Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs

Amanda J Hordern and Annette F Street

ABSTRACT

Objective: To explore the ways that patients and health professionals communicate about intimate and sexual changes in cancer and palliative care settings.

Design: A qualitative study using a three-stage reflexive-inquiry approach, with semi-structured, participant interviews ($n = 82$); textual analysis of national and international cancer and palliative care clinical practice guidelines ($n = 33$); and participant feedback at 15 educational forums for cancer patients or health professionals.

Setting: A large Australian public teaching hospital between 2002 and 2005.

Participants: 50 patients diagnosed with cancer, and 32 health professionals who had worked in cancer and/or palliative care for a minimum of 12 months.

Main outcome measures: Communication about intimacy and sexuality: patients' needs and experiences and health professionals' attitudes and experiences.

Results: There were mismatched expectations between patients and health professionals and unmet patient needs in communication about sexuality and intimacy. Most patients sought information, support and practical strategies about how to live with intimate and sexual changes after treatment for cancer, even if their cancer type did not affect fertility or sexual performance. In contrast, many health professionals assumed that patients shared their professional focus on combating the disease, irrespective of the emotional and physical costs to the patient. Health professionals overwhelmingly limited their understanding of patient sexuality to fertility, contraception, menopausal or erectile status. Many stereotypical assumptions were made about patient sexuality, based on age, sex, diagnosis, culture, and partnership status. There was a relationship between providing patient-centred communication about intimacy and sexuality and health professionals' understanding of their own attitudes and beliefs.

Conclusion: Resources are needed to help health professionals engage in an exploration of their own definitions of intimacy and sexuality and understand how these affect interactions with patients with cancer.

MJA 2007; 186: 224–227

In an era when health professionals are increasingly requested to provide patients with support and information about sexual and intimate changes after cancer,[1-4] there is an underlying assumption that they have the time, capacity and skills to do so. However, evidence suggests that health professionals in cancer[1] and palliative care settings[4] rarely communicate about patient sexuality and intimacy, but little is known about why.

Published studies mostly have explored the narrow relationship between the impact of cancer treatment on a patient's "sexual function"[5-7] or "sexual dysfunction".[8,9] Thus, patient sexuality is limited to fertility status or capacity for sexual intercourse, instead of it being understood as an ever-changing, lived experience affecting the way in which people view themselves, their body and their ability to intimately connect with significant others throughout life.[10] Qualitative researchers[4,11,12] argue that patients seek practical information and emotional support from health professionals to assist them to adapt to sexual and intimate changes after cancer.[11-13] We found only one published study[13] that investigated the reasons why health professionals did not discuss sexual matters; lack of time, lack of experience, or embarrassment were given as the reasons for avoiding discussing sexual changes with women with ovarian cancer.[13]

We present original findings related to communicating about sexuality and intimacy after cancer from the perspectives of patients and health professionals, and suggest how oncologists and other health professionals could improve communication with patients on this largely taboo topic.

METHODS

A three-stage reflexive inquiry[14] was conducted between 2002 and 2005 to explore health communication as a multidimensional and complex phenomenon, incorporating the experiences of health professionals with patients. A reflexive inquiry acknowledges that sociocultural values can shape a sense of self and influence relationships in terms of assumption, expectations and communication patterns.

We took a multilayered approach to data collection — the analysis of each layer informed the analysis of the next layer. Transcriptions of interviews with participating patients and health professionals were examined alongside a textual analysis of national and international cancer and palliative care clinical practice guidelines, to facilitate a deeper understanding of structural and cultural influences on patient and health professional constructions of sexuality and intimacy. Preliminary interview data were then presented at forums (attended by patients or health professionals) to provide further data validation.[14] The feedback from these forums led to a further level of analysis, enabling researchers to identify contradictions, unmet needs and mismatched expectations, and to refine possible communication strategies.

Recruitment and sample

Patients with cancer and health professionals working in cancer and palliative care settings within the largest public teaching hospital in Victoria were invited to participate in the study. Recruitment information detailed the nature of the research. Interested people were asked to contact the researcher to set up an interview at a convenient time and place. Semistructured interviews were held with 50 patients receiving treatment for cancer (aged 22–85 years), and 32 health professionals who had been working in cancer and or palliative care settings for a minimum of 12 months (Box 1).

