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Ethical Issues for Hospice Volunteers

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Health care professionals usually receive professional education in ethics, but the half million hospice volunteers in the United States may receive only brief training that is limited to confidentiality and the volunteer role. The purpose of this study was to explore ethical issues hospice volunteers confront in their work. Interviews with 39 hospice volunteers were conducted, audio recorded, transcribed, and analyzed using qualitative methods. Prominent themes were dilemmas about gifts, patient care and family concerns, issues related to volunteer roles and boundaries, and issues surrounding suicide and hastening death. Suggestions for training include discussions of ethics after initial training once volunteers had confronted ethical issues, with special emphasis on strategies for negotiating their uneasy role positioned between health care professional and friend.

Keywords: hospice; volunteer; ethics; end-of-life; palliative care

Introduction

Health care professionals regularly grapple with ethical issues at end of life and many receive professional education in ethics.[1,2] Hospice volunteers, however, often receive only brief training in ethics, and that is largely limited to confidentiality and fiduciary relationships (such as accepting gifts, personal/professional boundaries). They have little opportunity to reflect on potential moral and ethical issues and even less opportunity to debrief real situations. Because volunteers function in the dual roles of representative of hospice and friend, this role ambiguity may create a variety of ethical dilemmas and problems not commonly experienced by other health care professionals.

The minimal scholarly literature addressing this topic suggests a need for more extensive inquiry. Of more than 500 Kentucky hospice volunteers, 4% reported being asked to help a patient end his or her life.[3] With half million hospice volunteers active in the United States,[4] this extrapolates to tens of thousands of hospice volunteers likely confronted with requests to assist with the suicide of a hospice patient.

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Four major types of ethical challenges were identified by Canadian palliative care volunteers.[5] The first was communication, especially about who should know a patient's prognosis, for example, a 6-year-old asking "Is my mommy going to die?"[5(p80)] The second involved conflicts of interest, in which volunteers were asked to "take sides" or state opinions on care, funeral options, or other issues. The third type dealt with confidentiality, such as when a volunteer was asked by an outsider whether a specific person was being cared for by the hospice and his or her status. The fourth type involved compromised care, such as when a volunteer believed that the patient was suffering because of inadequate medication.

Although ethics were not queried directly, a survey about communication issues observed and experienced by hospice volunteers[6] further suggests that volunteers confront ethical issues. Examples included whether to address honestly the patient's questions about whether she was dying while also respecting the family's wishes that she not be told, whether to help a patient go to his garage (at some physical risk and with great difficulty) to destroy materials he did not want his wife to see, whether to write a letter from the patient to someone the caregiver would not approve of, whether to speak up when the volunteer believed that the patient was seriously overmedicated, and how to address issues of morality raised by the patient herself regarding a long-held secret about a pregnancy before her marriage.

Hospice volunteers are not left to manage ethical challenges without help or preparation. Typical hospice volunteer training includes history of hospice, role of the interdisciplinary team, communication and listening skills, special needs of the dying, self-care and setting boundaries, stress management, spiritual care, caring for the family/caregiver, pain management, and grief, all topics under which ethical issues may arise. Training may also include topics specifically related to ethics such as Health Insurance Portability & Accountability Act (HIPAA) laws governing confidentiality, constraints on imposing one's own beliefs, accepting gifts, confidentiality, requests for assistance, and boundary issues.

Even though volunteer training may include ethics, content related to ethical dilemmas for volunteers is neglected in accepted guidelines or standards of practice for hospice volunteer training. In addition to following specific guidelines and consulting with hospice staff members, including the volunteer coordinator, volunteers may manage ethical challenges by drawing on their general knowledge of death and dying or personal experience as a caregiver, by weighing loyalties (perhaps competing) toward the person who is dying, family, and caregivers, and by turning to personal values that become apparent only when an issue arises. In addition, Giblin proposes that the virtues of compassion/empathy, faithfulness, justice/advocacy, and practical wisdom may serve as a basis for ethical decision making for hospice staff and volunteers.[7]

In summary, the research literature indicates that hospice volunteers are commonly confronted with ethical issues or dilemmas, but little is known about the nature of those issues or how they are managed. This study was guided by the following specific aims:

1. To investigate ethical issues that arise for hospice volunteers in working with patients, families, and caregivers at the end of life.
2. To identify general types of ethical situations or dilemmas experienced by hospice volunteers that fall outside of guidelines suggested by their volunteer training.
3. To learn more about the resources hospice volunteers use to manage ethical issues and challenges.

