Clergy Views on a Good Versus a Poor Death: Ministry to the Terminally Ill

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Abstract

Background: Clergy are often important sources of guidance for patients and family members making medical decisions at the end-of-life (EOL). Previous research revealed spiritual support by religious communities led to more aggressive care at the EOL, particularly among minority patients. Understanding this phenomenon is important to help address disparities in EOL care.

Objective: The study objective was to explore and describe clergy perspectives regarding “good” versus “poor” death within the participant’s spiritual tradition.

Methods: This was a qualitative, descriptive study. Community clergy from various spiritual backgrounds, geographical locations within the United States, and races/ethnicities were recruited. Participants included 35 clergy who participated in one-on-one interviews (N = 14) and two focus groups (N = 21). Semistructured interviews explored clergy viewpoints on factors related to a “good death.” Principles of grounded theory were used to identify a final set of themes and subthemes.

Results: A good death was characterized by wholeness and certainty and emphasized being in relationship with God. Conversely, a “poor death” was characterized by separation, doubt, and isolation. Clergy identified four primary determinants of good versus poor death: dignity, preparedness, physical suffering, and community. Participants expressed appreciation for contextual factors that affect the death experience; some described a “middle death,” or one that integrates both positive and negative elements. Location of death was not viewed as a significant contributing factor.

Conclusions: Understanding clergy perspectives regarding quality of death can provide important insights to help improve EOL care, particularly for patients highly engaged with faith communities. These findings can inform initiatives to foster productive relationships between clergy, clinicians, and congregants and reduce health disparities.

Introduction

Religion significantly influences end-of-life (EOL) care in the United States, as approximately two-thirds of terminally ill patients report religion is very important and more than half are visited by community clergy.1,2 Religious communities appear influential in patients’ medical decisions and utilization, especially among racial minorities.3,4 An intriguing finding from a previous multisite, prospective study of terminally ill cancer patients (the Coping with Cancer study) was that spiritual support by clergy and religious communities led to more aggressive care at the end-of-life (EOL).1,3–6 Specifically, African American and Latino patients who reported being well supported spiritually by their religious communities were less likely to enter hospice, more likely to receive aggressive medical treatment, and...
more likely to die in the intensive care unit (ICU). A clearer understanding of this phenomenon is critical, as greater medical care intensity at EOL can result in poorer patient and caregiver quality of life, and significantly impact the death experience. Hence, this follow-up study investigates community clergy perspectives (with an emphasis on Christian-affiliated Black clergy) regarding the quality of the death experience within the participant’s spiritual tradition. The broad goal of this research is to improve partnerships among clergy, congregants, and health care providers, and to meet calls to improve care for the dying.

Methods

Sample

Eligible participants included ministers and pastors (i.e., clergy) currently serving in a community congregation. The project preidentified clergy characteristics (race, theological orientation, educational level, and denomination) hypothesized to be associated with more intensive medical utilization at EOL; this led to the selection of a predominantly Christian and theologically conservative sample. Within each geographical region of the United States a key informant with access to local community clergy identified and recruited potential participants in consultation with the principal investigator (MB). Clergy were interviewed in one-on-one interviews (N = 14) or focus groups (N = 21) within five U.S. states (California, Illinois, Massachusetts, New York, and Texas). All participants provided informed consent per protocols approved by the Harvard/Dana-Farber Cancer Center institutional review board.

Protocol

Clergy were enrolled between November 2013 and September 2014. Semistructured interview guides were developed by an interdisciplinary panel of medical educators and religious experts. Interviews were organized around a core set of open-ended questions exploring the viewpoints of clergy regarding death (see Table 1). Research staff underwent a half-day training session in interview methods and received ongoing supervisory guidance from MB ensuring homogeneous interview procedures. Two interviews were conducted in Spanish and transcripts were translated into English. Interviews and focus groups ranged between 45 and 120 minutes in duration and participants received a $25 gift card as compensation.

Qualitative methodology

The protocol’s methodology includes triangulated analysis and involvement of multidisciplinary perspectives (nursing, medicine, sociology, theology), maximizing the transferability of interview data. Interviews were audiotaped, transcribed verbatim, and participants were deidentified. Following principles of grounded theory, a set of themes and subthemes inductively emerged through an iterative process of constant comparison. Transcripts were analyzed independently by all authors, and the final coding scheme was then derived through a collaborative process of building consensus among all authors. After finalizing the codes, transcripts were then reanalyzed using NVivo 10 (QSR International, Doncaster, Victoria, Australia) by AB and SN, each coding independently based on derived categories and themes.

Results

Demographic information is provided in Table 2. Consistent with the intent of this study, minority clergy were oversampled (including a focus group comprised of all Black clergy) in order to deepen understanding of minority clergy views on death and medical utilization.

Primary themes and key determinants of the death experience

Participant responses focused on perceived qualities and characteristics of the death experience from both their individual perspective as clergy ministering to patients and families with unique circumstances and needs, and within the larger context of their respective faith tradition. The death experience was interpreted broadly by participants and involved preparing for death, the physical and spiritual act of dying, and the bereavement period. Clergy discussed a good death as one characterized by wholeness and certainty; whereas a poor death was characterized by separation, doubt, and isolation. Quality of death was described as involving both positive and negative elements, and location of death was discussed in terms of its potential influence on the death experience.

Characteristics of good and poor dying

Participants frequently described a factor they felt contributed to wholeness and certainty (e.g., a “good” death) and then discussed its absence, or opposite, as consistent with contributing to separation, doubt, and isolation (e.g., a “poor” death):

A good death, I say a “holy death” [you] will be surrounded by family and friends in an atmosphere of prayer in which you have had the chance to reconcile with people… and you are at peace with God… and, of course, in the physical part, if you have your medicine that helps you with the pain, that is part of it as well. We can take any one of those elements and remove them, and then you have a poor death (CM1217).

Clergy identified four core factors contributing to either wholeness and certainty (a good death) or separation, doubt, and isolation (a poor death): dignity, preparedness, physical

| Prompt 1: Please share any memorable examples of what you would consider a good or poor death. |
| Prompt 2: Does where someone dies affect your thinking about a good or poor death? For example, does the location of death such as the person’s home, or hospice, or a nursing home, or medicalized settings, such as the hospital or intensive care unit, affect whether it was a good or poor death? |
Theological orientation (n = 34)

<table>
<thead>
<tr>
<th>Clergy characteristics</th>
<th>N = 35</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male gender</td>
<td>32</td>
<td>91.4</td>
</tr>
<tr>
<td>Average years serving as clergy (N = 32)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geographical location</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>11</td>
<td>31.4</td>
</tr>
<tr>
<td>Southwest</td>
<td>11</td>
<td>31.4</td>
</tr>
<tr>
<td>Midwest</td>
<td>10</td>
<td>28.6</td>
</tr>
<tr>
<td>West</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Race (N = 32)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>16</td>
<td>50.0</td>
</tr>
<tr>
<td>Black</td>
<td>14</td>
<td>43.7</td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
<td>6.3</td>
</tr>
<tr>
<td>Ethnicity (N = 30)</td>
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<td></td>
</tr>
<tr>
<td>Latino/Hispanic</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>Religious tradition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protestanta</td>
<td>27</td>
<td>77.1</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>Eastern Orthodox</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Jewish</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Other (Center for Spiritual Living)</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Educational level (N = 34)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below master’s degree</td>
<td>6</td>
<td>17.7</td>
</tr>
<tr>
<td>Master’s degree (e.g., M.Div.)</td>
<td>15</td>
<td>44.1</td>
</tr>
<tr>
<td>Doctoral degree</td>
<td>13</td>
<td>38.2</td>
</tr>
<tr>
<td>Theological orientation (N = 32)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Theologically “conservative”</td>
<td>21</td>
<td>65.6</td>
</tr>
<tr>
<td>Theologically “liberal”</td>
<td>11</td>
<td>34.4</td>
</tr>
<tr>
<td>Received prior training in end-of-life care (N = 31)</td>
<td>23</td>
<td>74.1</td>
</tr>
</tbody>
</table>

*DProtestant clergy identified with the following Protestant denominations: Assemblies of God (2), Baptist (5), Congregational (4), Episcopalian (1), Methodist (3), Nondenominational (6), Presbyterian (1), and Seventh-Day Adventist (1). Four Protestant clergy did not disclose specific denominational information.

