also how the need of sexuality changed over time into a more anxious need to have a good relationship.

“Then of course my sexuality has changed over the years, previously it was about showing my love in bed, that was the main thing. I was showing my love that way, but as time has passed I do not feel that it is so important anymore, it is more important to have a good and open relationship, that is love, it can be just as important as having sex, perhaps more important.”

They also described sex as a tension that needed release, and they expressed a view of sexuality as something quantitative, something that builds up and needs a relief.

“I've also noticed that if I do not do it for a while, for instance when I am away, I become more charged, more aggressive maybe, there is a difference in myself, I can get a little irritated and things like that.”

2.2 Satisfying myself

The men masturbated now and then and found it rewarding. However, masturbation did not replace the longing for sexual experiences with women. Consequently, they did not see masturbation as a separate act, it was a substitute instead of being with a woman. The men also showed an ambivalent relation to porn, not least as it usually left a bitter aftertaste.

“I can satisfy myself, but not as before. Before, I imagined myself in different situations with girls, now I check out something on the internet, and then it's over. /.../ It is quite satisfactory but once it's over you feel you do not like it, but in the meantime it is good. There are things on the net that is disgusting, well, you should not be judging, you should not be hateful to the Internet, but I do not know. It is helpful, you don't have to look at everything.”
There were some worries how the porn affected their sex-life, and they described it as a
distraction but not that rewarding. It also tended to be like a compulsive behaviour, something
that was needed in order to relax or before going to sleep. Also, not least, there were worries
that it would tarnish and ruin their ordinary - and not that spectacular - desire.

“I think the porn affects my sexuality, as soon as you see something
new you start thinking about it. One does not want to replace a normal
relationship with a girl, you want to get turned on by a girl when you
see her, you should not need a lot of cool stuff and so.”

2.3 Hopes and expectations

There was an obvious desire to be with a woman, and have a relationship, and their
expectations were often something ethereal and not entirely sprung from sexual experiences.
A tinge of sadness came through; over stray chances and lost opportunities. In order not to be
too disappointed they dismissed the hope of love.

“A little spark remains of course, but that I dismiss quite quickly, it's
not for me, that is what I think, it is not for me.”

They also dismissed the whole project of love in the name of not getting dissapointed; like
belittling the women or reducing the possible options. They devaluated sexuality for example
through fears of sexually transmitted diseases. However, behind this devaluation the longing
seemed to persist. Regarding the question of approaching women and the available selection,
there were thoughts about the advantages of the internet, even if there was fierce competition
on the net according to one of them.

“Internet is good in some ways when it comes to love. I have met
three or four girls on the net, there are more and less reputable sites
on the net, but getting to know a girl before you meet, that is good. It
is not a quick meeting, depending on the looks, you will spend
energy and time, you get a deeper contact.”

There were also thoughts, due to the fact of the difficulty of meeting someone in Sweden, to
go abroad in search of love. However, the fear of eventually being scammed prevented that
project.

“I've thought a bit about these other girls, from across the globe, the
Philippines and those from Thailand, but I think it seems too expensive
and too far from home, of course it is a possibility, but you are
supposed to send money to their relatives, I do not think I can afford
it.”

The men described incidents when they had been used and scammed out of vulnerability and
poor judgement. They alas expressed an idea that one needed money too start seeing a girl.

“It is important that she is honest and kind, it is the most important,
honesty, I think it is important, I have felt cheated, I have been cheated
out of money by the ones I have fallen in love with. I have bought
things for them to capture their interest, but it has not worked. Then I just continued to buy things for them and I just felt drained.”

In the narratives it became evident how elusive their desire was, that it always was in some other place, it shifted constantly, desire was never satisfied but was constantly shifting. Their imaginations about satisfying the other’s need became their own need. They mentioned that it was about satisfying the other’s imagination, hence, a step further than satisfying a need.

“That I will fulfill her fantasies.”

Furthermore, meeting someone was not given exclusively to hope, it was also a question of one’s own effort.

“Much is about taking the opportunity, it's about a few brief seconds between getting a partner and not getting a partner.”

There was also an eagerness to be active, a demand that produced ambivalence.