Methods

Study participants included 39 hospice volunteers, 33 of whom volunteered with a large hospice program (average daily census of 2700 patients with more than 500 active volunteers) in a large metropolitan area in the Southwest United States. The remaining 6 volunteered with smaller programs serving a mix of urban and rural areas in the western and southwestern United States. Participants tended to be older (average age 64), women (76%), Caucasian (100%), highly educated (median = college graduate), professional, and Protestant (42%), or Catholic (26%), with a median of 4 years volunteer experience, and a median of 20 patients/families cared for. Three volunteers reported working with 100 or more patients in a residential hospice facility.

Following University Institutional Review Board approval, prospective participants were recruited through the volunteer coordinators of hospice programs. Volunteers interested in participating were scheduled for an interview at the most convenient hospice office, where informed consent was obtained, including consent to audio-record the interview. Participants were also asked to complete a brief demographic questionnaire. Participants were offered a $10 gift card to a local merchant as a token of appreciation for their participation in the study. The 2 investigators conducted 38 interviews with 39 hospice volunteers (a wife-and-husband volunteer team interviewed together). The following opening statement and questions were used:

Often volunteers tell us that they are faced with what we call ethical or moral issues. By that we mean a situation in which you had difficulty deciding what was the right or wrong thing to do from a moral or ethical point of view. Often volunteers tell us that they feel unprepared to deal with situations that come up at the end of life. Think about your entire experience as a volunteer.

1. Describe a situation in which you were not sure about the right or wrong thing to do from a moral or ethical point of view.
2. How did you feel about it?
3. What did you do?
4. Did you talk to anybody or consult any other sources of information? If so, please explain.
5. How was the issue resolved and if it was not, why not?
6. Say you are asked to help train the next group of volunteers. Dream big here. Tell us how you might better prepare volunteers to deal with issues similar to the ones you have described.

Additional probe questions and prompts were used if needed to assist participants to further

explain their experiences and perspectives. In some cases, participants were given examples of an ethical dilemma (accepting gifts, request of assistance in hastening death). Questions about ethics were part of more lengthy interviews that ranged from 30 to 90 min in length and were audio-recorded and transcribed verbatim by a professional transcriber.

Qualitative analysis followed standard and accepted procedures for data reduction, data display, and drawing conclusions.[8] The initial data analysis approach was guided by the topics asked in the interview questions. Phrases or sentences that conveyed one specific idea related to ethical issues were considered as the unit of analysis and were selected for analysis. These phrases were then coded into tentative categories by each of the authors who then met to identify common themes and overarching constructs represented in the data. The final themes were then used by each author to review the interviews to assure that no major themes were overlooked.

Results

In the 38 interviews, 29 identified ethical and/or moral issues encountered in their role as hospice volunteer. Recalling particular experiences and patient/family situations often evoked emotional reactions ranging from sadness and tears to laughter. Although we interviewed only active hospice volunteers and did not ask them directly, no one reported experiencing so much distress that they considered resigning their volunteer position. Analysis of the 29 interviews where ethical and/or moral issues were identified yielded 4 predominant themes related to: receiving gifts, patient care and family concerns, volunteer role and boundaries, and suicide or hastening death.

