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Ethical Guidelines for Counselors When Working With Clients With Terminal Illness Requesting Physician Aid in Dying

Layla J. Kurt and Nick J. Piazza

In 2005, the American Counseling Association (ACA) introduced a new ethical standard for counselors working with clients with terminal illness who are considering hastened death options. The authors' purpose is to inform counselors of the Death With Dignity Act and explore relevant ethical guidelines in the ACA Code of Ethics (ACA, 2005).

Keywords: death with dignity, *ACA Code of Ethics*, end of life, physician aid in dying

The state of Oregon voted to approve the Oregon Death With Dignity Act (Or. Rev. Stat. 127.800 *et seq.*, 1994) in 1994, the first law in the United States establishing individuals' right to hasten their own deaths in the face of a terminal illness. The state of Washington followed suit in November 2008, when voters approved the Washington Death With Dignity Act (Wash. Rev. Code 70.245, 2008). Since these changes in legislation, the National Association of Social Workers (Mackelprang & Mackelprang, 2005), the American Psychological Association (Farberman, 1997), and the American Counseling Association (ACA) have made revisions in their professional codes of ethics to address the role of the counselor in working with these individuals.

As right-to-die battles for individuals with terminal illness reach widespread coverage in the media, there has been a growing appreciation for the counselor's role in working with clients facing end-of-life issues. To address some of these deeply personal ethical issues, the *ACA Code of Ethics* (ACA, 2005) has included a new standard (A.9.) to guide counselors working with individuals with terminal illness who are considering hastened death options. There are several end-of-life concerns currently making headlines in the media. In this article, we focus

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specifically on adult individuals with terminal illness who request physician aid in dying, ethical guidelines for professional counselors in the *ACA Code of Ethics*, and the role of the counselor working with this population.

TERMINOLOGY

According to the organization Compassion & Choices (n.d.), *hastened death* is a term used when an individual with terminal illness makes a rational decision to take self-directed action and choose when, within the final 6 months of life, death from terminal illness will occur. The term *physician aid in dying* is also considered apt terminology for discussing the choices of terminal illness in a manner that allows compassion and dignity for individuals facing end-of-life decisions (Tucker, 2008).

Suicide or *physician-assisted suicide* are not considered to be appropriate terms because of distinguishable differences between hastened death factors and suicidal intent as defined under Oregon's Death With Dignity Act. To understand these differences, counselors need to understand the rationale of individuals with terminal illness who request physician aid in dying and to have knowledge of safeguards that have been put in place to protect those who may be experiencing depression. Individuals with terminal illness cite combinations of the following reasons for requesting physician assistance with hastened death: intolerable pain, mind-altering side effects from medications, loss of bodily functions, loss of identity, desire for autonomous control, fears about future quality of life while dying, and negative past experiences with the dying process (Pearlman et al., 2005). According to the American Association of Suicidology (2012), individuals who are suicidal exhibit the following characteristics: a sense of hopelessness, rage or uncontrolled anger, reckless behaviors, increased drug or alcohol use, withdrawal from support systems, unusual anxiety, dramatic mood swings, and thinking there is no reason for living. Individuals who are terminally ill report a desire to live, but also ask to have options to choose a peaceful and dignified death that allows for control and autonomy in the final stages of life (Compassion & Choices, n.d.).

UNDERSTANDING THE DEATH WITH DIGNITY ACT

Both Oregon (1994) and Washington (2008) have passed a Death With Dignity Act that legalizes physician assistance for individuals to hasten their own deaths from a terminal illness. The Death With Dignity Act has stringent measures in place, requiring that individuals making the request are mentally capable adults with a terminal illness who have less than 6 months to live and who voluntarily request physician aid in dying (Chin, Hedberg, Higginson, & Fleming, 1999; Tucker, 2008; Werth & Holdwick, 2000). Individuals must be a resident of the state in which the request is being made, and their physician must determine

whether they meet medical criteria. Furthermore, eligibility must be agreed upon by both the attending physician and a consulting physician. Individuals must be referred for counseling if either physician has suspicions that the person making the request has impaired judgment because of clinical depression or a psychological disorder (Chin et al., 1999; Tucker, 2008). If all the criteria are met to comply with the Death With Dignity Act, physicians can then prescribe lethal doses of medication. Persons with terminal illness must fill the prescription on their own and self-administer the medications.

According to DiCamillo and Field (2006), 62% of California residents report that they believe that individuals who are incurably terminally ill should have the right to request physician aid in dying. In application of the Death With Dignity Act, in 2000, 1 in 6 requests for aid in dying were granted (Tucker, 2008). In 2007, 46 individuals took the prescribed medications out of 85 prescriptions that were granted in Oregon (Oregon Health Authority, 2008). In the 11 years since the Oregon Death With Dignity Act was passed in 1997, 341 individuals with terminal illness have died with physician assistance under the conditions of the law (Oregon Health Authority, 2008).

