A patient-centred approach to sexuality in the face of life-limiting illness

Amanda J Hordern and David C Currow

ABSTRACT

- Sexuality is intrinsic to a person's sense of self and can be an intimate form of communication that helps relieve suffering and lessens the threat to personhood in the face of life-limiting illness.
- Health professionals struggle to accept that people with life-limiting illness, especially older people, continue to be sexual beings.
- People facing life-limiting illness may appreciate the opportunity to discuss issues of sexuality and intimacy with a trusted health professional.
- Practical strategies to assist health professionals to communicate effectively about sexuality and intimacy include creating a conducive atmosphere, initiating the topic, using open-ended questions and a non-judgemental approach, and avoiding medical jargon.

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We make love every night, for who knows when it will be the last time we can share this moment together.

70-year-old woman with advanced cancer

PATIENTS AND THEIR PARTNERS value opportunities to discuss issues of sexuality and intimacy with trusted health professionals.[1,2] In advanced disease, people often feel robbed of past joys which their sexuality may help them to regain.[3,4] Communicating about sexuality can be difficult for health professionals; they may lack time, may not know how to begin the conversation, feel they know little about sexuality or do not have the answers patients seek.[5] Health professionals also struggle personally and professionally to accept that people with a life-limiting illness, especially older people, continue to be sexual beings.[6,7]

Definitions of sexuality and intimacy

There is an assumption that sexuality equates with sexual intercourse and function.[8,9] Publications that focus on a person's ability to perform sexual intercourse after the diagnosis of a life-limiting illness reinforce this narrow view of sexuality.[10] Sexual function is only one dimension of sexuality and intimacy.[1,2,9]

The World Health Organization defines human sexuality as:

> a central aspect of being human throughout life [encompassing] sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.[11]

Cultural beliefs,[12] stressors[13] and all relationships affect a person's unique sexuality.[1,14] Intimacy, touch, self-esteem,[15,16] emotional and social interactions with people,[1,17] and communication[14] help capture sexuality. Sexuality is inextricably linked to a sense of wholeness, which is threatened by life-limiting illness.[3]

"Intimacy" is often used as a euphemism for sexual function.[15] However, intimacy has been described as the sharing of identity, mutual acceptance, closeness and reciprocated rapport, which are more closely linked to communication than to sexual function.[18] Intimacy, like sexuality, is intrinsic to a sense of self. By contrast, the diagnosis of a life-limiting illness can be the ultimate threat to the sense of self, and the basis of suffering.[19]

Attitudes of health professionals

Attitudes, values and assumptions about patient sexuality have an impact on communication by health professionals.[5,15] Patients in qualitative studies reflect that few health professionals are willing to engage in open discussions about sexuality.[9,20,21] Patients "suffer in silence" as they assume that, if sexuality and intimacy were important, health professionals would discuss them.[1,22,23]

As elderly people make up 65% of those needing palliative care,[24] ageist assumptions by health professionals have particular impact. Health professionals may assume that elderly people are no longer sexually active and not interested in issues related to intimacy.[6,17] Our community is just beginning to "come to terms with sexual behaviour continuing into old age".[17]

Patient experience and expectations

Little has been published about patient perspectives on sexuality or intimacy in palliative care.[3,4] In the face of a life-limiting illness, it is often assumed that a person's desire for

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1: Communicating about sexuality and intimacy with patients who face life-limiting illnesses

General approach

Create an atmosphere conducive to open discussion (privacy, no interruptions, sit close to the patient).

Introduce the topic and ascertain the patient's readiness for a discussion.

Use open-ended questions to gauge the patient's level of understanding and concerns.

Use a non-judgemental approach based on trust and confidentiality.

Make no assumptions about the patient's relationships, sexuality, intimacy or knowledge about these issues.

Do not use medical jargon.

Specific phrases to help open the discussion

Some people who are going through an illness like yours have been concerned about their sexuality.

You have been through so much since your diagnosis. This may affect the way you see yourself as a woman/man.

You must be wondering how all of this will affect you sexually or intimately. Let's talk about that.

You look so tired, and it must be hard to feel good about yourself after all that you have been through. This illness may have impacted on your relationship and other intimate areas of your life.

Other women who have been given this treatment have experienced a dry vagina.

