SPIRITUAL CARE AT THE END OF LIFE

Some Clergy Lack Training in End-of-Life Care

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Religious leaders historically served as both physical and spiritual healers.[1] However, by the mid-19th century there was a clear division between science and religion.[2] The division progressively separated the clergy from significant roles in physical healing, which was relegated to medicine and its practitioners. The rapid advances of medical science and technology in the late 20th century widened this division. The ascendance of medicine and physician dominance over the realms of injury and illness may have been accelerated by a contemporaneous retreat from the bedside of seriously ill or acutely grieving people by clergy. Little information exists about present-day clergy's values and attitudes regarding the provision of spiritual care during times of illness, dying, death and grief, or about their experience with those phenomena.[3]

Research indicates that people value spiritual care and spiritual well-being at the end of life.[4] In 1997 the Life's End Institute (LEI), Missoula,

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MT, conducted a mailed survey of 1,200 randomly selected community residents. Eighty-nine percent of the respondents indicated that spiritual well-being would be important to them at the end of life. In a recent study that AARP (formerly the American Association of Retired Persons) conducted of its members in North Carolina, 92 percent said that being at peace spiritually would be important at the end of life.[5]

The clinical literature reveals a growing recognition that spiritual care can contribute to dying persons' quality of life and is an important domain of quality of medical and nursing care.[6] In Missoula, a structured interview study involving family members of people who died a non-sudden death in 1996-1997 found that spiritual care can make a positive difference. As part of the interviews, the researchers used the Quality of Dying and Death (QODD) questionnaire developed by J. Randall Curtis and Donald L. Patrick. Respondents reported higher ratings of the decedent's quality of dying and death as a result of being read to from a spiritual book, talking with a spiritual leader or counselor, praying together as a family or community, having the support of friends from a spiritual group, and going to a church or place of worship.[7] Not all spiritual care carried the same impact. Religious or spiritual experiences that were not associated with statistically significantly higher QODD scores included the patient's identifying with an organized religion or having a spiritual orientation, talking with the health care team about religious or spiritual concerns, making amends before dying, having a chance to talk about beliefs, and participating in final rites of a faith community.[8]

A 1997 Gallup survey, "Spiritual Beliefs and the Dying Process," suggested that people may not always receive the level of support and spiritual care they desire.[9] Gallup survey respondents

indicated that, if they were dying, they would want human contact (54 percent), especially with someone with whom they could share their fears and concerns (55 percent). Many expressed a desire for holding hands or touch (47 percent). Fifty percent indicated that prayer would be very important, as would having a person to help them become spiritually at peace (44 percent). These practices lie within the traditional domain of the ministry. Yet people currently have low expectations of clergy. Only 36 percent of the Gallup survey respondents felt the presence of a clergy person would actually be comforting for them at such a time.

Previous research in the Missoula community substantiates these national data. Respondents to the 1997 mailed community survey indicated that, as they near life's end, they would be more likely to rely for support on a spouse (81 percent), children (71 percent), other immediate family members or relatives (66 percent), and friends (46 percent) than on a faith community (23 percent). Of note, 68 percent of the survey respondents described themselves as religious or spiritual. These results are similar to the findings of the AARP survey of North Carolina members, in which 83 percent of the respondents indicated that they considered themselves religious or spiritual; 54 percent reported attending services regularly; and 21 percent reported doing so occasionally. Fifty-one percent said they "find strength in religion or spirituality" one or more times a day and 20 percent reported doing so a few times a week.[10]

The importance of religion and spirituality in people's lives and the relatively low prevailing expectations of faith communities and their leaders have led researchers at the Institute of Medicine to raise questions about the training ministers receive.[11] Two writers, K. J. Doka and M. Jendreski, suggest that clergy's lack of education about grief is an obstacle that prevents them from being of greater solace to the bereaved.[12]

A COMMUNITY-BASED STUDY

In 1997 LEI convened a Missoula Faith Community Task Force, composed of lay people and clergy representing 14 different Missoula local faith communities. The task force was intended to be the central part of a long-term community-based effort to improve end-of-life spiritual care in Missoula County.[13] The task force determined that before beginning efforts to improve the quality of end-of-life spiritual care, it must first get information from a broader representation of Missoula faith leaders. LEI

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researchers, the authors of this article, conducted the study, a summary of which is presented here.