Receiving Gifts

Gifts were commonly discussed, especially efforts to balance the need to follow hospice guidelines by refusing gifts against trying to be polite and avoid hurting the feelings of patients or caregivers, as illustrated in the quotes below. Most gifts were small tokens of appreciation that did not present major dilemmas, but others were of considerable value or were not even wanted. Gifts illustrate the dual roles of volunteers and the issues that accompany them. Professionals would probably not be offered gifts as often, and friends would probably not refuse them, but volunteers are put in the awkward position of being neither. It was very common for volunteers to call their volunteer coordinators to ask about how to handle gifts, but several did not.

> And the patient's wife, she says, I've got something for you. I thought, Okay, so I go over, and she was good friends of the management of a hotel chain, and she was giving me a certificate for a free night at a resort, and I said, "I really can't accept that." She says, "You will hurt me if you don't accept that." So I thought, "What do I do? What do I do? It's almost like a gift." And I know it didn't cost her anything, but that's not the principle, and I said, "Do I give it away?" And she was very adamant that I accept it, and so I didn't want to hurt her feelings, so I took it, right or wrong or indifferent, and I invited other people that, you know are friends from Hospice a long time, and maybe I shouldn't have. I just didn't know what to do with that. And I didn't tell anybody.
>
> I mean, I've had them give me little mementos, and I don't. . .They say you're not supposed to take anything. Well, I wouldn't take anything that was of any value, but, you know, to me, I'm being polite. . .um. . .and I don't. . .if it's money or anything, I just donate it to Hospice, but I don't think that that's. . .I don't even. . .I don't make a big deal of it."

Patient Care and Family Concerns

The theme of patient care and family issues also reflects dual roles. Volunteers are often in a position to observe patients' care but are neither a professional nor personal caregiver who could legitimately raise clinical concerns. As the quotes below illustrate, volunteers come to care deeply about patients and want what is best for them without being able to openly make suggestions. Volunteers often reported they tried to intervene indirectly through other members of the hospice team or the family, but on occasion took matters into their own hands.

> "the CNA came to bathe her and everything, and the CNA wanted to. . .um. . . the lady was in quite a bit of pain. . .the patient was, and I told her, I said, "You know, let's just do. . .just. . .let's not do a lot of stuff with her because, you know, I. . .she was in a coma, yet she was in a lot of pain, because for some reason the husband was withholding the pain medication, and I said, "You know, let's not move. . .let's not reposition her, and move her, because she's gonna. . .she's

gonna die, you know, and I don't want that to happen when her husband's not here." Okay. And the CNA was very adamant about it, and I just. . .and I refused, and I said, "No, you know, you can't do that. Get out of here." (LAUGHS) You know. "Go away!"

"The frustrating part was, as he got more and more almost comatose, she and/or her son would waken him, put every effort into trying to get him awake to eat. He had to eat. He didn't want to wake up. He fought that so badly. And they would just. . .they harassed him to bring him to consciousness. They were both reluctant to let him go. . ."

Volunteer Role and Boundaries

Dual roles were most apparent in cases falling under the third theme of volunteer role and boundary issues. Issues might be as simple as being asked to stay for longer hours as one might ask of a friend but not of a professional. More wrenching examples concerned providing medical care (such as pain medication in the second quote below) as one would ask of a professional or personal caregiver, but which is beyond the scope of the volunteer role. Although this volunteer clearly understood the hospice guidelines for dispensing medication, she or he was distressed by having to watch the patient suffer. Volunteers reported they usually circumscribed their roles according to hospice guidelines but on occasion did what the patient or family wanted.

the person asked me if I would. . .if I would stay 8 hours – for the day, and I told 'em, "No, that's really not my job." I said, "It's a four-hour shift and I'll be glad to do that, but 8 hours. . .that's really a lot."

Larry was in pain, and made it very clear that he wanted his morphine, which, of course, is an absolute. . .you know, that's a no-no, as far as. . .you know, I'm not supposed to be dispensing medication, as you well know....it was, for me, a very uncomfortable and difficult situation to be in, cause on the one hand, you don't want to watch a human being suffer. On the other hand, it was made very clear to me that, you know, "this is something you don't do!"