*Clergy were categorized as theologically conservative if they agreed with the following statement: “My religious tradition’s Holy Book is perfect because it is the Word of God.”

*Not all participants responded to every question.

Preparedness

A second key determinant of the death experience was preparedness. Clergy discussed this sense of readiness in multiple, interconnected domains—spiritual/emotional, social, and practical. Adequate preparation depended on acceptance of death (at least to some degree) by the patient and family. Without acceptance, preparation within any domain was impeded, rendering dying more difficult.

Spiritual and emotional preparedness. Spiritual preparedness was seen in the larger theological framework of experiencing peace with God and possessing a confident and hopeful outlook about the afterlife. Rituals that facilitated spiritual preparedness included prayer, baptism, saying confession and seeking forgiveness, making a final commitment of faith, receiving religious rites and sacraments before death, and having the opportunity “to get right with God” (focus group participant, MJB 1030FG-C). Patients unable to achieve these goals—either due to circumstances surrounding their death or an unwillingness or inability to spiritually prepare—were seen to be at high risk for a poor death. Clergy viewed abrupt and untimely deaths that precluded appropriate emotional preparation, such as traumatic or violent accidents, sudden medical events, suicides, or the death of a young person, as especially difficult and sad deaths. Spiritual and emotional preparedness, when achieved, were viewed as bringing harmony and overall well-being to the patient and family/caregiving unit.

Social preparedness. Social preparedness manifested as reconciliation between individuals and the resolution of relational conflict. Clergy discussed many examples from their own ministry of how anger, regret, and conflict threatened social preparedness. One participant recalled witnessing two adult children physically fighting at a patient’s funeral; another remembered a dying congregant whose lack of regard for others created great strife: “This was an angry, determined person who just said, ‘I am not going to let this [illness] get me. … I don’t care who I hurt.’” (MB107).

Practical preparedness. Patients who put their domestic and financial affairs in order, and were able to leave a positive legacy for survivors, demonstrated practical preparedness. Ideally, this sort of practical preparation was handled proactively before a crisis, and involved deliberate and concrete actions, such as executing a will to ensure peaceful distribution of one’s assets.

Physical suffering

Clergy were unanimous in their shared opinion that the quality of the death experience depended on the amount of pain and distressing symptoms a patient experienced. Even if a patient was spiritually ready, unrelieved physical pain was viewed to have the potential to transform the EOL experience into a highly negative event. No participant discussed physical suffering as having an inherently positive value.
TABLE 3. SUMMARY OF PRIMARY THEMES AND KEY DETERMINANTS
AFFECTING THE QUALITY OF THE DEATH EXPERIENCE

<table>
<thead>
<tr>
<th>Good death</th>
<th>Poor death</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary theme:</strong></td>
<td><strong>Primary theme:</strong></td>
</tr>
<tr>
<td>Wholeness and certainty</td>
<td>Separation, doubt, isolation</td>
</tr>
</tbody>
</table>

**Dignity**

I think what is important in dying is that a person is able to die with dignity. … Being able to carry out some of the wishes of the dying, so that person says, ‘I would like to die at home, I want to be at home’—giving them that opportunity to do so is very important—dying with that dignity. (MJB1030FG-E)

I think to me a good death is a death with dignity. And also at peace in the person’s own heart. (TC1030)

A good death is one in which a person’s wishes were honored. (MJB1030FG-B)

I said, ‘Do you want to accept Him [Jesus]?’ He [the patient] said, ‘Yes.’ I said, ‘Okay, let me call your family. … I’m not going to do anything if you personally don’t feel a desire that you want to do it.’ (MB1021)

**Preparedness**

A good death is where the person is absolutely confident of what’s happening on the other side, where there’s no doubts, no uncertainty, where they are sure where they’re going. (MB107)

When they put in the balance the things that they did and on the other side the things that they could not accomplish or even the wrong things, at the end they are satisfied. (JP414)

For me the difference is a good death is when you are prepared; a poor death is when you are unprepared. (MJB1030FG-K)

They recognize that this is just another stage, a portal, to something else that God has prepared for us theologically. (MB107)

I would characterize a good death … when people have an opportunity to perhaps reconcile relationships. (MJB1030FG-D)

A good death is also when they prepare themselves to leave their legacy behind. (MB129)

A ‘good death’ is when the person, at various stages in his or her life, put their house in order; they decided who is going to get what; not making that decision at the time when that transition occurs. (MJB1030FG-G)

I would say a good death is one that helps you to be reconciled and at peace with yourself, with your past life, with God and with others; so to be at peace in those three areas, with your own life, with God and with others. (CM1217)

Then after explaining [to] them some principles and truths about scripture most of them enter into this sphere of peace. Then I ask them again, ‘How do you feel now?’ And many times I have heard something like, ‘I am ready. I am ready.’ (JP414)

I’ve witnessed people who have had a good death when they have understood … that there was definitely going to be closure to life and had an understanding that they need to be prepared for that end. (MB129)

**Preparedness**

[A good death] is the pain and the deterioration of the health makes the person feel like subhuman or even look like subhuman because of the sickness … the clothing poorly changed and smell. (TC1030)

I knew of a patient who did not want to be resuscitated but the family wanted him to be resuscitated. It was not a good sight. For me a poor death is one who dies and his or her wishes are not honored. (MJB1030FG-B)

A poor death would be a death in which a person’s freedom of choice and self-determination has been removed. (RT0819)

But if a dying patient feels out of control, his life is in the hands of physicians, nurses, other people, hospital administrator, then it is not a good death. (TC1030)

There’s another one … which I considered a bad death, was someone who would not accept it under any circumstances—‘I will not die’—even though it was inevitable. And fought the system … irritated physicians by more and more demands. ‘I want alternative treatment and if you can’t get me alternative treatment I’ll find someone who will.’ And ended up going to other places around the world for alternative medicine. … There’s a lot of self-created angst and anxiety by the absolute refusal to accept the death. (MB107)

Dying unrepented or not reconciled with God and angry or hating, that would be a terrible and very poor death. (CM1217)

There was this Mexican dancer—he was dancing with his dance team … and a pole fell and hit him dead. And now his family is devastated. ‘Our young son is dead and he is twenty-something years old.’ I don’t know if I would call it a bad death, but it is something that feels abrupt; it feels sad in a different kind of way. (MJB1030FG-A)

I would say that the opposite would be reflected for a bad death which is fear. Disoriented, in a way, they don’t know where they are going. Many questions, many, many questions to themselves; to God. (JP414)

A bad death would be without Jesus. It’s a bad one because you’re distancing, because you can be saved by accepting Jesus as your savior, so if you do not accept Jesus and you die, according to the Bible, you’re lost. (MB1021)

Poor death is a lot of fear. Anxiety about what is happening after death, the final destiny. (TC1030)

They had a stroke and lasted about a week, but they died with a lot of unresolved issues. I don’t think that is the way it should happen. (MB129)

It really depends on whether you believe this or not. If you don’t believe in this afterlife you are actually going to the termination of your life. It is a terrible process and you will be scared to death. (TC115)

(continued)
A good death is certainly having those who you love most around you. (MB1030)

I firmly believe that we are born into a community and we die in a community. . . . We ought to be able to really celebrate a person’s life . . . and we do that in community as well. (MJB1030FG-H)

Comfortable, cared for, loved, family and friends, community around together. (CM1219)

A good death, I say a ‘holy death’ will be surrounded by family and friends. (CM1217)

Community

Being surrounded by “loving and concerned persons”, (CG124) was articulated by multiple participants as a key factor in determining the quality of the death experience. The absence of a loving community was seen as a potential source of destructive and painful emotions. A loving community was defined broadly, and expanded beyond a patient’s immediate family circle; some clergy made a special point to mention that a loving community can include the team of hospice or hospital health care providers. Clergy described an effective and positive community as supportive of the patient’s autonomy and easily accessible to the patient and family.