Missoula County is in western Montana. It has a population of approximately 88,000 people, some 50,000 of whom live within the city of Missoula. The latter figure includes more than 10,000 people at the University of Montana. Missoula County is 96 percent Caucasian and 3.4 percent Native American. The average annual income is about $20,000.

LEI charged the task force with enhancing individual, family, and congregational preparation for dying, death, and bereavement. In collaboration with task force members, LEI developed a Faith Community Leader (FCL) survey as an instrument with which it could study the levels of training, perceived assets and liabilities, and experience of local clergy in regard to the provision of spiritual care to dying people and their families. The FCL survey was one component of a baseline assessment of the clergy members' prevailing values, the extent of their training, the patterns established in their spiritual care practice, and their comfort with that practice.

Methods We hypothesized that faith community leaders who lack training in areas of illness, death, funerals, and bereavement will:

• Experience lower levels of comfort ministering to people in end-of-life situations

• Provide end-of-life spiritual care services less frequently

• Provide a narrower range of spiritual care services to people at these times of life

Instrument We began development of the FCL survey by reviewing the literature. We then wrote a preliminary draft, which was critiqued by both task force members and scholars in related fields, and made repeated refinements to it. The survey was structured as a self-assessment tool. It was designed to gather a range of information about respondents' backgrounds; education and training; congregations; personal experience; values; attitudes; and beliefs related to illness, dying, death, and grief, as well as to their sense of personal and professional preparation for spiritual care through life's end.

One section of the survey assesses respondents' comfort level with providing spiritual care for seriously ill and dying people, with bereavement counseling, and with performing pertinent rituals. The survey asks about the strengths respondents think they bring to providing this spectrum of spiritual care and about perceived barriers. Several items inquire about respondents' experiences in working with other professionals (health care clinicians, chaplains, funeral directors, nurs-

ing home personnel) in the community, and about perceived patterns of communication related to illness, care, and grief with health care professionals.

Pilot Survey To test the ease with which respondents would comprehend and complete the survey, we used a late draft of it to conduct a pilot study involving faith community leaders living outside Missoula County. Pilot questionnaires were completed and returned by 12 respondents. We then revised the survey in response to pilot data.

Recruiting Subjects We compiled a list of faith community leaders in Missoula County, using lists from the two local ministerial associations, the local telephone directory, a chamber of commerce directory, and newspaper listings. Task force members and other local faith leaders reviewed the list for possible omissions.

Procedures To the people on our list we mailed packets that included an introductory letter, an LEI brochure, an LEI newsletter, a coded survey questionnaire, and a postage-paid return envelope. One hundred twenty-two surveys were mailed. Recipients were asked to complete and return the survey within two weeks. As an incentive to do so, we offered each a copy of *A Handbook for Busy Parish Pastors on End-of-life Discussions and Decisions* by Carol Garman, a pastor in Minneapolis. We made a single follow-up phone call to recipients who were delayed in returning the survey.

THE SURVEY'S RESULTS

Of the 122 mailed surveys, 41 were completed and returned, for a response rate of 34 percent.

Demographics The median age of respondents was 51; 80 percent were male and 20 percent female. Fourteen percent had been ministers for 10 years or less, 56 percent had been such for between 11 and 30 years, and 22 percent for more than 30 years. Respondents identified their religious affiliations as Lutheran (20 percent), Catholic (15 percent), other mainline Protestant churches (23 percent), evangelical churches (40 percent), and the Church of Jesus Christ of Latter-Day Saints (2 percent).

