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SEXUALITY AS AN ASPECT OF NURSING CARE FOR WOMEN RECEIVING CHEMOTHERAPY FOR BREAST CANCER IN AN IRISH CONTEXT

Abstract

In this article, findings are presented from a study that aimed to explore the perceptions and experiences of a sample of nurses in addressing sexuality as an aspect of care for women receiving chemotherapy for breast cancer. A sample of 10 oncology nurses was selected from oncology units at three hospitals in Ireland, and each participant was interviewed in depth. A qualitative strategy was employed to analyse data. Findings indicated that participants tended to construct sexuality in broad terms, and were well aware of the effects of chemotherapy on a person's sexuality. In addition, they considered sexuality education to be a legitimate and important aspect of their role. However, they also revealed that they avoided addressing sexuality with patients, or encountered structural obstacles in doing so. Some participants expressed anger and frustration when discussing barriers to incorporating sexuality into their practice. A strong theme in data was participants' perceptions that they were not adequately prepared in either pre-registration or post-registration programmes to incorporate sexuality as a dimension of patient care, although post-registration programmes were more likely to furnish them with knowledge about sexuality. Finally, participants' views on sexuality care are considered in the context of Irish culture which until recently was dominated by Catholic Church teachings.

Key words: Ireland; oncology; sexuality; breast cancer; education; qualitative methodology.

Introduction

Sexuality as an aspect of nursing care has gained increasing prominence in recent decades with the development of the concept of holism in nursing. Despite the fact that since the 1970s, there has been much written in the literature about sexuality, there is a great deal of diversity displayed as to the precise meaning of the term. Sexuality is one of the more difficult areas of human experience to define, as it is complex, diverse and uncertain. The World Health Organisation (1975:6) defines sexuality as 'the integration of the somatic, emotional, intellectual and social aspects of a human being in ways that will enhance personality, communication and love.' Smith (1993:36) describes sexuality as a 'deep pervasive aspect of the total person, the sum of one's feelings and behaviours', whilst Fogel (1990: 23) views sexuality as being 'inextricably woven into the fabric of human existence'. These definitions, frequently invoked in nursing literature, are arguably closer to the concept of 'holism' than to the specific realm of the erotic. While this renders them almost meaningless, it also signals the sheer complexity of conceptualising sexuality. For the purposes of this study, drawing on Jackson and Scott (1996) we consider sexuality to have a broader significance than simply the coital sex act, yet locate it within the parameters of the erotic in terms of desires, practices and identities, and our sense of ourselves as men and women.

Issues surrounding sexuality would seem particularly pertinent in the context of cancer care, since the more common treatments for cancer such as surgery, chemotherapy, radiotherapy, hormone therapies and/or biological responses can impact upon sexuality (Ganz *et al*, 1998; Meyerowitz *et al*, 1999). Chemotherapy is a systemic treatment associated with the side-effects of ovarian toxicity resulting in premature menopause (Young McCaughan, 1996; Knopf, 1998, Ganz *et al*, 1998), infertility (Krebbs, 2000; Thaler Demers, 2001; McCoy, 2004), alopecia and altered body image (Burt, 1995, Turner, 2004).

Although sexuality is identified as an important aspect of patient care in nursing and medical literature, it has been suggested that nurses often fail to adequately carry out this

role in practice (Baggs and Karch 1987; Wilson and Williams, 1988; Matocha and Waterhouse 1993; Young McCaughan, 1996; Guthrie 1999 Wilmoth 2001). Moreover, some studies suggest that nurses do not see sexuality as an important aspect of their nursing role. In investigating why nurses do not incorporate sexuality into their practice, Kautz *et al* (1990) found that while nurses considered themselves to be knowledgeable in the area of sexuality, they viewed it as an area of low priority and they did not see other nurses addressing it. A more recent study carried out by Kelly and Quinn (2000) explored the level of support that was available to patients who addressed sexuality and fertility concerns, as well as nurses' experiences and suggestions. Findings revealed that nurses did recognise their role in addressing sexuality and fertility concerns with patients but often avoided this aspect of care. Reasons for this avoidance included lack of experience, insufficient education at pre and post-registration levels, lack of time, insufficient privacy and fear of making a mistake or causing offence.

