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Citation: McCann, E. (2010). Investigating mental health service user views regarding sexual and relationship issues. *Journal of Psychiatric and Mental Health Nursing*, 17(3), pp. 251-259. doi: 10.1111/j.1365-2850.2009.01509.x

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Investigating mental health services user views regarding sexual and relationship issues

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Abstract

To date, very few empirical studies exist that investigate sexual and relationship issues and people who experience enduring mental health problems and less attention has been paid to the personal accounts of clients in this respect. The present study, carried out in the UK, involved 30 people who were asked about past and present relationship experiences and elicited hopes and aspirations for future sexual and relationship needs. A semi-structured interview schedule was constructed that specifically addressed potential sexual and relationship concerns and was conducted face-to-face. The aim was to capture in-depth perspectives of people with a medical diagnosis of schizophrenia regarding intimate relationships. The results of the study showed that people are willing and able to articulate thoughts, feeling and beliefs in the area. The findings are presented, and the implications in terms of mental health practice, education and research are discussed.

Keywords: psychosis, schizophrenia, service user views, sexuality

Accessible summary

- The study presents the views and opinions of service users.
- User perspectives are captured and clearly articulated.
- The study also highlights important issues that may be addressed in practice, research and education.

Introduction

The area of human sexuality continues to present challenges to nurses and others within the mental health professions (McFarlane 1997, McCann 2000, Higgins *et al.* 2009). This is despite the fact that government policies in the UK and beyond have been explicit in supporting the implementation and development of more inclusive and recovery focussed health and social care initiatives. Such documents include the *NHS and Community Care Act* (Department of Health 1990a), *The Care Programme Approach* (Department of Health 1990b), the *National Service Frameworks* (Department of Health 1999), *Vision for Change* (Department of Health and Children 2006), *Rights, Relationships and Recovery* (Government of Scotland 2006) and *A Recovery Approach within the Irish Mental Health Service* (Mental Health Commission 2008). As a result, more attention is being paid to detailed holistic assessments of the needs of individuals who experience a range of mental health problems, including psychosis. Fundamental elements in the process involved in recovery from psychosis relate to aspects such as housing, education, occupation, leisure, socialization and medical care (Perkins & Rinaldi 2002, Slade & Hayward 2007, Gilburt *et al.* 2008). Further important elements have been highlighted in the latest guidelines for the treatment of schizophrenia such as cognitive behavioural therapy, family and carer work, physical health and ethnicity (National Institute for Clinical Excellence 2009). However, the intimate sexual and relationship needs of people with a medical diagnosis of schizophrenia largely remain ignored (Lewis & Scott 1997, McCann 2003, Higgins *et al.* 2005). As far back as 1992, *The Health of the Nation* directives separated sexual health and mental into distinct entities (Department of Health 1992). The former highlighted teenage pregnancies and sexually transmitted infections while the latter concentrated on reducing suicides (Adler 1997). These targets may seem appropriate for the whole populations; however, the intimate relationship concerns of people with psychosis appear to have been marginalized. In the UK, the National

Survey of Sexual Attitudes and Lifestyles (Wellings *et al.* 1994), one of the largest sexual studies since the Kinsey Report (Kinsey *et al.* 1948) failed to include mental health. In 2001, the government responded by publishing a national strategy for sexual health and HIV and was explicit about the services and treatments people could expect to receive (Department of Health 2001). Yet, plans of care do not normally include an assessment of sexual and relationship need. The current study investigates the hopes, expectations and aspirations of people who are striving to recover from psychosis and presents service user viewpoints that may help guide future therapeutic activity, education and policy initiatives.

Review of the literature

The health literature considered in the review was accessed using CINAHL, PsychLit and Medline. A search of the Social Sciences literature was conducted using IBSS. The keywords used included schizophrenia, psychosis, sexuality, service user views and relationships. The articles that specifically addressed sexuality issues and psychosis were logged and classified. An indexed bibliography of all the articles is available from the author. The studies chiefly related to mental health issues in the USA. The subject of HIV/AIDS and perceived 'risky' behaviour received most coverage (McKinnon *et al.* 1993, Susser *et al.* 1993, Herman *et al.* 1994, Gottesman & Groome 1997, Grassi *et al.* 1999). Some of the studies explored the effects of stigma and discrimination (Bacharach 1992, Crisp 1999). Other studies looked at the effects of medication including cognitive and physical responses (Bhui *et al.* 1997, Fortier *et al.* 2000). Support systems were investigated along with notions about marriage, family planning and vulnerability (Shanks & Atkins 1985, Coverdale *et al.* 1997). Potential professional responses were examined including assessment, planning of services and therapeutic interventions (Lukoff *et al.* 1986, Pepper 1988, Bell *et al.* 1993). Only one ward-