“I have to risk more, enjoy sex more, and so, then maybe I would get a girl and so, not too dry. The first thought is that sex is sinful and should not occur very often, but I need to dare more and like sex more.”

2.4 The fear of approaching

To expose themselves to another, based on an unclear picture of the other, was a frightening enterprise. Recurrent was an experience of an insufficiently understanding of the other, and unrewarding experiences of relationships, sometimes on account of a poor judgment of people they choose to associate with, and not seldom they were limited and directed to others in the margin. The onset of illness coincided for these men with young adulthood, a time when many experiment with their identity, and find out what they like and dislike, for example experience their first sexual encounter. Illness and hospitalization had removed them from this important and delicate period. Furthermore, after the recovery they had been relatively isolated, and also heavily medicated. A result of this setback was a sprained and wavering confidence in themselves and their future. A lot of fears remained from the period of sickness, not the least, which of course reduced the capacity to meet someone, a fear of meeting new people and being out in social settings.

“It means putting a lot at stake when you want someone.”

The men expressed that it took a great effort, and also involved fear to invest emotionally in someone else. They described disappointment that they had not grasped the opportunity when it existed. They did not know then, that the chances would be so few. They felt limited in their approach to others. They thought they could not be open with themselves, which they equated with being open about their illness, as if transparency about personal matters and openness required each other.

“I find it hard to share personal things of my life, to open up, to tell things which for them is good to know. That's what I mean by going in 100 %, I might just go in 70 % of my full potential.”
They also described difficulties to socialize casually, like for instance small talk. One reflection related to this might be that when you really want something you generally want to avoid wasting time on trivialities. This alas the women likely perceived as rather too abrupt.

“If someone is interested I should perhaps make contact then or say something or so, but I'm not so great at such things, what is it called now, to make small talk like that, I can talk to a man like that, but it should preferably be something anxious, which has a quality in itself, it can be fun to just talk, but I do not really know what to say, it is difficult, one can talk about movies and things like that, it's fun, weather of course, but that's not what you want to talk about either.”

A recurrent theme was about courage to act and take a step forward, regardless of prior disappointments and uncertainty over what the other wanted.

“To dare to venture, to dare to put yourself out there, as is done in the sexual act, it is important that you dare to do it, otherwise it is not rewarding.”

Some also mentioned a lack of knowing how to relate to a woman, how to proceed in the courting, and not knowing how to make it happen. Resonating obviously here was the risk of being turned down, deselected, and brushed aside.

“What scares me the most is that she opposes me, that she rejects me, to get a no, really, not because it is very dangerous, but often if you bet on someone, it is because that you really want it, that is, casual sexual relationships is one thing, but when one invests something real in someone, and it does not turn out the way you want, it drains you from energy, and one is lazy, you do not want it to happen.”

The common human concerns we all share, such as having relations and a sexual life, were accentuated by a great uncertainty.

“It is difficult to know when someone is attracted to you, it's really hard, who will flirt, who will make the first move, who will do what, is really difficult to tell, of course I can see if someone looks at me in a special way, and then I at least think that there could be an attraction, she seemed to like me, she seemed to think I was good looking, it is such things one goes around looking for all day (laughter) when will she look at me then, it's actually so, one does so all the time, on the bus and the train, looking for partners.”

2.5 Difficult to talk about

In many ways, it was clear that the informants felt that sexuality was an area that was important, but also difficult, to talk about. Explicitly by their statement it was difficult to express themselves concerning sexuality. To avoid reflecting on the topic, they sometimes responded with an instant decline or a referral to their ignorance.
“What are you thinking about other's sexuality, is it easy or hard to understand?”
“No, I do not know.”

At other times there was a quick and elusive flight into normality, though only initially. After a few diversionary maneuvers by the men, and some support from the interviewer, the men could express themselves on the subject. Their wish to normalize was also recurrent.

“There is nothing [in my sexuality] that is strange, I'm pretty happy with how I feel and things like that.”

Not the least were the difficulties illustrated by many of their evasive and oblique responses, especially one of the interviewees appeared regularly to avoid thinking about difficult matters such as problematic things concerning his sexuality.