Middle death

Some clergy resisted labeling a death as good or poor and described more nuanced experiences at the EOL. Clergy who verbalized this sentiment acknowledged that the death experience involves both positive and negative elements that occur along a continuum and cannot be easily dichotomized. One participant described this, fittingly, as “middle death” (MB107) (see Table 4).

In describing middle deaths there was a strong sense of conditionality and a recognition that the quality of the death experience was inherently subjective and could only ever be truly known or characterized by the dying person. Some clergy were particularly attuned to the cultural context and diversity among their congregants that could result in a middle death. In working to help congregants make sense of middle deaths, particularly ones that involved complex or distressing events, clergy discussed their unique ability—and theological obligation—to serve as translators and interpreters to help process these difficult situations.

Location of death

Overall, participants did not describe location of death (e.g., home versus hospital) as a key factor in contributing to a good or poor death (see Table 5). Discussions regarding location of death (similar to middle death) were characterized by a sense of conditionality, based on a patient’s previously expressed wishes, family dynamics, cultural beliefs, and medical care requirements. In general, the quality of the microenvironment—a context to loving, competent caregivers and feeling secure—and the spiritual status of the dying person, were reported as more important than the location of dying.

Clergy reported that most patients expressed a preference to die at home, and clergy themselves generally perceived home as the more comfortable option. However, clergy also
Table 4. Clergy Perspectives on the Characteristics of a Middle Death

<table>
<thead>
<tr>
<th>A Middle Death: A Mixed Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>And there are some ‘middle deaths.’ There was a person in the church and it took her a year and a half to die of cancer. And it was kind of a mixed event. It was an interesting combination of experiences there. So that was a mixed death. (MB107)</td>
</tr>
<tr>
<td>It’s subjective. … We as humans often see based upon what our own experience is or what we read that experience should be, in the Bible, but that is not necessarily what that person’s experience is. (MJB1030FG-I)</td>
</tr>
<tr>
<td>We as clergy are called to minister to diverse populations and they are all in our congregations: We might have the gangster, and a good death to him or her is going out in a blaze of glory shooting up somebody. How would you interpret that to your congregation and to that family because most people will agree that it is a poor death, but that person was prepared everyday to go out in that way. And that might be called a good death to him or her in that community to which they exist in. We got guys that have died tragically and they saw it as good. But it is how we as clergy interpret or reinterpret that for the community. (MJB1030FG-K)</td>
</tr>
<tr>
<td>It’s subjective. And that is subjective to anyone except that individual who is judging it based upon their own experience. (MJB1030FG-I)</td>
</tr>
<tr>
<td>So I think a good death for me would be in the eyes of the patient and not so much in my eyes. (RT7292014)</td>
</tr>
</tbody>
</table>

*Participant identifiers that include “FG” indicate that the quote is from a focus group; the letter afterwards indicates the specific speaker.*

Table 5. Clergy Perspectives on the Influence of Location of Death on the Quality of the Death Experience

| I think it all depends. … More importantly it is the people who are around them. I would say that for most people as long as they are with their loved ones they will be fine. (JP414) |
| In a sense it [location] does and in a sense it doesn’t [matter]. If you’re getting good attention and have freedom of visitors in ICU it can be just as positive as being at home. I think it depends on the quality of the environment around them. (MB107) |
| I would much rather see it at home with people around in a place where they are feeling comfortable and secure as opposed to—I mean you walk into an ICU and it scars the heck out of you. (CM1219) |
| I think staying in the home would be better because I was in the hospital and no, you cannot sleep there. There is something always beeping or some alarm. (TC115) |
| In a hospital probably you can receive the best care, because of the staffing and the equipment. Hospice is next, but at home most family members don’t know how to handle the situation. And there is also some cultural factor playing in here because most Chinese people don’t want a person to die in their house. (TC1030) |
| It doesn’t matter, because what happens is you die. So wherever you die, it doesn’t really make any difference. (MB1021) |
| I think the place makes a difference to the extent that to be the place of the person’s choosing, if you have that control, if you are able to say, ‘I’m going to die at home’ and that is honored, I think that is important. If it is kind of open then it might not make such a difference. (MJB1030FG-H) |
| It is not about when, where, how, circumstances, heart attack, car crash, disease. The fact is as clergy we need to teach our congregation the fact that death is a reality on this earth. I think we owe it to ourselves as clergy to make sure that we are responsible enough in our ministry to have our congregation informed about death. (MJB1030FG-C) |
| And I’m not sure it [location of death] is a theological point for me. It is a human dignity point which flows into my theological point. (MJB1030FG-G) |
| I think it depends on the overall situation, but I think at home around family is a good death. (RT7292914) |

*Participant identifiers that include “FG” indicate that the quote is from a focus group; the letter afterwards indicates the specific speaker.*

recognized dying at home was not always in the best interest of the patient or family, and that very practical factors could influence the ability to carry out previously expressed wishes, such as the patient’s insurance coverage. When discussing location of death, clergy gave multiple examples of congregants dying suddenly in public places; in these abrupt situations location was largely viewed as irrelevant, as specific circumstances were less important than spiritual preparation for the reality of death.

Perhaps most importantly, the prevailing sentiment from clergy was that location may matter “from a dignity point, yes, but not from a theological point” (MJB1030FG-I). Being in relationship with God, and surrounded by love, was more important than the physical site of a patient’s death, and clergy believed this goal could be achieved equally well in the home or in a clinical setting.

Discussion

The primary theme that characterized a good death was one of wholeness and certainty. In contrast, the overarching theme that characterized a poor death was one of separation, doubt and isolation. Similar to other studies,12-14 clergy emphasized that quality of death involved factors of patient dignity, preparedness, physical suffering, and community. Interestingly, participants also described a middle death, or one that integrated both positive and negative elements. Location of death was not viewed as a particularly strong contributor to a good versus poor death, and was generally seen as secondary and contingent to other material factors.

Participants in our study placed a strong emphasis on patient autonomy. Preserving autonomy was viewed as foundational to maintaining dignity, a key criterion to achieve a good death. This finding suggests clergy that share similar theological perspectives regarding the sanctity of dignity may prioritize preserving patient and family autonomy above the potential medical consequences of particular EOL choices. In other words, being allowed to choose may be more important, according to some clergy, than the medical outcome of the choice. Understanding this dynamic may be especially helpful to palliative care clinicians and other health care providers who care for patients supported by clergy at the EOL.

