

Sexuality issues and people who experience psychosis

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Abstract

There is a lack of studies that specifically investigate the subjective sexuality concerns of people with a serious mental illness such as schizophrenia. The present study canvassed thirty people about past and present relationship experiences and elicited hopes and aspirations for future sex and relationship needs. A semi-structured questionnaire was constructed that addressed potential sexual and relationship concerns and was carried out face-to-face. The aim was to provide a holistic depiction of the views of people with psychosis regarding intimate relationships. The results of the study are presented and recommendations made in terms of mental health practice, education and research.

Key words: Schizophrenia, psychosis, sexuality, mental health, sexual health

Introduction

Since the introduction of the *NHS and Community Care Act* [1] and the *Care Programme Approach* [2] in the United Kingdom, more attention has been paid to detailed and holistic assessments of the

needs of all individuals suffering from severe and enduring mental illnesses. Priorities include housing, occupation, medical and psychiatric care, socialisation and risk assessment. The intimate sexual and interpersonal needs of affected individuals have only recently emerged as a legitimate concern for carers [3]. *The Health of the Nation* targets compartmentalised sexual health and mental health as separate and distinct entities [4]. The former concentrated on teenage pregnancies and sexually transmitted diseases and the latter aimed to reduce suicides [5]. While these targets seem laudable for the whole UK population, the sexual needs of individuals with psychosis appear to have been marginalised. In the UK, the *National Survey of Sexual Attitudes and Lifestyles* [6], one of the largest sexual studies since the *Kinsey Report* [7], only referred to physical health. More recent publications have outlined government strategies which aim to tackle issues pertinent to users, carers, and significant others regarding mental health provision through the *National Service Frameworks* [8] and *Our Healthier Nation* [9]. Additionally, the Government has published a national strategy for sexual health and HIV that is clear about the treatments and services people can

expect to receive [10]. However, despite these initiatives, plans of care do not normally include an assessment of sex and relationship need.

Literature review

A systematic review of the available literature relating to sex and relationship issues and people with a diagnosis of schizophrenia or psychosis was undertaken [11]. The studies mainly concerned mental health populations in the USA with very few studies, and no empirical research having been carried out in the UK. The subject of HIV/AIDS and perceived 'risky' behaviours received most coverage [12-16]. There was some exploration into the effects of stigma and discrimination and the apparent damaging effects of such treatment of mentally ill people by society [17-18]. Several studies examined the effects of medication on a person's sexual functioning and included cognitive as well as physical responses [19-20]. Some support systems were studied along with notions about marriage, family planning and vulnerability [21-23]. Further, literature concerning possible professional responses, particularly the

identification, assessment and planning of service and therapeutic provision was extrapolated [24-25]. The final picture revealed distinct gaps in psychosexual knowledge in relation to patient needs and this provided the rationale for the present study. Few studies appeared to examine subjective experiences of people with schizophrenia such as the meanings associated with love and intimacy and the influence upon a person's future ambitions towards forming intimate relationships.

Study aims

The literature review revealed that few studies actually canvassed people with a diagnosis of schizophrenia about their sexual and relationship requirements. Many of the studies, specifically related to risk behaviours and none of the studies enquired about thoughts, feelings and beliefs in relation to sexuality aspects. Therefore, the focus of this study was to elicit relevant subjective factors and lived experiences of those people living with the condition. In order to address some of the gaps in the literature, the aims of the present study were to establish clients' intimate relationship experiences, to

discover impediments to the expression of sexuality and to explore experiences of specific issues that service users considered important. The final aim would be to present recommendations for mental health practice, education and research.

Methods

Sampling

A recognised sampling procedure was followed [26]. The population under study consisted of people with a case-note diagnosis of schizophrenia, living in North London, UK, and regularly attending a depot clinic to receive anti-psychotic medication. A total of one hundred and nine people with a diagnosis of schizophrenia attended two clinics on either Wednesdays or Fridays. It may have been useful to access both clinics but in light of time constraints and resources, the Friday clinic was chosen. A list of attendees was obtained from the Locality Team administrator and totalled forty- seven. Fifteen men and fifteen women were conveniently recruited to take part in the study. The Community Psychiatric Nurses, who knew the patients well, would then administer the injection and make a clinical

judgement on the suitability or wellness of the person to take part in the interviews.

