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The expression of sexuality in people with psychosis: breaking the taboos

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Abstract

While mental health professionals should recognize that people suffering from schizophrenia have sexual and relationship requirements, there appears to be a failure to address adequately the subject of human sexuality, particularly in the area of psychosocial rehabilitation. The broad aim of this small study was to identify the sexual and relationship needs of people being cared for in hospital and preparing for a return to community living. The objectives of the study were to discover the clients' sexual expressions in the past and present, and to try to elicit hopes and aspirations for the future. An attempt was made to uncover some of the obstacles to the expression of sexuality and explore some of the clients' subjective experiences of the issues. The number of respondents was 11 from a possible 15. Data were collected through: a questionnaire on demographic characteristics; an adapted version of a questionnaire investigating the determinant factors of sexual behaviour through life; and a semi-structured interview devised to elicit subjective experiences regarding sexual expression. The findings show that people with psychotic illness are prepared to discuss issues relating to sex and relationship matters. No interviews had to be prematurely terminated. No exacerbations of symptoms were noted. All of the respondents showed an openness to discuss a range of intimate feelings. Most respondents seemed hopeful about the opportunity to form intimate and fulfilling relationships in the future. A drive towards more rigorous holistic nursing assessments and appropriate psychosocial responses is proposed.

INTRODUCTION AND LITERATURE REVIEW

Sexuality and mental health

The issue of human sexuality presents mental health professionals with some of the most difficult ethical, moral and legal problems. Nursing policy on sexual activities involving patients has needed the challenge of acquired immune deficiency syndrome (AIDS) and human immunodeficiency virus (HIV) to initiate action on confronting the issues. Recent studies in the United States of America (USA) have examined the prevalence of HIV risk behaviours among chronic mentally ill adults and recognize the potential for the rapid spread of HIV among psychiatric populations (Goisman et al. 1991, Kelly et al. 1992, Cournos et al. 1994, Kalichman et al. 1994).

Statistics show that 1% of the population world-wide suffers from schizophrenia (Kaplan 1992). In financial terms, 1.6% of the total healthcare budget is spent on treating schizophrenia (Davies & Drummond 1994). The Health of the Nation (Department of Health 1992) separated its strategies concerning sexual health and mental health. The targets included tackling teenage pregnancies, sexually transmitted diseases and a reduction in the national suicide rate (Adler 1997). Sexual need in people with psychosis was not addressed. One of the largest national studies on sexual attitudes and lifestyles since The Kinsey Report (Kinsey et al. 1948) was published recently in the United Kingdom (UK) (Wellings et al. 1994). Physical health was covered abundantly. There were no data on mental health.

The introduction of the English National Health Service (NHS) and Community Care Act (Department of Health 1990a) and the Care Programme Approach (Department of Health 1990b) has guided mental health professionals in the systematic detailed assessment of the needs of individuals with serious and enduring mental health problems. Further, the Secretary of State for Health issued a 10-point plan for initiatives in mental

health (Department of Health 1995). These included 'The development of standards for the care and treatment of people with schizophrenia'. However, plans of care do not normally include an assessment of sex and relationship need. Psychosexual interventions are not usually offered. The intimate psychosexual needs of affected individuals have only recently become apparent to carers (Lewis & Scott 1997). In the clinical arena, particularly in the area of psychosocial rehabilitation, practitioners have had to deal with very complex situations that have involved predominantly older populations. The emergence of a younger group with quite different expectations around sex and relationship issues poses new challenges for mental health professionals. Many of these individuals are striving for a 'normal' life in the community (d'Ardenne & McCann 1997).

The wide range of problems apparent in practice settings may include: very limited social access and social skills; poor self-image and confidence; limited self-care; poverty and its links with prostitution and exploitation; sexual abuse in childhood and adulthood; the sexual content of positive symptoms; sexual disinhibition and the risk to self and colleagues; the adverse effects of psychotropic medications on libido; the secondary effects of medication, including disabling extrapyramidal signs; the results of institutionalization and stigmatization; hospital policies and the expression of sexual need in institutional settings; education and consent; safe sex and contraception; and homelessness (Birley & Hudson 1991, Rowlands 1995, Attenborough & Watson 1997, Coverdale et al. 1997, d'Ardenne & McCann 1997).