Suicide or Hastening Death

Volunteers reported requests for assisted suicide, but did not seem to anguish over such requests; rather they recognized very clearly that those were beyond their roles as volunteers (see the quotes below). More problematic was talk about suicide, and the volunteers were concerned about possibly encouraging the patient by listening empathically. Often they reported their concerns about suicide to other hospice team members to alert them.

she was so miserable, she wanted me to contact this Dr. Kevorkian, and so trying to talk her out of it without disparaging her wishes, or you know, disappointing her was. . .it wasn't that I was tempted to contact the Doctor Kevorkian, but it was a moral question, you know, she. . .she wanted to be right with God, but she was talking about having, you know, ending her own life".

. . .there's a book, Final Exit. Well, this lady. . . had read it already, and I said, "Well, there's another book," and so after she had brought the topic up of suicide and that, how she'd tried it, and she wasn't able to. . .to do it, and she was just ready, and so talked about the book and that, and talking about suicide with a patient. . .in an In-patient Unit, and I know it's not the philosophy, but it was her discussion, and I didn't promote it or anything. It was just a discussion to talk about, so I guess talking about that with somebody would be considered. . .kind of like I shouldn't be doing it, but it interested me to talk to her about it, and she was a very open person, and everybody around. . .in there, knew that she wanted to die, and she was ready, and she ended up passing away there a week-and-a-half later.

For the most part, volunteers felt well supported, especially by the volunteer coordinator and other members of the hospice staff. When responding to the questions addressing their actions, volunteers indicated they would call the volunteer coordinator, other staff on the hospice team (which included the nurse, social worker, and chaplain), or the family. Others indicated that unless they felt they should not, they did what the patient wanted. Most everyone said, in addition to calling for help or advice, they would "just listen."

When asked about how to include ethical issues in training more effectively, volunteers offered some advice. Several indicated that training in advance does not help much because, as one volunteer stated, "volunteers don't get a handle on issues until they are confronted with them," and suggested follow-up in-services once volunteers had several months of experience. One volunteer suggested the use of

simulated scenarios so that volunteers could discuss and work through ethical concerns in specific situations. Others said that volunteers should use their own ethical judgments, with one summing it up by saying "you have to search your own heart."

Discussion

Ethical and/or moral issues were commonly reported by hospice volunteers, but the general types varied from results of earlier research. They recognized that assisted suicide was unethical and did not seem torn about what to do, but struggled with whether to discuss assisted suicide with patients for fear that it might encourage them to take their own lives. Compared to earlier studies, this research demonstrated less concern about communication, confidentiality, and conflict of interest. Earlier studies also revealed volunteers' concern for inadequate care whereas volunteers in this study were also concerned with unnecessary care that may have caused patients to suffer.

Several issues found in this study not highlighted in previous research pertained to the unusual status of volunteers as neither health professionals nor friends. Gifts draw volunteers into dilemma of either accepting a gift and violating hospice rules or refusing the gift and offending the giver. If friends, they could have accepted the gift; had they been professionals it might not have been offered. In addition, boundary violations such as asking volunteers to stay longer treated them like friends whereas asking them to administer needed medication treated them like professionals.

There are several implications for educating and supporting volunteers in orientation and on an ongoing basis throughout their volunteer experience.

1. In training, acknowledge the dual roles that volunteers serve as "not quite health care professional" and "not quite friend" and the consequences.
2. Reinforce the reasons underlying hospice guidelines related to accepting gifts, intervening in medical care, and circumscribing the volunteer role.
3. Consider developing follow-up in-service training using typical scenarios that volunteers might encounter and options for dealing with them.

Volunteers, many would argue, are the "heart" of hospice care in the United States. They often witness the entire range of the experience of death and dying for patients and families, including difficult real-world ethical issues. In responding to these challenges, the volunteer must negotiate the gray area between the roles of friend and health care professional. Those of us who work with hospice volunteers are called upon to prepare and support them in addressing ethical issues in their important work.

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