With virtually no existing studies on sexuality relating to nursing care (in any clinical realm) in Ireland, this study set out to address the following research question: 'What are the perceptions and experiences of nurses in addressing sexuality as an aspect of care to women receiving chemotherapy for breast cancer?'

Methodology

In view of the nature of the research question, a qualitative research strategy was deemed to be the most appropriate, using in-depth interviews with nurses. Three general hospitals, each with a specialised oncology unit, were approached for access to potential participants via the Directors of Nursing, and ethical approval was gained via the formal approved mechanisms at each institution. A purposeful sampling procedure was used to select participants, with 3 nurses from each of two hospitals and 4 nurses from the third. All 10 participants were employed at the chemotherapy day unit at the hospitals. The participants were required to be at least three years' qualified and have undertaken their pre-registration nursing education in Ireland. The requirement that participants be

educated in Ireland was to increase the homogeneity of the sample, since historically, Ireland had been identified with sexual repression and 'Catholic guilt' about sexuality that might spill over to the nursing education system¹. To ensure that participants would have sufficient experience to provide rich data, inclusion criteria also required that they have at least one year's experience in administering chemotherapy as well as a post-registration qualification in oncology nursing. Each potential participant was provided with an information leaflet. All participants were women, and the sample was comprised of mainly younger nurses, in keeping with the age profile of nurses in the unit, with 8 in the 25 to 40 years age bracket, and 2 of them aged between 40 and 55 years.

Interviews took place in a private office at each participant's place of employment. The interviews were tape-recorded and the tapes were later transcribed. Data analysis involved an intensive reading and re-reading of data to identify themes. Like items of data were clustered using the constant comparative method (Glaser & Strauss, 1967; Glaser, 1992). To enhance the credibility of data, two participants were given a report of the findings of data to determine whether the account of their perceptions and experiences had been accurately described. Both informants expressed satisfaction as to how these were presented.

Results

Data are presented under five themes: 'participants' constructions of sexuality'; 'the effects of chemotherapy on sexuality'; 'sexuality: important but avoided'; 'unprepared by nursing education', and 'the influence of a culture of sexual repression'.

Participants' constructions of sexuality

¹ Because of the large numbers of men and women in Ireland who remained unmarried throughout their lives after the famine of the mid 1800s until the 1960s, the sexualities of these were kept in check by the strict doctrines of the Catholic Church, who persistently preached about the 'dangers of sex' (O'Faolain, 1954:115) and the 'sins of the flesh' (MacMahon, 1954: 213).

How participants defined sexuality varied greatly among the sample. It was evident from the verbal and non-verbal cues of the participants in many of the interviews that they were experiencing difficulty verbalising their understanding of sexuality. This difficulty is expressed explicitly in the following quotations.

P4: It [sexuality] is very hard to describe it in a sentence or even a few sentences.

P2: It [sexuality] is not just cut and dry, it is not a simplified sort of thing. It is so complex, because it is not only the physical but the mental and trying to tap into people's mental attitudes and appreciation of where they are at the present can be very difficult.

However, all of the participants suggested that sexuality was a multidimensional concept, and an important part of human existence. A number of participants proposed that the meaning that one attributes to sexuality very much depends on the individual. This is reflected in the following quotations.

P4: It can be your gender, your status, your approach to things, your coping mechanism, and an array of things to each individual.

P2: I think it is a very individual thing... I mean the actual scope of sexuality within an oncology setting in particular varies from one person to another...I think sexuality is very individual.

The following statements indicate that participants believed that female sexuality was related to how a woman actually perceives herself (her sense of 'self') and how other people viewed her (her identity), thereby influencing her well-being:

P6: I suppose her outlook, her general outlook. I know her self-esteem, her self-image and that but what other people perceive her as being or how she looks.

P1: Clothes, body, make up, personality and body image...love you for your body, love you for the person that you are.

It was clear from these extracts that the majority of participants viewed sexuality as much more than a physical concept, instead associating it to a considerable extent with the emotional, psychological and social realms.