Training The majority of respondents had a college degree or higher (69 percent). Of these, 17 percent had bachelor's degrees, 12 percent master's of arts, 32 percent master's of divinity, and 10 percent doctorate of ministry. Of the remainder, 29 percent had other types of training, ranging from classwork in college or Bible school to experience in missions or on-the-job training with ministers. A majority had some training in spiritu-

> A majority of survey respondents had some training in spiritual care pertinent to end-of-life situations.

al care pertinent to end-of-life situations. Sixty-one percent reported training in ministry during times of death. Slightly fewer indicated that they had received training in illness (54 percent) and bereavement support (54 percent). Forty-nine percent of survey respondents received training in funerals or memorials. Only one-third (34 percent) indicated that they had no training in any area of end-of-life ministry: illness, death, funerals, or bereavement.[14]

Values Clergy respondents held strong values with regard to end-of-life experience and care. On a seven-point scale, 98 percent strongly agreed (6 or 7 rating) with the statement, "Dying is an important stage of life." One hundred percent agreed (6 or 7 rating) with the statements, "Caring for people who are dying is beneficial for those giving care" and "The end of life can be an important time for spiritual growth."

On items with an 11-point scale, from 0 to 10, 80 percent of respondents strongly agreed (at a rating of 8, 9, or 10) that "the presence of a spiritual caregiver is comforting to those who are ill and their family members." Ninety percent indicated (8 or higher) that "talking with a dying person and the family about death is more helpful than disturbing." Without exception, responding faith community leaders felt that "listening is a powerful ministry of spiritual caregivers who work with the ill and dying," and that "giving spiritual care at the end of life is a meaningful experience for the spiritual caregiver."

Personal Experience All of the respondents indicated they had personal experience with one or more end-of-life experiences and situations. Illness (95 percent) and death (95 percent) were the areas of experience most frequently reported. Personal experience of funerals or memorials was reported by 90 percent of the respondents, whereas 83 percent reported personal experience with bereavement.

Personal Practice Most of the respondents had discussed their end-of-life wishes with their immediate families (95 percent). A smaller majority (66 percent) indicated that family members had a clear understanding of each other's wishes. A minority of 29 percent had signed advance directives. Twenty-four percent (24 percent) had pre-planned their funeral or memorial service.

Professional and Personal Preparation Professional preparation for assisting others with end-of-life issues and personal preparation for dealing with end-of-life issues were assessed using an 11-point scale from "worst possible" (0) to "best possible" (10). Slight majorities felt that their professional education had prepared them well (designated as

a rating of 8 or above) for assisting others with issues of bereavement (51 percent) and death (54 percent). Sixty-three percent felt their education had well-prepared them for dealing with funerals and memorials. In contrast, a minority (34 percent) gave a high rating (8 or above) to their professional preparation for assisting others with illness.

Larger percentages of respondents highly rated their personal preparation for dealing with issues of bereavement (63 percent), illness (66 percent), death (76 percent), and funerals or memorials (83 percent).

Comfort with Ministry As shown in **Table 1**, a majority of respondents indicated high levels of comfort (8, 9 or 10 rating) for all listed aspects of care associated with illness, death, and bereavement, in all health care settings, as well as with interactions with professionals. The sole exception was medical terminology, in which a sizable minority of 44 percent reported comfort. A slight majority, 56 percent, said they felt comfortable dealing with issues of physical symptoms of illness. Comfort providing spiritual care varied by setting. Respondents were more likely to feel comfortable ministering to people who are seriously ill at home with hospice care (85 percent) than in the hospital (80 percent), a hospice house (76 percent), at home without hospice (76 percent), or in a nursing home (71 percent). Fewer respondents expressed high levels of comfort interacting with doctors (66 percent) than with hospice staff (76 percent), nursing home staff (78 percent), funeral home staff (78 percent), or hospital staff (80 percent).

Relationship between Training and Ratings of Professional and Personal Preparation The survey asked respondents to evaluate how well training and personal experience had prepared them to deal professionally with illness, death, funerals or memorials, and bereavement support. The

responses showed that, in general, Missoula County clergy felt they had been well-prepared in these areas by both training and experience.

