

# University of Nebraska at Omaha DigitalCommons@UNO

Social Work Faculty Publications

School of Social Work

11-28-2016

# Ethics at the End of Life: A Teaching Tool

Cara L. Wallace

Kara J. Thielman

Andrea N. Cimino

Heidi Adams Rueda

Follow this and additional works at: https://digitalcommons.unomaha.edu/socialworkfacpub



Part of the Social Work Commons

Please take our feedback survey at: https://unomaha.az1.qualtrics.com/jfe/form/ SV\_8cchtFmpDyGfBLE



# Ethics at the End of Life: A Teaching Tool

Cara L. Wallace, Kara J. Thielman, Andrea N. Cimino, and Heidi L. Adams Rueda

To cite this article: Cara L. Wallace, Kara J. Thielman, Andrea N. Cimino & Heidi L. Adams Rueda (2017) Ethics at the End of Life: A Teaching Tool, Journal of Social Work Education, 53:2, 327-338, DOI: <a href="https://doi.org/10.1080/10437797.2016.1243499">https://doi.org/10.1080/10437797.2016.1243499</a>

### **ABSTRACT**

Social workers rarely receive education and training in the areas of grief, bereavement, and death and dying, which may lead to difficulties in compassionately and ethically addressing concerns in end-of-life or grief-related con- texts. This article presents actual and potential outcomes from three challenging end-of-life case studies using Mattison's ethical decision-making model as a framework. The case studies were drawn from student interviews with experienced master's-level social workers. This pedagogical article helps to promote self-reflection and consideration of ethical issues in grief and death-related situations as well as supplement death education and ethics curricula to include end-of-life content.

The social work profession is known for working with diverse populations across a range of settings. Although social workers often specialize in a particular area of practice, the Council on Social Work Education's (2015) *Educational Policy and Accreditation Standards* presents core competencies intended to ensure that knowledge, values, and skills are applicable across concentrations and interests. Demonstrating ethical and professional behavior, the first of nine core competencies, is integral to all areas of practice, yet few social work students are fully prepared for the ethical complexity that may arise in end-of-life situations (Csikai &

Raymer, 2005). Values and ethics in death and dying may call into question one's religion, spirituality, and the meaning of life as well as a host of legal issues that may threaten client self-determination. When a client is dying or has died, ethical boundaries may become blurry as social workers try to honor the client's end-of-life wishes and adhere to professional standards. How can social workers balance human emotion and the natural desire to relate personally with dying clients with ethical and professional boundaries? Should an elderly client's desire to die at home be preserved over a caseworker's recommendation for intensive care? Is it acceptable to break a deceased client's confidentiality to provide solace to a grieving father? Using real-life case studies, this article applies Mattison's (2000) ethical decision-making model to three end-of-life situations, specifically exploring when professional responsibilities and personal values and motivations are in conflict.

### Literature review

End-of-life situations occur beyond hospice and health care settings, which are known to provide services for seriously ill and dying patients. In 2011 there were about 2.5 million deaths in the United States (Hoyert & Xu, 2012). Thus, it is no surprise that social workers in fields such as mental health, education, and child welfare also face issues of death and dying (Kramer, Hovland-Scafe, & Pacourek, 2003), suggesting a need for expanded course content on death and grief. Death education in social work programs is commonly offered through elective courses and may be omitted from core courses (Walsh- Burke & Csikai, 2005). For instance, a content analysis of frequently used textbooks in social work found that only 3.4% of all material addressed end-of-life care (Kramer et al., 2003).

Although death education has expanded in the United States, providers in many fields feel unprepared to help clients with grief and death-related issues or to deal with their own emotional reactions (Hunt & Rosenthal, 2000; Kirchberg, Neimeyer, & James, 1998; Smith & Hough, 2011). A number of studies have noted that social workers may not have the knowledge necessary to feel competent in their roles with clients facing death or bereavement (Black, 2007; Kramer et al., 2003;

Sanders, 2004; Stewart, Lord, & Mercer, 2000). Being faced with death and dying may provoke discomfort, anxiety, and fears in students and practitioners and may also decrease empathy, which can lead to avoidance and inadequate care for clients (Schimel, Whol, & Williams, 2006; Terry, Bivens, & Neimeyer, 1995). In particular, those who have had little to no exposure to death and who feel unprepared to face these situations may encounter difficulties, whereas those with greater exposure and death education may respond with less fear (Haas-Thompson, Alston, & Holbert, 2008; Kirchberg et al., 1998: Terry et al., 1995).

Given these factors, ethical concerns such as boundaries and client selfdetermination may be jeopardized in the absence of adequate education and training in areas related to end of life. Reamer (2014) summarized current ethics education in social work as encompassing four key areas: "the value base of the social work profession and its relationship to students' values, ethical dilemmas in social work, ethical decision making, and ethics risk management" (p. 14). Dodd and Jansson (2004) suggested an additional focus on ethical advocacy, or "obtaining entrée into ethical deliberations" (p. 58) in organizational settings and ensuring that consideration is given to client perspectives. There are multiple decision-making models that are used, but they have been criticized for focusing on a rational framework with little attention to the intuitive, emotional aspect of complex ethical dilemmas (Gray & Gibbons, 2007). Hugman (2005) described ethics as a subject "which cannot be taught" (p. 543), emphasizing the important role of learning by doing in developing ethical practices. Using case studies of ethical dilemmas in the social work classroom is one way students can engage in learning by doing, offering the opportunity to reflect on others' and their own understandings (Dolgoff, Harrington, & Loewenberg, 2011). Mattison's (2000) model suggests that social workers take note of their own value preferences, motivations, and attitudes, and that they build connections between past ethical decisions and potential decisions in the future.