The effects of chemotherapy on sexuality

The participants interviewed were well aware that many of the women they encountered had had surgery prior to chemotherapy, and the additional impact on sexuality that this was likely to create. In terms of the specific effects of chemotherapy, all participants displayed a comprehensive understanding of the potential effects of this on a woman's sexuality:

P1: Chemotherapy affects a woman's physical, cognitive and mental well being.

P5: With the tiredness, the nausea, the vomiting, the awful fatigue, the side effects have a huge impact on their sexuality . . . they have no interest except for getting through this chemotherapy'.

Participants displayed knowledge of the menopausal effects of chemotherapy and the potential impact it has on fertility. It was also evident that participants had a clear understanding of the possible impact of chemotherapy on the woman's body image as well as an awareness of how chemotherapy can lead to psychological, emotional and social trauma.

P3: So it affects their social life as well because they are very conscious of this flushing and they are conscious of the sweating . . . they are so tired out at night they feel that they can't go out . . .

Sexuality: important but avoided

The vast majority of participants viewed sexual issues as important for women receiving chemotherapy.

P6: Sexuality in all aspects of cancers is huge. Say it is as important as discussing alopecia or discussing nausea and vomiting or discussing constipation. It is like up there, it is more important.

P2: Sexuality is as important as other effects and it should be approached if we are to provide holistic care . . .

P8: It [sexuality education] is vital, not even to your breast cancer patients but to any patient to educate with cancer.

In spite of the importance afforded to sexuality as an aspect of care, participants revealed that it was rarely integrated into their nursing care. Indeed, all ten participants agreed that sexuality as an aspect of care for women undergoing chemotherapy for breast cancer was inadequate.

P2: 'I think sexuality is a neglected part of patient education...it is like a quick flash over...oh fertility...oh sexuality...you know about that or that is irrelevant, I think it is a bit of a hit and miss job, even in this day and age...'

P4: I have never heard anyone saying, 'I am going into deal with this person's sexuality.' It is never mentioned, people will brush over it and they will let the conversation drift from sexuality. I don't know any nurse that is efficient at this and I have years of experience dealing with people...

When asked if they would raise the issue of sexuality with a woman whilst educating them about their chemotherapy, half of the participants claimed that they would wait for the patient to bring up the subject. This is illustrated in the following extracts:

P1: Sometimes it is easier to avoid it unless the woman brings it up herself. I have in the past.

P6: ‘emm [pause] no...no, I do not broach it [sexuality]... that’s wrong I know but I’m being honest.’

However, it was evident from the interviews that participants did not always allow patients the opportunity to raise the subject of sexuality themselves. This is depicted in the following extracts:

P6: I don’t think that we give women the opportunity to raise concerns regarding altered sexuality. Issues are being left and not addressed.

P10: Nurses in general don’t probe, sexuality is not considered an issue if the woman does not bring it up themselves . . .

Some participants expressed anger and frustration when discussing barriers to incorporating sexuality into their practice. While these emotions were sometimes related to inhibiting factors in the immediate environment in which the nurses worked (such as telephones ringing, the proximity of patients to one another, and the workload), dissatisfaction was also expressed about how nurses often underestimate the importance of addressing sexual issues with patients:

P10: ‘...it [sexuality] is not considered a priority, the side effects of chemotherapy are considered a priority and that is what is talked about, like nausea and vomiting, nurses tend to focus on that, I have heard people go through the toxicities with their patients and they never ask about sexuality, it is not good enough really.’

Embarrassment was frequently cited as a reason for avoiding raising the issue of sexuality:

P1: ‘...I would certainly feel very uncomfortable with it... embarrassing to discuss...’

P9: 'But it is something that people are a little embarrassed I guess, most nurses are as well...I know for a fact I am...'

Some participants expressed fear at broaching the subject of sexuality out of sensitivity to the delicacy of the topic - they feared that they might upset the woman or 'say the wrong thing'. This is depicted in the following quotation:

P6: 'I suppose there was a bit of fear that you don't want to say the wrong thing. You try to say the right thing. But you don't want to make a mistake or say something that is not going to help, you know. You would have to really test the water to see how you were doing. Then you don't want to offend...'

