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**Citation:** McCann, E. (2010). The sexual and relationship needs of people who experience psychosis: quantitative findings of a UK study. Journal of Psychiatric and Mental Health Nursing, 17(4), pp. 295-303. doi: 10.1111/j.1365-2850.2009.01522.x

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**Link to published version:** https://doi.org/10.1111/j.1365-2850.2009.01522.x

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# The sexual and relationship needs of people who experience psychosis: quantitative findings of a UK study

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# **Accessible summary**

- Distinct lack of studies exist that explore sexual and relationship issues.
- Captures important experiences of people who use mental health services.
- Reveals potential obstacles to the expression of sexuality.
- Identifies a diversity of needs.
- Presents issues that may guide mental health practice, education and research.

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Abstract

Few studies have investigated the experiences of people regarding sexual and relation- ship issues in the

area of mental health. This study presents the quantitative findings of a larger study that was conducted in

London, UK. The aims of the study were to establish client's sexual and relationship experiences and

perceived needs. A total of 30 people with a medical diagnosis of schizophrenia, living in the community,

were interviewed using three questionnaires. The first related to demographics, the second used relevant

parts of the Camberwell Assessment of Need (CAN) and the third looked at possible determinants of sexual

behaviour. The CAN also captured keyworker responses to issues related to their clients sexual and

relationship requirements. The results showed that 83% of the clients were currently experiencing sexual

feelings. Some 90% of clients felt some need in relation to sexual expression and 83% for needs related to

intimate relationships. Only 10% of staff recognized sexual expression as a need in clients in their care

and 43% perceived a need for intimate relationships. Furthermore, most clients interviewed thought that

their psychotropic medication caused sexual problems. Contrasts are made with other studies to help

highlight the important issues that emerged for service users.

*Keywords*: psychosis, relationships, schizophrenia, sexuality

# **Background**

In the UK there have been government drives to make health and social care more responsive and inclusive. Earlier documents include the NHS and Community Care Act (Department of Health 1990a) and the Care Pro- gramme Approach (CPA) (Department of Health 1990b). More recent publications have outlined government strat- egies which aim to tackle issues pertinent to users, carers and significant others regarding mental health provision focussing on the process of recovery. Such documents include 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). Additionally, the Government has published a national strategy for sexual health and HIV (Department of Health 2001), a document addressing domestic and sexual violence (Department of Health 2006) and a proposal for potential therapeutic interventions (Department of Health 2007). As a result, more attention has been paid to detailed assessment of the needs of all individuals suffering from mental illnesses such as schizophrenia and psychosis. Topics of importance include housing, occupation, education, medical, social and psychiatric care, socialization, risk assessment and recovery (Davidson et al. 2006, Buchanan- Barker & Barker 2008). However, over time, the intimate sexual and interpersonal needs of affected individuals have emerged as a justifiable concern for mental health practitioners (Lewis & Scott 1997, McCann 2003, Higgins et al. 2009). The Health of the Nation (Department of Health 1992) targets compartmentalized sexual health and mental health as separate and distinct entities. The former con-centrated on teenage pregnancies and sexually transmitted diseases and the latter examined ways of reducing suicides (Adler 1997). While these targets seem praiseworthy for the whole UK population, the sexual needs of indivi-duals with psychosis appear to remain marginalized and neglected. In the UK, the National Survey of Sexual Atti- tudes and Lifestyles (Wellings et al. 1994), one of the largest sexual studies since the Kinsey Report (Kinsey et al. 1948), only made reference to physical health. (McCann 2003) carried out a systematic review of the available literature relating to sex and relationship issues and people with a diagnosis of schizophrenia or psychosis.

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 (McKinnon *et al.* 1993, Herman *et al.* 1994, McDermott *et al.* 1994, Gottesman & Groome 1997). 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 (Bacharach 1992, Rowlands 1995, Crisp *et al.* 2000). Several studies examined the effects of medication on a person's sexual functioning and included cognitive as well as physical responses (Bhui *et al.* 1997, Smith *et al.* 2002). Some support systems were studied along with notions about marriage (Lane *et al.* 1995), family planning (Miller & Finnerty 1996) and vul- nerability (Read & Argyle 1999). Further, literature con- cerning possible professional responses, particularly the identification, assessment and planning of service and therapeutic provision was extrapolated (Park Dorsay & Forchuk 1994, Dilloway & Hildyard 1998). The final picture revealed distinct gaps in psychosexual knowledge in relation to patient needs and this provided the rationale for the present study.

# Study aims

- 1. To discover the clients' sexual and relationship experi- ences in the past and present and to elicit hopes and aspirations for the future.
- 2. To uncover some of the obstacles to the expression of sexuality in people with serious mental illness living in the community.
- 3. To present recommendations for mental health practice, education and research.