based study, conducted in the UK, expressly canvassed service users and their views around sexuality issues (McCann 2000). The overall conclusion revealed distinct gaps in psychosexual knowledge in relation to client needs and this provided the impetus for the present study. There was a noticeable lack of studies that examined the subjective accounts of people with a medical diagnosis of schizophrenia such as meanings associated with love and intimacy and the influence upon the person's future hopes and aspirations towards forming and maintaining intimate relationships.

Aims of the study

In relation to the current literature, no studies exist that specifically capture the views of people with a diagnosis of schizophrenia living in the community. Therefore, at the heart of the present study was the exploration of personal experiences of the people living with and recovering from the condition. In order to address some of the shortcomings in the literature, the aims of the present study were to:

- establish clients intimate relationship experiences;
- explore specific issues important to service users;
- uncover potential obstacles to the expression of sexuality;
- present recommendations for mental health practice, education and research.

Methods in practice

Context

The people involved in the study all had a medical diagnosis of schizophrenia, schizotypal and delusional disorders as defined by the *International Classification of Diseases* (World Health Organisation 1992). All of the participants regularly attended a clinic in London,

UK, to receive antipsychotic depot injections. A list of clients was obtained from the Mental Health Locality Team administrator and totalled 47. The study involved 15 men, and 15 women were invited to take part in the study. All agreed and the community psychiatric nurses, who knew the clients well, would administer the injection and make a clinical judgement about the suitability of the person for interviewing.

Demographics

A total of 15 men and 15 women were conveniently recruited to take part in the study. All had a case-note diagnosis of schizophrenia and were living in the community. Ages ranged from 22 to 57 years (mean 41 years). The sample was ethnically diverse and fairly representative of the local population. A majority were White UK (46.7%) the remainder of people identified as White European (16.7%), Black African (6.7%), Black Caribbean (26.7%) and Indian (3.3%). Other figures revealed lesbian, gay, bisexual, and transgender (LGBT) (26.7%), heterosexual (73.3%), currently in a relationship (40%) and were parents (33.3%). A majority had enrolled in further education (70%), and most had less than 10-year contact with mental health services. The average number of previous admissions to a psychiatric hospital was five.

Semi-structured interviews

The interview schedule was designed specifically for the purpose of the study that would capture client's subjective experiences around sexual and relationship issues. It consisted of 37 open ended questions (see Appendix I) and addressed issues such as intimacy, love, relationships, sex education, sex experiences, sexual preferences, family planning, medication issues, supports, stigma and self-esteem. The schedule was developed through the research team at the University and included service user input. Interviews lasted for approximately 1 h, were conducted in a private office in the clinic and were tape-recorded.

Ethical issues

Approval to carry out the study was granted by the local ethics committee (Reference number: P98210). Signed consent to take part in the study was gained from participants. All of the interviews were carried out face-to-face whereby the interviewer could gauge any discomfort, offer support and provide clarification. Participants agreed to be tape-recorded, and people were assured that they could stop the interview at any point. Anonymity was guaranteed. All data were stored securely.

Study results

Data were gathered using the semi-structured interviews, was tape-recorded and eventually transcribed. Analysis of the data used techniques such as data reduction, data display and conclusion drawing and verification (Miles & Huberman 1994). A computer software package was used to help in the data analysis (QSRNUD*IST). Categories and subcategories emerged and were organized systematically. The key categories included perceptions of intimacy, establishing and maintaining relationships, sexual concerns and issues, sexual knowledge and understanding, stigma and self-esteem, family planning and parenting, views about prescribed medication, formal and informal supports. Each category is presented and demonstrates what people articulated about the issues that were important to them.

