Is There a Place for Sexuality in the Holistic Care of Patients in the Palliative Care Phase of Life?

Margaret J. Redelman

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Is There a Place for Sexuality in the Holistic Care of Patients in the Palliative Care Phase of Life?

Margaret J. Redelman, MD, MPsychotherapy

Being diagnosed with a life-limiting condition is a traumatic event. The journey to the moment of death is usually only done once—so it is a time of fears and uncertainty. Sexuality is particularly vulnerable at this time. It may be difficult for both patient and partner to deal with the changes in sexuality without professional assistance. It is “sexuality” rather than “sex” that defines the meaningful relationships people have with themselves and significant others. When sexuality is lost or changed, important benefits may be lost. Studies show that many patients do value sexuality and want assistance in making the best of their sexual potential during the palliative care phase. Health professionals regularly acknowledge the importance of sexuality for their patients but have difficulties acting on their beliefs. Sexuality, within the patient’s functional ability and desire for it, must be acknowledged and included in holistic management. It is the health professional’s responsibility to raise this issue.

**Keywords:** sexuality; palliative care

For each patient, dying is a process of personal trial and error.¹ The sexual journey, with its real and projected losses, is influenced by the unique milieu of the patient, their partner and their relationship. As death and the loss of a significant other are approached, the sexual changes created may be difficult to manage unassisted.

Most societies have taboos around sexuality, illness, and dying. This further compounds the difficulties for the patient and also the health professionals who are influenced by the same sociocultural setting.

In the crisis period following diagnosis of a life-limiting disease and the immediate focus on treatment, many patients, partners, and health professionals make the assumption that all energy and needs should be on survival² and that sensuality, sexuality, and intimacy are unimportant or frivolous. But what if people want or need to connect intimately in the most life-affirming way possible³,⁴ at this vulnerable time?

There may be different needs depending on the age of the individuals and the duration or stage of the relationship. Many dying individuals will be in the older age group where the sexual needs between the couple may have found a nongenital/physical sexual expression, where sensuality expressed by hugging and cuddling has become the norm.⁵ This may allow for an easier transition to socially/institutionally acceptable interaction in this period. However, this may contrast sharply in a younger couple where an active sexual relationship is lost relatively suddenly, where there may be anger over losing an aspect of oneself that was enjoyed, resentment at losing an enjoyable connection to the partner, frustration if there is conflict with the partner’s needs, guilt, sadness, and stress.

What happens for individuals as they approach death if they want and need to touch and be touched, need to communicate physically and receive sensuality/sexuality but the partner does not, or is scared to, or the institution denies the opportunity? The current reality is that when sexual needs are not acknowledged there is a potential for the patient’s needs to go unmet.⁶-⁸ This unmet need may adversely affect self-esteem, stress, and depression.⁹
As death approaches, people struggle with a balance between closer engagement and disengagement, in anticipation of the final separation from each other. The need for closeness by the patient may be at odds with the needs of the partner who may be starting to distance so they can manage the pain of loss when it comes.

What Is “Sexuality?”

Sexuality is a very individual concept that cannot be easily defined or categorized and which includes feelings, values, beliefs, and experiences related to one’s sexual preferences. It is expressed within a context of communicating with an “other,” as well as personally expressing oneself as a sexual being. Sexuality is quite distinct from sexual activity. Girks defined sex as something we do and sexuality as something we are. Sexuality is an intrinsic lifelong aspect of being human and not limited by age, physical appearance, health, or functional ability. Gilley very succinctly defined sexuality in the context of palliative care as “the capacity of the individual to link emotional needs with physical intimacy” within the constraints of their ability.

Sexuality is about who we are and how we express that aspect of ourselves to the outside world—so much broader than the specific genital act. Every individual's sexuality is with them from birth till death. One never loses it even in the face of the obstacles that most societies have, with strong taboos against talking openly about sexuality and in particular, sexuality when sick, disabled, unattractive, old, and/or dying.

The sexual mythology and stereotypes that exist overtly and covertly in societies and in people’s minds around sexuality and terminal illness/dying are damaging because they are based on prejudiced misconceptions, and because they deny individuality. Myths such as “sex equals intercourse” or “sex depletes you” usually have some grain of truth in them that helps them pass as total truths, which they are not.

Sexuality means different things to different people at different stages of their life. There is no average patient, partner, health professional, or health care institution. The needs of the patient change frequently depending or whether it is a good day filled with some good enough conditions for sexuality such as freedom from pain, availability of a willing partner, privacy, and so on, or a bad day with physical symptoms, preoccupation over losses, anger over unresolved tasks, or fear of dying.

Many patients who are not able to be physically sexually active still maintain their ability to have sexual dreams and cognitions, feelings, and fantasies. It can be very special to be able to acknowledge or share these with someone important. At all times the patient’s/couple’s autonomy needs to be respected and the opportunity for discussion given but not pursued if unwanted.