Teaching ethics in social work education has evolved amid an increase in challenging dilemmas in the field and is "among the most remarkable developments in the profession" (Reamer, 2014, p. 14). However, because of the ever changing

landscape of practice, social workers must recognize that unforeseen ethical challenges are likely to develop in the future. Social work educators must continue to explore their ethics curricula to ensure they are up to date and address current practice needs. With the growth of technological advances and social media, for example, ethical gray areas have emerged across practice settings. Although social workers are required to pursue continuing education on ethics and boundaries, social workers also need to understand the "subtle boundaries undulating between life and death" (Keigher, 2001, p. 132) and thus require adequate death education that prepares them for potential ethical dilemmas in this area.

Administrators of social work programs and organizations have recognized the need for adequate death education and the consideration of ethics in end-of-life care. The National Association for Social Workers (NASW, 2004) released *Standards for Palliative and End of Life Care*, in which ethics and values is the first of 10 practice standards. The NASW (2003) also developed a policy statement titled "Client Self-Determination in End of Life Decisions," and Csikai and Chaitin (2006) published *Ethics in End-of-Life Decisions in Social Work Practice*, an entire text devoted to the importance of end-of-life care. Although these publications have helped address ethical dilemmas in end-of-life care, not all social work students receive this kind of content in the core social work curriculum, and additional tools may be needed.

The purpose of this pedagogical article is to apply Mattison's (2000) ethical decision-making model to situations involving ethical dilemmas and end-of-life issues. This model is already a commonly used tool for teaching ethics in social work (see Boland-Prom & Anderson, 2005; Gray & Gibbons, 2007; Guttmann, 2013) and promotes attention to personal values and emotions in addition to rational decision making. Such an application may serve as a social work teaching tool to better prepare all students for practice relating to death and grief, cutting across specialty areas. In addition to presenting an analysis of end-of-life case studies, we conclude the article with questions that can help guide in-class discussions on common ethical dilemmas.

### Case studies

Case studies for this article were derived from interviews conducted by MSW students with practicing social workers as part of an online elective course, Social Work Ethics. The purpose of the assignment was to help students apply course concepts to real-life ethical dilemmas and to prepare students for practice concerning a range of ethical situations. Interviews took place in person or over the phone. Students asked interviewees to describe (a) an ethical dilemma they had encountered in practice; (b) how they handled the situation; (c) how their values and training influenced their decision making; (d) how issues of culture, gender, or religion played a role; and (e) what they found particularly difficult about the situation. All interviewees had an MSW degree and 2–28 years of postmaster's experience. Students wrote an anonymous paper summarizing the interview and sharing their personal reflections, which included an evaluation on whether they would have done anything differently from the social worker they interviewed and why. Approval to use the student papers was granted from the governing university's institutional review board.

### End-of-life cases

Nearly 20% (n = 8) of the 43 interviews dealt with death and dying, suggesting that ethical concerns in end-of-life care are not uncommon across practice settings. Of these, we selected three end-of-life cases (each interview conducted in person) that depicted minimal consideration of ethical concerns (e.g., questionable practices, violation of confidentiality, safety concerns). All three cases involved direct-practice social workers.

### How we applied mattison's model

Wallace, Thielman, and Cimino separately applied a set of preexisting themes from Mattison's (2000) ethical decision-making model to the chosen cases.

Because this often called for information not included in each case study, we also reasoned how use of the model might have altered potential courses of actions and outcomes in the original case study. When disagreements arose, we came together

to discuss the concepts applied and to reach consensus. An audit trail was kept to ensure credibility, and we further engaged in self- and shared reflection concerning our views and experiences with death and dying. Because students were retelling the interviewee's accounts of an unethical situation, portions of the narrative may be over- or underexaggerated. Furthermore, we were unable to probe or expand on events that were reported in the cases.

# Mattison's ethical decision-making model

Before presenting specific cases, it is helpful to review Mattison's ethical decision-making model, which has seven steps. The first steps involve considering background information and case details, separating practice considerations from ethical components, and identifying value tensions. Once these are recognized, the next steps are to identify principles in the NASW (2008) Code of Ethics relevant to the case, identify possible courses of action, and assess which priority or obligation should be accorded primacy and to justify the chosen course of action. The seventh and final step is the resolution of the ethical dilemma.

## Case studies and application of the model

In the following section, we present three case studies involving end-of-life situations where greater attention to ethical concerns was warranted. For each case, a summary of the setting, events, and ethical dilemma; the social worker's motivations and actions; and the outcome of the dilemma are provided, based on the student's report from the interview. Mattison's (2000) ethical decision-making model is then applied to these cases to highlight the ethical concerns involved and to apply a process to resolve them. Cases are delineated following the themes of Mattison's (2000) model, with the social workers' self- reflections and personal motivations captured during the student interviews, guiding an understanding of conflicting values and chosen courses of action in each case. Pseudonyms are used to protect the identity of participants.

