

Sexuality and Life-Threatening Illness: Implications for Social Work and Palliative Care

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Social workers in hospice and palliative care settings have been charged with the responsibility of addressing sexuality with their patients and families. However, little direction has been offered as to how to approach this difficult subject within the context of palliative care. This article provides a critical analysis of the previous literature on sexuality and terminal illness. The authors address systemic barriers, such as institutional policies that marginalize already vulnerable groups. Several recommendations are provided for social workers, including skills, core dimensions for assessment and intervention, and implications for interdisciplinary teamwork.

KEY WORDS: *dying; end of life; intimacy; relationships; sex*

We must grapple with the fact of our own mortality and the realization that intimacy occurs in the face of eventual loss.

—John S. Rolland, 1994

In 2001, the National Hospice and Palliative Care Organization (NHPCO) identified the assessment of sexuality as a core competency for social workers in end-of-life care settings (Hay & Johnson, 2001). Other prominent organizations and social work leaders have agreed, recognizing sexuality as a fundamental dimension of a comprehensive assessment when working with people who are critically ill (Gwyther et al., 2005; Lynch, as cited in Moore, 1984; National Association of Social Workers [NASW], 2003; National Consensus Project for Quality Palliative Care [NCPQPC], 2004). Although sexuality has been identified as an important part of a thorough psychosocial history, little guidance has been offered about how practitioners can address the subject. In response to this lack of direction, this article summarizes the available literature on sexuality during terminal illness; explores the role of social work in assessments of, and interventions regarding, sexually related issues at the end of life; describes clinical skills needed to address barriers to sexuality in palliative care settings; and identifies four instrumental dimensions of a comprehensive sexual assessment. Implications for interdisciplinary teamwork are also discussed.

Of course, when it comes to addressing issues of intimacy and sexuality at the end of life, social

workers do not hold a monopoly. Practitioners in a variety of other health disciplines—such as nursing, medicine, and psychology—may have the clinical skills to adequately attend to these types of concerns. However, with their extensive training in relationship dynamics and communication patterns, social workers may be uniquely prepared to handle the complex issues of sex, intimacy, and romantic interactions during a terminal illness (Cort, Monroe, & Oliviere, 2004). Although this article focuses primarily on the social work discipline, readers should not infer that social work is the *only* discipline that should be involved when sexuality-related concerns arise. In fact, we believe these issues are best addressed using a collaborative, interdisciplinary approach.

A fair amount of literature exists on the topic of sexuality in palliative care, but the vast majority of the scholarship has been written by, and addressed to, nurses and physicians. This article intends to contribute to the knowledge base in two key ways: (1) focusing on the social worker's role in addressing sexuality within the context of an interdisciplinary approach to palliative care and (2) identifying practice-based strategies for social work assessment and intervention. The ultimate goal is to provide practitioners with some direction as to how to approach this subject with patients and families—to further bridge the gap between research and practice.

BACKGROUND

Sex and death are two sensitive and value-laden subjects in contemporary society. Lemieux, Kaiser,

Pereira, and Meadows (2004), Stausmire (2004), and Hordern and Currow (2003) all noted that sexuality at the end of life has been a neglected topic in social science research. Many authors have suggested that this is the result of a vast societal discomfort with issues of mortality and sexuality (Hordern & Currow, 2003; Hordern & Street, 2007a, 2007b, 2007c; Redelman, 2008) or, as Jaffe (1977) called it, a "double-barreled taboo." In the 1960s, 1970s, and 1980s, Masters and Johnson (1966, 1970) and Kaplan (1979, 1995) pioneered research in the field of human sexuality. Although their studies paved the way for academic discussions on the topic of sex, the intersection of sex and death was still effectively "off limits" (Grigg, 1995). Grigg argued that diagnoses such as AIDS, breast cancer, and prostate cancer forced the issue of sexuality at life's end into the research spotlight in the mid- to late 1980s. Since then, researchers have found that loving relationships, intimacy, and sexual contact remain significant concerns during terminal illness (Gianotten, 2007; Hordern, 2008; Lemieux et al., 2004; Panke & Ferrell, 2004; Singer, Martin, & Kelner, 1999; Zeiss & Kahl-Godley, 2001). Moreover, sexuality has been identified as an important component of holistic care, psychosocial functioning, and overall quality of life (Hordern, 2008; Hordern & Currow, 2003; Lemieux et al., 2004; Redelman, 2008; Stausmire, 2004; Wilmoth, 2007; Woodhouse & Baldwin, 2008). Thus, the convergence of sexuality and terminal illness is a very relevant concern for those interested in advancing the welfare of dying individuals.