ETHICAL GUIDELINES FOR COUNSELORS

In response to public opinion, numerous scholarly debates, and research studies about physician aid in dying, ACA (2005) introduced a section in the *ACA Code of Ethics* specifically addressing the ethical considerations of the counselor. ACA has not endorsed a moral position in the matter of physician aid in dying; rather, Standard A.9. takes a stance supporting informed decision making and the right to self-determination for end-of-life decisions (ACA, 2005; Kaplan, 2008). Standard A.1.a. states that the primary responsibility of the counselor is to “respect the dignity and to promote the welfare of clients” (ACA, 2005). Research among counseling professionals gives considerable attention to ethical principles of beneficence, nonmaleficence, autonomy, and justice. Much of this research and debate has indicated that, with legal safeguards and ethical standards of practice in place, it is ethical and reasonable for individuals with terminal illness to make rational decisions to hasten death with physician assistance (Kaplan, 2008; Lokhandwala & Westefeld, 1998; Werth, 1999).

In an interview with David Kaplan (2008), Christine Moll and Vilia Tarvydas determined several factors to be of importance in ethical decision making regarding end-of-life issues and the Death With Dignity Act. Standard A.9. was written specifically to address the ethical concerns of counselors when working with those who are terminally ill and request physician aid in dying. The fundamental tenets for end-of-life care include concern that individuals with terminal illness (a) “obtain high quality end-of-life care for their physical, emotional, social, and spiritual needs” (Standard A.9.a.1.); (b) are empowered “to

exercise the highest degree of self-determination possible” (Standard A.9.a.2.); (c) are “given every opportunity possible to engage in informed decision making” (Standard A.9.a.3.); and (d) “receive complete and adequate assessment regarding their ability to make competent, rational decisions on their own behalf from a mental health professional who is experienced in end-of-life care practice” (Standard A.9.a.4.).

Farberman (1997) made a strong point when she emphasized that counselors remain neutral by prohibiting personal values from influencing their ability to work with individuals with terminal illness who have requested physician aid in dying. According to Farberman, the counselor’s role is “to attempt to ensure that the end-of-life decision-making process includes a complete assessment of the patient’s ability to make a rational judgment and . . . to help protect the patient’s right to self-determination” (p. 545).

There are stated concerns considered in the *ACA Code of Ethics* (ACA, 2005) in regard to protecting clients from self-harm. As Tarvydas and Moll explained, the new ethical standards are developed to help clients have the highest quality of life, to focus “on the need to be alive until the moment of death” (Kaplan, 2008, para. 9) and “developing and implementing plans that will increase and enhance the client’s ability to make decisions and remain as independent and/or self-determining as possible” (Kaplan, 2008, para. 10).

Standards A.9.b. and A.9.c. of the *ACA Code of Ethics* (ACA, 2005) address the matter of confidentiality when working with individuals with terminal illness who are considering options to hasten their own deaths. Standard A.9.b. states that “counselors may choose to work or not work with terminally ill clients who wish to explore their end-of-life options,” and Standard A.9.c. states that counselors who work with individuals with terminal illness “have the option of breaking or not breaking confidentiality, depending on applicable laws and the specific circumstances of the situation and after seeking consultation or supervision from appropriate professional and legal parties.”

Individuals who have a terminal illness may seek the help of counselors in deliberating end-of-life issues and options for physician aid in dying. It is reasoned that counselors are able to help individuals look at multiple perspectives on end-of-life concerns in order to make informed decisions (Abeles & Barlev, 1999). In accordance with Standard A.9.b., it is within ethical parameters for counselors to work with clients who are considering hastened death options (Kaplan, 2008). Tarvydas explained the importance of the “Quality of Care” section inherent in the focus

on making sure that we are attuned to helping clients obtain high-quality end-of-life care for their physical, emotional, social and spiritual needs, exercising the highest degree of self-determination possible, giving them every possible opportunity to engage in informed decision-making regarding their end-of-life care and receiving

complete and adequate assessment regarding their ability to make competent, rational decisions on their own behalf from a mental health professional who is experienced in end-of-life care practice. (Kaplan, 2008, para. 23)