## Case study 1: Only being human

Jackie is a social worker in a residential psychiatric facility providing counseling to adults with severe mental illness. Jackie worked closely with a client, Mark, for several years. They had developed a very close bond and processed a lot of emotions Mark had about being a gay man with a strict religious upbringing, including shame about his sexual orientation. Mark's family had disowned him when he disclosed he was gay, and he had few friends since being diagnosed with HIV and moving to the facility. As Mark's health declined, and he approached death, he expressed fear of dying, in part because he was afraid that his HIV/AIDS status might be a punishment for being gay and for some of his choices in life. Jackie, who also identifies as a member of a sexual orientation minority, deeply empathized with Mark's loss of friends and family support. She recognized that Mark lacked social support in general and tried to provide that support in their sessions together. Eventually, Mark's physical health deteriorated, and he was transferred to an intensive care unit (ICU), where he was placed on life support.

Jackie went to visit Mark in the ICU but forgot her hospital identification badge, which she needed to be allowed to visit as a staff member. As it was after regular business hours, and it seemed Mark would die before long, Jackie chose to sign in at the ICU as a friend so she could say her last good-bye. "I was [visiting him] more for myself," she said. Jackie noted that she was "thinking with [her] heart and not [her] mind" and that transference and countertransference had been especially difficult with Mark. Her supervisor discovered she had visited Mark after her workday had officially ended and that she had signed in as a friend, not as his social worker. As a result, Jackie was cited for an ethical boundary violation. Although the professional consequences were minor, this case stuck with Jackie as being especially difficult. She noted that she felt the Code of Ethics requires social workers to "not be human" and stifles feelings of love and caring for their clients. She acknowledged that part of her motivation in visiting Mark was to meet her own emotional needs and that she did not fully consider her ethical obligations. Jackie believed she was simply being a caring human being when she visited Mark in the hospital and contemplated during the interview with the student whether signing in as a friend was a subconscious way of expressing that she cared personally for

# Model application

Using Mattison's (2000) framework in examining case details, Jackie could consider the history of the therapeutic relationship between herself and Mark, including their shared status as members of sexual orientation minorities. Additional client factors relevant to this dilemma include Mark's internal conflict over his sexual orientation and personal choices, social isolation, history of mental health problems, HIV status, worsening health status and hospitalization, and fear of dying. Clearly, more information (known to the social worker but not reported) would be helpful, such as the nature of the client's mental health problems and whether he was alert and oriented during his ICU stay.

Several important practice considerations arise from this scenario, including the role of the social worker in relationship to a dying client, whether a client remains on a social worker's caseload while in the ICU, and any agency policies about visiting clients hospitalized for medical reasons. Ethical components include whether the social worker developed a dual relationship with her client, and, if so, whether this could have been avoided or was harmful, and concerns about misrepresentation by signing in as a friend and not as a professional. Jackie admittedly felt a personal need to say good-bye, which may conflict with agency policy. Another tension includes whether to prioritize human relation- ships when they oppose professional obligations; in cases such as this, the commitment to the well-being of a client who lacks social support and the feelings of attachment that accompanied this commitment caused turmoil as they posed a threat to the social worker's job. The NASW (2008) Code of Ethics states that dual relationships should be avoided when "there is a risk of exploitation or potential harm to the client" (1.06c). Although it seems unlikely that a hospital visit would pose a risk to the client in this case, more details about the therapeutic relationship should be considered. If the client was alert and oriented, he may have had expectations for the social worker as a friend that might have extended beyond her professional capacity. The code also states that social workers should "ensure that their representations ... are accurate" (4.06c)

and that they "should not participate in, condone, or be associated with dishonesty, fraud, or deception" (4.04). Jackie may have misrepresented her relationship to the client and her affiliation with the hospital by signing in as a friend, as she omitted that she also had a professional relationship with the client. However, other ethical components include the *Code of Ethic*'s stated values of the "inherent dignity and worth of the person" (section 3, para. 4), "the central importance of human relationships" (section 3, para. 5), and the importance of client well-being. The potential emotional consequences for the social worker and the client resulting from the social worker's not visiting before the client's death must be considered within context-specific agency or hospital policies.

In this case, the social worker decided to sign in as a friend and visit her client rather than letting him die without saying good-bye, suggesting the priority she accorded to his well-being and the importance of human relationships. However, her acknowledgment of the transference and countertransference issues in this relationship raises the possibility that her own needs may have played a central role in her decision. Although strong emotions are common in end-of-life settings, reflection on them is warranted. This course of action allowed her to visit the client before he died but resulted in a citation from her agency for misrepresenting herself. An alternative option, which may have honored the relationship and hospital and agency policies, might have been to return the next day with the necessary identification. Although this option has the benefit of avoiding misrepresentation and following policy, it runs the risk that the client may have died or became unconscious by the time the social worker returned.

It is unclear whether Jackie reflected on the multiple ethical concerns inherent in this situation or whether she considered alternatives. In assessing the dignity and worth of the client and the obligation to represent oneself accurately, which priority should be accorded primacy? Although she may have decided on the same course of action using a decision-making model, moving through the model's steps may have led to greater self-reflection, clarity of values and motivations, and more confidence in her decision. A lack of consideration of these ethical concerns, on the other hand, may have left Jackie vulnerable to ethical boundary violations in

the future.