#### **Methods** in practice

# Sampling

A recognized sampling procedure was followed (Kuzel 1992). The population under study consisted of people with a case-note diagnosis of schizophrenia, living in the community, and regularly attending a depot clinic in North London to receive anti-psychotic medication. The follow- ing selection criteria were

used:

• case note diagnosis of schizophrenia;

• aged between 16 and 64 years;

• taking neuroleptic medication;

• regularly attending the depot clinic.

The participants were recruited from one depot clinic. A list of attendees was obtained from the Locality Team administrator and totalled 47. Participants were conve- niently recruited to take part in the study. An office was provided in the clinic that afforded privacy where partici- pants were informed about the study and consent sought, The Community Psychiatric Nurses administering the injection would make a clinical judgement on the suitability or wellness of the person to take part in the study.

#### Ethical considerations

Approval for the study was gained from the local hospital ethics committee (Reference number: P98210). At all times the investigator was respectful of the participants while administering the questionnaires. Time was invested in explaining the purposes and aims of the research. Participants were assured that should they wish to stop the interview for any reason they would be free to do so. Furthermore, participants were guaranteed anonymity and were informed that names would not appear on any documents. They would not be identifiable. The data from the study, which included the completed questionnaires, were kept in secure locked cupboards within the University. Written consent was gained. Participants were invited to ask questions and seek clarification before beginning the interviews and at the end.

#### **Data collection**

Three questionnaires were used to obtain data.

A questionnaire relating to demographic data

This included racial identity, gender, age, education, marital status, whether in a relationship or not, number of children, medical diagnosis, number of hospital admissions and last hospital admission (Table 1).

\*\*Table 1 here\*\*\*

Relevant parts of The Camberwell Assessment of Need (CAN) (Phelan et al. 1995)

The CAN is a well-validated and reliable tool devised to assess the complex clinical and social needs of people with severe mental illness (Slade *et al.* 1999). The questionnaire incorporates both staff and user assessment of issues over the past month. There are 22 items in the full assessment schedule. The chosen parts used in the present study spe- cifically address the issue of intimate relationships and sexual expression. Both user views (Table 2) and staff opin- ions (Table 3) were rated. The user and staff responses relating to need identification were collated (Table 4).

A structured interview schedule incorporating the determinant factors of sexual behaviour through life (Pfeiffer & Davis 1972) modified version (McCann 2000) The original determinants of sexual behaviour (DSB) questionnaire relates to interest, frequency and satisfaction of sexual activity in younger years and at the present time. It also records reasons for stopping sexual relations. Pfeiffer and Davis used the questionnaire on a population of 502 subjects aged between 46 and 69 years. The modified version uses additional questions related to views about medications (Table 5).

\*\*\*Tables 2,3,4,5, here \*\*\*

# Results and data analysis

# Data analysis

The data were analysed using the Statistical Package for the Social Sciences (spss v9) (Brace *et al.* 2000). The analysis is divided into two parts:

- 1. descriptive statistics which provide information relating to the sample characteristics;
- 2. inferential statistics investigating relationships between selected variables.

The data were manipulated after entry into spss, includ- ing some recoding to enable the execution of further inferential statistical analyses. It was necessary to split cases,

e.g. male and female, to determine certain responses. Additionally, 2¥2 contingency tables were constructed

to allow for the computation of specific statistical tests.

# Description of the client sample

From a total of 47 patients attending a Health Centre in London to have depot medication administered, 30 people were interviewed. The participant characteristics are shown in Table 1. The age group of the sample varied between 22 and 57 years (mean = 40.93 years). Most people identified as White UK (46.7%), although within the sample, there was a rich mix of ethnic backgrounds, reflect- ing 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 (World Health Organization 1992). A significant percentage of people had less than 10 years contact with mental health services and the average number of previous admissions was five and a half.

To allow for a further analysis of the data, chi-squared tests were used to compare relevant responses (Greene & d'Oliveira 1999). A cross-tabulation of the variables 'sex' and 'children' showed significant results, where more females then males were more likely to parent children ( $c^2$  9.600, d.f. = 1, P = 0.002). There were no other statistically significant relationships between demographic variables.

# Results of the CAN

The CAN staff responses were completed by the 'named' CPA community keyworkers who worked in the locality team. With regard to intimate relationships, most users (70%) gave this maximum scoring in each of the three sections, seeing this as a serious unmet need. Staff (13%) and users (17%) perceived this as an area of no need. A large number of staff (43%) were unable to say if a need existed for their clients, with some (23%) perceiving this as a serious unmet need.

In response to the items on sexual expression, a very high proportion of staff (60%) could not say if there

was a need for clients in this area. Conversely, all users were able to articulate responses to every question. More than half of users (53%) reported serious unmet need compared with staff responses (7%). A larger proportion (37%) of users reported sexual expression as being a met or partially met need as opposed to (3%) of staff.