However, responses differed when it came to specific practices. When respondents were asked, for example, to "indicate how frequently you provide spiritual care for those within your faith community who are at the end of life?" they revealed that those possessing a higher level of education were likely to provide end-of-life spiritual care more frequently than those with a lower level. Respondents who were trained to deal with issues of illness, death, and bereavement support reported providing prayer and quiet presence

Table 1: Clergy Comfort Level

How comfortable respondents are with:	Number who said they were comfortable
Illness and Death:	
• Being with a dead body	33 (80%)
• Physical symptoms of illness	23 (56%)
Pastoral Care: *How comfortable respondents are with:*	
• Performing rituals for people who are dying	39 (95%)
• Discussions about imminent death	37 (90%)
• Being with the family of a dying person at the time of death	37 (90%)
• Providing quiet presence with people who are dying	36 (88%)
Death Rituals: *How comfortable respondents are with:*	
• Performing a memorial service (without the body present)	36 (88%)
• Performing a funeral (with the body present)	33 (80%)
Bereavement Care: *How comfortable respondents are with:*	
• Visitation of bereaved friends and family	37 (90%)
• Being with the family of the deceased after the funeral	35 (85%)
• Referral support for bereaved friends and family	30 (73%)
• Providing grief support for family and friends	28 (68%)
Care Facility: *How comfortable respondents are with:*	
• Ministering to seriously ill people in hospice care in their homes	35 (85%)
• Ministering to seriously ill people in the hospital	33 (80%)
• Ministering to seriously ill people at the hospice house	31 (76%)
• Ministering to seriously ill people at home without hospice care	31 (76%)
• Ministering to seriously ill people in a nursing home	29 (71%)
• Ministering to families at a funeral home	28 (68%)
Professional Caregivers: *How comfortable respondents are in:*	
• Interacting with hospital staff	33 (80%)
• Interacting with funeral home staff	32 (78%)
• Interacting with nursing home staff	32 (78%)
• Interacting with hospice staff	31 (76%)
• Interacting with physicians	27 (66%)
• Understanding medical terminology	18 (44%)

more frequently than those who did not have these types of training. Respondents trained to conduct funerals also provided prayer more frequently than did those not trained in this area. Those trained in bereavement support were more likely to report frequently practicing "holding hands or appropriate touch" than those who were not trained in that area. Respondents who were not trained in any of these areas were less likely to engage in holding hands or appropriate touch, prayer, offering quiet presence, or providing sacrament of the sick than those who were trained in at least one of the areas.

Of the 12 ministerial practices specified during times of bereavement (see **Table 2**), visitation by clergy (95 percent) and cards and letters expressing sympathy (93 percent) were provided most frequently. Grief support (17 percent), financial counseling (22 percent), and education about grief (37 percent) were provided the least frequently.

Personal experience also had an impact on professional preparation. Respondents who had personal experience with funerals showed a higher level of professional preparation for conducting funerals or memorial services than those who lacked such experience. Respondents who had personal experience with death showed a higher level of professional preparation for extending bereavement support than those who did not have similar experience.

WHAT DID WE LEARN?

Before reporting the study's conclusions, we should say a word about its limitations. One limitation was the small sample size. Subgroup analyses are not possible in situations in which there are a small number of respondents per group. Thus it was not possible to examine the impact of all of the variables in this survey on clergy comfort or practice. Further research on larger samples would be required for more rigorous analyses. This, in turn, would contribute to a better understanding of the relationship of clergy training, comfort, and practice.

However, the findings of this small study do indicate that leaders of faith communities value end-of-life experience and care and recognize they have a role in supporting ill and dying persons and their families. The study reveals discrepancies between several aspects of ministerial practice that faith community leaders' value and the frequency and extent of services they routinely perform. Our findings emphasize the importance of clerical training in these aspects of spiritual care and highlight current deficiencies. Strong positive associations were found between training and perceived professional preparation and personal preparation for dealing with illness, death, funerals or memorials, and bereavement support. Importantly, we also found direct relationships between levels of training and the range and frequency of services ministers provide.

The relationship between training and comfort is less straightforward. Clergy generally reported high levels of comfort whether or not they had training in end-of-life spiritual practices. Although no significant relationship was found between training and comfort in four broad areas of illness–dying, funerals or memorials, bereavement support, and comfort with specific ministerial services—overall those respondents who had training tended to have higher levels of comfort with end-of-life spiritual care practices than did those who lacked training.

Several statistically significant associations and trends were found between areas of comfort and specific spiritual care practices. This is an area that warrants further study. It is possible that a larger sample would have revealed additional direct correlations.