Unprepared by nursing education

All of the participants felt that sexuality was not dealt with adequately (or in some cases, not at all) in their pre-registration nursing education and the majority of nurses in this study had the same opinion about their post-registration oncology course. The following quotations demonstrate participants' perceptions and experiences of how sexuality was taught in theory in their pre-registration educational preparation:

P2: [Was sexuality addressed?] 'Absolutely not [laughs], in the classroom the emphasis was on learning the necessary information to gain marks in exams, but I mean regarding how a person felt mentally, or how they were after their chemotherapy, you were not told how they could be or how to sit and talk to a patient with altered body image, or how you would communicate on a face to face basis...'

P7: I am sure we had nothing and I can't really remember that much of our general training but I don't think we had anything at all on sexuality really.

The majority of participants felt that they were not taught how to address sexual issues with patients in the clinical area and in many cases their role was seen to involve providing physical care only. The following extracts illustrate this point:

P5: In our training you had to be seen to be busy the whole time and you certainly did not talk to patients, the emphasis was on physical care, be busy the whole time, do something instead of sitting and talking...

P2: I would openly admit that I would talk about all the other side effects of chemotherapy to a woman before I would refer to sexuality and that is really a reflection on that lack of openness of where I trained...

Although all participants had undertaken a post-registration course in oncology nursing, the greater majority claimed that whilst sexuality was addressed during this post-registration education, it was insufficient to prepare them to incorporate sexuality into their nursing practice. This is evident in the following quotations:

P1: It [the oncology course] did discuss sexuality certainly more than pre-registration. Sexuality was not touched on in too great a depth . . . [They] did not teach you how to address it, no open discussion about it, more theory based . . . [We were] not given the opportunity to practise skills on dealing with sexuality.'

P2: Sexuality would have been dealt with reasonably in the oncology course but I did not feel ...Whow!...that there was a whole big section on sexuality. It certainly was addressed and it wasn't shyed away from but at the same time there could have been more scope for it. We were not taught skills in how to address sexuality.

Only one participant claimed that the oncology course that she undertook positively impacted on her ability to educate patients regarding sexual issues. This nurse had completed her post-registration programme at a different university to the other six participants holding the same qualification. Her experience is captured in the following statement:

P10: My oncology course has enabled me to be very open about sexuality ...In our learning contracts, all eight of them, we had to address certain aspects of sexuality in each

contract, for example an expected outcome would be that the patient would have greater knowledge on the area of sexuality.

In general, it is evident that little emphasis was placed on the subject of sexuality, in theory or practice in pre-registration nurse education. At post-registration level, the majority of participants felt that sexuality was dealt with insufficiently as part of the curriculum.

The influence of a culture of sexual repression

All of the participants asserted that Irish culture had impacted on nurses' ability to address sexuality with patients in an Irish context. Sexuality was generally viewed as a topic that is not openly discussed in Irish society. This is demonstrated in the following quotations:

P1: I think as a nation of people we do not explore our sexuality...I mean, your past, your upbringing, your education, your training, your social environment and everything else can impact on you ...it is a cultural thing, we are sexually repressed.

P10: Lots of things were never spoken about, I even remember my own mother saying, 'We don't talk about that'.

All ten participants spoke of the impact of religion on sexuality in Irish society. It was evident that the participants saw the Catholic Church as a powerful influence that resulted in a sexually repressed nation of people. This is depicted in the following extracts:

P3: It probably has a lot to do with religion and our Catholic upbringing, and em...an awful lot of Irish people would not have talked about those things, you know. Sexuality was repressed.

P9: The Catholic Church, I guess influenced us, you were younger which I suppose inadvertently moulds how you deal with things.

A few of the participants expressed optimism that Irish culture is changing and nurses are becoming more open regarding sexuality. However, many of the women whom participants encountered were in late middle age, and of a generation where sexuality was heavily repressed, making it difficult to address sexual issues with any degree of ease.

P6: I suppose women now in their 50s or 60s are very private, they won't like to ...emm... I am only generalizing that they would not like to discuss their sexuality with a 20 odd ['odd' here is colloquial for 'approximate'] year old girl. Maybe they don't find that appropriate.