This study also found that location of death was not viewed by most clergy as particularly important in determining a good
death. The absence of a clear emphasis related to location of
death was surprising given that surveys consistently indicate
that most people prefer to die at home. 15,16 In contrast, clergy
expressed that a good death could happen in a variety of lo-
cations—home, an inpatient hospice facility, or the ICU—and
verbalized much greater concern for the spiritual status of
the dying patient, and the people surrounding them, than for
the physical location of the death event. Clergy did not
appear to strongly link some of the key factors they felt
influenced the death experience (dignity, community,
physical suffering, preparedness) to a physical location’s
ability to support these factors. This may be related in part to
a more limited understanding regarding the realities of the
death experience in an acute care setting. For example,
physicians and nurses are keenly aware that patients who die
in the ICU are often subjected to painful procedures (im-
pacting physical suffering), typically have limited access to
family and friends (impacting community), and may expe-
rience significantly decreased levels of autonomy when se-
dated and intubated (impacting dignity and preparedness). It
may be that clergy lack sufficient medical knowledge or
experience in highly technological settings such as the ICU
to adequately assess the impact of acute care interventions on
quality of life and the death experience. 8

Another intriguing finding from this study is the pervasive
sense of conditionality (“it depends”) as expressed by clergy
throughout the interviews. Participants repeatedly mentioned
the need to consider situations on a case-by-case basis, and
expressed significant appreciation for contextual factors that
affect the death experience. This was particularly evident
when clergy discussed the death experience as existing along
a continuum and struggled to categorize a patient’s death as
uniformly good or poor. “Middle death” captured the reality
that the quality of death often involves both subjectively
viewed negative and positive elements.

Many clergy were reluctant to apply a single approach to
spiritual counsel at the EOL. In fact, few clergy expressed
dogmatic opinions concerning dying. Clinicians may mis-
takenly assume that theologically conservative clergy coun-
sel patients and families at the EOL with inflexible
theological doctrine. In this sample, clergy attempted to
closely align themselves with a patient’s wishes, and per-
ceived their role more as interpreters or translators. 17 Many
participants expressed a strong desire and obligation to help
congregants process and make sense of death, particularly
sudden or tragic events.

These results confirm factors previously identified by
clergy that affect the death experience (such as physical suffer-
ing) and expand our understanding of clergy’s atten-
tion to contextual factors surrounding the death experience.
Future work must translate these findings into relevant edu-
cational programs for clergy and clinicians (including chap-
lains), and measure the effectiveness of such programs in
improving dialogue between health care providers and reli-
gious communities. Our findings are especially salient when
one considers that minority patients in the United States are
both more likely to be engaged with a faith community 18,19
and also to experience significant health disparities at the
EOL. 20,21 Understanding and working collaboratively with
clergy who support and counsel terminally ill ethnic and ra-
cial minority patients is therefore a key strategy to improve
care among these patient populations. 22,23

Clinical implications

There is a well-documented need for more EOL edu-
cation and training for pastoral care practitioners, 24,25 and
these results provide evidence for potential content. For
example, clergy may need additional training to gain a
clearer picture of how location of death can have a direct
impact on some of the key factors clergy espouse to be
important for a positive death experience. Similarly, it is
helpful for health care providers to understand that clergy
may perceive a good death not in terms of location, but
rather in terms of certain theological goals that transcend
physical and material considerations. Clergy who are
closely involved with medical decision making at the
EOL may need case-specific information about medical
consequences of EOL decisions, and how the outcomes of
certain decisions may impact the patient’s ability to ex-
perience a good death according to the patient’s religious
tradition.

Limitations

This study is designed to be hypothesis-generating and
is not generalizable. Results intentionally reflect per-
spectives from a predominantly Christian-affiliated sample
of community clergy within the United States. Consistent
with national clergy demographics, the sample was pre-
dominantly male and theologically conservative. 26 Further
studies of EOL views among spiritual leaders of other
demographic, cultural, and religious backgrounds are
required.

Conclusion

Clergy described a good death as characterized by whole-
ness and certainty; a poor death as characterized by separa-
tion, isolation, and doubt; and middle deaths as consisting of
both positive and negative elements. Four key determin-
ants influenced the quality of the death experience: dignity,
preparedness, physical suffering, and community. Clergy
were attuned to contextual factors that impact the death ex-
perience, but did not always recognize how certain factors,
such as location of death, may influence dignity, prepared-
ness, physical suffering, and community. These findings can
aid in shaping interventions to enhance spiritual care pro-
vided by clergy, religious communities, and clinicians and to
decrease health care disparities at EOL. An important next
step is to implement these results into relevant educational
programs for community clergy (and those who collaborate
with clergy, such as clinicians and hospital-based chaplains)
and find feasible and effective ways to measure such a pro-
gram’s impact on EOL care for patients and family care-
givers.

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How Community Clergy Provide Spiritual Care: Toward a Conceptual Framework for Clergy End-of-Life Education

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University of Virginia School of Nursing (V.T.L.), Charlottesville, Virginia; Harvard Medical School Center for Bioethics (P.T.S.) and Gordon-Conwell Theological Seminary (P.T.S.), Boston, Massachusetts; Dana-Farber Cancer Institute (R.Q., C.N., J.J.S., T.A.B., M.J.B.), Boston, Massachusetts; Scripps Clinic (R.T.), La Jolla, California; Harvard/MGH Center on Genomics, Vulnerable Populations and Health Disparities (A.E.S.), Massachusetts General Hospital, Boston, Massachusetts; and Initiative on Health, Religion, and Spirituality (T.A.B., M.J.B.), Harvard University, Cambridge, Massachusetts, USA

Abstract

Context. Community-based clergy are highly engaged in helping terminally ill patients address spiritual concerns at the end of life (EOL). Despite playing a central role in EOL care, clergy report feeling ill-equipped to spiritually support patients in this context. Significant gaps exist in understanding how clergy beliefs and practices influence EOL care.

Objectives. The objective of this study was to propose a conceptual framework to guide EOL educational programming for community-based clergy.

Methods. This was a qualitative, descriptive study. Clergy from varying spiritual backgrounds, geographical locations in the U.S., and race/ethnicities were recruited and asked about optimal spiritual care provided to patients at the EOL. Interviews were audio taped, transcribed, and analyzed following principles of grounded theory. A final set of themes and subthemes were identified through an iterative process of constant comparison. Participants also completed a survey regarding experiences ministering to the terminally ill.

Results. A total of 35 clergy participated in 14 individual interviews and two focus groups. Primary themes included Patient Struggles at EOL and Clergy Professional Identity in Ministering to the Terminally Ill. Patient Struggles at EOL focused on existential questions, practical concerns, and difficult emotions. Clergy Professional Identity in Ministering to the Terminally Ill was characterized by descriptions of Who Clergy Are (“Being”), What Clergy Do (“Doing”), and What Clergy Believe (“Believing”). “Being” was reflected primarily by manifestations of presence; “Doing” by subthemes of religious activities, spiritual support, meeting practical needs, and mistakes to avoid; “Believing” by subthemes of having a relationship with God, nurturing virtues, and eternal life. Survey results were congruent with interview and focus group findings.

Conclusion. A conceptual framework informed by clergy perspectives of optimal spiritual care can guide EOL educational programming for clergy.