Some men taking this medication have problems having an erection.

survival overshadows their sexuality and desire for intimacy.[18] While this may be true immediately after diagnosis, most people hope to "get on with life", with sexuality and intimacy playing important roles.[3,25] In addition, at the time of diagnosis of a life-limiting illness it is common for a person to long to be held, with touch as an intimate form of communication to help redress suffering.[5]

Patients are often relieved to hear that other people with life-limiting illness have experienced similar issues with intimacy and sexuality. Many value discussing sexuality with a health professional they know, rather than being referred to someone else,[26] and most do not want counselling or referral to a sexual counsellor.[22] They are usually seeking validation of their concerns, normalisation of their experience, and practical advice.[2] People want to reaffirm themselves as sexual beings, take control of their health and adjust to their changing circumstances.[15] Discussing changes in their sense of self and sexuality is empowering for patients and for the health professionals caring for them.[1,21,22]

Practical strategies

Setting the scene

Research has identified ways in which health professionals control the directions taken by consultations.[27] This control may be to avoid confronting taboo issues such as patient sexuality, using tactics such as closed and leading questions, direct statements, and a narrow focus on disease-related issues.[27] Contrasting strategies to assist communication about sexuality and intimacy are shown in Box 1.

Communication between patient and partner

Communication between partners is important to treatment outcomes for sexual dysfunction.[10] However, it is common for a person with a life-limiting illness to be less intimate or trusting during the crisis phase of the illness.[10] In addition, changes in body image or self-perception have the potential to affect intimacy and social relationships.[25]

A key role for health professionals is to encourage people in their care to explore changes in sexuality and intimacy with their partners. Directly sharing with each other their feelings about their altered situation may be very difficult given the changes both face, but is a good starting point for this communication process.

Specific symptoms

Fatigue

Many patients experience fatigue and lethargy, which directly affects the way they feel as a person and the way they relate to others. Health professionals can ask how fatigue is affecting the patient and their relationships, emphasising the importance of non-penetrative sexuality, and encouraging them to explore what makes them feel good about themselves and the type of things they once enjoyed sharing with their partner. By using their best time of the day (when they have more energy, less pain, or fewer problems with other symptoms) and by setting realistic goals, people can begin to feel more in touch with themselves and their partners.

Pain

Sexuality and intimacy can be a time of gentle relaxation for patients, when sharing and touch can improve their sense of well-being.[14] If patients have incident pain, the health professional should specifically ensure that they take breakthrough analgesia before times of intimacy or physical sexuality.

Incontinence

Incontinence has a devastating impact on the way people feel about themselves,[4,15] yet issues of incontinence are

2: Resources for health professionals, patients and carers

For health professionals

Akkerman D. Breast cancer, sexuality and self esteem. A computerised consultation & counselling information system — oncall publication information sheet. Melbourne: Cancer Council Victoria, 1999: 1-5.

Bourgeois-Law G, Lotocki R. Sexuality and gynaecological cancer: a needs assessment. *Can J Human Sex* 1999; 8: 231-240.

Cancer Council of New South Wales. Talking about sexuality, body image and cancer. A teaching resource for health professionals. Sydney: The Council, 2002.

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Hordern A. Intimacy and sexuality for the woman with breast cancer. *Cancer Nurs* 2000; 23: 230-236.

Hughes MK. Sexuality and the cancer survivor. *Cancer Nurs* 2000; 23: 477-482.

Murkies A. Sex and the postmenopausal woman. *Aust Fam Physician* 1996; 25: 509-517.

Phelps K. Sex: confronting sexuality. Sydney: HarperCollins, 1993.

Rice A. Sexuality in cancer and palliative care 1: effects of disease and treatment. *Int J Palliat Nurs* 2000; 6: 392-397.

Roberts R. Importance of the sexual dimension in psycho-social assessment. *Aust Soc Work* 1992; 45: 37-42.

Rogers M, Kristjanson L. The impact on sexual functioning of chemotherapy-induced menopause in women with breast cancer. *Cancer Nurs* 2002; 25: 57-65.

Schover LR. Better sex after serious illness. *Bottom Line/Health* 2002; 16: 11-13.

Shell JA, Smith CK. Sexuality and the older person with cancer. *Oncol Nurs Forum* 1994; 21: 553-558.

For patients and carers

Schover LR. Sexuality and cancer: for the man who has cancer, and his partner. Atlanta: American Cancer Society, 1988.