Description of the sample

From a total of forty-seven people attending a Health Centre in North London to have depot medication administered, thirty people were interviewed. The age group of the sample varied between 22 years and 57 years (mean = 40.93 years). Most people were White UK (63.3%), although within the sample, there was a rich mix of ethnic backgrounds, reflecting the diversity of the local population, including: Kurdish, Black African and Black Caribbean. A majority of the sample were heterosexual (73.3%), not in a relationship currently (60%) and had no children (66.7%). Most people had engaged in further education (70%). The entire sample had a clinical diagnosis of schizophrenia, schizotypal and delusional disorders, as defined by the International Classification of Diseases [27]. The bulk of people had less than 10 years contact with mental health services and the average number of previous admissions was five and a half.

Semi-structured interview schedule

A semi-structured in-depth interview survey was devised to elicit client's subjective experiences regarding sexual expression and initially covered conceptualisations of intimacy, relationship experiences, sex education, sexual experiences, family planning, safe sex, medication issues, statutory and non-statutory supports, stigma and self-esteem. The first interview schedule was pre-tested amongst two people attending the depot clinic. The interviews were taped. The draft version of the semi-structured interview initially consisted of seventeen questions. The responses were presented to the research team at the University and suggestions were made around addressing the following: The effect of medication on emotions and feelings; aspirations about having children; sexual orientation issues; stigma and illness; genetic worries and family planning; family support/attitudes; sexual experiences in the past; future hopes and aspirations; attractiveness of self and pride in appearance.

The researcher rated anxiety on a scale of one to ten pre and post interview. Low levels of anxiety were recorded on both occasions and the ratings remained consistent throughout the interview.

Ethical issues

All of the client interviews were carried out face-to-face. This was considered the most appropriate way as an appreciation of the sensitivity and potential complexity of the topic. Any sources of discomfort could be identified and the extent to which people would discuss sexuality issues could be gauged. Approval for the study was gained from the local hospital ethics committee. Participants were assured that should they wish to stop the interview for any reason they would be free to do so. Furthermore, patients were guaranteed anonymity and were informed that names would not appear on any documents. The data from the study, which included interview tapes and completed questionnaires, were kept in secure locked cupboards within the University. Written consent was gained from patients. Participants were invited to ask questions and seek clarification before beginning the interviews.

Data analysis

The data generated by the semi-structured interviewing utilised analysis techniques such as data reduction, data display and

conclusion drawing/verification [28]. The interviews were tape-recorded and the information transcribed. All of the transcriptions were scrutinised and corrections made to the texts. This was facilitated by the use of a computer software package: Qualitative Solutions and Research Non-numerical Unstructured Data Indexing Searching and Theorising (QSRNUDIST) - a computer programme devised to help researchers effectively work with Non-numerical and Unstructured Data in qualitative analysis. Following input into QSRNUDIST, the data was further examined, coded, text searches conducted, and organised into themes that would reflect what people thought and felt about sexual and relationship issues.

Findings

All of the information that was gained from the semi structured interviews was imported into QSRNUDIST. Categories and sub-categories emerged from the data and this was organised in a systematic way to enable further analysis. The main categories that emerged included: intimacy (description and meaning); relationships (past, present, future); sex education; sexual issues (concerns, safe

sex, advice); children; medication; supports; sociability; stigma and self-esteem.

To begin with, most people were able to articulate what intimacy meant for them and spoke, not just about sexual intercourse, but feeling aspects such as love, closeness, caring and the importance of support. The respondents provided vivid descriptions of what an intimate relationship consisted of and this included ideas such as trust, warmth, companionship, affection and loyalty. For one gay man, sensuality and touch was just as important as intercourse:

...Doesn't necessarily have anything to do with penetration as long as it is very tactile...cuddling, sometimes kissing and stroking the flesh. (Respondent thirty)

Another example was the evocative description provided by one man. He gave a rich metaphoric depiction of the emotional feelings associated with love:

*It's like being on cloud nine. My mind is full of loving feelings
– like being off the planet. (Respondent twelve)*

Some people spoke of feeling wary about experimental sex due to the perceived threat of HIV and AIDS. One woman, who had had multiple sex partners in the past, was now very wary about 'playing the field' due to increased anxiety brought about by HIV/AIDS risks:

*Oh I don't know.... Not too experimental, whereas in the past
I would have tried anything. Not now because this AIDS is
terribly frightening... (Respondent six)*

On the subject of relationships, most people had positive past experiences. However, some spoke of abusive relationships and one woman detailed the physical abuse endured by her at the hands of her ex-husband. She still carried the physical and psychological scars from the experience:

Six weeks...that's all it lasted. He was an absolutely violent man. He gave me a fractured skull. I was lucky to get out of it alive. I still get pains from the fracture. I was hoping it would heal (Respondent ten)

Other people spoke of feeling awkward or lacking the experience or skills necessary to forge or maintain a relationship. Some men were paying for sex and would visit prostitutes if and when they could afford to. Through listening and responding empathically during the interviews, some of the obstacles to forming future relationships became evident. Under half of the people who took part in the study were currently involved in a relationship. Social and environmental issues, such as living arrangements (e.g. hostel accommodation) seemed to be the biggest problem that affected people. A forty year old man, who lived in a street homeless hostel, talked about relationships he had at school and the difficulties he has had since then. He joined the army when he was twenty and was not keen to

discuss his experiences whilst serving. He was a political refugee and may have suffered Post Traumatic Stress Disorder:

It's too hard to love somebody. It's no good. He [his father] loved with his heart and not his brain. Love with innocence, like a child. It's natural. I was in love with a girl at school for two years. She came from another country. I can't say which one. My father has tried to introduce me to a partner- it's a respect thing. He doesn't bother now. There is no pressure from my family now. (Respondent twenty-five)

The expectations of his family were being weighed against his own psychological and social situation that could possibly lead to tensions within his support network.

One gay man, who now lived with his long-term partner, mentioned his past marriage, his children and eventual 'coming out' and the complexities involved in this decision. He identified the stress

associated with the decision to 'come out,' and the pain of seeing his family life disintegrate, as a major precursor to his illness:

My marriage? It was decision time, one or the other and that was one of the times it made me ill. I was always gay I knew that...now an upstanding citizen, perfect marriage, children, a house, a car... I now wanted to be free but it was very painful the separation but I still wanted it to be a friendship...She decided that I couldn't see the children or couldn't even speak to them and that made me go mad.

(Respondent thirty)

In order to establish future hopes and aspirations around relationships, people were asked who their ideal partner might be. Some respondents identified existing partners as 'ideal.' Others, mainly men spoke of famous women and their physical attributes e.g. big breasts. Some people mentioned respectfulness, understanding and supportiveness as the main qualities they would expect in a

potential partner. Some wondered about the reaction they might get from people once they discovered their mental health history:

I look at girls in the street but don't know what to do. The kind of girl's I meet in the drop-in...they are having a hard time in their heads. That's not the kind of girl I want. I want one I can marry and have kids with. I met a girl in the hospital and we saw each other for a while...Wanted to have children and marry but it's that stigma thing... People with mental illness only meet the same type of people with the same type of problems. (Respondent fourteen)

There appeared to be a feeling of shame or fear of the consequences (e.g. rejection, persecution) of divulging such information. This led neatly onto the question about obstacles to meeting potential partners. Important concepts emerged such as the narrowing of opportunities to meet people outside of the mental health system and the possible reactions from others. People went on to detail the financial implications of trying to survive on benefits with most

people describing a 'hand to mouth' existence that left little to spend on socialising. Some people had the volition but felt ashamed that they could not afford to go on a date. Other participants spoke of the vulnerabilities associated with their condition. By far the greatest concern for most participants was the results of stigma and the emotional effects that were felt. This would create seemingly insurmountable barriers and affect a person's core beliefs about themselves and others. People would talk of feeling worthless and hopeless. The effects of stigma were closely linked with self-image and the way people fought to present themselves to others, knowing that they would perhaps be prejudged and subjected to ridicule and further discrimination:

My ideal partner would have to understand that I was on drugs, and perhaps we wouldn't have a normal sexual relationship. With these tablets, I'm up and down. With these injections, I might be better you know, as long as they understand that. There's this stigma attached to people with mental illness you know, that's the trouble. Would anybody

be interested if they'd know about that? I suppose I could keep it quiet and not say anything. I don't think that would be right somehow cause they'd probably find out anyway.