Schizophrenia

The aetiology of schizophrenia is unknown although strong biological and genetic theories have been postulated (Liddle 1994, Shields 1978, Van Horne & McManus 1992). It is sometimes considered the most devastating of the mental illnesses because its onset is

often early in a patient's life and its symptoms can have a profound effect on individuals and significant people in their lives (Kaplan 1992). In assessing and planning therapeutic interventions, consideration should be given to positive symptoms such as delusions, hallucinations, thought disorder and persistent bizarre behaviour; and negative symptoms such as affective flattening, alogia, avolition, anhedonia and attentional impairment. These symptoms, along with bizarre and sometimes unpredictable behaviour, can have an adverse effect on the processes required to establish and maintain close relationships (Perry & Braff 1994). Secondary disabilities such as social problems, stigmatization and institutionalization are especially important when looking at sex and relationship problems.

People with a major mental illness can have a public stigma that can compromise self-esteem and add to a sense of powerlessness (Bhui & Puffett 1994). The misconceptions of society can lead to ostracism and alienation. Societal disapproval and fear regarding the production of offspring could further impede relationship formation. The problems associated with the debilitating side-effects of medication (shuffling gait, masked expression, bulging eyes, dribbling, dystonias, dyskinesias, and weight gain) also need to be addressed. The presence of disfiguring movement disorders may greatly affect the potential to form relationships. People may feel self-conscious and may perceive themselves as unattractive which can lead to diminished morale.

Although the biopsychosocial manifestations of the illness are profound, Arieti (1974) believes that the sexual life of someone with schizophrenia contains nothing specific that couldn't be repeated for non-psychotic individuals. Bancroft (1989) claims that changes in behaviour, emotional reactions and thought processes are so gross and so pervading it would be surprising if sex and relationship repercussions did not occur. Verhulst & Schneidman (1981) conducted an inpatient survey that

showed little evidence of sexual problems other than those attributed to medication: premature ejaculation, anorgasmia and vaginismus.

The effect of the institution on sexual behaviour has received far less attention than the ways psychotropic medications impact on sexual functioning and sex drive (Kotin et al. 1976). Primary disabilities may be compounded by life in an institution and by the opinions of professionals. There is a general assumption that people with schizophrenia 'don't do sex'. There is perhaps a fear that to address the subject will be seen as actively encouraging widespread institutional promiscuity. Despite the inclusion of social skills training in rehabilitation programmes, sexual education is rarely a component (Civic et al. 1993).

Sexuality and nursing

According to the World Health Organization, the aim of taking sexuality into account in health care is to promote sexual health (Mace et al. 1974). This includes:

- A capacity to enjoy and control sexual and reproductive behaviour in accordance with a personal and social ethic.
- Freedom from fear, shame, guilt, false beliefs and other psychological factors inhibiting sexual response and impairing sexual relationships.
- Freedom from organic disorders, diseases and deficiencies that interfere with sexual and reproductive functions.

Although this interpretation may be useful in describing some of the problems inherent in sexual health, the following quotations from the literature help to illuminate the human aspects of a person's sexuality.

Adams (1976 p. 166) states that:

The definition of sexuality can be as narrow as the act of intercourse or as broad as seeing the entire universe. Each individual determines the answer to defining their sexuality. Sexuality is a celebration of oneself, a voyage into body, mind and spirit. It is based on one's cognition, emotions and physical functioning.

Stuart & Sundeen (1979 p. 356) argue that:

Sexuality is an integral part of the whole person. Human beings are sexual in every way, all the time. To a large extent human sexuality determines who we are. It is an integral factor in the uniqueness of every person. People are sexual beings all of the time, whether they are healthy, ill or disabled. They experience their sexuality in unique individual ways.