Perceptions of intimacy

It is presumed by some that people with a schizophrenia diagnosis do not possess the capabilities required to think and feel like other people who do not have the condition (Akhtar & Thomson 1980). Nevertheless, all of the participants were able to articulate their views of intimacy and mentioned aspects such as love, closeness and caring.

Well I'd like a sexual relationship but I'd have to like the person as well, but it's not just sex I mean I've got to love the person as well. You can't get a girlfriend unless you are secure with yourself first. (Respondent 5)

Yes taking care of each other, talking with each other, discussing your feelings with each other, yes that's what makes love. You make someone happy then it makes you happy . . . (Respondent 17)

Someone who accepts you for what you are . . . no questions asked. Someone who cares and wants to support you through thick and thin, who will be about for you when times are rough. (Respondent 26)

I mean a good intimate relationship would just be kindly and mutually respectful, supportive and loving and generous, that is what I would expect and that is what I give. That is what I would expect of any intimate relationship . . . (Respondent 29)

Establishing and maintaining relationships

A fundamental part of the process of recovery is the development of meaningful relationships (Government of Scotland 2006). Of the 30 participants, only one respondent said he had never been in a relationship. Three men and nine women were currently in a relationship. People were able to expand on their experiences and some of the challenges they face in forming and maintaining relationships.

Well when I was with my fella for 10 years, we had sex when he was drunk, because you see when he doesn't drink he's too shy-about the old penis. So when he'd had a drink he used to say come let's have a go and to be honest with you sometimes I didn't feel very much – but I just thought we're together, he's good to me. He hasn't got anyone to turn to so, there you go. (Respondent 4) 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 10)

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. It's hard man . . . (Respondent 14)

I am seeing a woman in the hostel. We have been together for three years. She has schizophrenia and learning difficulties. We want to get married and live together. The staff have only found out that we are seeing each other and are not happy . . . (Respondent 12)

It's like if you talk about sex in the hospital or try to make a sexual contact, but not touching, but talking in a sexual way you get in trouble for that and there's many pretty women in hospital. When I told one of them that we could make beautiful babies together, I think she took it the wrong way and I got in trouble for that. I got sent out to the locked ward . . . (Respondent 21)

They don't like it if you go into the male dormitories. Dave who was admitted, and he is a really good friend of mine, all I wanted to do was go and have a chat with him and I wanted to ask him if he had got any fags and I had just walked in there and I was just sitting on his bed talking to him and oh well, Christ you think

. . . they think you are having it off and nurse came in and she went ballistic. (Respondent 1)

Sexual concerns and issues

People spoke about past experiences and present concerns including pre-illness activity, AIDS/HIV, safe sex issues, specific sexual problems and concerns in institutional settings.

For 4–8 years I was a bit more active – maybe it was sex then I wouldn't call it love-making . . . to me there is a difference – to me sex is when you just put it in there, you don't enjoy it and love-making is everything: we have foreplay, we have sex and then afterwards you just stay there for more play, we get up and have a shower or a bath or something like that. So, what I received before I was sick – I wouldn't call it lovemaking. (Respondent 4)

The only trouble with 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 5)

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 2)

Sometimes. Jack is a bit rough and I get sore. I get, you know, dry and he just forces it in. I tell him to stop, but he just carries on. (Respondent 11)

Well, it takes a long time and there's that feeling of suffocation. I mean sexually and emotionally. I have a really strong psychological hold over my sort of sexual drives and feelings. I am sure that is why I have never had an orgasm because there is something in me that always holds back and always sets apart and removes myself from the sexual act. That is a really big problem . . . (Respondent 29)

There is no privacy around here. There's not much chance to have sex. We're under the staff. Staff just come into the room, they don't bother to knock. I have no one to talk to about this stuff and I get worried that I may harm her. I feel anxious about it and it makes us both unhappy. (Respondent 12)

Sexual knowledge and understanding

People were asked to describe education opportunities in the past including school and while in hospital.

I definitely had no sex education. We had hygiene lessons, where the PE teacher told us about trimming pubic hair, and using deodorant. But, no sex education at school or at home. I learned most from my friends, if anything . . . (Respondent 29)

It started off with us being taught about the human body, biology . . . male and female, to say we received sexual education – no not really. Oh no, nothing in the hospital, it was never discussed. (Respondent 9)

Stigma and self-esteem

Several studies endorse the view that people with mental health problems are likely to experience devaluation and discrimination from members of the community at large which could potentially affect all aspects of community integration and effective recovery (Rosenfield 1997, Prince & Prince 2002).