The user and staff responses relating to need identifi- cation were collated (Table 4). A high number of user respondents (90%) recognized that there was some need in the area of sexual expression, whereas very few staff (10%) thought that this was the case. With regard to inti- mate relationships, 83% of users identified some need, whereas 57% of staff respondents reported no need/not known. The merging of the responses 'no need' and 'not known' may be problematic as staff could not say whether there was an identified need or not. Presumably, they had never asked their patients about these specific areas of need.

#### Results of the DSB interview

More than half of the respondents (57%) had no enjoy- ment of sexual relations before receiving treatment with 43% reporting some degree of enjoyment. At the time of interview, 37% of the respondents were claiming to have had a satisfactory sex life. Only13% reported having no enjoyment whatsoever. A significant number of people (83%) said they were experiencing sexual feelings at the present time although 49% reported that they were not having 'sex relations' at the moment. More than half (67%) noted a decline in sexual interest or activity with a majority of people reporting a diminution in the last 5 years. Moreover, sex ceased for 50% of the sample between 1 and 5 years ago. The main reasons given for stopping sexual relations were: illness of self (17%); separation/divorce (17%) and lack of opportunity (17%). A large number of respondents (77%) knew the names of the medications they were taking. Significantly, 60% of people interviewed, thought that medication caused sex problems.

Chi-squared tests were used to determine levels of sig- nificance between selected variables on the DSB question- naire. The responses 'enjoyment of sex relations before receiving treatment' and 'frequency of sex relations now' were cross-tabulated and revealed significant results ( $c^2$  28.249, d.f. = 9, P = 0.001)

suggesting that people who never enjoyed sex pre-treatment were still not having sex. There were no other statistically significant results between the other variables.

# Relationships between the demographics and CAN

Using the chi-squared test, relevant participant character- istics were compared with the results gained in the CAN questionnaire, to determine whether there were statistically significant differences in staff and user responses to sexual problems and relationship difficulties. No significant differences were noted on the variables sex, ethnicity, age, chil- dren, diagnosis and service contact. However, there was a strong significant difference between heterosexual and non- heterosexual perceptions of intimate relationship problems ( $c^2$  8.727, d.f. = 1, P = 0.003) which may suggest that gay and lesbian respondents were more satisfied with their relationships.

#### Relationships between the demographics and DSB

Chi-squared tests were applied to the demographic charac- teristics and the DSB results of the present sample (n = 30). The only significant differences between responses were found in the categories *in relationship* now and *frequency of sex relations at the present time* ( $c^2$  15.502, d.f. = 2, P = 0.000), suggesting that people in a current relationship were more likely to be having sex.

# Relationships between the CAN and DSB

Chi-squared statistical tests were carried out between selected variables from both questionnaires. No statisti- cally significant results were found between the responses.

# Comparison between the ward and community groups

The data from the present study was compared with data obtained from an earlier hospital ward-based study (Table 5). The ward was situated in a large Victorian psy- chiatric hospital in the East End of London. There were fifteen patients being cared for in this locked acute rehabilitation environment. It

was a mixed-sex ward and culturally diverse. A total of 11 (73%) patients agreed to be interviewed from a possible 15. The entire group had a primary medical diagnosis of schizophrenia. Over half of the sample (64%) had spent between 1 and 5 years in psychiatric hospitals (McCann 2000).

In the community sample, a significant number (87%) said they enjoyed sexual relations at the present time compared with ward respondents (27%). More than 40% of the inpatients enjoyed sexual relations before hospitalization. Over 60% felt aware of a decline in sexual interest or activity, which almost equates with the community respondents. In both of the studies, over 50% reported a decline occurring within the last 10 years. Most could not remember exactly when, but over half stated '. . . since coming into hospital'. Sex relations stopped for over 70% of the sample since being hospitalized.

When asked why sex relations had stopped, the ward respondents mainly identified illness of self (36%) and lack of opportunity (36%). The community group identified illness of self (17%), separation/divorce (17%) and lack of opportunity (17%). A proportion of the community sample reported active sex relations (27%). Each of the client groups (over 70%) knew the medication they were taking. Of the 11 participants, two people said that their medication contributed to sex problems in contrast to a much higher proportion (60%) of community respondents. Chi-squared tests were run on the data to test whether there were significant differences between ward and com-munity responses for each of the categories on the DSB questionnaire (Table 5). Questions 1, 5, 6 and 9 all had similar scores and showed no significant relationship between each of the variables. There were significant differ- ences in response to the question enjoyment of sex now, with the ward sample scoring high on no sex (73%) compared with (13%) in the community. This may be attributed to the strict rules and regulations operating within ward environ-ments. The question related to *sexual feelings now* showed significant differences. Both groups had strong sexual feel- ings with a high lack of opportunity expressed in the ward sample. Results from the question frequency of sex now revealed significance with 82% of ward respondents never having sex compared with 49% of the community group. A fair number of community respondents (22%) reported having sex once a week or more. Significant differences were shown in response to the question relating to when sex stopped, with 27% of the community respondents saying sex had not stopped compared with sex ceasing to happen for the entire ward sample. Again, this is not surprising when consideration is given to the oppressive nature of some inpatient environments. Moreover, when asked about reasons for stopping sex, 36% of the ward sample stated lack of opportunity. Finally, significant differences were apparent in response to the last question about medication and sex problems with 60% of the community respondents stating that they felt that medication did contribute to sexual difficulties as opposed to 18% of the ward sample. This may be due to the fact that a relatively high number of people living in the community were perhaps involved in sexual activity and were experiencing problems.