# Case study 2: Disabled and disregarded

Richard is a case manager for an agency serving disabled adults. Most of Richard's responsibilities are to provide resources or access to resources such as food, financial assistance, and Social Security and Medicaid as well as to provide direct support to his clients, conduct home visits, and advocate for their needs. Brad, a 70-year-old man in very poor health who lived alone, was one of Richard's clients. A long-time sufferer of diabetes, Brad was wheelchair bound after having his leg amputated. He also had kidney disease that warranted dialyses three times a week. On occasion, Richard transported Brad to dialysis treatment, as it would often leave Brad in a mental state unsafe for driving. Richard and Brad became close over their two years working together and shared similar values, including each wanting to die in his own home.

One day Richard was unavailable, so two other caseworkers went to visit Brad in his place. Brad's health had taken a turn for the worse, and he was unable to get to the door to let them in. Eventually, the caseworkers found a hidden key and entered the home. Once inside, they realized that Brad's condition was critical as he was severely incapacitated. They attempted to contact Richard but with no success. The caseworkers felt that Brad's home was unsafe for him in his deteriorating physical state, so they removed Brad from his home and had him placed in inpatient hospice care. The caseworkers determined that Brad was unable to make an informed decision about his care, and his closest living relative, who lived out of state, provided consent for the move to hospice. During moments of clarity while at the hospice facility, Brad was vocal in expressing his desire to leave. The caseworkers and hospice staff attempted to explain that the facility was the best place for him. Nevertheless, Brad continued to ask to be taken back home and demanded to see Richard. Richard knew how strongly Brad had desired to die in his own home, but he did not advocate for this because he agreed that the hospice facility was the safest place. Brad died there a few days later before Richard was able to visit.

When Richard found out that Brad had died, he felt as if he had abandoned him at the end of his life. Richard felt remorse for not advocating for Brad's wishes to die at home and recognized he had felt helpless to influence his colleagues after their decision. Moreover, Richard was disappointed that his work and training had left him unprepared to effectively help clients who were dying. He admitted that he felt uncomfortable when considering whether to visit Brad in hospice, which delayed his decision until it was too late. Ultimately, Richard regretted how the situation was handled and that he had not been a stronger advocate for Brad.

Model application When Brad was moved to the hospice facility by Richard's colleagues, Richard was unsure about whether he should step in to advocate for Brad's desire to die at home. Mattison's (2000) model might have helped him in making a clearly thought-out decision, considering and potentially resolving some of his own conflicting emotions. In examining case details, Richard would need to have considered the severity of Brad's illness, his limitations and potential supports, and the condition of his home as well as Brad's wishes and his ability to make competent decisions in his current state.

As in the first case study, Brad needed to consider his role in caring for a patient who was under another agency's care. His agency may have policies about either discharging patients who have moved into hospice care or about collaborating with hospice. Either way, the transition itself is an ethical responsibility for the social worker. Other ethical components of this case include the importance of human relationships, whether the client's self-determination was respected in regard to the hospice transfer, the client's overall well-being and safety, and the social worker's sense of competency and confidence related to caring for a dying patient.

There are a few competing values in this scenario, including the client's wishes and right to self-determination versus the client's well-being and safety and the social worker's commitment to the client versus respect for his colleagues and agency guidelines. The NASW (2008) *Code of Ethics* calls upon social workers to "promote the well-being of clients" (1.01) and to "respect and promote the right of clients to self-determination" (1.02). A central question to consider is whether

the client's wish to remain at home posed "a serious, foreseeable, and imminent risk" (1.02) to him and if there were any available resources, such as home hospice care, that could have been provided in the home. In Richard's absence, his coworkers made the determination that Brad was unsafe and transported him to the hospice facility. However, Richard still felt he had a commitment to his client and felt an obligation to respect his wishes, yet he was hesitant to express disagreement about the placement. This may have stemmed, in part, from his sense of being unprepared to navigate this difficult end-of-life situation. Certainly, the *Code of Ethics* states that social workers should practice within the bounds of their competence (NASW, 2008), but support from colleagues might have been sought in this case.

Additional aspects that complicated Richard's decision about how to proceed were his own emotions about the matter. He expressed feelings of incompetence in providing services to patients at the end of life and acknowledged a conflict between wanting to make sure the client was safe without overriding the client's wish to die at home. He also felt uncomfortable expressing disagreement with colleagues and advocating for the client to return home. Ultimately, Richard's decision to do nothing disregarded Brad's wishes, possibly indicating that the client's needs for safety and well-being were the priority. Brad may have felt abandoned during his final days as Richard's continued absence may have resulted in ruptured trust and disappointment.

An alternative option might have been for Richard to advocate for Brad to return home with additional support. Because Brad was close to death, this may have been a realistic option with the support of short-term continuous care, a level of care in hospice that is equivalent to inpatient care. With this course of action, respect for client self-determination might be the foremost priority. Although Richard admitted he lacked knowledge in caring for patients at the end of life and may not have been able to assess whether short-term care was a real possibility, it could have been explored with the hospice agency. Richard also could have discussed care options with Brad's relative, who provided consent for hospice, and informed him of Brad's wishes to return home. Additionally he could have explored other community

services to assist Brad in his home. The benefits of Richard's advocating for Brad in this manner would be that Brad's wishes would have been supported by someone he trusted and that he might have had his wish honored to die at home. This may have also resolved any feelings of guilt Richard experienced. Potential drawbacks to this action are that Richard might have felt discomfort in going against his coworkers' decision and that a second transfer in the client's condition may have been too difficult for the patient to tolerate.