The participants were requested to comment on questions related to self-image and identify perceived obstacles to sexual expression.

Yes, yes – there are all these good-looking guys they just want you for one thing and go sleep with women, the uglier they are the more faithful. (Respondent 6)

I am reluctant [to approach women] because I'm afraid they all know that I am not well. I am very reluctant to go next to my own Kurdish people because of the shame I feel. (Respondent 16)

The only thing that would stop me [meeting someone] is that I was neglecting myself. I wasn't wearing nice clothes; I was always walking down the street trampy 'cause I was confused in my brain, with all the evil people around attacking me everyday. That drove me down to such a deep state of depression, and I wasn't looking after myself. Whenever I looked for the right sort of clothes all I could find were clothes that my mum had brought me, and not ones I would choose. (Respondent 21)

I wouldn't mind meeting somebody from one of these centres who has an insight with you. I really would prefer somebody who is not mentally ill but it's very difficult because they'd probably end up taking advantage of me. Also, I wouldn't want somebody who is very sick because they may have a relapse. They might burn down my flat, kick the door in or just be a pest. I can't win can I . . . I lose to choose. (Respondent 4)

I would like to have a girlfriend. I would like to have relationship with normal girls. I feel bad about having to pay for sex. (Respondent 16)

Family planning and parenting

The earlier literature concerning family planning and those with mental health problems would appear to be fuelled by controversy with some studies warning against the production of offspring lest women make poor or uninformed judgements and 'suffer' the consequences of unwanted pregnancies (McEvoy *et al.* 1983). In the present study, people were asked to express their views about children and potential hopes and aspirations they may have about producing offspring.

I'd really like to have children, but maybe it's too late now. We're trapped in this place.

I'd like us both to live together in a flat in London. Could we have children? I don't know . . . (Respondent 12)

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 Piportil injection, so I can't get pregnant anyway. (Respondent 4)

My girlfriend is pregnant. We need a flat and money to survive. I spent £18 a week on travelling to and from work. It puts a great strain on things. My girlfriend wants to get rid of the baby because we can't afford to keep it. This makes me very sad . . . (Respondent 24)

Views about prescribed medication

In other studies, a variety of adverse effects commonly reported included weight gain, decreased libido and desire, premature ejaculation, erectile problems, decreased satisfaction with sex and less pleasure at orgasm (Lyketsos *et al.* 1983, Bhui *et al.* 1997).

Participants were asked to comment on the effects the medication they were taking may impact upon their sex life.

I had gone off sex and started on Prozac. I began to have lots of sex and I wanted more and more and I was so horny on Prozac. My sex drive went super high, I was stuck to the ceiling, so high it was incredible. (Respondent 9)

The only thing I can think can possibly help is for the psychiatrist to study the medication to find out which one is causing sexual problems. That would be very, very difficult but I think it's something that can be done. We need to change our sex lives, it is something that I really need in my heart . . . (Respondent 4)

Well, I can't let myself go like I used to. I can't trust people. Because of the depot injection and these other drugs that they put me on. He [the doctor] put me on an anti-depressant and I went right off sex altogether. I think that is probably one of the reasons we broke up . . . I think it is all these drugs that, affected, what do they call it. You're sex drive or something. (Respondent 15)

Now that my urge has come back after all this time, if this relationship breaks up, I can't see me meeting anyone else. Being overweight, I don't feel that I am attractive. These injections make you put on weight. (Respondent 10)

It sometimes stopped me from having sex because I cannot relax to do sexual movements. I get stiffness in my arms and legs. Slowness too, and it does something to the muscles, I was like with myself the other day and couldn't make it hard, like a few days ago like I could swear it can stop your sex life completely. (Respondent 21)

Medication constantly reminds me of my condition. If I didn't have to take it then I could sort of like deceive myself that it is not there. It is the same if I take Becotide; it tells me that I have asthma. The main effect of psychiatric drugs makes me constantly worry about my erections. I worry because it can damage the libido and things like that. (Respondent 30)

Formal and informal supports

Often loved ones have had to make huge personal sacrifices in order that they can better look after the person who is ill, e.g. giving up work, not socializing. The increased burden of care placed upon families and others can put additional strains on familial relationships that can eventually lead to greater conflict and crises (Fadden 1998).