Benefits of Sexuality

There are relatively few studies that look at the benefits of good sexuality and many of these studies have small sample sizes.

Sexuality is vital to many people’s self-concept and a sense of personal integrity—being a man or a woman. This sustains adaptability and resilience enabling ability to cope with adverse circumstances and ability to work out personal solutions. This aspect is critical for many patients if they are to find peace, acceptance, and contentment at the end of life.

Sexual behaviors involve endocrine systems capable of decreasing hypothalamic–pituitary–adrenal axis activity, thereby modulating the autonomic nervous system. This possibly accounts for the health benefits attributed to loving relations. Oxytocin release in men and women acts on the emotional centers of the brain, generally leading to comforting feelings of warmth and relaxation. Oxytocin also acts as a natural antistress neurotransmitter.

Sexual activity can result in improved sleep quality and may have a sedative effect. An interesting American study found that many women masturbate to help themselves fall asleep. This study also found that women masturbated for pain relief with menstrual cramps. Other researchers have found that vaginal self-stimulation can result in increased pain thresholds. The self-stimulation produced analgesia rather than anesthesia.

What Is the Palliative Care Phase?

The palliative care phase starts when active, potentially curative treatment ceases and the focus turns to enabling each individual to have maximum quality of remaining life. Individuals will fluctuate from day to day, and during the day, with what they want...
and are able to do. Studies show that many terminally ill patients continue to have sexual thoughts and feelings and would value freedom for some sexual expression.\(^5\),\(^28\),\(^29\)

The actual process of dying can take days, weeks, or months, and individuals will have good days and bad days, and days when they may have different needs and varying amounts of energy for meeting them. The imposed belief that the dying patient should be asexual limits the possibilities for the patient to make the best of the time left to them.

The palliative care phase is often difficult for non-palliative health professionals who may see giving up active fighting of the disease process as failure. Sadly, this giving of active treatment, often with many side effects, can take away what little energy there is at this time, so that quality time is not possible.

**Is Sexuality Important to a Dying Person?**

People behave sexually to meet many needs other than procreation: to get skin hunger needs met, that is, that important and soothing effect of being firmly held skin to skin, to relieve nonsexual tension, to affirm that one is still alive, to relieve boredom/insomnia, to have “time out,” to have fun and more. So a meta-communication vacuum and loss of a major source of relaxation and fun may occur when sexual activity stops.

For those individuals for whom sexuality has been and is important, “given the impact that sexuality has on quality of life, it is just as relevant and important to enquire about, as bowel action and sleep.”\(^30\)

On the other hand, for some patients, sexual intimacy is not a desirable or available form of closeness. This needs to be accepted and respected. Here, the definition of sexuality becomes important. Lemieux et al\(^5\) found that sexuality continues to be important at the end of life although it is often emotional connection to others that is more important than the physical expression. However, all his subjects felt that the subject of sexuality should have been brought up after their initial cancer treatment.

Research looking at whether individuals value sexuality and want opportunities to talk about it and seek assistance show overwhelmingly that individuals want this opportunity.\(^5\),\(^28\),\(^29\) The reality is that patients “suffer in silence”\(^31\) as they assume that, if sexuality and intimacy were important, health professionals would discuss them. Hordern and Street\(^32\) showed that

Many patients searched for practical strategies and emotional support about how to come to terms with their altered sense of sexual or intimate self, yet assumed if the topic was not raised by health professionals caring for them, these issues must not be important.

Or worse still, that there was something further wrong or odd with them, if they were experiencing this difficulty, that was not experienced by other people. Silence is not a good communicator or educator.

**Health Professionals**

Often health professionals grow up in the same/similar environments as their patients and many have not been taught to deal with sexuality or with patients’ sexuality at the “end of life.” There is a gap between the theory and the practice in including sexuality in the care of palliative care patients.\(^12\),\(^33\)

That is, health professionals agree that sexuality is important, but a discrepancy occurs when it comes to the practical application of this belief. This discrepancy occurs at 3 levels.\(^34\)

Individual practitioner: personal awareness, comfort, and willingness for talking about sexuality with patients.

Organizational level: for example, private rooms, sex-positive policies, for instance, partners staying overnight, locks on doors for privacy, decorations that encourage expression of sexuality, location of equipment, general environment.

Systems of care delivery: for example, inclusion of sexual health care from beginning, delegated positions responsible for sexual health.

Most institutions, if they do espouse sex-positive systems of care delivery, set a very broad definition of sexuality. The acceptance is usually of cuddling over sexual function, genital involvement, and orgasm.\(^33\)

The items in Table 1 often serve a protective function for health professionals. It needs to be very clearly understood by both parties that the discussion is only for the benefit of the patient/partner and
that the information is not for the health professional’s gratification and will not be used against the patient/partner.

The issue of “empathic grief or fear” in the health professional is often not addressed. It is important to acknowledge the avoidance and defense mechanisms activated when a patient “similar enough” to oneself is dying or has a sexual/relationship difficulty. And depending on the age and gender differential between the patient and the health professional, different personal reactions will be activated. Health professionals need to be trained to anticipate, and deal with, these feelings, and have opportunities for supervision and help.