P10: I find the 50 to 60 year old age group are very unwilling to talk about it. I don't know is that just a cultural thing, where you did not talk about your personal business.

Discussion

The preceding data suggest that participants had difficulty in articulating their understanding of sexuality, and viewed it in broad terms. It is plausible that these 'broader' definitions of sexuality were invoked to avoid addressing the more overtly erotic issues. Alternatively, participants may have been reflecting back the more nebulous discourses on sexuality presented in contemporary nursing texts (as indicated earlier). However, since constructions of sexuality are socially derived, and there is no single concept of sexuality 'out there' waiting to be discovered, the interviewer did not impose a predetermined version of the concept on participants.

The majority of the participants in this study displayed a clear awareness as to how chemotherapy-induced altered sexuality can adversely impact on relationships and how it can be a genuine concern for women undergoing treatment, supporting existing work (Holmberg *et al*, 2001). However, all participants in our study considered that dealing with issues around sexuality was a very important aspect of patient care, a finding that is at variance with existing literature that found that nurses did not tend to see sexuality as a component of their nursing care (Williams *et al*, 1986; Kautz *et al* 1990). The importance afforded to sexuality as an aspect of the nursing role among all participants in our study may be accounted for by virtue of the fact that ours was a volunteer sample, and the study may have attracted those nurses who had a particular interest in developing sexuality as an aspect of their practice. One participant, as indicated in data, expressed anger that other nurses did not perceived sexuality to be an important dimension of their role.

In spite of the fact that participants saw sexuality education as an important part of their role, they also felt that they did not perform adequately in this role. Obstacles to addressing sexuality adequately included structural barriers in the clinical context, and also discomfort and embarrassment or fear of causing offence in broaching the topic. Existing literature also indicates that nurses often experience embarrassment when addressing sexuality with patients (Lewis and Bor, 1994).

In this study, participants clearly articulated that they were inadequately prepared to address sexuality by their pre and post-registration nurse education. This finding concurs with other research over the past two decades indicating that nurses rarely have the necessary theoretical knowledge to be able to teach or care for their patients in the area of sexuality (Briggs, 1994; Grigg, 1997). In relation to their pre-registration education, all participants stated that sexuality was barely touched on, and for some, not even mentioned. No studies have explored the quality of nurse education in relation to the area of sexuality within the Irish nursing education system. All of the participants had undertaken the traditional certificate nursing course and it is interesting to note that the word 'sexuality' was not mentioned at all in the syllabus for the education and training of general student nurses in this traditional system (An Bord Altranais, 1980, 1993). Almost all participants spoke of the immense emphasis that was placed on the physical aspect of patient care in the clinical area, that ultimately resulted in their gaining little experience in addressing a patient's emotional needs. This programme is now obsolete - since September 2002, all those entering general nursing programmes in Ireland undertake a four-year BSc programme, and the first groups of graduates are due to complete in 2006. Time will tell whether these educational changes, and the wider cultural shifts that have created a greater openness about sexuality will impact upon nursing practice in the future.

With regard to post-registration education, the majority of participants recognised that sexuality was incorporated into their post-registration oncology course and some claimed that their knowledge of sexuality had improved following the course. The findings of this study are supported by Fisher and Levin (1983) who found that oncology nurses who

had undergone further education had greater knowledge scores in the area of sexuality than those without further education. However, the majority of participants claimed that undertaking the oncology courses did not improve their ability to incorporate sexuality into nursing care. It was disappointing to find in this study that post-registration education in oncology failed to do this. However, this may reflect the very complexity of sexuality itself as an aspect of nursing care that may be impossible to pin down, since several versions of 'normal' sexuality compete with one another and shift over time (see Potts, 2002). 'Giving' sexuality care is not a straightforward business, and nurses have to work through the various and often contradictory ways in which 'normal' and 'abnormal' sexuality may be constructed. In exploring the issues identified in this article, we have not considered the substantive nature of the discourses of sexuality that cancer nursing literature presents and that educational programmes might subsequently deliver. This is a matter for a wider debate.