Introduction

Spiritual concerns are particularly pressing at the end of life (EOL), and roughly half of all terminally ill patients in the U.S. rely on community-based clergy for spiritual support. Clergy spend an average of 3–4 hours per week visiting the ill and are especially...
important in meeting the spiritual needs of minority patients.\textsuperscript{3} Despite their central role in ministering to terminally ill patients,\textsuperscript{5, 6} most clergy report inadequate knowledge regarding EOL care and a desire for more EOL training.\textsuperscript{7–9} This lack of knowledge regarding EOL care among community-based clergy is an issue of critical importance, given recent data that show patients who receive significant community spiritual support are less likely to use hospice and more likely to receive intensive medical care near death.\textsuperscript{10}

In essence, community-based clergy—who provide the most spiritual support to patients at EOL\textsuperscript{11, 12} and can have a dramatic impact on the patient’s death experience—receive minimal, if any, EOL training. Also, little is known about actual clergy practices and goals in counseling patients at EOL. This study aims to address these gaps by 1) exploring clergy perspectives on optimal spiritual care provided to terminally ill patients and 2) using these findings to inform a conceptual framework for clergy EOL education. This study is part of the larger National Cancer Institute-funded “National Clergy Project on End-of-Life Care,” a mixed-methods study examining clergy beliefs and practices in providing EOL spiritual care in the U.S. regarding EOL care. Relevant to this report, clergy were asked the following open-ended questions from the interview guide: "When you care for patients who may be facing death, such as terminal cancer, how should a minister in a congregation provide spiritual care? What does spiritual care ideally look like in your opinion and experience?" Research staff underwent a half-day training session in interview methods and received ongoing supervisory guidance from M. J. B., to ensure homogeneous interview procedures. Interviews and focus groups were conducted in English or Spanish (n = 2) and ranged between 45 and 120 minutes in duration. Participants received a $25 gift card as a token of appreciation for their participation.

**Quantitative Measures**

Before the interview or focus group, participants completed a survey assessing age, race, gender, educational level, denominational affiliation, prior EOL training, and experiences in ministering to the terminally ill. As part of the survey, participants were asked to recall the most recent incident in which they provided spiritual care to a dying individual and to describe the length of the patient-clergy relationship, the types of spiritual care provided to the patient, and the timing of death relative to the survey.

**Methods**

**Sample**

Methods for the study have been previously reported.\textsuperscript{13} In brief, this study used interviews, focus groups, and surveys to describe community clergy experiences with EOL care and their perceptions of optimal spiritual care. We sought to recruit a sample representative of U.S. clergy (not the general population) demographics, and we oversampled from minority clergy to capture a diverse range of perspectives. A key informant with access to local community clergy, in consultation with M. J. B., recruited clergy leaders currently serving in a community congregation based on preselected criteria including race/ethnicity, congregational size, and denomination. Thirty-five clergy were interviewed in one-on-one interviews (n = 14) and two focus groups (with a total of 21 participants) within five U.S. states (California, Illinois, Massachusetts, New York, and Texas). All participants provided informed consent per protocols approved by the Harvard/Dana-Farber Cancer Center Institutional Review Board.

**Protocol**

Clergy were enrolled between November 2013 and September 2014. An interdisciplinary panel of medical educators and religion experts developed a semistructured interview guide to explore clergy perspectives on optimal spiritual care and a desire for more EOL training. Before the interview or focus group, participants completed a survey assessing age, race, gender, educational level, denominational affiliation, prior EOL training, and experiences in ministering to the terminally ill. As part of the survey, participants were asked to recall the most recent incident in which they provided spiritual care to a dying individual and to describe the length of the patient-clergy relationship, the types of spiritual care provided to the patient, and the timing of death relative to the survey.

**Analytical Procedures**

Interviews were audio taped, transcribed, translated, and verified if in Spanish, and participants were deidentified. Following principles of grounded theory,\textsuperscript{14} transcripts were reviewed by R. Q. and C. N., and an initial set of subtheme categories along with corresponding coding frequencies was generated. Subtheme categories were then refined after further independent review of the transcripts by additional members of the research team, and a broader set of conceptual codes (themes) was created during an interactive data analysis session representing the interdisciplinary perspectives of nursing (V. T. L.), psychology (C. N.), and theology (M. J. B., R. Q.). After finalizing the coding schema, transcripts were then reanalyzed (NVivo 10; QSR International, Burlington, MA) by R. Q. and C. N., each coding independently based on derived subtheme categories and themes (Kappa = 0.68). Descriptive statistics were used for quantitative items of the participant surveys.

**Results**

**Quantitative**

Clergy demographic information and types of spiritual care provided to the most recent patient who died are provided in Table 1. Offering prayer and reading scripture were the most common
Table 1
Sample Characteristics of Clergy Participants and Selected Results From Quantitative Surveys

<table>
<thead>
<tr>
<th>Clergy Demographic Information</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total participants</td>
<td>35</td>
<td>100</td>
</tr>
<tr>
<td>Male gender</td>
<td>32</td>
<td>91.4</td>
</tr>
<tr>
<td>Average years serving as clergy (n = 32)</td>
<td>20 yrs</td>
<td></td>
</tr>
<tr>
<td>Geographical location</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>11</td>
<td>31.4</td>
</tr>
<tr>
<td>Southwest</td>
<td>11</td>
<td>31.4</td>
</tr>
<tr>
<td>Midwest</td>
<td>10</td>
<td>28.6</td>
</tr>
<tr>
<td>West</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Race (n = 32)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>16</td>
<td>50.0</td>
</tr>
<tr>
<td>Black</td>
<td>14</td>
<td>45.7</td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
<td>6.3</td>
</tr>
<tr>
<td>Ethnicity (n = 30)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Latino/Hispanic</td>
<td>2</td>
<td>6.7</td>
</tr>
<tr>
<td>Religious tradition (n = 35)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protestant</td>
<td>27</td>
<td>77.1</td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>Jewish</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Eastern Orthodox</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Other (Center for Spiritual Living)</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Theological orientation (n = 32)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Theologically conservative</td>
<td>21</td>
<td>65.6</td>
</tr>
<tr>
<td>Theologically liberal</td>
<td>11</td>
<td>34.4</td>
</tr>
<tr>
<td>Educational level (n = 34)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below master’s degree</td>
<td>6</td>
<td>17.7</td>
</tr>
<tr>
<td>Master’s degree (e.g., MDiv)</td>
<td>15</td>
<td>44.1</td>
</tr>
<tr>
<td>Doctoral degree</td>
<td>13</td>
<td>38.2</td>
</tr>
</tbody>
</table>

Educational preparation in EOL care

| Prior receipt of EOL training (n = 31) | 23 | 74.2 |
| Type of training received (n = 25)    |   |   |
| Clinical Pastoral Education           | 13| 56.5|
| Seminary course                      | 13| 56.5|
| One-on-one mentorship                 | 9 | 39.1|
| Book                                  | 9 | 39.1|
| Desire future EOL training (n = 29)   | 21| 72.4|

Most recent patient visited by clergy who died from illness

<table>
<thead>
<tr>
<th>Length of time between patient’s death and survey (n = 19)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 3 months</td>
<td>10</td>
<td>52.6</td>
</tr>
<tr>
<td>3–6 months</td>
<td>3</td>
<td>15.8</td>
</tr>
<tr>
<td>6–12 months</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>1–2 yrs</td>
<td>4</td>
<td>21.0</td>
</tr>
<tr>
<td>Length of time clergy knew patient (n = 29)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>5</td>
<td>17.2</td>
</tr>
<tr>
<td>About a year</td>
<td>2</td>
<td>7.1</td>
</tr>
<tr>
<td>1–2 yrs</td>
<td>4</td>
<td>13.8</td>
</tr>
<tr>
<td>3 yrs or more</td>
<td>18</td>
<td>62.0</td>
</tr>
</tbody>
</table>

Types of spiritual care provided (n = 28)