La Trobe University and Austin Health ethics committees gave approval for the study. All interview participants provided written consent and the data were de-identified.

Data collection and analysis

We used standard qualitative research techniques[15] to conduct semistructured, tape-recorded interviews with health professionals and patients. The interviews lasted an average of 45 minutes and explored experiences of communication about patient sexuality, unmet needs and considerations that might help or hinder the communication process. Transcriptions from the 82 taped interviews, electronic versions of 33 national and international cancer and palliative care clinical practice guidelines, and documented feedback from participants attending 15 educational forums for cancer patients or health professionals were imported into NVivo (Qualitative Research Computer Analysis Package)[16] to facilitate tallying and sorting of codes and categories within the raw data. Open coding resulted in each transcription being examined line by line to determine initial themes and categories, so that central concepts were recognised by each of us independently and the codes compared for differences.

A total of 147 codes were identified and analysed conceptually,[17] using the work of Anthony Giddens on sexuality, intimacy and reflexivity[18,19] as a framework to make further sense of the data. Researcher verification[20] maximised validity and transferability of findings to other clinical contexts. As the study progressed, we noted consistent documented evidence of increasing congruence between the responses of forum participants to the research data. Key issues emerging from the data are presented here.

RESULTS

Two major themes that emerged were unmet needs of patients and mismatched expectations in the communication process between patients and health professionals when exploring issues of intimacy and sexuality in cancer and palliative care.

Unmet needs

The diverse range of patient responses were conceptualised as "cluster responses" along a continuum, ranging from the more traditional responses of the clustered themes "*Survival is more important than my sexuality*" and "*Trust in the expert*", to more "reflexive" responses of self-reflection and adjustment indicating a desire for negotiated communication. The latter were typified by those listed in the clustered themes "*Search for options*", "*Am I normal?*" and "*Tell it to me straight*" (Box 2). While participants were not confined to a particular cluster, each cluster represented their overall attitudes and beliefs about issues of intimacy and sexuality at the time of the interview.

1 Demographic characteristics of participants — number (%)

Patient population (*n* = 50)	
Age (years)	
21–30	4 (8%)
31–40	3 (6%)
41–50	9 (18%)
51–60	12 (24%)
61–70	8 (16%)
71–80	11 (22%)
80 +	3 (6%)
Cancer type	
Breast	10 (20%)
Prostate	11 (22%)
Bowel	5 (10%)
Lung	5 (10%)
Haematological	8 (16%)
Other	6 (12%)
Time since cancer diagnosis	
< 1 year	25 (50%)
1–2 years	12 (24%)
3–5 years	4 (8%)
6–10 years	5 (10%)
Health professionals (*n* = 32)	
Discipline	
Doctor	10 (31%)
Nurse	13 (41%)
Social worker	4 (13%)
Occupational therapist	1 (3%)
Physiotherapist	2 (6%)
Pastoral care	1 (3%)
Volunteer	1 (3%)
Sex	
Male	8 (25%)
Female	24 (75%)
Years of experience — cancer and palliative care	
1–3	7 (22%)
4–6	9 (28%)
7–10	5 (16%)
10 +	11 (34%)

Most patients wanted negotiated communication with health professionals, to enable them to discuss intimate and sexual changes related to cancer at a time and in a manner that best suited their individual needs. Irrespective of patient age, sex, partnership status, culture, or site of cancer, many patients believed their needs were not met by health professionals, as they searched for practical advice, information and emotional support about how to live with sexual and intimate changes after a cancer diagnosis.

As we explored these unmet needs, it became apparent that structural influences governing these clinical cultures, including clinical practice guidelines, made it difficult for patients to be regarded as individuals with divergent views about the importance of sexuality and intimacy in their lives. When patient sexuality and intimacy remained invisible in clinical cultures, there were mismatched expectations about the communication responsibilities of health professionals in relation to patients and their families.