“Is there something about the issues surrounding sexuality that you have given a lot of thought?”
“No, I have not done that.”
“There hasn’t been any reason to think about it?”
“No.”
“Would you say that it is an area that worked out pretty well?”
“To and from.”

Difficulties to talk about sexuality was described as something that the helping system should have helped them with and there was a strong wish to get the opportunity to talk about sexuality in a meaningful and respectful way. There seemed to have been a neglectance from the health care to address issues about sexuality. However, one of the informants spoke about an initiative to form a group of patients in the same situation and talk about these issues, for example how the medicine affects and impairs the ability.

“Meeting with others in the same situation would be an advantage, then they could tell me how they did and like that. Sharing information and experience I lack, it's an important thing in having the opportunity to grow. If you do not know how to do it, you can not do it.”

Furthermore, there were witnesses of professionals very clumsily approaching questions about sexuality.

“I raised it with a doctor many years ago. He wrote in my papers that I was impotent, just like that, just because I asked such a question, that was the only answer I got.”

Even though these men rarely spoke to someone about sexuality they had a wish and an expectation to do so. Overall they felt neglected by the health care in not addressing these issues in a proper way.

“Well, I have been visiting an outpatient clinic at some point where they asked if I were sexually active, if I had a partner, but no information in that way, no one addressed issues of sexuality.”
The informants expressed a wish that sexuality should be a common topic in the care. The one person who received help early on to talk about himself after the onset of the illness was clearly the most reflective, and also the one that seemed to have conquered a functional and fulfilling life for himself. For the other two there seemed to be a substantial risk to stiffen, and turn these important issues into non-issues. Even the health care seemed, concerning sexuality, to have surrendered and reduced it to a practical approach towards these questions of sexuality in the absence of an idiosyncratic and personal stance. Nevertheless, some optimism prevailed inasmuch as there was, surely based on an accurate assessment of what was important in the moment, opportunities to talk about love-relationships in general.

“I have never talked about sex in my contact with the health care, but I talk a lot about me wanting to meet someone.”

In this second theme predominating was that the informants found sexuality important but often a need that was not sufficiently satisfied. An uncertainty in approaching women was mentioned, it adopted such proportions that words like fear, fright, dangerous and scare kept recurring. There was a strong wish to get the opportunity to talk about sexuality in a meaningful and respectful way among this group, alas there seemed to have been a neglectance from the health care to address issues about sexuality but in a pedagogic way, often about side effects of medication - disregarding other crucial obstacles in forming relationships.

Discussion

In this study, three male patients suffering from psychosis were interviewed about their experience of sexuality; i.e. how sexuality was affected and described based on the special situation these men had ended up in. Since the area is under-researched and would benefit from a broader description, the focus was to give a broad description of the data set, and less a detailed account of a few aspects. The analysis shows that the informants expressed some common features, however, they differed in terms of other aspects. The common experience was due to the disease but of course also due to the fact that they shared the same time, culture, gender, and not the least that they were human beings with needs, desires, and shortcomings. To discern what was specific for this group and what was in fact universal human problems is difficult to tell. It is reasonable to think that these three men mediated both ordinary human difficulties as well as difficulties related to their mental disease. Former studies that have raised the specific question of sexuality often contained quite small samples, and the more extensive studies have not been particularly interested in this specific question. This study was an attempt to, although with a very small sample, with an open mind probe this issue and fill in the gap of knowledge based on this group’s own experiences.