<table>
<thead>
<tr>
<th>Types of spiritual care provided (n = 28)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Who clergy are (“Being”)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express compassion</td>
<td>22</td>
<td>78.6</td>
</tr>
<tr>
<td>Listen to spiritual concerns</td>
<td>15</td>
<td>53.6</td>
</tr>
<tr>
<td>Who clergy do (“Doing”)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pray</td>
<td>26</td>
<td>92.9</td>
</tr>
<tr>
<td>Read scripture</td>
<td>23</td>
<td>82.1</td>
</tr>
<tr>
<td>Offer a religious ritual (e.g., communion)</td>
<td>15</td>
<td>53.6</td>
</tr>
<tr>
<td>Help sort through medical decisions</td>
<td>13</td>
<td>46.4</td>
</tr>
<tr>
<td>What clergy believe (“Believing”)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talk about talk about death or an afterlife</td>
<td>15</td>
<td>55.6</td>
</tr>
<tr>
<td>Talk about sources of peace</td>
<td>13</td>
<td>46.4</td>
</tr>
<tr>
<td>Talk about forgiveness</td>
<td>8</td>
<td>28.6</td>
</tr>
</tbody>
</table>

(Continued)

Table 1
Continued

<table>
<thead>
<tr>
<th>Clergy Demographic Information</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talk about sources of meaning</td>
<td>7</td>
<td>25.0</td>
</tr>
<tr>
<td>Otherd</td>
<td>7</td>
<td>25.0</td>
</tr>
</tbody>
</table>

EOL = end of life.

aNot all participants responded to every question; therefore, “n” may not total 35.

bProtestant clergy identified with the following Protestant denominations: Assemblies of God (2), Baptist (3), Congregational (4), Episcopalian (1), Methodist (3), Nondenominational (6), Presbyterian (1), and Seventh-Day Adventist (1). Four Protestant clergy did not disclose specific denominational information.

cClergy were categorized as “theologically conservative” if they agreed with the following statement: “My religious tradition’s Holy Book is perfect because it is the Word of God.”

d“Other” included: Interfacing with family (n = 5) including conflict, reconciliation, and presence; provide comfort in personal area of faith (n = 1); and providing life review with patient (n = 1).

forms of clergy spiritual care reported; approximately half indicated that they “help [patients] sort through medical decisions.” Of note, 72% of clergy respondents indicated a desire for more EOL training.

Qualitative Themes

In describing their perspectives regarding optimal spiritual care for terminally ill patients, clergy responses focused on two primary, interrelated themes: the challenging spiritual and temporal struggles faced by terminally ill patients and their family caregivers, and the ways in which clergy professional identity helps congregants navigate these struggles at the EOL (Table 2). The primary theme of “Patient Struggles at EOL” highlighted commonly encountered existential questions—many of which were spiritual/religious in nature—as well as practical/temporal concerns and difficult emotions related to terminal illness. The primary theme of “Clergy Professional Identity in Ministering to the Terminally Ill” was characterized by descriptions of Who Clergy Are (“Being”), What Clergy Do (“Doing”), and What Clergy Believe (“Believing”). “Being” was supported by subthemes related to various manifestations of Presence; “Doing” by subthemes of religious activities, spiritual support, meeting the needs of patient/families, and mistakes to avoid; and “Believing” by subthemes of having a relationship with God, nurturing virtues, and eternal life.

Primary Theme I: Patient Struggles at EOL

Clergy perceived three common struggles that require attention at the EOL for patients and their family caregivers: existential questions, practical and temporal concerns, and difficult emotions (Table 3). Existential questions focused on issues such as “Did
I waste my time? Did I live a good life? Why is this happening to my family member? Why do I remain sick and not healed?" A Christian Asian-American minister from China explained:

They normally say "Why me? Why is God letting me walk in this way? I'm still young. Why is God giving me this trial in my life, walking in this path?" So that is always the question in their heart. I think some people receive this question well. Some people not (TC115).

Clergy indicated that practical and temporal concerns encountered by patients at the EOL included issues regarding leaving loved ones behind without adequate financial or emotional resources; missing important life events; doubts and confusion related to disease and treatment decisions; fractured relationships.

Difficult emotions
Anger, frustration, anxiety, blame, despair, fear, sadness, depression, regret, denial

Primary Theme II: Clergy Professional Identity in Ministering to the Terminally Ill

Who Clergy Are ("Being")
Presence
Be available, listen, provide support, guidance, serve as confidante, provide temporary distraction away from illness

What Clergy Do ("Doing")
Facilitate religious activities
Pray, administer the sacraments, listen to confession, read/interpret scripture, sing/listen to hymns

Provide spiritual support
Reassure congregants of the love of their Christian community; help patients feel useful/wanted; remind patients they will live on in people’s memories; encourage patients not to waste time or important moments; relieve despair; facilitate reconciliation with others

Meet the needs of patient/family caregivers
Counsel and support family caregivers; provide personalized care; address cultural beliefs and practices; honor human dignity; encourage legal/emotional/financial preparation for death

Mistakes to avoid
Misunderstanding that prayer will automatically lead to a cure; focus on religious conversion vs. spiritual needs of patient; too much talking and not enough listening; make patient feel guilty; give unrealistic hope in miracles

What Clergy Believe ("Believing")
Having a relationship with God
Reconciliation with God; importance of forgiveness; acknowledge different forms of healing; trust in God’s love and His ability to offer strength to help carry burdens; awareness that illness is not punishment

Nurturing virtues in illness and dying
Hope, love, compassion, acceptance, patience, balance, strength

Faith in eternal life
Embrace the reality of heaven; knowing peace; theological reassurance of God’s unbreakable love; assurance of salvation after death

Table 2
Summary of Primary Themes

<table>
<thead>
<tr>
<th>Primary Theme I: Common Patient Struggles at the End of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Existential questions</strong></td>
</tr>
<tr>
<td>Did I waste my time? Did I live a good life? Why is this happening to my family member? Why do I remain sick and not healed?</td>
</tr>
<tr>
<td><strong>Practical and temporal concerns</strong></td>
</tr>
<tr>
<td>Leaving loved ones behind without adequate financial or emotional resources; missing important life events; doubts and confusion related to disease and treatment decisions; fractured relationships</td>
</tr>
<tr>
<td><strong>Difficult emotions</strong></td>
</tr>
<tr>
<td>Anger, frustration, anxiety, blame, despair, fear, sadness, depression, regret, denial</td>
</tr>
</tbody>
</table>

Table 3
Primary Theme I: Supporting Quotes of Clergy Perceptions of Common Patient Struggles at the End of Life*

<table>
<thead>
<tr>
<th>Existential questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;... I’ve been praying for it, my friends are praying for it; they’re fasting, they’re asking, heal me, heal me, heal me, and He hasn’t done it. Why not? Why hasn’t He healed me?&quot; So they’re going through that as well. Then what I say is if you look around most people are not healed. There are times in church history when people were, and there were times when they were not; right now that’s just not happening. God is not moving that way. And in a sense you are being healed; this is the way God is choosing to heal you is by bringing you to Him face to face and that’s the best healing.</td>
</tr>
<tr>
<td>MB109</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Practical and temporal concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think there is a sense where you can relieve some of the burden and worry they feel for their family members. So to be able to say “you don’t have to worry about this”. To make sure there is a support system around for them. I think of a guy who is dying and leaving his wife and kids, there are folks around. There is a real helpfulness I think you feel for those that are grieving for the ones dying; to relieve them of that, or share that burden with them.</td>
</tr>
<tr>
<td>—FGMJ8416-B</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Difficult emotions</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think some people have regrets that they never healed or repaired damaged relationships, especially with people that are no longer living. People often have profound regrets about past behaviors that they now recognize as having been harmful or destructive either of themselves or other people.</td>
</tr>
<tr>
<td>CG124</td>
</tr>
</tbody>
</table>

*Participant identifiers that include “FG” indicate that the quote is from a focus group; the letter afterward indicates the specific speaker.
think about treatment when I am going to die?" Out of the multiple options for chemotherapy, "Which one do I take? I don’t know, I’m going to die. I can’t make a decision." So we need to find a way to have these conversations. So we know what is going on earlier than at the end of life (CM1219).