Review of the data suggests, although this was not captured in formal statistical analysis, that respondents were more likely to feel comfortable

Table 2: Services Provided to Bereaved Families

The clergy members who responded to questions about the following services were free to define the services as they wished.

Types of Services	Number who provided them
Visitation by clergy	39 (95%)
Cards and letters	38 (93%)
Visitation by lay members	37 (90%)
Meal preparation and delivery	33 (80%)
Memorial celebrations	31 (76%)
Plant or flower donations	27 (66%)
One-on-one support from a fellow bereaved member of your faith	26 (63%)
Referral to support groups or counseling	24 (59%)
Special invitation to faith community functions	18 (44%)
Education about grief	15 (37%)
Financial counseling	9 (22%)
Grief support group	7 (17%)

with and provide more discrete ministerial services, and immediate, short-term types of support, such as visitation, or sending cards and letters. They were less likely to report convening grief support groups and participating in education about grief. Illness and grief are complex issues and present unpredictable challenges. Because society has extended the length of the dying processes—today fewer people die suddenly—the contemporary dying experience means more "in between" times: more waiting, more chronic illness, and more disability.[15] Ministering to people with life-threatening illness and to family during months of grief may be less well defined and require a more intensive level of training than do rituals at funerals or memorial services.

IMPLICATIONS

The values that clergy hold regarding illness, dying, death, and grief are consistent with those of the general population. It is reasonable to expect the training of clergy to be aligned with these values. At present, apparent discrepancies exist between the roles clergy feel are important and accept within the purview of ministerial practice, on one hand, and the scope of their training, on the other. These discrepancies appear to contribute to constrictions in clerical practice. As a result, the range of services many faith community leaders provide is narrower and less inclusive than their own values and those of the public they serve would suggest.

Our study's findings highlight the importance of training and continuing education of clergy with regard to end-of-life spiritual care. The findings suggest specific areas for attention. Comfort with medical terminology was comparatively low. This is an area that lends itself to simple education. Participating clergy were relatively less comfortable talking with physicians than with other clinicians, which suggests that interdisciplinary training or continuing education may improve collaborative practice to the benefit of the patients and families both professions serve.

It is tempting to posit a causal chain linking clerical training in issues of illness, dying, death, and grief, on one hand, to a clergy person's sense of preparation, his or her sense of comfort with those phenomena, and to the frequency and range of spiritual care that he or she practices, on the other. Although such a chain is plausible and intriguing, our study's size and design do not allow for examination of all the links in it. At present, the existence of a causal chain remains a hypothesis that warrants further study. Studies

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are warranted to examine whether enhanced training of clergy in end-of-life matters can expand the scope of clerical practice and raise expectations and satisfaction among congregants regarding spiritual care they receive during times of illness, dying, and grief.

Discrepancies between what clergy clearly value and their patterns of practice may reflect an aspect of the cultural medicalization of dying that occurred during the 20th century. Personal and social aspects of dying have been subordinated by medicine, and medical terminology has come to dominate the language of dying. Health care remains essential for people who are dying or in grief, but by itself cannot meet all of people's needs during these difficult times in human life. Technology-based care cannot provide spiritual comfort and peace. The time may be right for clergy, drawing encouragement from surveys of public attitudes and values, to reclaim and renew their traditional roles in attending to the needs of patients and families during illness, dying, death, and bereavement. Faith community leaders have an historic—and still valued—role for care and family support during the times of illness, dying and grief. □

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GIVING PATIENTS A "GOOD DEATH"

gram? "Enlist a champion who's dynamic, gung-ho, passionate, and respected in the community and the hospital," urges Dr. McDonah. "Also, get a very good administrative person, since passion and organizational skills don't often go together. And look at care for the caregiving team, to prevent burnout."

"Identify key people to serve on the team who represent various disciplines but share the same philosophy of care," advises Lammers. "They must be comfortable discussing end-of-life issues and have no agenda. The level of support from the top down must be generated and sustained. And education is key—you must engage the community. End-of-life issues aren't black-and-white, and it's not cookbook medicine. There's no algorithm for end-of-life care; you have to work with patients and their families on an individual basis. And meet them where they are.

"It's tough work," Lammers says. "I go home emotionally exhausted. But I wake up the next day and I want to be here." □

NOTES

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