The final theme considered the mediating influence of the traditional Irish culture of sexual repression on participants' ability to provide sexuality care. Ireland's late industrialisation relative to the rest of the Western world (and concomitant traditional worldviews), and the heavy influence of the Catholic Church until the recent period has left a generation of Irish women with poor sexual literacy. This makes it very difficult for nurses to address particular issues around sexuality with them. Ireland is now one of the wealthiest countries in Europe, and Irish sexual culture has changed rapidly in recent years, with adolescent sexual attitudes and behaviours and legal availability of contraception now comparable to that found in other European countries such as Britain (see Inglis, 1998, and Hyde & Howlett, 2004). A recent study found that adolescents in Ireland reported that they are no longer influenced by Church teachings when it comes to matters of sexuality (Hyde & Howlett, 2004). Furthermore, relative to the recent past, contemporary health policy in Ireland positions itself to a considerable extent within a more liberal discourse on sexuality. Although a highly conservative culture remains in some fields such as in the area of new reproductive technologies and abortion (see Hyde et al, 2004), there is also an emphasis on responsibility, informed choice, and contraception rather than on sexual repressiveness (Martin, 2000; Department of Health

and Children, 2001). However, the generation of women born before the 1960s are most likely to be in the age cohort of those now presenting with breast cancer. These women were socialised in a culture of celibacy or alternatively, compulsory heterosexuality, where sexual obligations took precedence over sexual pleasure, and there was intense heterosexual male dominance. It is important to note that Ireland was far from unique in terms of this gendered sexual control over women of this generation, since this is a pervasive feature of patriarchal societies more generally, and gender politics is far from resolved even in the more egalitarian climate of contemporary Europe. However, the intense influence of the Catholic Church in Ireland (that had *slowly* begun to be challenged since the 1960s, and took a major nose-dive in the 1990s following scandals of double standards and sexual abuse among Catholic clergy) is likely to have had a stronger effect on women in Ireland (see Hilliard, 2004). It may even be unrealistic to expect nurses to unpack the layers of socialisation and uneasiness associated with this cultural dimension that they encounter in middle-aged and older women.

This study is limited by the relatively small sample size, and we are aware that this limits the empirical scope for supporting theoretical propositions. We recommend further research on the topic using a larger sample. In addition, the focus on breast cancer in this paper circumvents a discussion of sexuality in male contexts. Future research on sexuality relating to cancer might address this issue, and indeed the impact of a largely female cancer nursing workforce on the manner in which sexuality care is approached with both male and female clients. Furthermore, in alluding to holism at the outset of the article, we have not addressed the broader debate regarding the extension of the nurse's role into the psychosocial domain of which sexuality is a part. The crux of this debate is that the extension of the nurse's role into the psychosocial domain affords them greater power over an increasingly number of areas of patients' lives, as well as privileging them as 'experts'. This issue, while necessary to flag here, is a matter for another paper.

Before concluding, we would like to note that since this study was conducted in 2003, one of the authors (ML) has been engaged in sexuality workshops in an effort to address some of the deficits highlighted by participants. In light of the findings of this study, a

working group was established (in collaboration with the Irish Cancer Society) to develop a one-day workshop to guide nurses in addressing the issue of sexuality and body image with oncology patients. Having received permission from the Cancer Council of New South Wales, the workshop format was derived from a modified version of their teaching tool (*Talking about Sexuality and Body Image: A Teaching Resource for Health Professionals*) and included lectures, role-play and discussion. Fourteen nurses attended the first pilot workshop, which was held in November 2004; immediate post-workshop evaluations revealed that it met the needs of the participants and provided the guidance they required to address this sensitive aspect of care with patients. In addition, participants were furnished with questionnaires to complete and return three months after the workshop to explore if and how the workshop had influenced their clinical practice. At the time of writing, this phase of the evaluation process is awaited. It is anticipated that this workshop will be held regularly and that more nurses will become facilitators so that it will become available nationally. Whilst it will some take time to enable nurses to appropriately address body image and sexuality with patients, it is anticipated that these workshops will provide a good starting point to addressing the problems identified in this study.

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