Difficult emotions that characterized patient struggles at the EOL included frustration, anxiety, fear, sadness, blame, despair, depression, regret, denial, and anger. A rabbi explained:

People will tell me up front, when I walk in, they know that I am the rabbi and the first thing they want to do is talk theology with me or talk anger at God or anger from God. I don’t usually have to fish for it (FGMJB416-J).

In some cases, clergy indicated that grappling with these difficult emotions ultimately led patients to accept their situation and helped them to acknowledge that there are no simple answers to these complex issues.

Primary Theme II: Clergy Professional Identity in Ministering to the Terminally Ill: Who We Are, What We Do, and What We Believe

Clergy professional identity was described in terms of three core dimensions: Who Clergy Are (Being), What Clergy Do (Doing), and What Clergy Believe (Believing; Table 4). Providing optimal spiritual care to patients and family members at the EOL necessitated manifestations of all three facets of clergy professional identity working in tandem.

Who Clergy Are (“Being”). The essence of Who Clergy Are was described primarily as the embodiment of Presence, illustrated by the following statement:

[It is important] with the patients themselves, just to be present. To try to be present, not necessarily offering a whole lot of reasons for anything, but just trying to be present, supportive listening, encouraging. That is a role that the church and the congregation can play in the person’s life who is facing terminal illness (MB129).

Clergy presence involved a commitment to being available to the patient and family, and manifested in listening, providing support and guidance, serving as a confidante, and sometimes helping to shift the focus away from illness (even if just as a temporary distraction).

What Clergy Do (“Doing”). Clergy’s identity of Doing was described by specific actions deemed spiritually relevant to congregants at the EOL. Key aspects of Doing included religious activities and rituals (prayer, administering the sacraments, listening to confession, reading scripture, singing and listening to hymns), providing spiritual support (reassuring congregants of the love of their faith community, helping patients to feel wanted/useful despite the limitations of serious illness, reminding patients that they will live on in people’s memories, encouraging patients not to waste time or important moments, relieving despair, facilitating reconciliation with others), and meeting the needs of the patient/family (counseling family caregivers, providing personalized care, addressing cultural beliefs/practices, honoring human dignity, and encouraging legal/financial/emotional preparedness for death). These subthemes are illustrated by one Latino pastor who counseled a patient to reconsider other priorities beside cure:

I think that was one of the few times where I had the courage to say “Listen, I also believe in miracles, but hey, don’t waste this opportunity”—and I spoke directly to the man, [who] was the husband and father of the household—and I said, “Listen, you need to speak about the most important things for you in life. What are the things that you want to be remembered? What are the things that you want to share with your family?” (JP414).

An equally important aspect of Doing involved clergy relating what not to do when providing spiritual support to terminally ill patients and family caregivers. Clergy discussed mistakes they regretted in their own ministry, as well as other clergy practices they perceived as unhelpful or even harmful. For example, clergy discussed the potentially negative consequences of focusing on religious conversion at the expense of the individual spiritual needs and desires of the patient, too much talking and not enough listening, making patients feel guilty, and avoiding important discussions related to death and dying. Some also mentioned the mistake of fostering false hope:

I think one mistake is to give them unrealistic hope. Like telling them that you will not die and God will save you .... The fact is people do die and sometimes God wants us to die so that we can return to Him. Another mistake is to really make the patient feel like he or she is lacking faith (TC1030).

What Clergy Believe (“Believing”). Clergy identity regarding What Clergy Believe focused on substantive religious concerns including having a relationship with God, nurturing key virtues, and being assured of eternal life. Having a relationship with God involved an emphasis on active reconciliation with God, seeking and accepting God’s forgiveness, understanding that healing from God does not always entail physical recovery, knowing God’s love and strength in helping carry burdens, and awareness that illness is
I teach with Nurturing virtues in illness and dying

What Clergy Believe ("Believing")

Trying to preach to somebody who's dying. Trying to convince somebody to adopt a theological position while they're dying is unforgivable. The sole role of the there is so much focus on the person dying, but in my mind there is so much also with the family that is by the bed, the family that is in the waiting room.

Meet the needs of the patient and family

I would sense that people are a little bit reluctant, even with terminal illnesses, to talk about dying. I will say that, I will bring it up gingerly if I think the situation calls for it and it's often a relief for the patient to talk about it; to talk about both the process of dying but also the afterlife. I don't think I've created a sense of fear or misgivings, or that I made them give up hope by talking about dying. I feel like they're almost always relieved, they feel better after those conversations. The challenge for me is when to bring it up and I don't have a magic answer for that, it really depends on the family and the patient.

What Clergy Do ("Doing")

Facilitate religious activities

I would agree, that presence, being rather than doing, is so important but the physical touch, the holding of one's hand or even placing your hand on someone's shoulder, that physical connection, scriptures and particularly the psalms, those familiar passages that you know they are familiar with and that someone can strengthen and draw them back to that time where the felt most at peace with God. We use music, I don't sing but I have found that using smart phones as pulling up some YouTube video that has some old hymn of faith that draws them back to that time; that can be extremely powerful.

Provide spiritual support

Sometimes I encourage them to write down their feelings. To be at peace with other people, also. If they are still holding grudges to other people or have enemies, it's time to make peace. Or forgive or be forgiven. And I also encourage people to write about their life, about their experience; to leave some legacy. And I encourage people to pray. And I will tell them that you are not useless; even you lying in bed in a hospital. You are not useless; you can still serve people and serve God by praying for other people. So I will give them a sense of worthiness. You are still worthy. God gave you life and life is good. The reason why God still gives you life is that you can pray for other people, you can still serve them by praying for others.

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What Clergy Are ("Being")

Presence

... as a Catholic priest we've got lots in our tool bag. I mean, there are lots of things we can do. And I think what I would encourage the priests that I work with now in my experience, presence is probably the greatest thing; frequent visits. And what we tend to slip into and I've even had brothet priests say this, "well I anxioued them so they don't need me anymore." Or, "I gave them communion." It is like we did our thing and so I'm done. That, I guess I would say from our tradition, we feel those sacraments are great blessings but in a sense they're only markers for the relationship that should be there certainly with Christ but with his church and with representing the church ... To be present is probably the most powerful thing that the sacraments in our faith can work through.

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Mistakes to avoid

Trying to preach to somebody who's dying. Trying to convince somebody to adopt a theological position while they're dying is unforgivable. The sole role of the clergy at that time is to comfort the family and the person who's dying. They're in a state of transition and we're there to serve them.

What Clergy Do ("Doing")

Facilitate religious activities

I would agree, that presence, being rather than doing, is so important but the physical touch, the holding of one's hand or even placing your hand on someone's shoulder, that physical connection, scriptures and particularly the psalms, those familiar passages that you know they are familiar with and that someone can strengthen and draw them back to that time where the felt most at peace with God. We use music, I don't sing but I have found that using smart phones as pulling up some YouTube video that has some old hymn of faith that draws them back to that time; that can be extremely powerful.

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Meet the needs of the patient and family

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not a form of divine punishment. Most clergy considered the patient’s relationship with God as the most important spiritual matter to address. An evangelical pastor said:

Well, the first aspect of spiritual care is providing assurance of their eternal destiny. That question is discussed, clarified, so that they can have that certainty that the biggest issue in human existence is resolved. And I think spiritual care reminds and reinforces that proof (MB107).

Clergy also indicated important virtues for patients to foster within the context of serious illness and dying, including hope, love, compassion, acceptance, patience, balance, and strength. Assurance of eternal life involved clergy encouraging patients to embrace the reality of heaven, the truth of God’s love, and certainty of salvation after death. A Haitian pastor emphasized:

If the person is a Christian, I pray for this person to go in peace. If he’s not a Christian, my desire is for the person to accept Jesus before he dies. If the person is a Christian, I pray, and also tell the person, if the person is conscious and they understand, I say, “Okay, don’t worry too much about what’s going to be left behind or taking care of all these things, so if God calls you, don’t worry. Everything is okay” (MB1021).