Finally, a third course of action might have been for Richard to visit Brad in the facility and explain why he was unable to return home, thus honoring the importance of human relationships and Richard's commitment to his client's wellbeing, even if he could not fully honor his client's wishes. In either case, Richard would need to be prepared for some discomfort, either in advocating for another option with his colleagues or explaining to Brad that he could not help him return home. Richard's self-reflection on this case left him with regrets and feeling conflicted about the outcome. In addition to considering alternative courses of action, Mattison's (2000) model suggests for individuals to consider how a decision fits (or does not fit) with other difficult decisions in the past. In this case, Richard might consider whether he had avoided other client situations the way he avoided this one. Through this experience, Richard realized that he needs further training in caring for patients at the end of life. Although this is not the purpose of the agency where he is employed, it is unlikely that Brad will be Richard's last client with disabilities approaching death. Recognizing how he might do things differently, considering the available options, and reflecting on how they fit with his personal and professional values and ethics could help Richard be more confident when facing other difficult end-of-life dilemmas.

# Case study 3: Personal crusade to help a grieving father

Allie is a licensed clinical social worker with nearly 30 years of practice experience. For the first 10 years of her career, Allie worked for a private agency and contracted part-time with a university's student counseling center. At one point, Allie was asked to facilitate a traumatic grief group, even though she initially had no

formal training in grief counseling. Allie was especially sympathetic to death and loss because her sister and father both died from cancer. Allie personally worked on her grief issues and then later sought training by attending hospice groups and workshops where she learned the complexities of grief. In facilitating ongoing grief groups at the private agency, Allie said she was "appalled" to hear how untrained therapists traumatized many of the clients. For example, one bereaved mother reported that a therapist assigned her to smile three times a day, which failed to validate the depths of this mother's grief. According to her interview with a student, grief and bereavement work "soon became a crusade" for Allie, who expressed feeling honored that she is "allowed to walk by the side" of grieving individuals. In one session, Jerry, a new member to the group, was talking about his daughter, Mara, who had recently died as the victim of a tragic and highly publicized violent crime. There was an investigation and an upcoming trial, both of which were difficult for Jerry. A few weeks passed, and Allie realized that Mara was a former client of hers from the university counseling center. Allie was "holding back tears as [her] head was racing a million miles a minute" thinking of Mara's death and knowing the pain Jerry felt with the investigation. Around this time, Jerry asked to see Allie privately, something she did on occasion. Before agreeing, Allie informed her agency of the request and that Mara was a former client who was successfully discharged years ago at the university; the agency approved the private counseling on the condition that Allie would maintain Mara's confidentiality.

Allie saw Jerry privately for more than a year. She noted that Jerry would often place Mara "on a pedestal," minimizing her poor scholastics, struggles with boys, and trouble in the family, all of which Allie knew about from her sessions with Mara. Toward the end of their individual sessions together, Allie decided to tell Jerry that Mara came to her for counseling. Allie felt this was "a gift she could give him" and felt that she knew him well enough to predict that he would have a positive reaction to the information. Jerry reacted by saying, "Oh my God, she sat in this same chair, and came through this door" as he looked at his chair and touched the door's handle. Allie did not disclose details of her sessions with Mara but admitted that she exaggerated the truth at times. For example, Mara never told Allie she

loved her father, but Allie felt that she "knew from their sessions that they had a very good relationship." At a very trying time in Jerry's therapy, Allie told him, "Mara loved you very much" because, she said, "a therapist can handle the sorrow by being hopeful for these clients." In her interview, Allie maintained that breaking confidentiality was a gift to Jerry.

# **Model application**

Although Allie felt the outcome of this situation was positive, we lack Jerry's perspective and whether he viewed this disclosure as being beneficial. Using Mattison's (2000) framework could have helped Allie reflect on her own emotions in this case and to examine potential outcomes and risks at multiple points in time. In Step 1 of the model, Allie should have considered the background information in this particular case, including that the client's daughter had previously sought services with her. Allie must have also considered the highly publicized and violent nature of Mara's death and the impact this had on Jerry, alongside consideration of her own emotions about the violent death of a former client.

The first choice Allie was faced with in this case was whether to see Jerry individually. Important practice and ethical considerations include personal and agency policies about seeing clients across settings (e.g., privately and within a group) along with whether Allie would be able to separate her prior knowledge about Jerry and his daughter from current sessions and maintain Mara's confidentiality. Allie's intimate knowledge about Mara and her own reactions to her death may have clouded her ability to remain objective and to separate her feelings from Jerry's, potentially leading to overidentification with this client. Although Allie has worked with other clients who have experienced the traumatic death of a loved one, she was not connected to the deceased family member in those cases.

This scenario brought up several value tensions for Allie. First, there was a potential conflict of interest in agreeing to see Jerry individually. The *Code of Ethics* (NASW, 2008) instructs social workers to "avoid conflicts of interest that interfere with the exercise of professional discretion and impartial judgment" (1.06a). Second, once Allie accepted Jerry as a client, there was tension between maintaining Mara's

confidentiality and her sense that Jerry would benefit from knowing that his daughter was a former client. Allie stated she "knew in her heart" after working with Jerry and Mara that this disclosure "would only assist healing Jerry's pain." However, her own emotions about this case raise the possibility that she was basing her decision to disclose her relationship with Mara more on her own needs than on those of her client. This disclosure also conflicted with her professional ethics and responsibilities, as social workers are called to "protect the confidentiality of deceased clients" (1.07r). Breaking confidentiality is a serious matter that requires "compelling professional reasons" or "[preventing] serious, foreseeable, and imminent harm" (1.07c), and it is not clear that these conditions were met or whether Allie consulted a supervisor before making this disclosure.