Respondents were asked to talk about the kind of support they may receive from family,

friends and from health practitioners.

I like the very fact you've made me think of the issues. I didn't come looking for it . . . I'm open to the CPN enquiring about my partnership. I'm open to them asking me about it. If you asked me 20 years ago I'd probably be closeted. I'm proud to be lesbian. I thought your questions were about sexual positions and the like . . . like the Kinsey report. The questions are actually fine. (Respondent 2)

They [health professionals] are only interested if you were considered abnormal. Like, do you fancy kids or something like that then you would get a whole load of questions. I think they ask questions in a negative sense and that it was just one more mental box to cross off. (Respondent 9)

Cultural differences get in the way. Only once my brother helped me. Culturally the only thing the family will help you with is getting married. It will take some- time to change. (Respondent 16)

I just ask them a few questions [friends], for instance – have you had sex, how do you feel about sex, do you enjoy sex? To find out how my friends are getting on with her sex life and then compare it with mine. (Respondent 4)

Discussion

The results of the study present the views and opinions of a group of people living in the community who have rarely been canvassed about intimate relationships and sexual concerns. This was evident in the current available literature on the topic. In the study, there appeared to be great clarity in each of the respondent's perception of intimacy and at times this was articulated in a very emotive way. Apparently, not only does it consist of the sexual act, more importantly it has to do with trust, warmth, companion- ship, support, caring, loyalty and affection. Far and away, the most important ingredient of an intimate relationship was love

for one another, the bedrock upon which satisfying relationships may be built. This may enable us to question some of the thinking within traditional psychiatry, whereby people with a psychotic illness may be seen as unfeeling, or unable to experience emotional states because of 'negative' symptoms associated with the illness. Further, blunting of affect is one of the key pathological indicators in schizophrenia and is perceived as an impediment to the expression of emotion (Bancroft 1989). There is no evidence to support this assumption in the interviews. Where relationships were concerned, most people relayed positive experiences. However, some people spoke about abusive relationships and others about constraints such as lack of skills and experience, lack of opportunity or unsuitable living arrangements. Moreover, strict institutional rules together with attitudes of staff were seen as impediments to future intimate relationships. Vivid examples were provided by respondents of issues related to negative staff attitudes and particularly the problems around support and privacy. These findings resonate with those found in an acute ward study investigating inpatient mental health care environments (Alexander 2003), based on earlier work in the field (Goffman 1961). Others spoke of feeling wary about experimental sex because of the perceived threat of sexually transmitted infections, particularly HIV/AIDS.

Furthermore, sexual knowledge was problematic in that people rarely, if ever, were presented with the opportunity to learn about sexuality issues either growing up or in healthcare settings. Most of the lessons at school were covered in biology and concerned human anatomy. In hospital, the subject was never discussed, which is perhaps surprising, as this may be considered a key component within the holistic process of psychosocial rehabilitation or recovery (McCann 2000). Many people expressed a strong desire to have children but for many the obstacles seemed insurmountable. From the interviews, it became clear that people did not speak to health professionals about family planning. This perhaps compounds the controversial view that people with a schizophrenia diagnosis are somehow

‘asexual’ or should not be parenting (Jamison 1995). For some, the biopsychosocial consequences of taking neuro- leptic medication were expressed. For instance, people spoke of feeling slowed up, muscle stiffness, substantial weight gain, decreased desire and erectile dysfunction. Moreover, further obstacles to forming and maintaining relationships included stigma and shame and the narrow- ing of opportunities to meet people outside of the mental health system. The effects of stigma were related to self- image and the way that others people responded to the individual. Finally, people spoke about expectations related to different kinds of support and sexual and relationship needs. The responses were very varied. Some identified their Community Psychiatric Nurse or their General Prac- titioner as someone they may speak to, but only if directly asked and felt that practitioners were generally ‘too busy’. Some people would perhaps speak to friends. Where mental health assessments were concerned, one man thought that questions about sexuality issues were only asked as part of a risk assessment process.