### Comparison between CAN results and other studies

A search was conducted to locate studies that had used the CAN (Table 6). In a Scottish study (Simons & Petch 2002), that examined needs assessment and discharge from hospi- tal, the authors attempted a response to the National Service Framework for Mental Health (Department of Health 1999) Standard Five which states:

Each service user who is assessed as requiring a period of time away from their home should have . . . a copy of a written care plan agreed on discharge, which sets out the care and rehabilitation to be provided, identifies the care-co-ordinator, and specifies the action to be taken in a crisis.

In this study, the 22-item CAN was used to measure staff and patient perceptions of need. The patient responses (n = 173) for sexual expression were rated zero. The reason given was that the interviewers were uneasy discussing the issue of sexuality with the respondents. Only 3% of staff (n = 98) identified this as an unmet need. In the present study, 53% of patients felt their needs regarding sexual expression were not being met whereas only 7% of staff perceived this as an area of serious unmet need. Where intimate relationships were concerned, 10% of patients and 6% of staff respondents identified unmet needs in the Scottish study. This com- pares with patient responses (73%) and staff responses (23%) in the present study.

An earlier study (Slade et al. 1996) looked at the asso-ciation between the assessment of need by staff

and by severely mentally ill patients. The results of the staff responses are not that dissimilar to those of the present study. However, patient identification of need varies greatly on both domains of sexual expression (83%, 20%) and intimate relationships (90%, 27%).

The high ratings in the present study may be due to the overall nature of the study and the focus upon sex and relationship issues, which was made explicit to the participants before the interviews began.

#### **Discussion and conclusion**

In order to address the aims of the study, 30 people with a diagnosis of schizophrenia currently living in the com- munity completed the questionnaires. Some had spent many years in hospital while others had less familiarity with life in institutional settings. The composition of the sample was ethnically diverse and appeared to be fairly representative of the service users within the local population. Just under half were currently in a relationship. The CAN was used to gauge levels of need from a staff and user perspective and is considered to be one of the first rating instruments to do so (Phelan et al. 1995). The CAN survey revealed dramatic differences between staff and user perceptions of need around both intimate relationships and sexual expression. Nearly all of the service users (90%) identified need in terms of sexual expression. Staff gave this very low priority. This apparent disparity perhaps highlights the concerns around attitudes of staff in relation to client sexuality needs and the potential to talk about the subject (McCann 2000, Higgins et al. 2009). A comparison between the present study and other studies that used the CAN revealed problems on behalf of the researchers (Simons & Petch 2002). The research interviewers appeared to have an inability to gain infor- mation concerning sexuality concerns. This, it could be argued, may be due to their own discomfort in addressing sexual issues that could result in this important area remaining neglected or ignored completely. The opposite was true in the present study. Participants were very forthcoming in their responses and were keen to share additional information that flags the opportunity for future therapeutic activity. The DSB survey uncovered some notions about individual's past and present sexual and relationship behaviours. Valuable information emerged in relation

to the earlier ward study and the present study. For instance, there was huge disparity between sexual activities on the ward compared with people living in the community. This is perhaps not so surprising as strict rules apply on many wards with sexual behaviour being problematized or even ignored (Alexander 2003). The issues around neuroleptic medication were elicited and a majority of respondents (60%) who lived in the community attributed sex problems to medi- cation. The unwanted effects of medication and the related sexual problems, that often remain undetected, have been highlighted as one of the main reasons for non- concordance (Smith *et al.* 2002).

In conclusion, although some interesting and valuable findings emerged from the data, several limitations were acknowledged. The sample size was low in number and this reduced the power of statistical testing. Nevertheless, the data gathered and presented in this study informed the larger study that included semi-structured questionnaires in order that thoughts, attitudes and feelings of participants were determined. These findings are being presented else- where. However, it has become clear from the information gained in this study that nurses do not generally ask patients about sexual and relationship matters. All of the respondents, contrary to clinical opinion, were able to articulate their experiences around the issues of sexuality. Perhaps nurses' own anxieties create obstacles to the exploration of what may be deemed 'sensitive' topics. Additionally, societal pressures particularly surrounding the taboos of sex and the discussion of all matters sexual may obstruct the potential for dialogue between nurses and the people we care for and may impact upon a person's recovery trajectory.