(Respondent one)

Some people identified institutional rules and regulations as obstructive to future relationships. A couple living in a medium-high dependency hostel and being cared for by residential staff, were involved in a covert relationship with each other. They had been meeting secretly for three years. One of the interviewees had a medical diagnosis of obsessive-compulsive disorder as well as schizophrenia, and spoke of the disabling effects of his illness as well as the intrusive nature of staff surveying his movements in the hostel (having recently learned of their three-year relationship). He explained some of their frustrations:

I can't get going most of the time. I get stuck in the room and wait for her to get in from the day centre.

*I'm happy with V. I love her and care about her. Staff
come into my room the whole time and don't bother
to knock... (Respondent twelve)*

The attitudes of staff who worked in the hostel appeared problematic especially their intolerance and lack of support and understanding when it came to light that he had been in a three year relationship with a fellow resident. Another man spoke of the problems he had managing to remain free of illicit drugs and at the same time desperately wanting to meet a woman and embark on an intimate relationship. He struggled with trying to understand what happened in his previous relationship and appeared to have unresolved issues about this. He gave a vivid example of the unwanted effects of the medication he was taking, in particular, erectile problems and stiffness in his arms and legs. Although this caused him much distress, he felt embarrassed about talking to anyone about these issues:

The only trouble for her of course is my problem. I've been masturbating so much in hospital, when it comes to the real thing I can't ejaculate into her. It is painful for me when I do it. But I like oral sex you know, just messing about touching and things like that. I like that kind of thing. (Respondent five)

In this study, several people articulated concerns around exposure to the HIV virus. One lesbian recognised the problems associated with HIV transmission and reflected on the issues pertinent to women:

I'm a bit nervous about the safety aspect of sex. About HIV and what have you. I never really considered it an issue for women. (Respondent two)

She spoke about using protection such as 'Dental Dams' (used for oral sex) and taking care if involved in sado-masochistic activities. She also mentioned keeping sex toys clean and hygienic. For one other woman, the threat of not knowing what her partner was doing,

and with whom, was very concerning. He was allegedly having an affair with another woman:

I'm very worried. I don't know if he is protecting himself, because he's not telling me the truth. AIDS has come. I don't know if he's protecting himself.

(Respondent three)

The issues concerning the emotional and physical implications of safe sex were well articulated by one respondent:

Safe sex I would understand as being safe in regards to sexually transmitted diseases, so using condoms, but safe sex could have lots of connotations. Safe sex could be just sex and being comfortable with someone you think you know, who cares about you. Not necessarily long-term, but is enjoying that moment and that experience with you and it is just respectful sex as well where both parties know they

are getting something from it and care about the other party. (Respondent twenty-nine)

It is obviously important for this woman to achieve some sort of balance within the encounter. Safe sex could be seen as protective, not only against the possible invasion of infection into the body, but as guarding against the emotional impact of the intimate liaison.

The people being interviewed were asked about concerns with contraception when having sex. Naturally, all of the gay and lesbian respondents had no concerns as they had no need for contraception. Additionally, two women were Roman Catholic and had never used contraceptive devices due to their religious beliefs. Other people were not having sex so had no use for contraceptives. Two men mentioned fear about condoms splitting.

Most people mentioned their GP and some people thought that they would be able to provide advice or refer the person to someone who could give information. One person recognised the constraints imposed upon GPs due to increased workloads:

I'd see me doctor I suppose. That would be the obvious place to go, he seems alright. He never talks to me about Viagra or anything like that, or any of those sorts of things. He's busy anyway, he's always got a lot of patients to see. He just gives me my tablets then I go. I only see him once every 3 months.

(Respondent one)

He appeared to think that the natural port of call would be his GP. He never mentioned anyone in the mental health locality team and perhaps sees a dichotomy between physical and mental health issues (as many people do, including health and social practitioners).