THE ROLE OF THE COUNSELOR

People with terminal illness and their caregivers report a desire to talk about end-of-life concerns (Chapple, Ziebland, McPherson, & Herxheimer, 2006; Rabow, Hauser, & Adams, 2004; Terry, Olson, Wilss, & Boulton-Lewis, 2006; Wright et al., 2008). Among the many aspects of counseling and working with individuals with terminal illness who request hastened death, counselors make efforts to ascertain that the client is making carefully considered rational decisions free of external coercion (Farberman, 1997). Part of this may entail assessment of the client's mental health to continue to provide safeguards ensuring that the client has rational decision-making skills and is fully informed of and understands all treatment options (Abeles & Barlev, 1999; Farberman, 1997; Werth, 1999). To ensure safeguards to protect the client, many advocates take a position that counselors should be involved regardless of physician referral because of suspected clinical depression or mental disorder (Farberman, 1997; Werth, 1999). When speaking before the President's Council on Bioethics, the medical director of the American Foundation for Suicide Prevention, Herbert Hendin, went so far as to state that, in cases of physician aid in dying, "autonomy is further compromised by the failure to mandate psychiatric evaluation in cases of assisted suicide" (Hendin, 2005, para. 61).

Clients with terminal illness are in the final stages of life where emotional support is an imperative quality of good care (Kaplan, 2008). As individuals enter this stage and as the terminal illness progresses, clients are forced to cope with difficult and often unexpected emotions, such as grief, guilt, fear, anger, or other combinations of feelings. Often, these feelings are involved with multiple relationships in the individual's life and may include resolving lingering points of emotional discord (Daneker, 2006; Lokhandwala & Westefeld, 1998). Counselors can help provide a safe forum for clients to share their range of feelings and to prepare for loss as illness progresses and end-of-life approaches (Daneker, 2006; Lokhandwala & Westefeld, 1998; Werth, 1999). The counselor can assist the client with solving relational problems and can aid in the emotional growth and development that can be experienced during the dying process (Kaplan, 2008).

Competence in working with clients who are terminally ill means understanding the many ways these individuals are affected. Client needs may include aspects of emotional, spiritual, social, financial, and physical changes that individuals undergo as their illness progresses (Daneker, 2006; Kaplan, 2008; Lokhandwala & Westefeld, 1998). Loss of integrity and an individual's sense of identity are often affected by the quality of pain management, physi-

cal changes, and losses in abilities that are a natural part of the dying process (Daneker, 2006). Proactive palliative care, education, and counseling services can vastly improve the quality of a person's ability to cope with physical changes that affect emotional well-being during the final stages of life.

In addition to the compassion and support that a counselor can provide, help for extended family members can also be made available (Farberman, 1997). Counselors can help families communicate more effectively to resolve concerns and conflicts at times when it can be most difficult (Kleespies, Hughes, & Gallacher, 2000). Family and loved ones often have difficulty addressing emotional, legal, and ethical considerations when a loved one requests physician aid in dying (Kleespies et al., 2000; Werth, 1999). Loved ones also need to come to terms with the complex emotions of grief, rage, guilt, and desertion that accompany the loss of a loved one (Kleespies et al., 2000; Werth, 1999).

FUTURE IMPLICATIONS AND RECOMMENDATIONS

Tarvydas maintained that Standard A.9. was written to ensure that practitioners focus on helping clients who are dying to do so in a way that is consistent with belief systems in order to pass through the final stage of life with support and autonomy (Daneker, 2006). Medicare does not cover mental health services with counselors, thus leaving individuals confronting terminal illness with limited service options regarding end-of-life concerns and dilemmas. Additionally, many insurance panels do not cover counseling services that are not diagnosed by the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000), thus leaving services related to end-of-life decision making as nonbillable.

Advances in medical treatments and palliative care in the United States contribute to significant improvements in end-of-life care (Kleespies et al., 2000). It is important that counselors keep abreast of the latest research in palliative care and have an understanding of the types of illnesses associated with physician aid in dying (Kleespies et al., 2000). Efforts need to be made to understand pain management, treatment of anxiety and depression, closure of unresolved issues, and grieving and good-byes (Kleespies et al., 2000). Farberman (1997) recommended that more research be conducted regarding the factors that motivate a person with a terminal illness to request physician aid in dying in comparison with similar individuals who do not request hastened death.

CONCLUSION

The *ACA Code of Ethics* (ACA, 2005) indicates that it is permissible for counselors to work with individuals who are terminally ill and are considering hastened death options consistent with state laws. The ACA ethical standards further require that clients receive quality care that addresses the physical,

emotional, spiritual, and family needs in end-of-life care. To provide good services to clients with terminal illness, counselors need to have competence in end-of-life care, a clear understanding of professional ethical codes of conduct, and maintain up-to-date knowledge on laws related to terminal illness and hastened death considerations.

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