An awareness of the complexities of sexuality is an essential basis for assessing clients' needs for nursing care, planning and carrying out nursing interventions, and evaluating their effects. Sexuality involves the totality of being a person (Webb 1989). Patients are only given their full respect as people when nursing care has firm foundations in a truly holistic approach incorporating human sexuality as a vital component of humanity (Browning & Lewis 1973).

For many mentally ill people, some of the greatest needs are to express their feelings, to have their concerns acknowledged as valid, and to be given the information necessary to manage their lives. Nursing is in a unique position to provide for the sexual health care needs of clients. This care is important to the goals of health promotion and primary prevention in nursing. It allows nurses to function as advocates, and enables them to meet the growing demand for informed, responsible patient care. Weinberg (1982) describes further attributes such as: giving patients information; listening to patients' views and concerns; ensuring their need for confidentiality and privacy; and

involving patients in decisions about their care. In the UK many plans of nursing care use the activities of living model (Roper et al. 1981). However, the category entitled 'expressing sexuality' tends to be under- used or even ignored by nurses. Webb (1985) argues that this may be due to a lack of understanding of the complexities of sexuality, or difficulty in deciding how to collect and record information.

To enable nurses to fulfil this role confidently and competently, they need to be knowledgeable about the biological, psychological and social aspects of sexuality.

THE STUDY

Aims

- 1 To discover the respondents' sexual expressions in the past and present, and endeavour to elicit their hopes and aspirations for possible sexual relationships in the future.
- 2 To uncover some of the obstacles to the expression of sexuality for people with an enduring mental illness.
- 3 To explore the subjective experiences of the residents concerning their expression of sexuality.

Methods

Sample and context

The ward where the respondents were interviewed was situated in a large Victorian psychiatric hospital in the East End of London. There were 15 patients being cared for in this locked acute rehabilitation environment. It was a mixed sex ward and culturally diverse. A total of 11 patients agreed to be interviewed from a possible 15.

Instrumentation

Structured and semi-structured interview schedules were used:

- A questionnaire relating to demographic data.
- A structured interview investigating the determinant factors of sexual behaviour through life (Pfeiffer & Davis 1972).
- A semi-structured interview designed specifically for the study, consisting of five open-ended questions geared towards discovering patients' expectations and aspirations regarding sexual expression. This was developed when the limitations of the structured interview were identified.

The author and a female psychology assistant conducted the interviews. The interviewers had worked with the group for 2 years and 1 year, respectively. All questionnaires were administered to individuals in one session, lasting about 45 minutes each. Permission for conducting the study was gained from the responsible medical officer (RMO). Key workers were consulted and support assured. Patients verbally consented to participate in the study. The study was submitted to the local hospital ethics committee and was duly approved.

The structured interview

A questionnaire investigating the determinant factors of sexual behaviour was used (Pfeiffer & Davis 1972). It relates to interest, frequency and satisfaction of sexual behaviour in younger years and at the present time. It also notes reasons for stopping sexual relations. The instrument was devised for use with an elderly population. Other studies concerning people with a medical diagnosis of schizophrenia have used this questionnaire (Lyketsos et al. 1983, Bell et al. 1993).

The limitations of the structured questionnaire became apparent during the pilot survey. Respondents had difficulty comprehending some of the questions and the following suitable adaptations were made:

- Question number one read ‘enjoyment of sex relations in younger years’ which seemed too vague and non- specific. This was changed to read: ‘... before admission to hospital’.
- Many clients when asked about noticing any decline in sexual interest had difficulty remembering. ‘Since coming into hospital’ was added here.
- The question ‘Reasons for stopping sex relations’ was modified and responses were extended to include: lack of opportunity; no privacy; and in hospital.
- An additional question, ‘Does your medication contribute to your sex problems?’ was added, since a relationship between psychotropic medication and sexual functioning has been described in the literature (McCreadie 1993, Verhulst & Schneidman 1981).