Overall, the findings illustrate a range of issues and concerns that are important to people. The respondents provided poignant accounts of their experiences and were willing and able to do so. A crucial part of the process of recovery is for clients to be facilitated in recounting their experiences (Buchanan-Barker & Barker 2008). The poten- tial response of practitioners to the issues is now a fundamental consideration.

Conclusion

Despite the paucity of published data, particularly in the UK, around sex and relationship issues and schizophrenia, it has become clear from the present study that the subject deserves more attention. In 1975, the World Health Organisation provided guidelines regarding health strategies that included adopting positive attitudes to sexuality, that staff show understanding and offer support to clients, training programmes for staff and increased

resources to deal with complex issues around sexuality (World Health Organisation 1975). However, despite these early suggestions, and taking into account later government recovery directives, it would appear that this area remains relatively unexplored. Themes in the recovery literature include being believed in and encouraged, developing perspective on the past, taking personal responsibility for one's life, acting to rebuild one's life, changing other people's expectations of what one can achieve, developing new meaning and purpose in life and developing valued relationships and roles (Mental Health Commission 2008, National Institute for Clinical Excellence 2009). All of these attributes could serve as catalysts for building confidence and self-esteem as well as providing protection against the harm caused by stress and the recovery journey. What has become patently clear through the results of the present study is that people with a psychotic illness are perfectly astute in identifying their needs, and eloquent in their descriptions of their experiences regarding sexual and relationship matters. How practitioners may respond to this information and provide appropriate therapeutic interventions remains challenging. Some of the biggest issues that were raised in the present study were not about the inability to discuss sexual matters, but related to the opportunity to discuss sexual and relationship concerns. Perhaps people needed permission to do so and this creates an important chance to engage in dialogue. In order that practitioners can feel more confident and self-aware about embarking on an exploration of sexuality issues with patients, educators perhaps need to look at a range of teaching and learning strategies to support practitioners. Clinical supervision would form a pivotal part of the process. In terms of sexuality education, the biomedical model still appears to dominate in steering curriculum content where there is a need to consider the psychosocial and cultural aspects of sexuality. Where research is concerned, most funding for sexuality research was forthcoming only in the 1980s and 1990s in terms of targeting the potential risks to the general population in the midst of

AIDS/HIV (in the USA). It will be necessary to go beyond the disease prevention approach and focus more on therapeutic possibilities, for instance, accurate identification of need; organizational factors in supporting psychosexual practice; user involvement and sexuality; training programmes and sexually transmitted infections; practitioners and their approaches to sensitive topics; education and training techniques; and an evaluation of therapeutic frameworks. These activities would then inform policy directives. Furthermore, if we in the health professions are to be truly responsive to the needs of people with a serious and enduring mental health condition, we need to enquire about subjective experiences and a person's hopes, feelings, beliefs and aspirations regarding sexual and relationship fulfilment and provide suitable therapeutic responses.

Acknowledgments

The author gratefully acknowledges the contribution of the 30 clients who took part in the study. He would also like to thank Professor Len Bowers and members of the research team at City University, London for their support and Professor Agnes Higgins at Trinity College for helpful comments on a draft of the paper.

References

- Adler M.W. (1997) Sexual health – a health of the nation failure. *British Medical Journal* **314**, 1743–1751.
- Akhtar S. & Thomson J.A. (1980) Schizophrenia and sexuality: a review and a report of twelve unusual cases – Part I. *Journal of Clinical Psychiatry* **41**, 134–142.
- Alexander J. (2003) *The relationship between flexibility/ inflexibility of ward nursing regimes and patient outcomes*. Unpublished PhD thesis, City University, London.
- Bacharach L. (1992) Psychosocial rehabilitation and psychiatry in the care of long-term patients. *American Journal of Psychiatry* **149**, 11.
- Bancroft J. (1989) *Human Sexuality and Its Problems*, p. 26. Churchill Livingstone, London.