Mismatched expectations

It was evident that most health professionals fell into the trap of meeting patient needs on the basis of their own clinical priorities. Stereotypical assumptions were made about patient sexuality and intimacy based on the patient's age, sex, diagnosis, culture, and partnership status. Most health professionals believed patients would share their one-dimensional focus of combating the disease, irrespective of the physical, social or emotional costs to the patient. In stark contrast to the patient responses, the responses of these health professionals were clustered around the more traditional approach to sexuality and intimacy at the "*It is not life or death*" and "*I manage to avoid the topic*" end of the continuum. Within this belief system, there was rarely time or privacy to discuss issues of intimacy and sexuality with a patient. The clinical culture endorsed these attitudes and beliefs, so that health professionals believed they were addressing patient sexuality and intimacy when they spoke to patients about treatment-induced infertility, menopause, erectile dysfunction, reduced libido or contraceptive requirements. Overwhelmingly, patients felt that many assumptions were made about their sexuality and intimacy without consulting them, so that mismatched expectations in the communication process became a central theme.

A smaller number of more reflective health professionals were able to recognise and state that "*I can't expose my vulnerability*", or "*It is risky business*". These health professionals reported feeling embarrassed and unable to discuss such issues with people who might remind them of their own parents. Others felt vulnerable to the atti-

2 Intimacy and sexuality after cancer — selected participant responses, grouped by cluster theme

Patient issues

Survival is more important than my sexuality

He told me "no more erections" and . . . I am a little bit disappointed as it's an important part of your life . . . Better to be alive than dead

I don't look at myself any more

Trust in the expert

If it were that important they would have told me

I don't want to make them [health professionals] to feel uncomfortable . . .

Search for options

Can you have sex after chemotherapy? . . . I was looking for the option of discussing these concerns with a health professional. Now I will never know

I was searching for the right person who would understand how I was feeling

I want to be viewed as a person rather than my disease

Am I normal?

Has something gone wrong with my treatment? . . . Was there something they had not told me? My body has changed, my mind has changed, everything has changed . . . Is this normal to feel so ugly?

Is that normal to lose interest in sex? . . . it's a big worry for me

Tell it to me straight

I want to enter a partnership between the medical professional and the patient . . . which would see me as part owner of everything that is being done to me

My relationship is the most important part of my life . . . not just physically . . . mentally . . . nobody seems to understand that around here

You're brought up in an environment of trusting a doctor and believing them . . . But today . . . if something is diagnosed, I'll go home to the Internet and check it out so I know what they are talking about

Health professional perspective

It is not life or death

How can I bring up sex . . . I have far more important things to address with them!

Surviving . . . getting out of here [hospital] must be more important than all these personal issues

It's more that I talk at them . . . with a list of outcomes

I manage to avoid the topic

I understand my limitations . . . and I am sure somebody else is addressing this issue

If the treatment I am going to recommend is going to have some bearing on the sexual functioning . . . fertility . . . loss of libido, erectile function . . . menopause . . . They all need to be addressed via continued education . . . this was never discussed in my training

I can't expose my vulnerability

I come from a very strict background where sex is taboo . . . I still feel very uncomfortable talking about sex in my personal life . . . that has been ingrained in me since I was a child

The reaction of my colleagues was a bit horrified that I actually talked to a patient at that level

It may be considered an affront . . . that I am coming on to the patient . . .

It is risky business

I struggle when they come from another culture . . . am I offending them . . . I feel so ignorant

Once you get to the stage where you are talking about people who are as old as your parents . . . It's a bit of a "no go" there

If they are alone, no partner, well then I am not going to rub it in their face, you know, are they sexual?

Patient-centred and negotiated communication

I think it should be part of the overall health care and returning people to their normal life . . . and if I do not have the courage or expertise to bring it up in a safe environment, then I can't expect they [patients] do

I am comfortable with who I am . . . my own sexuality . . . You have to work yourself out first

The more comfortable I can be, the more intimate it becomes, in that people are likely to open up

◆

tudes of their patients and colleagues. Fears of over-involvement in the non-medical aspects of patients' lives, as well as the threat of patient litigation, were concerns that highlighted the dominant medicalised form of communication in this clinical culture.

