Sexual health in cancer care

The sexual concerns of patients have generally been neglected in health care (Doustow, 1994). In cancer care specifically there appears to be a conception that people with cancer do not have sex. But Shell (1995) suggests that supporting patients to retain an intimate relationship during their cancer treatment may allow them and their partner moments when they do not have to look cancer squarely in the face. Savage (1989) describes sexuality as the ‘uninvited guest’ in the nurse/patient relationship and comments that nurses and patients do not stop being sexual beings because they have adopted these particular roles. Smith (1989) states that a person’s sexuality cannot be left at home when he/she becomes a patient.

But it is also true to say that one’s sexuality cannot be left at home when one acts as a nurse. In attempting to support patients with sexual concerns we need, therefore, to be aware of our own sexuality because it is central to who we are. Tschudin (1997) comments that in caring for our patients we also need to care for ourselves.

Defining sexuality

Supporting a patient with a sexual concern can be difficult. Unlike many medical and nursing procedures it is a subject that is not backed up by a body of scientific knowledge (Clifford, 2000). Sexuality is continually being redefined by individuals as they grow and develop (Hordern, 2000). After many years of working with people with sexual problems Bancroft (1983) came to the conclusion that sexuality was ‘an enigma, a riddle and a mystery’. According to Weiss (1992): ‘Sexuality is about connecting our head with our gut through our heart. It is about genuinely caring for ourselves, finding what to say and, anyway, assumed it was dealt with in outpatients.

Listening to patients and colleagues

Clinical practice developments primarily addressing the nurse’s role in supporting clients with cancer facing sexual and fertility concerns were introduced following studies among nurses, fertility clinic staff and doctors in a London teaching hospital.

Facing infertility caused by cancer or the treatment involved can be a very lonely experience for those we care for. I remember the comment of one 22-year-old man who had recently been diagnosed with cancer describing how he felt after visiting the fertility clinic to bank sperm: ‘I just sat there and couldn’t do it; it is difficult to jack off [masturbate] into a pot’. In the previous 24 hours he had been diagnosed with acute myeloid leukaemia, told he would have to undergo many months of intensive treatment and that he would probably be infertile for the rest of his life. Another man described being so self-conscious of the central line inserted in his chest that he was unable to undress in front of his wife: ‘I have been married to my wife for 20 years but I can no longer undress in front of her’.

When I informally asked my colleagues what support they offered patients with cancer who are facing sexuality and fertility problems, one medical colleague said he offered no help because his patients were ‘too old’ and ‘would not be interested in sex’. However, now that the subject had been raised, he agreed to address the issues involved. Most of my nursing colleagues said that they avoided the issue, commenting that they did not know how to address it in patients who had not raised the topic themselves.

Table 1. Effects of treatment for cancer on fertility and sexuality

RISK OF INFERTILITY

- Many cancer therapies have potential harmful effects
- Toxicity depends on the nature of the treatment, dose, patient’s age and gender
- Radiotherapy – impact depends on field of treatment, dose of radiation and fractionation
- Chemotherapy – alkylating agents, especially, have an effect; combination therapy may have a greater effect than a single agent

CHANGES ASSOCIATED WITH SEXUALITY

- Impotence
- Premature menopause
- Vaginal dryness and stenosis
- Dyspareunia (pain during intercourse)
- Loss of body hair, unwanted facial hair
- Weight gain or loss
- Surgical removal of limbs, breast, womb, testicle, vulva, penis may affect body image, sense of self, sexual practice
- Reduced libido and increased fatigue
- Susceptibility to infections, including candida, genital herpes, vaginal warts
- Fears and anxieties
- Believing in myths; eg that cancer is contagious
- Loss of self-esteem, family role, social role, gender role, relationships and health
- Questioning the meaning of life.

Sources: Berthelsen and Skakkebaek, 1983; Kaeumper et al, 1983; Smith and Babaian, 1992; Kelly, 1995; Steele et al, 1995; Koeppel, 1995; Matthews et al, 1999; Cook, 1999; Hordern, 2000)
ecstasy in simply being alive, and giving creative voice to our ideas and feelings. It is about bridging physical pleasures with spiritual awareness and serenity’. Sexuality is an integral part of being human. It is difficult to see, therefore, how cancer treatment will not have an effect on the lives of patients and therefore on their sexuality. Table 1 indicates some of the effects of treatment for cancer on sexuality and fertility.

**Studies on sexuality and fertility**

One study which has been reported already (Quinn and Kelly, 2000) was carried out in a medical oncology unit. It focused on finding out what support was available to clients, who addressed sexuality and fertility concerns, and looked at nurses’ experiences and suggestions. A second study a year later (which is reported on below) was carried out in a bone marrow transplant unit. It involved nurses answering a questionnaire about their role in addressing clients’ sexuality and fertility concerns and medical staff being asked to describe their clinical practice.

**Findings**

In both studies the findings were similar. Nurses recognised their role in supporting patients and their partners, while medical and fertility clinic staff valued the nurses’ supportive role. But while nurses were keen to address sexuality and fertility concerns they admitted that they often avoided the issue, for a number of reasons. They spoke of their lack of experience in raising the subject with patients and their lack of knowledge in dealing with what they saw was an important but sensitive subject. They also reported that most of the pre- and post-registration nursing courses they attended rarely spent time addressing the subject. While the nurses were vaguely aware of the fertility options that existed for men, such as sperm-banking, they did not know what the procedure entailed and so were unable to give support. They had little or no knowledge of what support was available to women facing infertility – there was a sense that women facing infertility as a result of their disease had no fertility options. Although the nurses were aware that patients left the ward to attend the fertility clinic they rarely asked a patient how the appointment had gone. They commented that working in busy and open bed wards was not conducive to privacy or to giving time to patients and their partners to address the subject. All nurses voiced concern about making mistakes or giving wrong information.