Turning away from reality

In the efforts to comprehend the narratives about sexuality one aspect clearly emerged and this was the tendency to turn away from reality. Consequently, this signum of the schizophrenic was recurrent in the interviews. It is obvious that this aspect has been relatively absent in previous studies in this area, despite the highly prominent role that aspect plays in this group’s difficulties. This fact distinctly has a crucial impact on how one ought to understand this group, and subsequently how you ought to organize the caring interventions. For instance could an ambition to help, perchance well-intended, in a concrete and detailed level to bring about a harmonious sex life, also be misused when the absolutely critical aspect of sharing the same reality fails. In this material, these men’s outlook are in itself specific, the
psychotic has by definition turned away from the world, and built a private world with highly specific symbols. Their idiosyncratic outlook about sexuality might in a way be a common feature. Something noteworthy about mental illness is that it leaves its mark on not solely the content of the speech, but also on the shape of the speech. Consequently, the disease leaves its mark on how the disease-carriers talk about their illness. Many times, the disease is in fact the patients’ speech about themselves and others, it is the phantasmatic outlook on the world that is the disease itself. This of course, makes this area extremely complex. To make the material justice, this phantasmatic outlook must be considered and included in the analysis. Some of the subthemes, are constituted by the absence of certain discourse, especially the themes “Phantasy replaces reality” and “An area that is difficult to talk about”. The latter became a theme partly through one of the informants’ consistent avoidance of thinking about his situation, and sometimes an absolute misrecognition of what was considered to be normal.

Perhaps it is common for all of us to long for what one does not have, subsequently this dilemma recurred in the narratives of these three men. Besides one could more freely and easily attribute absolute good values to something one does not have. The wish to satisfy the other’s need and imagination, a decentering from ones own subjective desire, that was present in their narratives were interesting to note. Specifically in this patient-group, where a suffering from doubt and uncertainty of where ones own person begins and ends, and who actually feels what. The uncertainty constituted a major obstacle in the project of forming a relationship. The three men also described that there existed dangers engaging in close relationships. Sex involves making oneself vulnerable and a degree of risk-taking that can be difficult, especially for those with low self-confidence (Cook, 2000).

One interesting aspect is whether one sees psychosis as something external that influences an otherwise normally functioning sexuality or if you see the psychosins as just a description of a variety of odd behaviours including for instance the individual’s sexuality, i.e. that the formation of sexuality is just one part of the psychotic structure. It is a complex errand to examine a part of a group’s life that is in another way the very prerequisite for life. To focus on the sex-life becomes meaningful only if we also look upon relationships in general, how we form relationships, and our ability to navigate between too much closeness and too much distance. However, it is of relevance to know more about this group’s descriptions of sexuality in general, their specific sexuality, their practice, and their possible shortcomings. Differently put, how it is to be male in relation to sickness and sexuality.

This study did not contradict previous studies in the field, it confirmed especially those who have seen the problems for this group due to psychological factors. This group showed difficulties in forming relationships, and if that nevertheless succeeded, a poor judgement in the choice of partner was present. Furthermore, a general social inability (Kalichman et al., 1995) and a frequent deficient social context restricted these men’s possibilities to form a relationship as well as a low self-esteem due to the illness (Henley, 1994). Findings point to that this group lack a basic vocabulary to discuss sex (Rozensky & Berman, 1984), even if this lack was not unambiguous in the interview-material. However, it was clear that the informants had not before had the opportunity to talk to someone about their experiences of sex before. In part because of lack of sexual experience which of course meant that a vocabulary was not based on own experiences but also part due to a general isolation. Of course living in the community, compared to the former institutionalization, had increased their opportunities for sexual encounters (Nicholson et al., 1996). But difficulties to join and be part of a social context and establish themselves as citizens obviously still remained. Most studies report that antipsychotic medicine causes problems with libido, arousal, and orgasm.
(Sullivan & Lukoff, 1990), and these informants did not differ, they also described such problems. However, it is difficult to establish a unique link as many other factors come into play, for example is it hard to make the distinction between a general fatigue and a more specific lack of drive.

The findings in this study were that the issues of sexuality were quite absent in the everyday treatment of these patients, and when they appeared they were treated in a quite offhand and neglecting way. The three men felt that their sexual needs had not been regarded. They were treated as if they, in a way, were asexual, a finding prior documented (Buckley et al., 1999). When psychiatry in their eagerness to help, a help which is much needed, approach this issue in an educational manner, which is the current suggested mode (see Östman, 2008; Dincin, 1995; Bhui & Puffet, 1994; Lukoff et al., 1986) there is a risk that a gap to the patient's unique life world will be the result. At worst, the patients are categorized into psychopathological groups, and then treated according to a manualised program developed for that specific group, this instead of listening and trying to understand each specific patient. Furthermore, the sexual encounter is perhaps not suited for operationalization. It also seems that the civic society is a bit short-sighted and contradictory in their eagerness to enable a satisfactory sex-life and disregarding the fact that a connection between sex and reproduction still is valid, as a risk or possibility. Society still has a responsibility, despite the scandals with the forced sterilization in the fifties in Sweden, to create a good environment for the growing generation. There of course the psychic capacities of the parents are most significant. To promote a sex-life also entails increasing the possibility or risk that these patients become parents, and not necessarily sufficient capable parents. These two particular interests partially excludes one another.