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**Table 1** Demographic characteristics

Sex         Male Female (50,00)         15 (50.0)         15 (50.0)         40.93 (10.01)         15 (50.0)         40.93 (10.01)         Ethnicity         White UK (20,00)         40.93 (10.01)         14 (46.7)         14 (46.7)         White UK (20,00)         14 (46.7)         14 (46.7)         White European (20,00)         5 (16.7)         8 (26.7)         16 (20.7) </th <th>Variables</th> <th></th> <th></th> <th>n (%)</th>	Variables			n (%)
Female	Sex			
Ethnicity  White UK Black Caribbean White European Black African Indian Black African Indian Black African Black A		Male		15 (50.0)
Ethnicity       White UK       14 (46.7)         Black Caribbean       8 (26.7)         White European       5 (16.7)         Black African       2 (6.7)         Indian       1 (3.3)         Sexual orientation         Heterosexual       22 (73.3)         Gay       2 (6.7)         Lesbian       5 (16.7)         Bisexual       1 (3.3)         Further education         College       14 (46.7)         University       7 (23.3)         None       9 (30.0)         Marital status         Single       16 (53.3)         Ever married       14 (46.7)         Relationship now       Yes       12 (40.0)         No       18 (60.0)         Children       Yes       10 (33.3)         Yes       10 (33.3)         No       20 (66.7)         Clinical diagnosis       Schizophrenia       20 (66.7)         Schizo-affective disorder       10 (33.3) Service contact (years)         6 (20.0)       6-10       10 (33.3)         11-15       2 (6.7)         11-15       2 (6.7)         11-15		Female		15 (50.0)
White UK   14 (46.7)     Black Caribbean   8 (26.7)     White European   5 (16.7)     Black African   1 (3.3)     Sexual orientation   Heterosexual   22 (73.3)     Gay   2 (6.7)     Lesbian   5 (16.7)     Lesbian   5 (16.7)     Lesbian   5 (16.7)     Bisexual   1 (3.3)     Further education   College   14 (46.7)     University   7 (23.3)     None   9 (30.0)     Marital status   Single   16 (53.3)     Lever married   14 (46.7)     Relationship now   Yes   12 (40.0)     Relationship now   Yes   12 (40.0)     Children   Yes   10 (33.3)     No   20 (66.7)     Clinical diagnosis   Schizophrenia   Schizophrenia   20 (66.7)     Schizo-affective disorder   10 (33.3)   Service contact (years)     O-5   6 (20.0)     6-10   10 (33.3)     11-15   2 (6.7)     16-20   4 (13.3)     16-20   4 (13.3)     17-15   2 (6.7)     16-20   4 (13.3)     17-15   2 (6.7)     16-20   4 (13.3)     17-15   2 (6.7)     16-20   4 (13.3)     17-15   2 (6.7)     16-20   4 (13.3)     17-15   2 (6.7)     16-20   4 (13.3)     17-15   2 (6.7)     17-15   2 (6.7)     18-20   4 (13.3)     18-20   4 (13		Age: mean (SD)		40.93 (10.01)
Black Caribbean   8 (26.7)   White European   5 (16.7)   Black African   2 (6.7)   Black African   2 (6.7)   Indian   1 (3.3)   Sexual orientation	Ethnicity			
White European     5 (16.7)       Black African     2 (6.7)       Indian     1 (3.3)       Sexual orientation     4 (3.3)       Heterosexual     22 (73.3)       Gay     2 (6.7)       Lesbian     5 (16.7)       Bisexual     1 (3.3)       Further education     College     14 (46.7)       University     7 (23.3)       None     9 (30.0)       Marital status     Single     16 (53.3)       Ever married     14 (46.7)       Relationship now     Yes     12 (40.0)       Children     Yes     10 (33.3)       No     18 (60.0)       Children     Yes     10 (33.3)       Clinical diagnosis     Schizophrenia     20 (66.7)       Schizo-affective disorder     10 (33.3) Service contact (years)       O-5     6 (20.0)       6-10     10 (33.3)       11-15     2 (6.7)       16-20     4 (13.3)       + (26.7)     4 (13.3)       + (26.7)     4 (13.3)       + (26.7)     4 (13.3)       + (26.7)     4 (13.3)       + (26.7)     4 (13.3)       + (26.7)     4 (13.3)       + (26.7)     4 (13.3)       + (26.7)     4 (13.3)       + (2				14 (46.7)
Black African   1 (3.3)		Black Caribbean		8 (26.7)
Indian		White European		5 (16.7)
Sexual orientation		Black African		2 (6.7)
Heterosexual   Gay   2 (6.7)     Lesbian   Bisexual   5 (16.7)     Bisexual   1 (3.3)     Further education   College   University   7 (23.3)     None   9 (30.0)     Marital status   Single   16 (53.3)     Ever married   14 (46.7)     Relationship now   Yes   12 (40.0)     No   No   18 (60.0)     Children   Yes   10 (33.3)     No   No   20 (66.7)     Clinical diagnosis   Schizophrenia   20 (66.7)     Schizo-affective disorder   10 (33.3) Service contact (years)     O-5   6-10   10 (33.3)     11-15   2 (6.7)     16-20   4 (13.3)     16-20   4 (13.3)     20 (66.7)     16-20   4 (13.3)     20 (67.7)     16-20   4 (13.3)     20 (67.7)     16-20   4 (13.3)     20 (67.7)     16-20   4 (13.3)     20 (67.7)     16-20   4 (13.3)     20 (67.7)     20 (67.7)     20 (27.7		Indian		1 (3.3)