Schover LR. Sexuality and cancer: for the woman who has cancer, and her partner. Atlanta: American Cancer Society, 1988.

Schover L. Sexuality and fertility after cancer. New York: John Wiley and Sons, 1997.

Zilbergeld B. The new male sexuality. New York: Bantam Books, 1999.

relatively unexplored in publications about patient sexuality. Incontinence may represent loss of control and dignity. For catheterised patients, healthcare professionals can provide education on self-catheterisation for times when they wish to be intimate, and practical suggestions, such as showering beforehand, using the bath or shower areas as a place to explore intimacy, and using towels and plastic sheets to protect bedding.

Changing priorities

It is common for patients to re-evaluate their lives and even change priorities in the face of a life-limiting illness.[15,26] Spending time alone or with a partner and allocating time for self-indulgence may be a new priority. Yet negotiation and explanation between long-time partners may be required as part of the open communication process. Health professionals can encourage people to set aside specific times for sexuality and intimacy. At home, suggest turning on the answering machine, not answering the door, using babysitters, and putting sexuality and intimacy on the agenda. Patients may want to dress up for the occasion, have a bath alone or with a partner, and set the scene with candles and dim lighting.[28]

For inpatient units, creating an atmosphere of space, trust and respect is often difficult, but can be achieved. If a door is shut or a curtain closed, health professionals need to consider patient privacy. Knocking and asking permission to enter, providing and respecting "Do not disturb" signs, encouraging the use of family or "quiet rooms", and having a double bed for patient use are ways of adapting an inpatient environment.

Refocusing on sexuality and intimacy after illness

Learning to adapt to a changed body, new orifices or body parts (such as a breast or testicular prosthesis), altered sensory patterns, fatigue and ongoing illness takes time and patience. Health professionals can encourage people to communicate their fears and concerns and offer practical strategies, such as wearing clothing that increases their confidence in their changed bodies (eg, a camisole or waistcoat to conceal scars, and adhesive stomal bags or plugs to conceal stomas). Patients may also require advice about lubrication, position changes, and medication and its effects on libido and sexual function[29] (Box 2). They are sometimes also looking for guidance as to how and when they can share with their partner how it feels to have a life-threatening illness and how it has affected them psychologically and physically.

Conclusion

Health professionals must incorporate patient sexuality and intimacy into routine palliative assessments, so that every patient is given an opportunity to explore these issues. Patients and their partners will appreciate health professionals providing information, support and practical strategies related to issues of intimacy and sexuality throughout the course of care. Resources on sexuality and intimacy in the face of illness for health professionals, patients and carers, are shown in Box 2.

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Competing interests

None identified.

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Caring for the spirit: lessons from working with the dying

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ABSTRACT

- Spiritual care is integral to palliative care, and palliative care experience in offering spiritual care can be a resource for the emerging healthcare interest in spirituality.
- Spirituality is best understood in terms of the web of relationships that gives coherence to our lives, uniquely identifying each person.
- In palliative care, responsibility for spiritual care is shared by the whole team, with leadership given by specialist practitioners such as pastoral care workers. The palliative care approach to spiritual care may, however, be transferred to other contexts and to individual practice.
- Spiritual care encourages and supports people in a quest for meaning and personal autonomy. It is offered, not imposed.

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In the 1970s, the hospice movement, from which contemporary palliative care has emerged, established a model of care for dying people that encompassed physical, psychological, social and spiritual dimensions of need. Over the past 30 years, hospice and palliative care services have generated a rich store of accounts about the ways in which people face death.[1] These make it plain that the imminence of death, together with the changed circumstances associated with illness, cause many people to reflect on questions such as: Who do I belong to? What's the purpose of my life? What can I hope for?

Traditionally, questions like these received religious answers, and hospice care practitioners regarded attending to these questions as spiritual care. To do so, they drew at first upon religious resources, but soon began to develop a broader perspective in which spirituality was understood as "ultimate meaning". Concepts enunciated by Cicely Saunders — "openness, mind together with heart, and a deep concern for the freedom of each individual to make his or her own journey towards their ultimate goals"[2] — were considered fundamental to hospice practice. The role of practitioners was to be companions on this journey, responding to the dying person's spiritual quest rather than imposing their own views. They observed that people became aware of spiritual need in various ways: through trying to cope with their changed physical, emotional or

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