I have chosen to eliminate some problems by just interviewing male patients, assuming that the gender category influences their stance to this issue. The informants expressed views that overlap with a dominant heterosexual perspective, likely to secure a position as a heterosexual normal man. Their attitude towards abnormality and others' sexual orientations and preferences was relatively open-minded, in contrast to a harsher attitude to their own sexuality and identity. People with psychiatric disabilities of course manifest considerable strengths, like this trait of being more accepting of difference among other people and more tolerant of alternative and diverse viewpoints (Cook, 2000).

Remarks about the study

The aim in this study was to identify existing themes within the sample. Further studies with a different approach are needed to answer the question of prevalence among this group. The difficulties in finding interviewees was extensive, even though I had some contacts that made it possible for me to get in touch with the group in question. Many of those who were asked to recruit informants hesitated. This in line with the previously reported, though not confirmed idea, that talking about sexuality could trigger or aggravate psychosis. This might illustrate that this belief, i.e. that sexual activity could contribute to the development of schizophrenia, in some milieus still prevails (Pinderhughes et al., 1972). Some professionals who were asked to recruit participants thus thought that this interview-study in itself would upset the patients, and cause deterioration; in one sense an idea that the question in itself would create something that was not there beforehand. No other incentive than to contribute to the production of knowledge in the field was offered, which not made the situation more favourable regarding finding participants. Ultimately though, the participating informants testified that the interview was valuable, and rewarding in itself and for themselves.
“By talking about these things, it becomes clearer what I think about these issues. I understand a bit more what I think about these issues by talking to you about them, and I am grateful for that.”

Since a couple of informants declined at the last moment despite the prearranged meeting, this could indicate that this group has difficulties to openly talk about their situation, and in addition to that - to a stranger. Also of course a sign of the general difficulties that exist to speak about the topic of sexuality. To study this patient group’s experience of sexuality is surrounded with obstacles according to Pinderhughes et al. (1972). There was a threefold uncertainty, to themselves what they really thought and felt, to me as the interviewer and my responses and reaction, and lastly to the fact that it would be part of a study. To facilitate that the informants could talk freely and open-ended about their thoughts and feelings about sexuality I had to, in two of the interviews, now and then secure the situation, and my attitude was in those moments very validating. Clinicians are reported to hesitate asking the patient of potential sexual problems, even though patients are most eager to talk about these issues if the clinician raises them (Wasow, 1980; Bengtsson-Tops & Hansson, 1999). This is also the experience done in this study. However, that these specific informants expressed a wish that sexuality should be a common topic in the care was of course a logic consequence, due to the fact that these specific informants had chosen to talk to me. It was thus an illustration of their need. It could also be supposed that it was the openminded concerning sexuality who showed up. The fact that psychosis leaves it’s mark on the form inasmuch as the content of the speech makes the analysis of the material complex, and to do it justice analysis must occasionally go beyond what is actually said. By allowing that freedom the analysis must on the other hand be so close to the empirical data as possible, and not let the speculation about the material be unnecessary extensive.

As for the interviews one can always ask whether a relatively short interview offers the interviewees sufficient and adequate opportunities to say something substantial about such a complex issue as sexuality. The interview guide had been formulated on the basis of preconceptions and presuppositions around what this area may contain. That was an inevitable but indispensable aspect, and some embryos of the themes were present already in that stage. Allowing interviewees to more freely express themselves without the help of this proposed structure would in these cases have been difficult. That according in a certain sense to yet another preconception, that this group not seldom is characterized by being occupied by a set of serious, insist, and excluding issues, who without the structure would form the interview too much.

References