Gay       2 (6.7)         Lesbian       5 (16.7)         Bisexual       1 (3.3)         Further education         College       14 (46.7)         University       7 (23.3)         None       9 (30.0)         Marital status         Single       16 (53.3)         Ever married       14 (46.7)         Relationship now         Yes       12 (40.0)         No       18 (60.0)         Children         Yes       10 (33.3)         No       20 (66.7)         Clinical diagnosis         Schizo-affective disorder       10 (33.3) Service contact (years)         O-5       6 (20.0)         6-10       10 (33.3)         11-15       2 (6.7)         16-20       4 (13.3)         >20       8 (26.7)	Sexual orientation			
Lesbian   Bisexual   5 (16.7)     Bisexual   1 (3.3)     Further education   College   14 (46.7)     University   7 (23.3)     None   9 (30.0)     Marital status   Single   16 (53.3)     Ever married   14 (46.7)     Relationship now   Yes   12 (40.0)     No   No   18 (60.0)     Children   Yes   10 (33.3)     No   No   20 (66.7)     Clinical diagnosis   Schizophrenia   20 (66.7)     Schizo-affective disorder   10 (33.3) Service contact (years)     O-5   6-10   10 (33.3)     11-15   2 (6.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)     16-20   4 (13.3)     >20 (80.7)		Heterosexual		22 (73.3)
Further education  College University None  Single Ever married  Yes No No No  Collidren  Yes No		Gay		2 (6.7)
Further education    College		Lesbian		5 (16.7)
College 14 (46.7) University 7 (23.3) None 9 (30.0)  Marital status  Single 16 (53.3) Ever married 14 (46.7)  Relationship now Yes 12 (40.0) No 18 (60.0)  Children Yes 10 (33.3) No 20 (66.7)  Clinical diagnosis  Schizo-affective disorder 10 (33.3) Service contact (years)  O-5 6-10 10 (33.3) 11-15 2 (6.7)  16-20 4 (13.3) >20 (86.7)		Bisexual		1 (3.3)
University 7 (23.3)   None 9 (30.0)	Further education			
None   9 (30.0)		College		14 (46.7)
Marital status  Single Ever married  16 (53.3) 14 (46.7)  Relationship now  Yes 12 (40.0) No 18 (60.0)  Children  Yes 10 (33.3) No 20 (66.7)  Clinical diagnosis  Schizo-affective disorder  0-5 6-10 10 (33.3) Service contact (years)  10 (33.3) 11-15 2 (6.7) 16-20 4 (13.3) >20 8 (26.7)		University		7 (23.3)
Single 16 (53.3) Ever married 14 (46.7)  Relationship now  Yes 12 (40.0) No 18 (60.0)  Children  Yes 10 (33.3) No 20 (66.7)  Clinical diagnosis  Schizo-affective disorder  0-5 6-10 10 (33.3) Service contact (years)  6-10 10 (33.3) 11-15 2 (6.7) 16-20 4 (13.3) >20 8 (26.7)		None		9 (30.0)
Ever married       14 (46.7)         Relationship now         Yes       12 (40.0)         No       18 (60.0)         Children         Yes       10 (33.3)         No       20 (66.7)         Clinical diagnosis       20 (66.7)         Schizo-affective disorder       5chizophrenia       20 (66.7)         Schizo-affective disorder       0-5       6 (20.0)         6-10       10 (33.3)       11-15       2 (6.7)         16-20       4 (13.3)       20         20       8 (26.7)       3 (26.7)	Marital status			
Relationship now  Yes 12 (40.0) No 18 (60.0)  Children  Yes 10 (33.3) No 20 (66.7)  Clinical diagnosis  Schizo-affective disorder  0-5 10 (33.3) Service contact (years) 6-10 10 (33.3) 11-15 2 (6.7) 16-20 4 (13.3) >20 8 (26.7)		Single		16 (53.3)
Yes 12 (40.0) No 18 (60.0)  Children  Yes 10 (33.3) No 20 (66.7)  Clinical diagnosis  Schizo-affective disorder  5 10 (33.3) Service contact (years)  0-5 6-10 10 (33.3) 11-15 2 (6.7) 16-20 4 (13.3) >20 8 (26.7)		Ever married		14 (46.7)
No 18 (60.0)  Children  Yes 10 (33.3) No 20 (66.7)  Clinical diagnosis  Schizo-affective disorder  0-5 10 (33.3) Service contact (years) 6-10 10 (33.3) 11-15 2 (6.7) 16-20 4 (13.3) >20 8 (26.7)	Relationship now			
Children  Yes 10 (33.3) No 20 (66.7)  Clinical diagnosis  Schizo-affective disorder  0-5 6-10 10 (33.3) 11-15 2 (6.7) 16-20 4 (13.3) >20 (86.7)		Yes		12 (40.0)
Yes 10 (33.3) No 20 (66.7)  Clinical diagnosis  Schizo-affective disorder  5chizo-affective disorder  0-5 6-10 10 (33.3) 11-15 2 (6.7) 16-20 4 (13.3) >20 8 (26.7)		No		18 (60.0)
No 20 (66.7)  Clinical diagnosis  Schizo-affective disorder  0-5 6-10 11-15 11-15 16-20 20 8 (26.7)	Children			
Clinical diagnosis  Schizo-affective disorder  Schizo-affective disorder  0-5 6-10 10 (33.3) Service contact (years) 6-10 11-15 2 (6.7) 16-20 3 (4 (13.3) >20 8 (26.7)		Yes		10 (33.3)
Schizo-affective disorder     Schizophrenia     20 (66.7)       0-5     6 (20.0)       6-10     10 (33.3)       11-15     2 (6.7)       16-20     4 (13.3)       >20     8 (26.7)		No		20 (66.7)
Schizo-affective disorder     10 (33.3) Service contact (years)       0-5     6 (20.0)       6-10     10 (33.3)       11-15     2 (6.7)       16-20     4 (13.3)       >20     8 (26.7)	Clinical diagnosis			
0-5 6 (20.0) 6-10 10 (33.3) 11-15 2 (6.7) 16-20 4 (13.3) >20 8 (26.7)		Schizophrenia		20 (66.7)
6-10 10 (33.3) 11-15 2 (6.7) 16-20 4 (13.3) >20 8 (26.7)	Schizo-affective disorder		10 (33.3) Service contact (years)	
11-15 2 (6.7) 16-20 4 (13.3) >20 8 (26.7)		0-5		6 (20.0)
16-20 4 (13.3) >20 8 (26.7)		6-10		10 (33.3)
>20 8 (26.7)		11-15		2 (6.7)
>20 8 (26.7)		16-20		4 (13.3)
		>20		
		Previous admission	s: mean (SD)	