Similarly, an Orthodox priest explained:

I have had individuals who are very frightened because they have done terrible things in the course of their life. But again, the teaching is that if you truly regret these things and if you have made a good confession before God, and if you have received the prayers and the forgiveness then, as we say at the end of the confession, “Go in peace and have no further anxiety about the things you have confessed this day” (CG124).

**Discussion**

Using in-depth interviews, focus groups, and surveys with clergy participants, this study describes spiritual issues encountered by clergy when ministering to patients with serious illness and key manifestations of clergy identity in providing what they view as optimal spiritual care. Consistent with patient surveys on religion and EOL, clergy identified the most common areas of patient struggles at EOL as existential questions, challenging emotions, and practical needs. Key manifestations of clergy identity in providing optimal spiritual care were described as “Being”, “Doing”, and “Believing” (Table 2). Congruence between the qualitatively derived categories, and survey data further support a conceptual framework (Fig. 1) based on these findings to inform development of a clergy educational program.

“Being” was discussed most clearly and frequently using language related to “presence.” Most clergy articulated a sense of privilege in the opportunity to be present and recognized its intangible importance; all agreed presence was a critical dimension of caring for patients facing serious illness. Although Being was considered fundamental to delivering optimal spiritual care at the EOL, most clergy appeared to seek a balance between passive aspects of spiritual care (exemplified by listening and well-timed words) and acts that were religiously directive (as described in “Doing” and “Believing”). “Doing” largely involved facilitating religious activities, grounded within the clergy’s respective faith tradition, and recognized the importance of ministering not only to patients but also to family caregivers who concurrently suffer during a terminal illness. In addition, clergy were candid regarding mistakes they had made in their own ministry or witnessed with other clergy. Active reflection on the challenges and lessons learned from providing spiritual care at the EOL may be particularly helpful as a springboard for discussion in educational programming for clergy. “Believing,” the third aspect of clergy identity in providing EOL care, focused on fostering a relationship with God, reassuring patients of an afterlife and salvation, and nurturing particular virtues, such as forgiveness and love, for patients to embrace. Community clergy understood these core beliefs as doctrines that shape their communication with patients, and although a few clergy expressed that imposing religious beliefs on patients was unethical, most expressed that certain beliefs were essential to emphasize at the EOL. In this approach, clergy
indicated that they provided reassurance to patients experiencing spiritual doubt and, at times, challenged patients by encouraging a new or deeper relationship with God before death.

In developing a conceptual model that may be used for clergy education in EOL care, our data suggest that “Being”, “Doing”, and “Believing” are three dimensions of spiritual care that should operate in tandem when addressing patients’ spiritual concerns at the EOL. Historically, different religious traditions have tended to emphasize certain aspects of spiritual care such as presence among liberal Protestants, religious practices/rituals among Roman Catholics, and believing among Evangelicals, Pentecostals, and black clergy. Together, these three segments of American Christianity (Protestant, Roman Catholic, and Evangelical) comprise more than 90% of all U.S. clergy15 and approximately 70% of the U.S. population.16 Thus, EOL clergy education may likely need to give balanced attention to “Being”, “Doing”, and “Believing” to adequately engage multiple clergy viewpoints. This trifold understanding of optimal spiritual care may have important differences with interfaith and Clinical Pastoral Education hospital chaplaincy perspectives, which tend to de-emphasize “Believing” and stress a broad concept of spirituality (“Being”) vs. particular religious beliefs and practices.17,18 We propose that Clinical Pastoral Education, while an important model, may not be the best fit, or enough by itself, to train community clergy in EOL care. Our findings suggest that educational efforts for community clergy must incorporate all three dimensions of clergy identity (“Being”, “Doing”, and “Believing”) to effectively address patients’ religious needs at the EOL.

Similar to other reports,7 just over half of our clergy sample reported receipt of EOL training and two-thirds desired future training. Desire for EOL education among clergy provides palliative care leaders and educators an important opportunity to respond to national recommendations5,6 by equipping community clergy with the knowledge and training to improve care for patients at the EOL. Prior research suggests that as many as half of all U.S. patients apply religious beliefs to their experience of serious illness19 and receive input on medical decisions from their religious communities; this in turn impacts critical EOL choices, such as electing hospice or pursuing aggressive life-prolonging therapies.16 Although it is unsurprising that clergy offered prayer and read scripture when visiting the last congregational member who died, it is noteworthy that nearly half also helped the patient “sort through medical decisions” (Table 1). This dual role of providing spiritual support while helping patients and families navigate complex EOL medical decisions was described by one clergy participant as “helping [terminally-ill patients] to seek the balance of seeking treatment and accepting death” (TC1030). Future training may need to especially consider clergy influence on patient medical decisions.

The primary themes identified in our qualitative analysis suggest a theoretical underpinning to guide EOL programming for clergy and evaluate its impact. For example, in regard to helping patients navigate medical decision-making at the EOL, “Being” requires that clergy listen carefully to patients, families, and healthcare providers to understand more deeply the difficult medical choices under consideration; “Doing” may include praying for wisdom as patients face medical choices and direct facilitation of spiritual practices that remove anxiety, fear, and anger and help the patient look beyond their death to faith and hope in God; “Believing” may involve clergy and patients identifying the doctrines within their faith tradition that most appropriately apply to the medical context and specific choices that must be made. The theme of patient struggles experienced at the EOL (existential questions, practical concerns, and difficult emotions) suggests that these patient struggles are top priorities and could serve, at least to some degree, as possible outcome measures by which to evaluate the impact of educational programming designed to help clergy provide optimal spiritual care at the EOL.

A future clergy EOL curriculum will need to be especially attentive to the doctrinal beliefs that most appropriately apply to medical choices commonly encountered at the EOL, as some evidence suggests that religious communities may believe their “right” religious beliefs but apply them in the “wrong” manner.19–21 The palliative care community is especially equipped by virtue of their knowledge and expertise to respond to the growing recognition5,6 of the importance of partnering with clergy and clergy educators to develop EOL curricula that are both medically sound and theologically respectful.

Limitations

This study is designed to be hypothesis generating and, consistent with U.S. clergy demographics, reflects perspectives from a sample of predominantly Christian-affiliated, male, and theologically conservative clergy.15 The proposed conceptual framework represents the crucial (and understudied) perspective of community clergy and suggests an important first step in reconsidering how EOL training programs may be designed to best meet the educational needs of community clergy in a theologically holistic and respectful manner. However, our initial model does not incorporate the viewpoints of patients and family members or other healthcare practitioners who
provide spiritual support at the EOL; future work should look to broaden this initial framework by incorporating these additional perspectives and further explore how optimal spiritual care is defined within the context of minority faith traditions. Also, although our study provides insights into possible programming content within the three domains of “Being”, “Believing”, and “Doing”, more work is needed to fully determine the specific content that best fits within the conceptual model.

Conclusion

Clergy perspectives of optimal spiritual care provide important insights to support a conceptual framework that can be used to guide educational EOL programming for clergy. This study identified three core dimensions that underlie community-based clergy’s understanding of their role as spiritual caregivers: “Being”, “Doing”, and “Believing”. This trifold model can be applied to help clergy address crucial patient concerns at the EOL, including navigating complex medical decisions. Future research should focus on refining the conceptual framework by considering additional perspectives (such as patients and family caregivers) and look toward the design, implementation, and evaluation of an EOL curriculum for community clergy informed by this conceptual framework.

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