- Bell C., Wringer P., Davidhizar R., *et al.* (1993) Self-reported sexual behaviours of schizophrenic clients and non-institutionalised adults. *Perspectives in Psychiatric Care* **29**, 30–36.
- Bhui K., Puffet A. & Strathdee G. (1997) Sexual and relationship problems amongst patients with severe chronic psychosis. *Social Psychiatry and Psychiatric Epidemiology* **32**, 459–467.
- Buchanan-Barker P. & Barker P.J. (2008) The tidal commitments: extending the value base of mental health recovery. *Journal of Psychiatric and Mental Health Nursing* **15**, 93–100.
- Coverdale J., Turbott S. & Roberts H. (1997) Family planning needs and STD behaviours of risk female psychiatric outpatients. *British Journal of Psychiatry* **171**, 69–72.
- Crisp A.H. (1999) The stigmatization of sufferers with mental disorders. *British Journal of General Practice* **49**, 3–4.
- Department of Health (1990a) *NHS and Community Care Act*. HMSO, London.
- Department of Health (1990b) *The Care Programme Approach for People with Mental Illness*. HC (90) 23. HMSO, London.
- Department of Health (1992) *The Health of the Nation: A Strategy for Health in England*. HMSO, London.
- Department of Health (1999) *Modern Standards and Service Models – National Service Frameworks*. HMSO, London.
- Department of Health (2001) *The National Strategy for Sexual Health and HIV*. HMSO, London.
- Department of Health and Children (2006) *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Stationery Office, Dublin.
- Fadden G. (1998) Family intervention in psychosis. *Journal of Mental Health* **7**, 115–122.
- Fortier P., Trudel G., Mottard J., *et al.* (2000) The influence of schizophrenia and standard or atypical neuroleptics on sexual and sociosexual functioning: a review. *Sexuality and Disability* **18**, 85–104.
- Gilburt H., Rose D. & Slade M. (2008) The importance of relationships in mental health care: a qualitative study of service users' experiences of psychiatric hospital admission in the UK. *BMC Health Services Research* **8**, 92.
- Goffman E. (1961) *Asylums*. Anchor Books, New York. Gottesman I.I. & Groome C.S. (1997) HIV/AIDS risks as a consequence of schizophrenia. *Schizophrenia Bulletin* **23**, 675–684.
- Government of Scotland (2006) *Rights, Relationships and Recovery: The Report of the National Review of Mental Health Nursing in Scotland*. Scottish Executive, Edinburgh.

- Grassi L., Pavanati M., Cardelli R., *et al.* (1999) HIV risk- behaviour and knowledge about HIV/AIDS among patients with schizophrenia. *Psychological Medicine* **29**, 171–179.
- Herman R., Kaplan M., Satriano J., *et al.* (1994) HIV prevention with people with serious mental illness: staff training and institutional attitudes. *Psychosocial Rehabilitation Journal* **17**, 97–103.
- Higgins A., Barker P. & Begley C. (2005) Neuroleptic medication and sexuality: the forgotten aspect of education and care. *Journal of Psychiatric and Mental Health Nursing* **13**, 687–697. Higgins A., Barker P. & Begley C. (2009) Clients with mental health problems who sexualize the client–nurse encounter. *Journal of Advanced Nursing* **65**, 616–624.
- Jamison K.R. (1995) *An Unquiet Mind: A Memoir of Moods and Madness*. Vintage Books, New York.
- Kinsey A., Pomeroy W. & Martin C. (1948) *Sexual Behaviour in the Human Male*. W.B. Saunders, London.
- Lewis J. & Scott E. (1997) The sexual education needs of those disabled by mental illness. *Psychiatric Rehabilitation Journal* **21**, 164–167.
- Lukoff D., Gioia-Hastick D., Sullivan G., *et al.* (1986) Sex education and rehabilitation with schizophrenic male outpatients. *Schizophrenia Bulletin* **12**, 669–675.
- Lyketsos G.C., Sakka P. & Mailis A. (1983) The sexual adjustment of chronic schizophrenics: a preliminary study. *British Journal of Psychiatry* **143**, 376–382.
- McCann E. (2000) The sexual and relationship needs of people with psychosis: breaking the taboos. *Journal of Advanced Nursing* **32**, 132–138.
- McCann E. (2003) Exploring sexual and relationship possibilities for people with psychosis: a review of the literature. *Journal of Psychiatric and Mental Health Nursing* **10**, 640–649.
- McEvoy J.P., Hatcher A., Appelbaum P.S., *et al.* (1983) Chronic schizophrenic women's attitudes toward sex, pregnancy, birth control, and childbearing. *Hospital and Community Psychiatry* **34**, 536–539.
- McFarlane L. (1997) *Diagnosis Homophobic – The Experiences of Lesbians, Gay Men and Bisexuals in Mental Health Services*. PACE, London.
- McKinnon K., Cournos F., Meyer-Bahlburg H., *et al.* (1993) Reliability of sexual risk behaviour interviews with psychiatric patients. *American Journal of Psychiatry* **150**, 972–974.
- Mental Health Commission (2008) *A Recovery Approach within the Irish Mental Health Service: A Framework for Development*. Mental Health Commission, Dublin.
- Miles and Huberman (1994) *Qualitative Data Analysis*. Sage, London.
- National Institute for Clinical Excellence (2009) *Schizophrenia: Core Interventions in the Treatment and Management of Schizophrenia in Adults in Primary and Secondary Care*. HMSO, London.