Table 2
User (n = 30) assessment of level of need (%)

	No need,	Met or partially	Serious unmet	Not known,
CAN domain	n (%)	met need, $n$ (%)	need, <i>n</i> (%)	n (%)
Intimate relationships	5 (17)	3 (10)	22 (73)	0
Sexual expression	3 (10)	11 (37)	16 (53)	0

CAN, Camberwell Assessment of Need.

Table 3
Staff (n = 30) assessment of level of need (%)

CAN domain	No need, n (%)	Met or partially met need, n (%)	Serious unmet need, n (%)	Not known, n (%)
Intimate relationships	4 (13)	6 (21)	7 (23)	13 (43)
Sexual expression	9 (30)	1 (3)	2 (7)	18 (60)

CAN, Camberwell Assessment of Need.

**Table 4** Identified need by staff (n = 30) and users (n = 30)

CAN domain	Staff identifying need, <i>n</i> (%)	Not known/no need (staff), n (%)	Users identifying need, $n$ (%)	Not known/no need (users), $n$ (%)
Intimate relationships	13 (43)	17 (57)	25 (83)	5 (17)
Sexual expression	3 (10)	27 (90)	27 (90)	3 (10)
Mean	8 (26.5)	22 (73)	26 (86.5)	4 (13.5)

CAN, Camberwell Assessment of Need.

Table 5
Determinant factors of sexual behavior (%)