RESULTS

Demographic characteristics of the sample

The entire group of 11 respondents had a primary medical diagnosis of schizophrenia. The largest number of respondents were European (seven), two were African, one was African-Caribbean and one was of Turkish origin. Over half the sample (seven) were men and 4 were women, which reflects the male/female ratio on the ward. More than half (six) were aged between 30 and 39. Three respondents were aged 18–29. A large proportion (nine) had never married. The remainder were divorced. Every member of the respondent group is now single. One respondent had three children and two had one child. The majority (eight) had no children. More than half left school at 16 with no qualifications although three had attended college. One person went to university to study medicine. Just fewer than half the group (five) had six to 10 hospital admissions. Over half (seven) had spent between 1 and 5 years in psychiatric hospitals. Two respondents had spent between 6 and 10 years in hospital.

Reported sexual relations

A significant number (eight) had no sexual relations at the present time. Just under half the respondents reported that they had enjoyed sexual relations before hospitalization. More than half reported having strong sexual feelings before admission to hospital. Just under half said they had sexual feelings at the present time. Two respondents admitted to having sex relations at the present time, once a month and once a week, respectively. Over Seven respondents reported that they felt aware of a decline in sexual interest or activity. Most could not remember exactly when, but over half stated '... since coming into hospital'. Sex relations had stopped for three-quarters of respondents since being hospitalized. When asked why sexual relations had stopped, the following reasons were given: illness of self (four); lost interest myself (four); lack of opportunity (five); no privacy (three); in hospital (six).

Almost three-quarters of the client group knew the medication they were taking. Of the 11 subjects, two said that their medication contributed to sex problems. One respondent said that it made her angry, aggressive and violent. The other stated that he failed to ejaculate.

The semi-structured interview

Due to the limitations of the structured questionnaire, a semi-structured interview was designed. The advantages of exploring attitudes, values and beliefs as well as augmenting the richness of data was recognized (Hutchinson & Skodal-Wilson 1992). Further, Strauss (1994) believes that in most research into human subjects with schizophrenia the attention given to the subjective side of a person's experience is grossly inadequate. He concludes that 'the subjective in all its aspects is an essential part of our data'. A main task in interviewing is to engage and build enough trust for people to allow them to permit us

to see how they perceive the world.

A series of five open-ended questions were devised to elicit clients' subjective experiences regarding sexual expression.

- What does intimacy mean to you?
- Do you see yourself in an intimate relationship?
- Would you approach someone to discuss sexual/relationship problems?
 - If so, whom would you approach?
- What are your sexual rights whilst in hospital?

Analysis of results from the semi-structured interviews

A systematic method of data handling was used (Turner 1981). Data were sorted into categories. Themes and concepts were extrapolated. Content analysis was used on these responses.

Conceptualization of intimacy

All of the respondents displayed an openness to discuss a range of intimate feelings. They were eloquent in their descriptions of what intimacy may involve. It is interesting that respondents did not see intimacy as purely about sexual intercourse.

Kissing, cuddling, touching. Feeling wanted. (Respondent two) Being loved. I like being held. (Respondent six)

Sex, love, caring and sharing... things like that. (Respondent nine)

Aspirations for future relationships

Verhulst & Schneidman (1981) recognize the difficulties in developing and maintaining

satisfying sexual relationships in situations where interactions are 'primitive, repressive, regressive and often exploitative'. In light of the constraints of the institution, most of the respondents had positive aims regarding their future and appeared pragmatic about resolutions to the problems. Judging by the responses, a majority would like more opportunities to meet people and develop social skills away from the institution. The financial limitations of being in hospital were often expressed: I'd like to meet other people, but I've no money. I'd like to get married eventually. I'd like to go to the pub and dances. (Respondent one)

Yes I would like to meet someone, get a flat, get married and have kids. It's difficult in hospital. (Respondent five)

Think about it sometimes. Don't know what stops me [having a relationship]. I don't know what's going on around me. I'll look nice once I get a haircut. (Respondent seven)

Willingness to discuss sexual/relationship concerns One male respondent mentioned that through masturbation he was able to control the positive symptoms of his illness. There are also reports in the literature of three patients masturbating in order to counteract extrapyramidal side-effects of medication (Akhtar & Thomson 1980).