There were two health professionals who were comfortable talking about sexuality to all their patients as part of their overall communication. Their responses were located at the "*Patient-centred and negotiated communication*" end of the continuum (Box 2). In general, the more self-reflective health professionals were, the more likely they were able to articulate a relationship between personal definitions of sexuality and intimacy and how their personal assumptions about patients affected their clinical practice.

DISCUSSION

Cancer interrupted the lives of these patients and in most cases it created a time of self-reflection and adjustment when taken-for-granted assumptions were challenged. Patients within our study were actively searching for ways to adapt to their changed sense of self, which included how they experienced alterations to intimate and sexual aspects of their lives after cancer.[21] Many of the key issues from the patient perspective, including patients' requests to be regarded as individuals and active participants in their care,[12] their need for practical information and emotional support from health professionals,[22] as well as health professionals' assistance in adapting to their altered self-image,[12,23] have been highlighted throughout the medical literature.

We found clear examples of Gidden's notion of "plastic sexuality" in which people reconstructed the meaning of sexuality for themselves reflexively, exploring the effects of cancer on their bodies, emotions and relationships. Irrespective of the site of cancer, disruptions to constructions of masculinity and feminity were experienced by most patients. These findings have been traditionally associated with treatment for breast cancer[24] and prostate cancer. [25]

Structures which governed these cancer and palliative care settings made it difficult for patients to be regarded as sexual, in an environment and culture that emphasised medicalised, problem-based, health-professional-driven communication. However, it was not only made difficult by structural constraints or lack of education, but also by the personal pressures that health professionals felt when faced with the need to

3 Key findings

- Patients with all kinds of cancer, not just those with cancers affecting fertility and sexual performance, want open communication about intimacy and sexuality.
- Many assumptions are made by health professionals about patient sexuality and intimacy based on the patient's age, sex, diagnosis, culture, and partnership status without checking with the patient.
- Many health professionals feel vulnerable to the attitudes of their patients and colleagues, including fear of patient litigation, as well as reluctance to open "Pandora's box". They lack life experiences to help them communicate with patients about sexuality and intimacy after cancer.
- Health professionals need to engage in an exploration of their own definitions of intimacy and sexuality, and how these affect their profession, to provide the kind of open, honest and reflexive relationships patients seek.

◆

discuss intimacy and sexuality. An unexpected finding was the level of vulnerability expressed by health professionals about discussing these issues. It was personally confronting to raise these issues with people of particular ages or sex, particularly with those patients who reminded them of their own parents.

Limitations of the research are that the participants were self-selected to discuss issues of intimacy and sexuality in English with the researchers. Due to the broad range of participants, as indicated by their demographic data, we believe it is likely that the findings are representative of English-speaking people with cancer struggling to discuss issues of intimacy and sexuality with their health professionals.

Most patients were searching for a health professional they could trust to provide them with information, emotional support and practical strategies for adapting to the intimate and sexual changes they had experienced since their cancer diagnosis. Our study alerts us to the personal and professional difficulties facing health professionals and the kind of open, honest and reflexive communication styles patients desire (Box 3). It highlights the clinical shaping of health professional vulnerability and the social taboos that dictate how health professionals should speak to patients.

Paramount in moving from a medicalised communication pattern to a reflexive, patient-centred pattern is the requirement for health professionals to engage in a reflexive exploration of their own definitions of intimacy and sexuality and how these affect their professional world and their interactions with patients, including the assumption that "somebody else is addressing this issue". We believe that all patients are entitled to the option of discussing intimacy and sexuality with a member of their treatment team. Health professionals require advanced communication education, a formal referral process, and resources, strategies and tools designed to assist them to move beyond their personal assumptions and beliefs to facilitate a systematic approach to the kind of information and support patients need. Resources need to be researched, developed and incorporated into undergraduate and postgraduate education programs to change practice.

ACKNOWLEDGEMENT

Amanda Hordern would like to acknowledge La Trobe University Post-Graduate Research Scholarship funding to conduct this project.

COMPETING INTERESTS

None identified.