It is not surprising that researchers also discovered that physical relationships frequently become strained after someone receives a life-limiting prognosis (Hordern & Currow, 2003). This often occurs in tandem with the physically prohibitive effects of serious illness. Disease processes can drastically alter one's appearance, cause physical and emotional pain, and affect both libido and functionality (Bruner & Calvano, 2007; Johnson, 2004; Rice, 2000a; Shell, Carolan, Zhang, & Meneses, 2008). Unfortunately, these hindrances to sexuality come at a time when many patients want to strengthen relationships with the ones they love (Singer et al., 1999). Consequently, patients have indicated that they want health professionals to bring up issues of sexuality and intimacy (Hordern & Currow, 2003; Lemieux et al., 2004), and Sharp, Blum, and Aviv (1993) have suggested that social workers are in a "frontline" position to do this.

Because of these findings, numerous researchers and organizations have charged social workers in hospice and palliative care settings with the responsibility of assessing the sexual concerns of patients and their partners. Although recognized as a primary dimension of a comprehensive social work evaluation, sexuality is an uncomfortable subject for many practitioners (Caruso-Herman, 1989; Hordern & Street, 2007a, 2007b, 2007c; Jaffe, 1977; Roberts, 1992; Wasow, 1977) and is often avoided (Hordern & Currow, 2003; Panke & Ferrell, 2004). Previous research suggests that, within palliative care settings, patients are rarely given an opportunity to share sexuality-related issues with their health care providers (Hordern & Street, 2007a, 2007b, 2007c; Lemieux et al., 2004). Furthermore, Kutner, Kassner, and Nowels (2001) found that patients reported that the majority of the hospice care providers (63 percent), including social workers, lacked the information they needed to assess issues concerning sexuality.

The dilemma for the social work profession is that sexuality is an important facet of a psychosocial assessment, yet it appears that practitioners may not be adequately addressing the issue. Social workers might sidestep the topic of sexuality for a multitude of reasons (Gochros, 1986; Hordern & Street, 2007a, 2007c; Redelman, 2008). Practitioners may be unsure of what exactly is meant by "sexuality." Does it simply mean sexual orientation? Does it involve sexual health? Is sexuality relevant only in the context of couplehood, or is sexuality important to single individuals as well? According to Gochros (1986), "various devices and rationalizations are used [by social workers] to avoid dealing with the sexual concerns of those with whom they work" (p. 8). Perhaps social workers view sexuality as less important at the end of life, feel undereducated, lack the time needed to adequately address the subject, project their own fears of discussing sexual issues onto their patients, or assume that patients and families themselves will bring up the issue (Hordern, 2008; Hordern & Street, 2007a, 2007c; Redelman, 2008).

CLINICAL SKILLS

When addressing sexuality, social workers should be able to incorporate fundamental clinical skills such as rapport building, normalization, and validation (for example, framing worries about sexual issues as normal, legitimate health concerns). However,

according to the literature, palliative care social workers need a variety of advanced clinical skills and particular types of knowledge to effectively address sexually related concerns: knowledge of the possible meanings and dimensions of sexuality; awareness of cultural, ethnic, and religious diversity and how they relate to sexuality; demonstrated knowledge and skills in communicating with patients and families about sexual issues; and working understanding of areas for assessment and intervention to address concerns about sexuality at the end of life.

Defining Sexuality

If social workers are expected to assess and intervene when individuals have sexually related concerns, they should be aware of the possible range of meanings that "sexuality" can hold. Much of the literature on the subject acknowledges the complexity involved in explaining what sexuality is. A qualitative study by Lemieux et al. (2004) explored what sexuality meant to a sample of palliative care patients. They found that respondents tended to define sexuality as a type of "emotional closeness" and that, although physical expressions remained important, displays frequently evolved into activities other than sexual intercourse. According to the participants, intimacy was a part of this noncoital expression of sexuality. Research by Arrington (2000) and Cort (1998) suggests that patients and health care providers may prefer a broader, more subjective definition of sexuality. In other words, sexuality is whatever it means to the patient.

The prevalence of this subjective approach to sexuality is certainly patientcentric; however, the lack of a clear definition is problematic for practitioners who are expected to assess an individual or couple's sexuality. The challenge is to conduct evaluations of sexuality in a patient-centered way while giving social workers a concrete strategy to do so. In response, social workers can facilitate patient- or partner-led explorations of what sexuality means and what effects the illness has had on their lives. Individual perceptions of sexuality may be defined and redefined over the course of the patient's disease. In this way, personal understandings and expressions of sexuality can be viewed as an essential aspect of adaptation to illness and heightened awareness of death.

In addition, social workers may benefit from recognizing diverse, wide-ranging definitions of sexuality that can include extramarital expressions,

celibacy and abstinence, homosexuality, autoerotic practices, transgender sexuality, and nonprocreative displays of affection. By focusing on such diverse manifestations of sexual expression, social workers can acknowledge their own beliefs, biases, and prejudices. It is also critical that social workers avoid making assumptions about partner status or gender preference (Cort et al., 2004). Using relationship-neutral language (for example, "partner" instead of "husband") to inquire about relationships allows patients to feel safe discussing the unique circumstances of their sexual relationships. As Bevan and Thompson (2003) put it, "recognizing that sexuality, however expressed, is an important part of living and dying, whether the person is young, old, gay or disabled, is an important principle of both social work practice and the palliative care approach" (p. 188).

Cultural, Ethnic, and Religious Diversity

Palliative care social workers should be knowledgeable about how sexuality is viewed differently by a variety of cultural, ethnic, and religious groups (Cort et al., 2004). Such knowledge may include strategies for identifying and working within a patient or family's value system and a thorough exploration of the practitioner's own cultural biases about the subject. Social workers, however, should not reduce cultural, ethnic, and religious variations to a simple checklist of factors (Koenig, 1997). In other words, they should avoid the assumption that they know how a particular individual will view sexual issues solely on the basis of that individual's membership in a particular cultural, ethnic, or religious group. Instead, practitioners should use open-ended assessment questions to better understand the patient or partner's unique sociocultural framework, which may indeed hold that sexual issues are not a topic for conversation. Because patients frequently look to health care professionals to bring up the topic of sexuality (Hordern & Currow, 2003), it may be appropriate for providers to initiate the dialogue. Patients should be given an opportunity to air their concerns about sexuality in a way that legitimizes their experiences but does not pressure them to discuss uncomfortable issues (Hordern & Currow, 2003; Hughes, 2000; Woodhouse & Baldwin, 2008).

Communication

Patients and family members are often left to cope with their sexual concerns in silence (Katz, 2005).

Thus, being able to communicate openly with patients and families about sexuality is an essential skill for hospice and palliative care social workers. Nevertheless, discussions of sexually related issues are often "fraught with tension, shame, guilt, and embarrassment" (Wasow, 1982, p. 35). If individuals sense a practitioner's discomfort or unwillingness to entertain such topics, they may avoid airing sexuality-related concerns themselves (Carr, 2007). As Wasow (1982) argued, "perhaps the most important thing to get across is the knowledge that [social workers] are willing to and able to talk about sexuality" (p. 35).

One barrier to communicating about sexual concerns is the assumption that patients or family members will bring up issues of sexuality if these issues are important (Carr, 2007). However, Gochros (1986) contended that social workers and other health providers are responsible for broaching the subject of sexuality—not their clients. Furthermore, he argued that practitioners advertise their uneasiness with subtle clues like breaking eye contact, changing the subject, and using closed-ended questions and euphemisms. These gestures, intonations, and idiosyncratic cues clearly communicate a clinician's discomfort with the subject of sexuality. To help normalize the topic, a clinician might use several nonverbal techniques such as making direct eye contact and presenting an open and relaxed body posture while inquiring about sexual health concerns. However, because nonverbal communication is interpreted through an individual's cultural context, social workers should be mindful that their body language will take on different meanings for different people.

Also, social workers can learn to use "invisible language" rather than medical jargon or slang (Carr, 2007; Gochros, 1986; Hordern & Currow, 2003). By avoiding confusing acronyms and obscure medical terminology, clinicians can clearly articulate their points without disrupting the flow of a conversation. Phrases such as "coitus," "refractory period," and "mons pubis" may be easily understood by health professionals, but they are less so in the larger community. Invisible (that is, unobtrusive) language can be seen in statements like the following: "Touch is a very important part of maintaining intimacy; some partners are concerned about touching or initiating sexual touch out of fear of causing pain. Sometimes gentle massage is a wonderful way to stay connected physically." Tactfully incorporating sexuality into

the initial and follow-up psychosocial assessments can convey that sexuality is an important aspect of the patient's and partner's quality of life rather than a taboo subject.

ASSESSMENT AND INTERVENTION

According to Beckham and Godding (1990), adequate assessment of and interventions regarding sexual concerns can prevent chronic problems and eliminate unresolved concerns. Barriers to sexuality can deeply affect an individual biologically, psychologically, socially, and even spiritually. If social workers and other health care professionals are aware of barriers that obstruct sexuality, they should be able to enhance the quality of life of their dying patients by minimizing the complicating elements. Ideally, a good assessment can also identify well-intended medical interventions that may inadvertently impede patient-partner intimacy (for example, placing a patient in a single-occupancy hospital bed; pharmaceutical side effects, such as reduced libido or anorgasmia). On the individual level, social workers can address patient sexuality through education, support (including groups), and counseling.

Strategies for Assessment

Although there is no "magic formula" for assessing sexuality (Wasow, 1982), a variety of strategies have been advanced. In general, all of the strategies we have encountered endorse a progressive, open-ended approach (Cort et al., 2004; Hordern & Currow, 2003; Panke & Ferrell, 2004; Stausmire, 2004). For example, when working with a couple coping with terminal illness, Panke and Ferrell (2004) have suggested asking general questions exploring how the disease processes have affected the relationship, which may then open the door for a more targeted discussion of intimacy and sexuality (see Table 1 for recommendations regarding assessment). Hordern (2008) also noted that it is imperative that models of assessment accommodate for the negotiated nature of communication by providing a patient-centered approach with adequate time for reflection. A number of competing models of assessment are available for social workers to consider when evaluating the sexuality-related needs of patients and partners. The BETTER model (Mick & Cohen, 2003; Mick, Hughes, & Cohen, 2004); the ALARM model (Andersen, 1990); the PLISSIT model (Annon, 1976); and PLISSIT's more recent iteration, the Ex-PLISSIT model (B. Taylor & Davis, 2006), have

Table 1: Considerations when Addressing Sexuality in Palliative Care

1. Sexuality and intimacy should be a routine part of the palliative care assessment.
2. Work within the family's value system (that is, start where your clients are).
3. Convey warmth, empathy, relevance, and genuineness.
4. Indicate a casual attitude and a willingness to talk about sex.
5. Address the myths and misconceptions (for example, fears that cancer is contagious).
6. Be nonjudgmental; explore personal biases and values.
7. Pay attention to the environment; make sure it is a conducive to discussion.
8. Health professionals should initiate the topic.
9. Use open-ended questions and invitations to talk.
10. Use clear, nontechnical language, and avoid medical jargon.
11. Provide education.
12. Empower patients and families to bring up the subject.
13. Listen and use attending behavior.
14. Let patients and family members know that they are not alone.

Note: Compiled from Grochros (1986) (2-4, 6-13); Hordern and Currow (2003) (1, 2, 5, 6, 8-11); Sharp, Blum, and Aviv (2003) (3, 6, 9, 14); and Wasow (1982) (1-4, 6, 8, 9, 11).

all been proposed to assist health professionals when addressing sexuality in medical settings.

BETTER (Mick & Cohen, 2003; Mick et al., 2004) stands for bringing up the topic of sexuality; explaining to the patient or partner that sexuality is a part of quality of life; telling the patient about resources available to him or her and the team's ability and willingness to assist in addressing concerns and questions; timing the discussion to when the patient would prefer, not only when it is convenient for the practitioner; and recording in the chart that the conversation took place and any follow-up planned to further address patient's concerns or questions. This model may be an especially useful tool to guide practitioner documentation. However, this approach may not adequately emphasize the need for psychotherapeutic interventions or referrals to specialists.

The ALARM model (Andersen, 1990), which appears to incorporate and expand on Kaplan's (1979, 1995) triphasic model of sexual response, is another model of assessment and communication about sex and the sexual activities of patients. ALARM inquires about each stage of sexual intercourse along with the patient's medical history; it stands for activity, libido (desire), arousal, resolution, and medical information. The practitioner begins by assessing

the patient's sexual activity level prior to the point at which the identified problem or medical illness began, following up with an evaluation of changes in libido that may be causing, exacerbating, or prolonging the sexual problem that the patient is experiencing. Because this approach focuses primarily on the physical and behavioral aspects of sexuality, it may overlook key domains, such as intimacy, closeness, and self-image (Hordern, 2008).

Annon's (1976) widely referenced PLISSIT model (which stands for four levels of treatment: permission, limited information, specific suggestions, and intensive therapy) also provides an incremental approach. This model has been recommended as a useful template for the assessment of sexuality and sexual health in palliative care settings (Cort et al., 2004; Stausmire, 2004); and Claiborne and Rizzo (2006) have argued that PLISSIT is particularly well suited for social workers. The model provides a general framework on how to initiate a dialogue about sexual issues and how to further the discussion if warranted. This approach is versatile and can be applied to a range of situations, illnesses, and settings—both inpatient and outpatient. In this model, the latter levels of treatment build on the previous ones. However, the social worker (or other palliative care provider) can move back and forth between the levels of treatment on the basis of the patient's need. The PLISSIT levels progress as follows:

Level 1—Permission. This involves communicating a willingness to discuss sexually related topics and is often followed by an open-ended invitation to further the conversation (for example, "Those in similar situations have expressed concerns about intimacy and sex. What concerns are you having?"). By doing this, social workers are offering patients and partners permission to both have and discuss sexual concerns. Giving permission not only provides patients and partners with an opportunity to voice their sexual concerns, but also validates and normalizes their desire to engage in, or refrain from, sexual activity (Annon, 1976).

Level 2—Limited Information. This level involves providing brief education to patients and partners regarding common sexual side effects associated with an illness and its treatment, including its etiology, pathology, and complications. This information may be given in a short period of time or over several brief meetings to provide accurate and relevant information about patient and partner concerns.

Level 3—Specific Suggestions. At the third level, patients are given concrete suggestions on how to cope with the effects of the illness. If the patient is partnered, it may be best to see the couple together to understand the causes and dynamics of the problem and establish specific possible solutions (Monturo, Rogers, Coleman, Robinson, & Pickett, 2001). Health care providers may also benefit from exploring how the patient expressed and explored his or her sexuality prior to the diagnosis and how sexual pleasure was achieved. Some patients or their partners might express feelings of anger, guilt, grief, or resentment resulting from the inability to achieve sexual pleasure (Claiborne & Rizzo, 2006). This is especially pertinent during advanced disease and at end of life, as patients' losses and recognitions of changes in their sexual selves may be heightened by the alienation and physical deterioration they experience.

Level 4—Intensive Therapy. This final level addresses ongoing concerns and may involve a referral to a sex therapist or relationship counselor. A small minority of cases may require this type of intervention. For example, it is estimated that only 30 percent of the cancer population will need this last level of the PLISSIT model, for the majority of sexual function problems are resolved with providing permission, limited information, and specific suggestions (Derogatis & Kourlesis, 1981).

More recently, B. Taylor and Davis (2006) modified Annon's (1976) work by developing the extended PLISSIT model (or Ex-PLISSIT). The Ex-PLISSIT model suggests that the permission level should involve requesting permission to discuss sexual issues as well as permission to be a sexual being, and this should be integrated into each step of the model (B. Taylor & Davis, 2006). Therefore, when assessing a patient, a health care provider would offer permission in conjunction with limited information, specific suggestions, and a referral to intensive therapy. Another helpful application of the Ex-PLISSIT model is its incorporation of reflection and review by the health care practitioner after every interaction with the patient. This step holds the practitioner accountable for her or his interactions, biases, and reactions to the patient. It also encourages the patient to provide continual feedback and review. Incorporating these two additional steps of permission giving into each level of the PLISSIT model and designating opportunities for reflection and review allow for practitioner

accountability during a patient-directed assessment of sexual health needs.

Dimensions for Assessment and Intervention

Whether using one of the assessment models described earlier or another approach, once a dialogue has been initiated, social workers can explore four core psychosocial dimensions of sexuality for assessment and intervention: (1) body image and self-concept, (2) changes in sexual functioning and desire, (3) social and relational concerns, and (4) systemic barriers.

Body Image and Self-Concept. Grooming and appearance are integral aspects of sexuality (Caruso-Herman, 1989; Rice, 2000a; P. B. Taylor, 1983). Attention to an individual's body image can, in turn, affect the individual's self-esteem. Unfortunately, advanced disease often affects a person's appearance and, in turn, his or her sexual self. The presence of bandages, suction machines, catheters, ostomies, oxygen canulas, and nebulizers may affect a patient's perceived attractiveness. Moreover, bodily changes such as unpleasant odors, hair loss, swelling, changes in weight, bedsores, tremors, possible contagions, and incontinence can also negatively affect the desire for physical intimacy (Kovacs, 2003). Certain cancers, for example, can lead to excruciating pain, disfigurement, and malodorous lesions. These disease-related problems, which can deter sexual intimacy, may be magnified with head and neck malignancies as they are more difficult to conceal. Similarly, the lingering effects of surgical interventions can affect perceptions of body image and self-worth. Scar tissue and removed body parts (particularly the breasts, testis, ovaries, cervix, uterus, or prostate) are often unwanted reminders of the illness and can directly affect sexuality. According to Rabow, Hauser, and Adams (2004), these types of physical changes often lead to embarrassment, loss of privacy, and even resentment.

To address these concerns, social workers can explore the availability of aroma therapy to minimize odors (for example, eucalyptus or peppermint oils); alternate sexual positions to facilitate comfort; and increased access to services that enhance appearance, such as salon care, makeup, wigs, ostomy pouches, or prosthetics. A woman who feels less desirable after a mastectomy, for example, may benefit by having a social worker normalize her feelings: "After a mastectomy, it is not unusual for women to report

higher levels of dissatisfaction with their body image" (Fobair et al., 2006; Schover et al., 1995), followed up with a concrete suggestion such as "perhaps wearing a bra or camisole with a prosthetic during sexual intimacy would improve how you feel about yourself." The social worker could then explore alternative ways to address lingering concerns about body image, perhaps working to highlight other physical attributes. The social worker could also challenge socially constructed assumptions that link breasts to perceptions of self-worth and sexual desirability. This could include the identification of resources that positively focus on living without reconstruction, such as a reference to www.breastfree.org.

Changes in Sexual Functioning and Desire.

Dying individuals and their loved ones are often mistakenly viewed as asexual (Redelman, 2008). However, quantitative and qualitative evidence suggests otherwise—that dying individuals are sexual beings with a host of related concerns, fears, hopes, and aspirations (Gideon & Taylor, 1981; Hordern & Street, 2007a, 2007b; Jaffe, 1977; Lemieux et al., 2004; Rice, 2000b). Patients who internalize the assumption that their sexual concerns are irrelevant may end up experiencing a self-fulfilling prophecy of decreased sexual activity and interest (Rice, 2000b). Self-imposed abstinence, reduced displays of affection, and emotional disengagement may result. Similarly, lack of sexual ability and desire are often assumed but are not always realities.

Social workers can help to identify and minimize the impact of barriers to patient and partner sexuality at life's end. These can include medical and environmental hindrances to sexuality and intimacy, such as the potential side effects of pharmaceutical interventions or complications due to progression of the disease (Bruner & Calvano, 2007; Johnson, 2004; Rice, 2000a; Shell et al., 2008). Ducharme (as cited in Kovacs, 2003) wrote that "medical conditions such as arthritis, pain, and medications that restrict sexual positions, limit movement, and ultimately reduce sexual pleasure are primary factors in reducing sexual desire" (pp. 455–456). Other common disease-related factors can hinder sexual intimacy postdiagnosis, including anxiety, depression, substance abuse, and cultural ideals (Kovacs, 2003). Depending on the sexual needs of the patient or partner, the social worker might explore alternative methods of sexual expression, refer for pharmaceutical intervention, or help to align expectations within the reality of the disease

(Arrington, 2000). According to Mayers and Heller (2003), social work practitioners may intervene by offering romantic novels, erotic movies, or even means of self-stimulation.

Social and Relational Concerns. Acknowledging the importance of human relationships is a core social work value (NASW, 2000). Intimate relationships and continued social interaction are especially salient at the end of life, because, historically, dying people have been relegated to spending their final days behind closed doors and drawn curtains. Receiving a terminal diagnosis is frequently followed by marked social withdrawal, or, as Sudnow (1967) termed it, a "social death." Although a person remains alive, others treat him or her as a corpse. Especially after the advent of hospital-based medicine, those with life-limiting prognoses were often institutionalized and hidden from public view (Jaffe, 1977; Luptak, 2004). Unfortunately, institutional care environments are not conducive to intimate interactions. Private rooms are a rarity in hospitals and nursing homes and are usually offered only to those who can afford to pay for the additional care and individualized attention. Jaffe (1977) argued that "the hospital environment is pivotal in perpetuating the sexual problems of the terminally ill" (p. 281). This is especially disconcerting in that nearly 80 percent of today's deaths occur in an institutional setting, even though the majority of people indicate that they would rather die in the comfort of their own home (SUPPORT Investigators, 1995; Tang, 2003).

According to Jaffe (1977), when patients are seen as dying rather than living, sexuality becomes threatened. Thus, this perception of dying affects an individual's lived experience. A terminal diagnosis jeopardizes a person's core identity (of which sexuality is a part) and his or her basic beliefs about the world. In response to this, practitioners can learn to frame dying as "living yet to do" and recognize the opportunity for growth and meaning making in the late stages of disease (Bern-Klug, Gessert, & Forbes, 2001). In other words, the person should be the focus—not the disease.

When working with couples, social workers may use advanced clinical skills to create new ways of expressing their sexuality (Rolland, 1994) or to mediate concerns about asymmetrical pleasure giving (Barnard, 1990). When couples can externalize the illness, accept new roles, and adapt to the reality of the illness, they can begin to forge new avenues for sexual expression (Rolland, 1994). Rolland also sug-

gested that it is important to find alternate means of sexual reciprocity. It is important to note that the absence of sexual intercourse does not necessarily preclude physical and emotional closeness (Palm & Friedrichsen, 2008). Thus, social workers and other members of the palliative care team should respect the couple's need for privacy and intimacy.

Systemic Barriers. Institutional policies and government regulations can impede sexual expression and further marginalize already vulnerable groups. These types of systemic barriers are prime targets for social work intervention and advocacy. In fact, Gideon and Taylor (1981) felt that the sexual rights of critically ill individuals had been marginalized to the point that they drafted a "Sexual Bill of Rights for Dying Persons," with the express purpose of ensuring those rights. Similarly, Bevan and Thompson (2003) identify two concerns regarding the unequal treatment of sexuality with dying individuals, recommending that social workers work to uncover how critically ill patients are prohibited from freely expressing their sexuality and the oppressive hegemony of what is considered "normal" or "acceptable" sexual expression.

Social workers can advocate for macro-level changes to institutional rules and practices that might impede the expression of a patient's sexuality or intimacy in nursing homes, hospitals, or other adult care facilities. Potential changes could include more attention to privacy (for example, instituting a policy requiring staff to wait for permission before entering the room, providing every patient room with a "privacy please" sign), the availability of larger hospital beds that can accommodate two people (Panke & Ferrell, 2004), and provision of routine in-services on patient rights and intimacy needs. These interventions may also include education of the public (including lawmakers) about these issues that affect the lives of patients on a day-to-day basis. Social workers should be prepared to face resistance, because ensuring the sexual rights of dying patients may involve the breaking of old and irrelevant taboos (Gideon & Taylor, 1981).

Related to sexuality at the end of life, advocacy on behalf of lesbian, gay, transgender, and bisexual individuals is paramount (Barnard, 1990; Rolland, 1994; Thompson & Colon, 2004; Zeiss & Kasl-Godley, 2001), especially as it regards access to health benefits, decision making, estate planning, and care. The NASW (2000) *Code of Ethics* calls for social workers to advocate on behalf of vulnerable

populations. Current federal (and many state) policies do not guarantee family medical leave benefits, visitation rights, custody rights, and survivor benefits to those in same-sex partnerships or other "nontraditional" relationships. Although controversial, this is clearly an area where social workers can address social and economic inequities in existing laws and statutes (Thompson & Colon, 2004). Advocating for the rights of vulnerable populations at end of life can directly affect the dignity of dying people and their loved ones while honoring the importance of relationships and self-determination.

SEXUALITY, SOCIAL WORK, AND INTERDISCIPLINARY TEAMWORK

Hospice and palliative care providers endeavor to treat the whole patient, not just the disease. To accomplish this, care is provided by an interdisciplinary team that often consists of physicians, nurses, social workers, chaplains, psychologists, and other health care professionals involved in the patient's care. Coordination among team members is important "to ensure that sexuality is assessed and services are routinely offered by a member of the team and that additional services by a sexual counselor are available as needed" (Panke & Ferrell, 2004, p. 990). To avoid a diffusion of responsibility and ensure that these issues are addressed, palliative care teams may choose to designate one team member to address issues of sexuality and intimacy and to advocate on behalf of patients and their partners. Social workers may be especially well-suited for this role as they often evaluate relationship dynamics and communication patterns as a routine part of their psychosocial assessments (Cort et al., 2004) and advocacy is a central part of their practice (NASW, 2000). However, one of the strengths of interdisciplinary teamwork is that patients benefit from the various perspectives and expertise offered by each profession. Even if one team member is identified as a "sexuality advocate," sexual concerns may be best addressed through interdisciplinary collaboration (McKee & Schover, 2001). Depending on the nature of the problem, palliative care teams should continue to confer and deliberate to address the sexual health concerns of their patients.

Although little scholarship has explored how the Health Insurance Portability and Accountability Act of 1996 (HIPAA) (P.L. 104-191) governs communication within interdisciplinary teams, each team member should be mindful of the sensitive

nature of sexually related information. Provisions under HIPAA's privacy rule allow for the disclosure of some protected health information, as long as the goal is to facilitate the patient's care (U.S. Department of Health and Human Services, 2006). However, as with other sensitive health information, when sexuality is being addressed, clinicians should err on the side of protecting the patient's privacy and confidentiality. When dealing with potentially stigmatizing information, such as HIV status or same-sex relationships, a patient may prefer to withhold information—even from her or his own family. Thus, when charting palliative care, professionals should write discrete, parsimonious notes, providing only necessary information. Similarly, when addressing sexual issues in team conferences, participants should discuss only the pertinent details of a case.

CONCLUSION

The literature consistently suggests that a tactful and comprehensive assessment of sexuality is an important component of quality end-of-life care (Cort et al., 2004; Gwyther et al., 2005; Hordern & Currow, 2003; NCPQPC, 2004; Panke & Ferrell, 2004). Social workers can explore how a particular illness has affected patient or partner sexuality and offer a supportive environment in which to formulate and discuss client-led interventions. The primary goal of addressing sexuality is to help patients regain whatever degree of interpersonal intimacy and sexual satisfaction they desire (vonEschenbach & Schover, 1984). Mackelprang (1993) argued that social workers who are adequately prepared can have a substantial and positive effect on the psychosexual adjustment of clients coping with serious illness and disability; however, "it is up to the profession and up to the individual social workers to meet this important need" (pp. 86–87). Disregard of the importance of sexuality in hospice and palliative care settings may contribute to a culture of silence that has real-world consequences.

NASW's (2003) current *Standards for Social Work Practices in Palliative and End of Life Care* do not mention sexuality, sex, or intimacy; and although the NHPCO social work competencies identify sexuality as a core component of assessment, there are no discussions, explanations, or examples of how to do this (Hay & Johnson, 2001). These publications should be updated to acknowledge sexuality as a core aspect of end-of-life care and to better articulate the

role of social work. Because sexuality is an important and integral part of the human experience and an essential dimension of holistic palliative care, it should be addressed accordingly. When individuals are given a life-limiting diagnosis, priorities begin to shift. Many times, meaningful and loving relationships take precedence over other, more habitual and mundane concerns of living. If this "personal side of dying" is to be reclaimed, as Bern-Klug et al. (2001) have suggested, social workers should treat the subject of sexuality as a legitimate and relevant dimension of palliative care. **SW**

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