The features of a therapeutic alliance such as confidentiality, trust, rapport and familiarity seem apparent in the responses. Some of the respondents did, however, appear reticent about whether or not they would approach someone to discuss problems of a sexual nature:

You are the only one I have told these things to. (Respondent three)

I don't mind you, but if it was someone else... (Respondent six) I'd see a nurse, one I liked. (Respondent 11)

Awareness of sexual rights in hospital

None of the respondents were aware of sexual rights. Patients could be fearful of questioning their positions within the institution. To question may be seen as threatening to the power structure inherent in all institutions. There could be a blind acceptance of the status quo, often as a result of the institutional process.

Only one of the group admitted to having sex at the present time and talked of having clandestine meetings with sexual partners in the grounds of the hospital. He felt staff had the right to stop him if he was seen to be 'having sex' on the unit.

DISCUSSION

The patients appeared to respond well to the interviews. In fact many seemed pleased to be asked about concerns regarding something as fundamental as sex and relationship issues. There were no patient reports of distress or staff complaints about deleterious effects following inter-view sessions. No interview had to be prematurely terminated. Several studies have shown that clients with psychotic illness can be interviewed effectively and safely about their sexual interest and behaviour. No exacerbation of psychiatric symptomatology was observed in response to explicit sexual interviews (Bell et al. 1993, McKinnon et al. 1993).

The results represent a study of perspectives of a patient population that is rarely canvassed. Previous studies have used structured interviews only (Lyketsos et al. 1983). The semi-structured format gave the patients an opportunity to expand their views. This is imperative if we are to be truly responsive to the needs of our patients

when planning and implementing care. It is especially important if we are to claim the use of a holistic approach to the type of interventions we use and the care we provide for this group of individuals.

Limitations of the study

This was a very small sample concentrated in one unit of a psychiatric hospital, therefore it is not possible to generalize the findings. Also, weaknesses in the structured interview used have been identified, in particular the fact that it was devised for an elderly population. The questionnaire was modified for this client group and one would need to retest in future for reliability and validity. Further, it is recognized that people with psychotic illness may give inaccurate responses due to the symptoms of their psychopathology (Bell et al. 1993). Measuring instruments such as the Brief Psychiatric Rating Scale (Overall & Gorham 1962) and the Krawiecka Rating Scale (Krawiecka et al. 1977) would be useful for future studies in order that the degree of psychopathology of each subject could be determined.

CONCLUSION AND IMPLICATIONS FOR NURSING PRACTICE

There appears to be a dearth of literature pertaining to sexuality and schizophrenia. 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 also for health personnel. Before nurses can assist others with sex and relationship needs, they must examine their own attitudes, values, fears and beliefs. We must facilitate communication about sexuality, correct myths and misinformation, provide education and encourage exploration of the patients' feelings and resources.

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 private space for sexual intimacy. Masturbation, displays of affection, homosexuality, exhibitionism, and intercourse are all forms of sexual expression. How these behaviours are dealt with depends on the philosophy under which specific agencies are operating, either overtly or covertly. Practitioners have often had to rely in the past on their own common sense and clinical judgement in their drive to maintain order and propriety. Yet, they must still remain sensitive to the psychological, emotional and sexual needs of patients. Moral, ethical and legal dilemmas abound in this area of care.

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. A collaborative approach to exploring patients' thoughts, feelings and behaviours should prevail. Sex education should be offered to patients around issues of medication and possible side-effects, including sexual dysfunction. These important concerns may increase the risk of non-compliance with some patients wishing to stop taking medications altogether. Nurses need to be more aware and enquire about psychosexual matters routinely. Patients should be encouraged to express their own needs and preferred intentions. Subjective experiences are fundamental to the process of holistic assessment.

The human need for intimacy, warmth and sexual expression is universal. Much depends on the severity of symptomatology in patients with psychotic illness and the great variations in their social functioning. Prejudice, discrimination, oppression and negative attitudes towards those with mental health problems greatly affect self-esteem and personal development. Greater sensitivity is required towards

psychological, emotional and sexual needs of people with psychotic illness. The time is right for serious consideration to be given to this important area of health and social care. It is hoped that clinicians will rise to the challenge and start to address the issues in terms of practice, theory and research.

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