- Pepper E. (1988) Sexual awareness groups in a psychiatric day treatment program. *Psychosocial Rehabilitation Journal* **11**, 45–53.
- Perkins R. & Rinaldi M. (2002) Unemployment rates among patients with long-term mental health problems. *Psychiatric Bulletin* **26**, 295–298.
- Prince P.N. & Prince C.R. (2002) Perceived stigma and community integration among clients of assertive community treatment. *Psychiatric Rehabilitation Journal* **25**, 323–331.
- Rosenfield S. (1997) Labelling mental illness: the effects of received services and perceived stigma on life satisfaction. *American Sociological Review* **62**, 660–672.
- Shanks J. & Atkins P. (1985) Psychiatric patients who marry each other. *Psychological Medicine* **15**, 377–382.
- Slade M. & Hayward M. (2007) Recovery, psychosis and psychiatry: research is better than rhetoric. *Acta Psychiatrica Scandinavica* **116**, 81–83.
- Susser E., Valencia E. & Conover S. (1993) Prevalence of HIV infection among psychiatric patients in a New York City men's shelter. *American Journal of Public Health* **83**, 568–570.
- Wellings K., Field J., Johnson A., *et al.* (1994) *Sexual Behaviour in Britain*. Penguin, London.
- World Health Organisation (1975) *Education and Trends in Human Sexuality: The Training of Health Professionals*. WHO Teaching Reports Series No. 572. World Health Organisation, Geneva.
- World Health Organisation (1992) *Manual of the International Classification of Diseases, Injuries and Causes of Death, 10th Revision*. World Health Organisation, Geneva.

Appendix I

Semi-structured interview schedule

Interview No.

Date:

Duration:

1. What does intimacy mean to you?
2. Are you in an intimate relationship now?
3. What sexual relationships have you had in the past?
4. What were they like?
5. Ever talked to anyone about it?
6. What kind of sex education did you get at school?
7. What sex education did you get while in hospital?
8. What questions did doctors or nurses ask about your intimate relationships?
9. In what ways were you sexually active before going into hospital/receiving treatment?
10. Do you enjoy spending time alone or would you like to meet more friends?
11. Can you tell me about the sex you are having now?
12. What would your ideal partner be like?
13. Where would you go to meet a prospective partner?
14. Does anything stop you meeting potential partners?
15. Where would you go to have sex?
16. Do you have any worries or concerns about getting sex?
17. Do you have any worries or concerns about having sex?
18. How would you describe a good or satisfying intimate relationship?
19. What do you understand by safe sex?
20. What concerns do you have about contraception when having sex?
21. If you needed condoms/safe sex advice, where would you get them?
22. Do your friends/family know you are having/wanting sex?
23. What might they say?
24. Have you ever been in love with a person?
25. What does this mean/involve?
26. Do you need to be in love to have sex?
What do you think about having children?
27. Is there anything that stops you having children?
28. In what ways do you think you are attractive to other people?
29. In what ways do you take care of your appearance?
30. What medications do you take?
31. What effects may your medication have on your emotions and feelings?
32. What effects may your medication have on your sex life?
33. Who would you talk to about sexual relationships (general practitioner, community psychiatric nurses, partner, etc.)?
34. What support might you need with intimate relationships from friends or family?

35. Is there any help we might give you in your intimate relationships?

36. What do you think was most helpful/unhelpful for you during the interview?

Notes:

