

THE ROLE OF SOCIAL WORKERS IN THE END-OF-LIFE DEBATE

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Although many articles and books discuss the ethics of end-of-life issues, few publications are written specifically for social workers and social work students. The lack of relevant literature is problematic because social workers have different ethical obligations than other health care professions who work with clients who are contemplating assisted suicide. This paper will analyze the ethical dilemma that social workers face in end-of-life issues by reviewing the material available to social workers such as the NASW Code of Ethics and the relevant NASW Policy Statement. This paper finds that the different sources of information provided by NASW do not fully address the complexities surrounding the social work profession and end-of-life issues. Additional training and continuing education courses should be offered and a stronger policy statement is needed that explores the complexities faced by social workers in end-of-life care.

Advances in medical capabilities and technology have recently made it possible to extend life through artificial means (NASW, 2002). The National Association of Social Workers (NASW) acknowledges that, “unwanted utilization of medical technology may lead to a lessened quality of life, loss of dignity, and a loss of integrity for patients” (NASW, 2002, p.60). Social workers are being called upon to deal with quality of life issues as well as choices related to assisted suicide. Because of its recent and sudden growth mixed with the unavailability of clear guidelines, end-of-life care is an area of practice that many social workers are unprepared and unable to deal with effectively (Csikai & Raymer, 2003). To determine the appropriate course of action for end-of-life care, social workers must examine the pertinent resources, including NASW policy statements, available state guidelines, and the NASW Code of Ethics. Reviewing the available material for social workers reveals that current policy and resources for social workers are inadequate and the issue needs to be addressed further.

NASW Policy Statement

The NASW frequently publishes policy statements to help guide social workers in ethical dilemmas not specifically covered in the Code of Ethics. The NASW policy statement, “Client Self-Determination in End-of-Life Decisions,” states that client self-determination is “the right of the client to determine the appropriate level, if any, of a medical intervention and the right of clients to change their wishes about their treatment as their condition changes over time or during the course of their illness” (2003, p. 59). The appropriate role of social workers in end-of-life care is to help patients express their thoughts and feelings, to facilitate exploration of alternatives, and to deal with grief and loss. This policy statement justifies social workers’ facilitation of a client’s end-of-life decision making process, although it allows a caveat for those social workers who wish not to participate when it states that “social workers are permitted to participate in assisted suicide depending on their personal beliefs, attitudes, and value systems” (NASW, 2003, p. 61).

The Oregon Death with Dignity Act

Because Oregon is the only state where physician-assisted suicide has been legalized, the Death with Dignity Act is a model through which the role of social workers in the end-of-life debate can be explored. Whereas a doctor is committed to the beneficence of the patient, social workers in Oregon are committed to fostering the client’s self-determination by providing information about assisted suicide, answering questions, and forming a trusting relationship, thus empowering the client to make autonomous decisions about how to live out his or her final days (Ganzini, et al., 2004). The values and mission of social work distinguish social workers from other professions; therefore, social workers must handle assisted suicide differently than members of other professions.

The Death with Dignity Act legalizes physician-assisted suicide (Ganzini, et al., 2004) for terminally ill Oregon residents who are 18 years or older with a life expectancy of six months or less, as diagnosed by a primary physician and a consulting physician. The Death with Dignity Act enacts procedural safeguards to determine eligibility for a lethal prescription. In order to be considered for this lethal dose, a patient must have a terminal illness with only six months to live, make a written request for a prescription, and two oral requests, which must be separated by at least 15 days (Werth & Wineberg, 2005).

The prescribing physician must inform the patient about alternatives to lethal medication, as well as request that family members be notified of the patient's decision. It is also the responsibility of the prescribing physician to assess whether the patient's decision is informed and voluntary, and two additional people are to serve as witnesses. Physicians are required to establish patient competency and complete a patient assessment prior to prescribing a lethal prescription.

Eligibility for a lethal prescription under the Death with Dignity Act also requires that the patient's competency be established. Competency is usually assumed unless a court has declared the person incompetent or a mental illness raises doubts about competence (Farrenkopf & Bryan, 1999). A patient can establish mental capacity by showing he or she can make clear choices, is able to understand and accurately apply medical information to his or her condition, and can demonstrate internally consistent reasoning (Farrenkopf & Bryan). If a physician finds the patient's judgment impaired, they must refer the patient to a psychologist or a psychiatrist for a more thorough assessment (Werth & Wineberg, 2005). During this assessment, the patient should demonstrate his or her understanding of information relevant to his or her decision, such as the consequences of the decision and the risks and benefits of alternatives.

NASW Code of Ethics

Service

"Social workers elevate service to others above self-interest. Social workers draw on their knowledge, values, and skills to help people in need and to address social problems" (NASW, 2000, Ethical Principles, para 2). Social workers are obligated to respect a client's right to self-determination, even when the client's goals conflict with the worker's individual moral framework. Those opposed to the Act may argue that the principle of service is limited to those acts which pose no harm to the client or others. John Stuart Mill (1975) justifies interfering with autonomy only if it prevents infliction of harm upon others, not oneself, when he stated, "the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others ... Over himself, over his own body and mind, the individual is sovereign" (p. 11). Supporters for the Death with Dignity Act also assert that a client's sense of "human worth" increases if he or she is able to gain control over the dying process (Farrenkopf & Bryan, 1999).

Social Justice

“Social workers are sensitive to cultural and ethnic diversity and strive to end discrimination, oppression, poverty, and other forms of social injustice” (NASW, 2000, Preamble, para 2). It is the responsibility of social workers to help meet the needs of all populations, especially those who are vulnerable and oppressed. Critics of the Death with Dignity Act have expressed a fear that people who choose physician assisted suicide would be uneducated, poor, uninsured, or receiving inadequate end-of-life care (Csikai & Manetta, 2003). Some critics have suggested that people would turn to assisted suicide so as to not burden their families. However, palliative care is covered through the Oregon Health Plan. As a result, people do not have to worry about bankrupting their loved ones (Werth & Wineberg, 2005). In addition, 98% of those who have utilized physician assisted suicide have had private insurance or were covered by Medicare or Medicaid. While these reports suggest that the Death with Dignity Act does not target the poor, the issue needs to be examined in more depth.

Dignity and Worth of a Person

At the forefront of arguments surrounding social workers and the Death with Dignity Act is the dignity and worth of a person. It is the responsibility of social workers to *“promote clients’ socially responsible self-determination”* (NASW, 2000, Ethical Principles, para 4). Physician collected data has highlighted the importance of self-determination on end-of-life decisions. Patients have expressed that their reasons for choosing physician assisted suicide include future loss of control, being a burden, being dependent on others for personal care, loss of dignity, being restricted to bed more than 50% of the time, and experiencing severe depression (Csikai & Manetta, 2002). The values of the social work profession refer to strongly-held beliefs about the individual’s right to free choice and opportunity (Hepworth et al., 2003). Supporters maintain that the law is beneficial even to those terminally ill people who do not utilize a lethal prescription, because they gain peace of mind from knowing that the end-of-life is under their control (Greenhouse, 2005), illustrating the importance of autonomy on client satisfaction.

“Social workers may limit clients’ right to self-determination when, in the social workers’ professional judgment, clients’ actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others” (NASW, 2000, Social Workers’ Ethical Responsibilities to Clients, para 2). This statement asks social workers to limit clients’ self-determination in some cases,

but there is no clear distinction as to what actions will pose imminent risks for clients. Social workers have previously been advised that upholding the client's right to self-determination is a pillar of social work, but are now being instructed that upholding the beneficence of the client may now take precedent.

Competence

“Social workers should provide services and represent themselves as competent only within the boundaries of their education, training, license, certification, consultation received, supervised experience, or other relevant professional experience” (NASW, 2000, 1.04 Competence, para a). NASW does not define at what point social workers have an obligation to participate in end-of-life care, or at what point one is considered competent in a given area. “When generally recognized standards do not exist with respect to an emerging area of practice, social workers should exercise careful judgment and take responsible steps to ensure the competence of their work and to protect clients from harm” (NASW, 2000, 1.04 Competence, para c). Reamer (1998) suggested that social workers take into account a number of resources when encountering an ethical challenge: ethical theory, literature on ethical decision making strategies, social work practice theory and research, relevant laws and regulations, agency policies, and other relevant codes of ethics. The NASW also calls for state chapters to encourage their members to participate in local, state, and national level committees and task forces to study the issues of end-of-life care, in order to better inform themselves (Csikai & Manetta, 2002). In the absence of generally recognized standards, social workers should refer to the guidelines and principles listed in the Code of Ethics.

Recommendations

Practice Recommendations

Working with clients who are making end-of-life decisions is an area of discomfort to many people, including social workers. Social workers should be aware of any conflicts between personal and professional values and deal with them responsibly (NASW, 1996). Social workers should be informed of current federal and state legislation, and have an understanding of how this legislation intersects with their own values and beliefs.

Neither the Code of Ethics nor the policy statement addresses the relative importance of values surrounding the end-of-life debate. In one study, many social workers expressed views that were inconsistent with the policy

statement that defines end-of-life decisions as, “the choices made by a person with a terminal condition” (Manetta & Wells, 2001). Over half of the participants in this study favored physician assisted suicide even in situations where there was no fatal illness present, which is inconsistent with the Death with Dignity Act. This study illustrates how social workers’ personal beliefs and values can be inconsistent with NASW standards or state guidelines, and it demonstrates the importance of addressing this issue in greater detail.

Policy Recommendations

Although Oregon is the only state with physician-assisted suicide, it is important for social workers in all other states to advocate for the increased quality of care of patients at the end of their lives. Social workers should specifically advocate for public policy that respects clients’ rights to self-determination. Some of the most critical barriers to optimal end-of-life care are limited availability and coverage, ineffective service delivery, and poor provider communication (Yabroff & Mandelblatt, 2004). A large part of overcoming these and other barriers should be achieved through continuing education and training.

Social workers need more guidelines and guidance to determine the proper course of action when working with clients who are contemplating assisted suicide. A stronger policy statement is needed that explores the complexities faced by social workers in end-of-life care, rather than simply exploring the issue of assisted suicide. This policy statement should outline in greater detail the role and responsibilities of social workers, formally address the conflict between social workers’ professional and personal values, and mandate that social workers receive more education and training in order to improve their competency in end-of-life issues.

Conclusion

Social workers have a different role in end-of-life care because of their unique purpose and perspective. In order to make ethical decisions, social workers must examine state guidelines, NASW policy statements, and the Code of Ethics, as well as their own values and beliefs. The resources available to social workers for ethical dilemmas, such as the Code of Ethics and NASW policy statements, can further complicate decision-making rather than help to distinguish the ‘right’ answers. A stronger and clearer policy statement is necessary to address the complexities surrounding end-of-life issues.

Training should be offered to social workers entering the field of aging, and more continuing education courses should be mandated for social workers who are continuing in the field. Social workers can no longer afford to have only a vague understanding of prevailing ethical standards (Jayaratne et al., 1997).

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