Hordern and Street showed that the majority of professionals used denial, ignorance, or avoidance in dealing with the intimate or sexual aspects of a patient’s life. They also showed that there were mismatched expectations between patients and health professionals in communication about sexuality and intimacy. The result was often a reactive rather than a proactive stance, which contrasts negatively with other aspects of palliative care, where symptoms are actively sought, anticipated and where possible, prevented or dealt with in some way.

Despite a small increase in research looking specifically at sexuality needs in the palliative care period, the incorporation of real changes at all levels has been very slow.

### Table 1. Reasons Cited for Health Professionals Not Addressing the Sexual Concerns of Patients

<table>
<thead>
<tr>
<th>Reason</th>
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<tr>
<td>Boundary issues with fears of causing offense, seeming intrusive, being inappropriate</td>
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<td>Difficulty with the concept of including sexuality in holistic health care</td>
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<td>Personal discomfort with sexuality, discussing sexuality</td>
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<tr>
<td>Inadequate knowledge/skills in dealing with sexuality</td>
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<td>Anxiety in dealing with different groups, for example, different ethnic groups, sexual orientation, the elderly, or handicapped</td>
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<tr>
<td>Perception that dealing with sexuality is the responsibility of another health professional</td>
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<tr>
<td>Time/privacy constraints</td>
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<tr>
<td>Limited confidence with intimate communication</td>
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Sexuality needs to be considered during the palliative care phase of life and be brought up by sexuality-aware health professionals in an appropriate manner and at appropriate times.

Many couples have barely functional sex lives or no sexuality at all by the time they reach the palliative care phase due to lack of knowledge about what to expect at this time of life, lack of resources, poor communication skills, unresolved resentments and angers accumulated over many years, and the very significant stresses accrued during the disease history and treatment. Many patients have accepted the “no sex, we’re dying” paradigm by the time they reach the palliative care phase. However, many patients are sad and frustrated over the restrictions that are in place over their sexuality and these patients want and need health professionals to raise the issue of sexuality. Patients need to be treated as individuals and the sensitive health professional needs to be able to explore with each patient what that patient wants for himself or herself for their sexual expression at this stage of life. Differences need to be acknowledged and respected.

### Whose Job Is It to Bring Up the Issue of Sexuality in the Palliative Care Phase?

Gay and lesbian individuals may experience further grief during the palliative care phase. This added burden may be shared by other minority groups where others’ beliefs impose limitations and freedoms of sexuality expression.

With discrimination, there is pressure not to disclose and this may lead to the loss of intimate support for the patient. Patient and partner may experience disenfranchised grief, that is, isolated grieving of their real and profound losses that are not, or cannot be recognized/acknowledged. Because same sex behavior is still highly stigmatized and gay and lesbian individuals often defy stereotypes, they may remain hidden populations in their interaction with health professionals and institutions. The overt behavior between “friends” is different from that between “partners/lovers.” If touching and hugging cannot be open, if true sadness and grief cannot be displayed, then extra pain is suffered.

### Gay and Lesbian Experiences

Gay and lesbian experiences

Sexuality in the Palliative Care Phase / Redelman

### Conclusion

The sexuality of a terminally ill patient is largely determined by their sexuality before diagnosis, beliefs about how they are allowed to be during this
period of their life, sexual knowledge, and a cooperative and understanding partner. Sometimes, the continued sexual feelings can be a source of surprise or embarrassment to the patient, partner, or health professionals because many believe that this is not the appropriate time for such feelings and behaviors.¹⁰

Some dying patients want sexual activity as a clinging to “life” or closeness to another. Others avoid sexual activity out of fears such as dying during sexual activity, depleting their energy to fight for life, contaminating the partner, physical repulsion, fear of being judged by others, and other beliefs.

The partner of the dying person often shares the same beliefs and so avoids sexual contact because he or she believes that it is dangerous to touch a dying person, does not want to feel responsible for causing their partner’s death, does not want to tire the partner, and so on. Lack of communication skills often prevents couples from being able to explore these issues and fears. Without dialogue no resolution or compromise can be found.

All individuals and couples go through anticipatory grief and fluctuating degrees of disengagement during their journey. This is unlikely to be synchronous so there may be disparate needs between the partners for sexual union and sexual disengagement. People need help to understand and deal with this normal process.

Sexual needs are not static for the patient, or the partner, over this journey. It is only availability for ongoing discussions and the anticipation of sexuality changes that “normalizes” them. This understanding and knowledge decreases the stress for the individual and the partner especially if there is the understanding that there are options available. Health professionals must be adequately trained to assess problems in sexuality and to provide guidance related to maintenance of sexuality⁴¹ for those individuals who desire it. Sexuality, within the patient’s ability to function and desire for it, must be acknowledged and included in holistic patient management at this time.

References