Most nurses admitted to having only limited knowledge of how cancer and the treatments for it could directly or indirectly affect a person’s sexuality or fertility. However, they were concerned that they or the patient might be embarrassed, and so avoided the subject. This is not surprising, as nurses live and work in a society that generally avoids talking of sexuality or makes a joke of it (Shell, 1995).

Although sexuality was mentioned on the unit assessment sheet, most nurses stated that they usually avoided the question by focusing on the patient’s marital status. But they did voice concerns that they could cause offence by raising the subject of sexuality because of the person’s culture, gender or age. They questioned whether it was appropriate for young female nurses to ask an elderly man about sexual issues and when was the best time to raise the subject. The nurses admitted to being influenced by prevalent myths and prejudices about sexuality; for example: ‘People with cancer have more things to be concerned about than having sex’; ‘Older people are no longer interested in sex’, and ‘Gay men will not want to father a child’. A number of nurses said they were concerned that by addressing the subject of sexuality they might become involved in a situation that they felt inadequate to manage. For example, if a man or woman wanted to use the opportunity to talk of childlessness or ongoing abuse.

Both studies revealed that nurses felt support for patients was inconsistent, but all the nurses expressed a desire for help to enable them to address issues of sexuality and infertility. Much of what the nurses said has been reported in other studies (Smith, 1989; Kautz et al., 1990; Koeppe, 1995; Shell, 1995).

**Practice developments**

The nursing team felt strongly that they ought to take the lead in addressing the issue, therefore a working group was set up, comprising ward-based nurses and clinical nurse specialists, to respond to the nurses’ comments, following which a number of practice developments were put in place (Table 2).

Now, at the regular joint orientation programme held by the bone marrow transplant unit and the medical oncology unit for new staff, time is devoted to addressing issues of sexuality and fertility in cancer care. This teaching opportunity enables new staff to appreciate how the disease and the treatments can affect patients’ sexuality, and to recognise it as an important issue that needs to be addressed.

**TABLE 2. PRACTICE DEVELOPMENTS**

- All nurses supported and expected to address the subject of sexuality and fertility
- The issues of sexuality and fertility raised at oncology/haematology orientation programmes
- Ongoing teaching sessions
- Awareness of national and international developments
- Development of clinical guidelines
- Link nurse in each ward
- Visits to the fertility clinic
- Audit of patients’ views
- Information leaflet
- Networking with other disciplines
- Study days (with patient involvement)
- Sharing developments at UK and European conferences
- Continual reflection

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**KEYWORDS**

Cancer  Sexuality  Fertility

**REFERENCES**


For other articles on this subject and links to relevant websites see nursingtimes.net
addressed accurately and sensitively. The nurses are encouraged to reflect on their own sexuality and to recognise and address their own prejudices and biases using the personnel and resources available. All wards have an allocated link nurse whose role is not to be an expert but to act as a resource for colleagues.

All nurses in the two units are encouraged to attend regular updates through teaching sessions. Evidence-based guidelines have been developed by the working party (Table 3) to help the nurses to begin addressing the subject of sexuality before referring patients to the fertility clinic. The guidelines do recognise, though, that each nurse will use his/her own experience and reflective practice on how best to address the subject.

The nurses are encouraged to visit the local fertility clinic and to familiarise themselves with the procedures involved. They are expected to be aware of ethical issues and to understand the legal documentation patients will be required to sign if they wish to proceed with banking sperm, eggs, embryos or ovarian tissue. This means that the nurses will be able to explain any procedures to patients before their clinic visit. The patient’s partner, family member or a member of the nursing team can accompany the patient to the clinic if he/she wishes. At the same time, nurses must be sensitive to patients who may not be suitable for a fertility option. The nursing team tries to plan care to allow time for patients to be able to spend time with their partner alone if they wish.

An audit of patients’ views was carried out as part of the process of reviewing clinical practice. Most reported that a doctor or nurse had addressed fertility issues, but the audit also revealed that very few patients had been asked whether they had any concerns about sexuality. Some patients had been advised to use barrier contraception (condoms) during chemotherapy treatment so as to avoid exposing a partner to possible cytotoxic fluids, and to avoid pregnancy because of possible effects of treatment on a fetus.

Patients were not aware of other issues associated with cancer treatment such as fatigue, low libido, low self-esteem or sexual impotency. They suggested that a written leaflet informing them of how their sexuality and fertility might be affected and what support is available would help. A leaflet was therefore developed addressing the issues raised. It not only offers information but also encourages patients and partners to approach staff if they need further help.

Conclusion
An important part of the above developments has been networking with other departments within the local NHS trust, recognising, valuing and using the extensive experience of colleagues from other disciplines. Collaboration has involved working closely with medical and nursing experts in the field of cancer, haematology, gynaecology, fertility and endocrinology, and keeping up-to-date with national and international developments and the invaluable experience of patients.

To date, four study days focusing on supporting patients with cancer with sexuality and fertility concerns have been attended by over 140 nurses and therapists from London hospitals. The days include lectures, workshops, role play and discussion of the guidelines introduced as a result of the consultations of the working party. An important part of the day is listening to the personal and very moving stories of patients with cancer.

The nursing team is conscious of the need to continue building on the developments already initiated, by working with colleagues and patients in all areas of cancer care, particularly the often neglected areas of sexuality and fertility. If maintaining sexuality can add to the quality of life, then sexuality can no longer remain a neglected area of patient care (Coughlan, 1987:34).