The social worker's decision to disclose her professional relationship with Mara toward the end of Jerry's sessions also raises multiple considerations. The priority that appears to have taken precedence was a personal desire to help this grieving client and an intuition that sharing this information would have a positive outcome. However, Allie risked that Jerry would want to know more than her simple disclosure about her work with Mara. For instance, he might have probed for information about what they discussed in sessions and how his daughter felt about him. Although the desire to know details may be natural for a parent who has lost a child, it further jeopardizes client confidentiality and professional boundaries. Jerry might have additionally worried that Allie may not maintain confidentiality in relation to his sessions, or he might have become angry at Allie for withholding this information from him for a year. It is also unclear whether Jerry was able to fully process this information because it was given to him at the end of their sessions. This course of action also raises questions about honesty, as Allie admitted to embellishing during sessions with Jerry about what Mara told her about him.

There are several alternative courses of action Allie might have considered. First, she could have decided not to see Jerry in private counseling and refer him to another grief therapist. This would have eliminated her concerns about being able to remain objective and about separating her own emotional responses to Mara's death from her professional work with Jerry, who believed Allie had no personal

connection to his daughter. Maintaining the facade of not having known her client's daughter was likely difficult for Allie. Referring Jerry elsewhere would have required for Allie to reflect on her desire to help grieving clients and whether her distrust in other professionals' ability to properly manage grief issues is reasonable. With this course of action, professional integrity and a desire to uphold ethical standards would have been the obligations given primacy.

Seeing the client privately without ever disclosing that Allie saw his daughter is another course of action, and the one endorsed by her agency. It appears this is what Allie initially planned to do: accept Jerry as a personal client but respect her prior role as Mara's social worker. This course of action would have required a deep level of reflection; in this example, Allie may have been too affected by Mara's death to be able to provide competent care to her father. In the end, Allie was unable or unwilling to maintain confidentiality. One way Allie might have addressed this challenge is through the use of consultation to work through her conflicting feelings. Protecting Mara's confidentiality and privacy are the values that would have taken priority in this course of action while still providing care to Jerry.

A third course of action would have been to see Jerry privately and tell him at the outset that she also treated his daughter. In this case, Allie may have been breaking confidentiality without questionable justification for doing so but would have been up front with her client. This would have allowed her the chance to set any ground rules, such as stating that she could not divulge any information from her sessions with Mara. Jerry could have then considered whether he felt comfortable with continuing to see Allie. This course of action would have prioritized the social worker's desire to provide care to this client.

## Points of discussion

We presented three authentic case studies relating to death and dying and applied Mattison's (2000) ethical decision-making model to illuminate unique ethical dilemmas in end-of-life situations. The cases demonstrated a variety of circumstances, including the difficult task of saying good-bye to a client with whom a social worker had built a close relationship, a client wishing to die at home when

the safety of doing so was in question, and maintaining confidentiality of a deceased client when faced with a loved one coping with her death.

In textbooks and literature, a readily discussed ethical dilemma in end-of-life matters involves whether a client has the right to choose the timing of his or her death because of terminal illness or extreme pain and suffering (Corey, Corey, Corey, & Callanan, 2014; Dolgoff et al., 2011). Although this is an important ethical challenge, it is of the least salient among practicing hospice social workers (Csikai, 2004). The cases featured in this article highlight an array of other challenges in ethical decision making at the end of life such as dual relationships or friendships, confidentiality, self-determination and advocacy, competence, and the unique role of personal values in practice.

In the following sections, we explore these issues and provide discussion questions for the reader to consider about practice issues on death and dying.

### Dual relationships

The relationship between Jackie and Mark, and to some extent, Allie and Jerry, crossed a professional boundary, which led the social worker to act in a personally motivated manner. Boundary issues such as dual relationships can be complicated but are not always problematic (Reamer, 2012). For instance, boundary violations that are harmful, exploitative, or coercive, such as sexual or financial misconduct, are universally inappropriate (Gutheil & Gabbard, 1998). However, it is often the case that major boundary violations are preceded by minor or benign boundary crossings (Gutheil & Gabbard, 1993). In Jackie's case, the action (signing in at the ICU as a friend) was relatively harmless, but her actions resulted in her employer reprimanding her. Readers are urged to think about how their actions might be interpreted by others. Are you acting with personal or professional intent, and what are the potential consequences of your actions? Are there boundaries you might have crossed? How can you honor the genuine care and concern you have for clients while still maintaining a professional relationship? It may be helpful to think about what you can learn from routine consideration of professional boundaries and create an ongoing conversation with your colleagues

and supervisor.