People were asked about what they thought about having children and if anything stopped them from having children. Four respondents said they had never been interested in having children. Only one person chose to elaborate:

Didn't want the responsibility. I'm rather adverse to responsibility. You know it doesn't bring out the best in me. I tend to get heavy baggage and to become a rather objectionable sort of person. (Respondent nine)

Many people expressed a strong desire to have children but, for most, the obstacles that were presented appeared insurmountable. Some people spoke about medication issues:

Well, two kids died. At the moment, because of my illness – in case I get sick and they get put into a home...no children. Well at the moment I'm not having periods because of the Pipartil, so I can't get pregnant anyway. (Respondent four)

One person mentioned his concerns about genetics and the production of offspring:

Children they're great but.... I'm not having children this way...I'm mentally ill you see, the child might have downs syndrome or something. (Respondent five)

It became evident from the interviews that nobody had ever spoken to a health professional about their aspirations of having children. For the future, we perhaps need to look at family planning services and see if practitioners are attuned to the specific family planning needs and concerns of people with psychosis.

When asked about relationship opportunities, both men and women identified pubs and clubs as meeting places for potential partners. No one received any substantial sex education at school. In hospital, the only questions asked were about “abnormal” sex for one man and physical violence for one woman. A majority of the respondents admitted they didn’t speak to a professional regarding these issues but would if given the opportunity. No men spoke to their families about sex and relationship issues. Some women had spoken to their

family and one had spoken to her partner. Many men and woman took a pride in their appearance and would groom themselves each day. Both men and women found it useful to talk and some spoke of feeling relieved by the process.

Discussion

One of the most dramatic findings from this study is the paucity of published data on sexuality, especially in the UK, which may indicate a lack of interest in the field of human sexuality. It could be due to the constraints within the health service, financial and otherwise, that clinicians may see this area as low priority.

Internationally, the World Health Organisation (WHO) convened in 1975 to discuss sexual health issues and proposed guidelines and protocols regarding identification and implementation strategies regarding sexual need [29].

The fundamental health service guidelines included:

- Information about biological and psychological aspects of sexual development, human reproduction, variety of sexual behaviour, sexual dysfunction and diseases
- Positive attitudes towards sexuality and the chance for objective discussion of sexual matters
- Staff who show understanding and objectivity towards the expression of sexual concerns and to inform/advise about sexuality and sexual needs
- Training for health service staff in the area of human sexuality
- Sufficient knowledge and resources to deal with complex problems around sexuality

Despite these suggestions, and taking the findings of the present study into account, it would not seem to appear that clinicians, and those involved in policy making, have risen to the challenge in addressing the issues in terms of research, education and practice. Possibly, practitioners own feelings and attitudes regarding sexuality may act as a barrier to the exploration of sexual issues with patients. Before practitioners can assist others with sex and relationship needs,

they need to examine their own attitudes, values, fears and beliefs. In line with the WHO recommendations, there should be a conscious drive towards facilitating communication about sexuality, correcting myths and misinformation, providing education and encouraging exploration of the patients' feelings and resources. However, being supportive of a patient's sexuality should not be defined simply as permitting or condoning intercourse among clients. There is a broad continuum of therapeutic approaches to sexual matters: from answering clients' concerns with calm, informed responses, to providing a private space and other opportunities for sexual intimacy. Moreover, practitioners have often had to rely on their own common sense and clinical judgement in their drive to maintain order and propriety and still remain sensitive to the psychological, emotional and sexual needs of patients.

Where policy issues are concerned, each unit should have a clear written policy that covers acceptable, consenting activity, as well as topics such as harassment and sexual abuse. The policy should ensure that sexuality and sexual issues are considered as part of individual care plans. Such a policy is likely to vary in different

settings - policies on short-term acute admission wards will necessarily be different to those in settings where patients are admitted for more prolonged periods. Policies may include full consideration of wider unit or Trust policies, including issues of culture, ethnicity and patients' views.

If patients are to be discharged and thus expected to cope with the complexities of community living, they will need information and social skills with which to work. A forum must be provided for the discussion of sexuality matters not only for patients but for health personnel also. Moral, ethical and legal dilemmas abound. Full and comprehensive nursing assessments must be responsive and sensitive to clients sexual and relationship requirements. Staff education programmes should include methods of discussing issues around sexuality in order that accurate assessments and appropriate interventions can be undertaken. If we in the health professions are to be truly responsive to the needs of people with schizophrenia and their carers, then we have an obligation to ask about sexual and relationship issues. We need to enquire about subjective experiences and a person's hopes, feelings, beliefs and aspirations regarding

sexual and relationship fulfilment. Great care must be taken in ensuring that no further escalation exists in the discrimination, marginalisation and suffering of this already vulnerable group in our society.

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