AUTHOR DETAILS

Amanda J Hordern, PhD, Lecturer, Department of Health Sciences; currently, Deputy Director, Cancer Information and Support Service, The Cancer Council Victoria
Annette F Street, PhD, Director, Clinical School of Nursing
La Trobe University/Austin Health, Melbourne, VIC.
Correspondence:
Amanda.hordern@cancervic.org.au

REFERENCES

1 Schover LR. Sexuality and fertility after cancer. *Hematology Am Soc Hematol Educ Program* 2005; 523-527.
2 National Breast Cancer Centre and National Cancer Control Initiative. Clinical practice guidelines for the psychosocial care of adults with cancer. 1st ed. Camperdown, NSW: National Breast Cancer Centre, 2003.
3 National Cancer Institute. Sexuality and reproductive issues: health professional version. Bethesda, Md: NCI, 2004. http://www.cancer.gov/cancertopics/pdq/supportivecare/sexuality/healthprofessional (accessed Jan 2007).
4 Lemieux L, Kaiser S, Pereira J, Meadows L. Sexuality in palliative care: patient perspectives. *Palliat Med* 2004; 18: 630-637.
5 Bergmak K, Avall-Lundqvist E, Dickman PW, et al. Vaginal changes and sexuality in women with a history of cervical cancer. *N Engl J Med* 1999; 340: 1383-1389.
6 Ganz PA. Sexual functioning after breast cancer: a conceptual framework for future studies. *Ann Oncol* 1997; 8: 105-107.
7 Paridaens R. Sexual life and pregnancy before and after breast cancer. *Acta Clin Belg Suppl* 1993; 15: 51-55.
8 Barni S, Mondin R. Sexual dysfunction in treated breast cancer patients. *Ann Oncol* 1997; 8: 149-153.
9 Barton D, Joubert L. Psychosocial aspects of sexual disorders. *Aust Fam Physician* 2000; 29: 527-531.
10 Hordern A, Currow D. A patient-centred approach to sexuality in the face of life-limiting illness. *Med J Aust* 2003; 179 (6 Suppl): S8-S11.
11 Butler L, Banfield V, Terry S, Allen K. Conceptualizing sexual health in cancer care. *West J Nursing Res* 1998; 20: 683-699.
12 Wilmoth MC. The aftermath of breast cancer: an altered sexual self. *Cancer Nurs* 2001; 24: 278-286.
13 Stead ML, Brown JM, Fallowfield L, Selby P. Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *Br J Cancer* 2003; 88: 666-671.
14 Cunliffe AL. Reflexive inquiry in organizational research: questions and possibilities. *Hum Relat* 2003; 56: 983-1003.
15 Fontana A, Frey J. The interview: from structured questions to negotiated text. In: Denzin N, Lincoln Y, editors. Collecting and interpreting qualitative materials. Thousand Oaks, Calif: Sage Publications, 2003: 61-106.
16 Bazeley P, Richards L. The NVivo qualitative project book. London: Sage Publications, 2000.
17 Ezzy D. Coding data and interpreting text: Methods of analysis. Qualitative analysis: practice and innovation. Sydney: Allen & Unwin, 2002: 80-110.
18 Giddens A. The transformation of intimacy: sexuality, love and eroticism in modern societies. Cambridge, UK: Polity Press, 1992.
19 Giddens A, Pierson C. Conversations with Anthony Giddens: making sense of modernity. Cambridge, UK: Polity Press, 1998.
20 Creswell JW. Qualitative inquiry and research design: choosing among five traditions. Thousand Oaks, Calif: Sage Publications, 1998.
21 Hordern AJ, Street AF. Constructions of sexuality and intimacy after cancer: patient and health professional perspectives *Soc Sci Med* 2007 Jan 27; [Epub ahead of print].
22 Wilmoth MC, Ross JA. Women's perception: breast cancer treatment and sexuality. *Cancer Pract* 1997; 5: 353-359.
23 Bruner DW, Boyd CP. Assessing women's sexuality after cancer therapy: checking assumptions with the focus group technique. *Cancer Nurs* 1998; 21: 438-447.
24 Van der Reit P. The sexual embodiment of the cancer patient. *Nurs Inq* 1998; 5: 248-257.
25 Oliffe J. Constructions of masculinity following prostatectomy-induced impotence. *Soc Sci Med* 2005; 60: 2249-2259.

(Received 16 Jul 2006, accepted 20 Dec 2006) ❑