# Confidentiality

Breaking confidentiality is often discussed in ethical dilemmas. Of our case studies, Allie is the social worker who most egregiously violated the confidentiality of her deceased client, Mara, when she disclosed to Jerry that his daughter was a former client. In certain cases, such as trials or ongoing investigations, confidentiality must be broken. The reader is urged to consider agency policies regarding breaching confidentiality of a deceased client. Is there a period of time when records can be released and under what circumstances? What are the potential positive and negative outcomes of disclosing this information? Do these outcomes differ depending on who is receiving the information (e.g., a relative of the deceased vs. a lawyer or other professional)?

# Self-determination and advocacy

According to the NASW (2004), social workers should advocate for the needs, decisions, and rights of clients. Self-determination is at the center of the NASW's (2003) policy statement on end-of-life decision making. Richard regretted not advocating for Brad and felt responsible for not upholding Brad's wish to die in his home. The reader is asked to consider when conversations about end-of-life issues with clients may be appropriate. Do other relevant decision makers also know the client's wishes? What circumstances might supersede a client's right to self-determination? Other related ethical dilemmas at the end of life include client or family denial of a terminal illness or a family wishing to keep details about an illness secret from the client. Using the methods described in this article, how might you approach either of these situations?

## Competence, supervision, and training

Increasingly, it is common for social workers to face end-of-life situations regarding grief and loss even when it is not their area of expertise or practice. Richard, who worked with disabled adults, was not prepared or trained to handle

end-of-life situations, nor was Jackie, the counselor for adults with serious mental illness. When Richard's client passed away, he regretted not being a better advocate. Although it cannot be known for certain what motivated his actions, it seems possible that Richard's discomfort led to an avoidant approach to the situation; indeed, studies have found that avoidance in the face of death is not uncommon among unprepared providers (Hunt & Rosenthal, 2000; Kirchberg et al., 1998; Smith & Hough, 2011; Terry et al., 1995). Readers are asked to consider what training their agency offers in this area. Are there existing policies or procedures for compassionately and ethically addressing end-of-life matters? In Jackie's case, an open discussion with her employer about visiting Mark may have prevented her from being cited for a boundary violation. Do you have regular conversations or meetings with a supervisor where you can discuss client-related end-of-life matters? If so, have you developed a contingency plan for situations such as those faced by Brad and Jackie?

# Personal versus professional values

Demonstrating sensitivity to clients' rights requires social workers to be aware of how their personal values influence their practices (NASW, 2004). There were two ethical dilemmas in the case with Allie and Jerry where the social worker's personal values clearly influenced professional practice. The first was Allie's decision to see Jerry individually out of fear that no one else could help him, and the second was her own personal experience with loss and grief work. Allie reported that her "training, supervision and work with traumatic grief groups allowed her to work from her heart." Allie expressed that emotional aspects were particularly important in grief work, and for her, took precedence over more logical actions. It is unclear whether Allie's decision to tell Jerry that Mara was a client helped or harmed him—was Allie acting out of her own self-interest? Similarly, Jackie wanted to "feel human" as she also relied on her emotions in regard to ethical decision making. The first step in working through these potential conflicts is focusing on self-awareness (Hepworth, Rooney, Rooney, & Strom-Gottfried, 2013). We ask you to reflect on your own relationship with death and how this might influence your decision making. Finally, is your interpretation of an

action's harmlessness (e.g., breeching confidentiality, signing in at an ICU as a friend) shared by others? What are the potential consequences for the client, the bereaved family, your employer, and yourself?

### Conclusion

Working with clients in the context of end-of-life issues and grief can be challenging for social workers and other helping professionals who may face personal discomfort and lack of training and experience in these areas. As a result, ethical dilemmas may not be given sufficient consideration, and hasty decisions may be made. Self-reflection is critical to understanding and applying ethics (Corey et al. 2014; Mattison, 2000; Reamer, 2012). Adequate preparation for facing death-related issues and an understanding of how to resolve ethical dilemmas are needed. In this context, an ethical decision-making model may be helpful in resolving challenging situations, as it encourages full consideration of case details, practice concerns, value tensions, ethical components, potential courses of action, and possible outcomes in coming to a resolution of the dilemma. Although such a model does not determine which course of action is the right one, it can help social workers consider relevant issues and feel more confident about their choices in such situations.

### Notes on contributor

Cara L. Wallace is assistant professor at Saint Louis University. Kara J. Thielman is a PhD student at Arizona State University. Andrea N. Cimino is a faculty research associate at Johns Hopkins University. Heidi L. Adams Rueda is assistant professor at University of Texas at San Antonio.

#### References

Black, K. (2007). Health care professionals' death attitudes, experiences, and advance directive communication behavior. *Death Studies*, *31*, 563–572. doi:10.1080/07481180701356993

Boland-Prom, K., & Anderson, S. C. (2005). Teaching ethical decision making using

- dual relationship principles as a case example. *Journal of Social Work Education*, *41*, 495–510. doi:10.5175/JSWE.2005.200303117
- Corey, G., Corey, M., Corey, C., & Callanan, P. (2014). *Issues and ethics in the helping professions*. Stamford, CT: Cengage Learning.
- Council on Social Work Education. (2015). *Educational policy and accreditation standards*. Retrieved from http://www.cswe.org/File.aspx?id=81660
- Csikai, E. L. (2004). Social workers' participation in the resolution of ethical dilemmas in hospice care. *Health & Social Work*, 29, 67–76. doi:10.1093/hsw/29.1.67
- Csikai, E. L., & Chaitin, E. (2006). *Ethics in end-of-life decisions in social work practice*. Chicago, IL: Lyceum.
- Csikai, E. L., & Raymer, M. (2005). Social workers' educational needs in end-of-life care. *Social Work in Health Care*, *41*, 53–72. doi:10.1300/J010v41n01\_04
- Dodd, S. J., & Jansson, B. (2004). Expanding the boundaries of ethics education:

  Preparing social workers for ethical advocacy in an organizational setting. *Journal of Social Work Education*, 40, 455–465. doi:10.1080/
  10437797.2004.10672300
- Dolgoff, R., Harrington, D., & Loewenberg, F. (2011). *Ethical decisions for social work practice* (9th ed.). Belmont, CA: Thomson Brooks/Cole, Cengage.
- Gray, M., & Gibbons, J. (2007). There are no answers, only choices: Teaching ethical decision making in social work. *Australian Social Work*, *60*, 222–238. doi:10.1080/03124070701323840
- Gutheil, T. G., & Gabbard, G. O. (1993). The concept of boundaries in clinical practice: Theoretical and risk-management dimensions. *American Journal of Psychiatry*, 150, 188–196. doi:10.1176/ajp.150.2.188
- Gutheil, T. G., & Gabbard, G. O. (1998). Misuses and misunderstandings of boundary theory in clinical and regulatory settings. *American Journal of Psychiatry*, *155*, 409–414. doi:10.1176/ajp.155.3.409
- Guttmann, D. (2013). *Ethics in social work: A context of caring*. New York, NY: Routledge.
- Haas-Thompson, T., Alston, P. P., & Holbert, D. (2008). The impact of education and death-related experiences on rehabilitation counselor attitudes toward death

- and dying. Journal of Applied Rehabilitation Counseling, 39(1), 20–27.
- Hepworth, D., Rooney, R., Rooney, G. D., & Strom-Gottfried, K. (2013). *Direct social work practice: Theory and skills* (9th ed.). Belmont, CA: Brooks/Cole, Cengage Learning.
- Hoyert, D. L., & Xu, J. (2012). Deaths: Preliminary data for 2011. *National Vital Statistics Reports*, *61*(6), 1–52. Hugman, R. (2005). Exploring the paradox of teaching ethics for social work practice. *Social Work Education*, *24*,535–545. doi:10.1080/02615470500132772
- Hunt, B., & Rosenthal, D. (2000). Rehabilitation counselors' experiences with client death and death anxiety. *Journal of Rehabilitation*, 66(4), 44–50.
- Keigher, S. M. (2001). Clinical ethics, living and dying: New challenges for changing times. *Health & Social Work*, *26*, 131–135. doi:10.1093/hsw/26.3.131
- Kirchberg, T. M., Neimeyer, R. A., & James, R. K. (1998). Beginning counselors' death concerns and empathic responses to client situations involving death and grief. *Death Studies*, *22*, 99–120. doi:10.1080/074811898201623
- Kramer, B. J., Hovland-Scafe, C., & Pacourek, L. (2003). Analysis of end-of-life content in social work textbooks. *Journal of Social Work Education*, 39, 299–320.
- Mattison, M. (2000). Ethical decision making: The person in the process. *Social Work*, 45, 201–212. doi:10.1093/sw/45.3.201
- National Association of Social Workers. (2003). Client self-determination in end of life decisions. In *Social work speaks: NASW policy statements* (pp. 46-49) Washington, DC: NASW Press.
- National Association of Social Workers. (2004). *NASW standards in palliative and end of life care*. Washington, DC: National Association of Social Workers. Retrieved from http://www.socialworkers.org/practice/bereavement/standards/default.asp
- National Association of Social Workers. (2008). *Code of ethics*. Retrieved from https://www.socialworkers.org/pubs/code/code.asp
- Reamer, F. G. (2012). Boundary issues and dual relationships in the human services. New York, NY: Columbia University Press.
- Reamer, F. G. (2014). Ethics education in social work—Transformation of a

- profession. Social Work Today, 14(2), 14.
- Sanders, S. (2004). Death and dying content in undergraduate social work education: Student views of their preparation for end-of-life practice. *Journal of Baccalaureate Social Work*, *10*(1), 136–146.
- Schimel, J., Wohl, M. J. A., & Williams, T. (2006). Terror management and trait empathy: Evidence that mortality salience promotes reactions of forgiveness among people with high (vs. low) trait empathy. *Motivation and Emotion*, *30*, 217–227. doi:10.1007/s11031-006-9040-y
- Smith, L., & Hough, C. L. (2011). Using death rounds to improve end-of-life education for internal medicine residents. *Journal of Palliative Medicine*, *14*, 55–58. doi:10.1089/jpm.2010.0190
- Stewart, A. E., Lord, J. H., & Mercer, D. L. (2000). A survey of professionals' training and experiences in delivering death notifications. *Death Studies*, *24*, 611–631. doi:10.1080/07481180050132811
- Terry, M. L., Bivens, A. J., & Neimeyer, R. A. (1995). Comfort and empathy of experienced counselors in client situations involving death and loss. *Omega*, 32, 269–285.
- Walsh-Burke, K., & Csikai, E. L. (2005). Professional social work education in end-of-life care: Contributions of the project on death in America's social work leadership development program. *Journal of Social Work in End-of-Life & Palliative Care*, 1(2), 11–26. doi:10.1300/J457v01n02 03