	2000 study	Present study		
	Ward $(n = 11)$ ,	Community	Chi-squared	
	n (%)	(n = 30), n (%)	test	P value
Enjoyment of sex relations pre hospital/treatment			2.82	0.42
None	5 (46)	17 (57)		
Mild	2 (18)	5 (17)		
Moderate	2 (18)	4 (13)		
Very much	2 (18)	4 (13)		
Enjoyment of sex relations at the present time	_ ( · • )	. ()	86.78	0.01**
None	8 (73)	4 (13)		
Mild	1 (9)	7 (23)		
Moderate	2 (18)	8 (27)		
Very much	0 (0)	11 (37)		
3. Sexual feelings at present time	0 (0)	11 (37)	16.46	0.01**
Absent	1 (9)	5 (17)	10.40	0.01
Weak	4 (36)	7 (23)		
Moderate	. ,			
	1 (9)	8 (27)		
Strong	5 (46)	10 (33)	24.54	0.04**
4. Frequency of sex relations at the present time	0 (02)	45 (40)	34.56	0.01**
Never	9 (82)	15 (49)		
Once a month	1 (9)	8 (27)		
Once a week	1 (9)	2 (7)		
More than once a week	0 (0)	5 (17)		
5. Awareness of any decline in sexual interest or activity			0.19	0.65
Yes	7 (64)	20 (67)		
No	4 (36)	10 (33)		
6. At what age first noted (5-year age bracket)			2.25	0.52
No problem	4 (36)	10 (33)		
1-5 years ago	4 (36)	9 (30)		
6-10 years ago	2 (18)	7 (24)		
More than 10 years ago	1 (9)	4 (13)		
7. If sex relations stopped, when stopped?			41.86	0.01**
Not stopped	0 (0)	8 (27)		
1-3 years ago	2 (18)	8 (27)		
2-5 years ago	3 (27)	7 (23)		
6-10 years ago	3 (27)	4 (13)		
11+ years ago	3 (27)	3 (10)		
8. Reasons for stopping sex relations	- ( )		51.36	0.01**
Not stopped	0 (0)	8 (27)		
Death of partner	0 (0)	2 (7)		
Illness of self	4 (36)	5 (17)		
Illness of partner	0 (0)	1 (3)		
Self no longer able to perform sexually	1 (9)	4 (13)		
Separation or divorce from spouse	2 (18)	5 (17)		
Lack of opportunity		5 (17)		
9. What medications do you take?	4 (36)	3 (17)	0.43	0.51
Accurate response	8 (73)	22 (77)	0.43	0.51
·		23 (77)		
Don't know	3 (27)	7 (23)	27 70	0.04**
10. Do your medications cause any sex problems?	2 (40)	19 ((0)	37.78	0.01**
Yes	2 (18)	18 (60)		
No	6 (55)	9 (30)		
Don't know	3 (27)	3 (10)		

Table 6

Needs identified by staff and patients in separate studies

	Present	Slade et al.	Simons &
	study	1996	Petch
	(n = 30)	(n = 47)	2002
			(n = 173)
Staff responses, $n$ (%)			
Intimate relationships	13 (43)	14 (29)	26 (27)
Sexual expression	3 (10)	8 (16)	0
Patient responses, n (%)			
Intimate relationships	25 (83)	10 (20)	26 (26)
Sexual expression	27 (90)	13 (27)	0

- **4.** To uncover some of the obstacles to the expression of sexuality in people with serious mental illness living in the community.
- **5.** To present recommendations for mental health practice, education and research.

# Methods in practice

# Sampling

A recognized sampling procedure was followed (Kuzel 1992). The population under study consisted of people with a case-note diagnosis of schizophrenia, living in the community, and regularly attending a depot clinic in North London to receive anti-psychotic medication.

The follow- ing selection criteria were used:

- case note diagnosis of schizophrenia;
- aged between 16 and 64 years;
- taking neuroleptic medication;
- regularly attending the depot clinic.

The participants were recruited from one depot clinic. A list of attendees was obtained from the Locality Team administrator and totalled 47. Participants were converiently recruited to take part in the study. An office was provided in the clinic that afforded privacy where participants were informed about the study and consent sought, The Community Psychiatric Nurses administering the injection would make a clinical judgement on the suitability or wellness of the person to take part in the study.

#### Ethical considerations

Approval for the study was gained from the local hospital ethics committee (Reference

number: P98210). At all times the investigator was respectful of the participants while administering the questionnaires. Time was invested in explaining the purposes and aims of the research. Partici- pants were assured that should they wish to stop the interview for any reason they would be free to do so. Furthermore, participants were guaranteed anonymity and were informed that names would not appear on any docu- ments. They would not be identifiable. The data from the study, which included the completed questionnaires, were kept in secure locked cupboards within the University. Written consent was gained. Participants were invited to ask questions and seek clarification before beginning the interviews and at the end.

\*\*\*Table 1 here \*\*\*

Data collection

Three questionnaires were used to obtain data.

Table 1

Demographic characteristics

Variables			n (%)
Sex			
	Male		15 (50.0)
	Female		15 (50.0)
	Age: mean (SD)		40.93 (10.01)
Ethnicity			
	White UK		14 (46.7)
	Black Caribbean		8 (26.7)
	White European		5 (16.7)
	Black African		2 (6.7)
	Indian		1 (3.3)
Sexual orientation			
	Heterosexual		22 (73.3)
	Gay		2 (6.7)
	Lesbian		5 (16.7)
	Bisexual		1 (3.3)
Further education			
	College		14 (46.7)
	University		7 (23.3)
	None		9 (30.0)
Marital status			
	Single		16 (53.3)
	Ever married		14 (46.7)
Relationship now			
	Yes		12 (40.0)
	No		18 (60.0)
Children			
	Yes		10 (33.3)
	No		20 (66.7)
Clinical diagnosis			
	Schizophrenia		20 (66.7)
Schizo-affective disorder		10 (33.3) Service contact	
	0-5		6 (20.0)
	6-10		10 (33.3)
	11-15		2 (6.7)
	16-20		4 (13.3)
	>20		8 (26.7)
	Previous admissions: mean	(SD)	5.53 (5.06)