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PAPER

The role of religious beliefs in ethics committee consultations for conflict over life-sustaining treatment

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ABSTRACT

Previous research has suggested that individuals who identify as being more religious request more aggressive medical treatment at end of life. These requests may generate disagreement over life-sustaining treatment (LST). Outside of anecdotal observation, however, the actual role of religion in conflict over LST has been underexplored. Because ethics committees are often consulted to help mediate these conflicts, the ethics consultation experience provides a unique context in which to investigate this question. The purpose of this paper was to examine the ways religion was present in cases involving conflict around LST. Using medical records from ethics consultation cases for conflict over LST in one large academic medical centre, we found that religion can be central to conflict over LST but was also present in two additional ways through (1) religious coping, including a belief in miracles and support from a higher power, and (2) chaplaincy visits. In-hospital mortality was not different between patients with religiously versus non-religiously centred conflict. In our retrospective cohort study, religion played a variety of roles and did not lead to increased treatment intensity or prolong time to death. Ethics consultants and healthcare professionals involved in these cases should be cognisant of the complex ways that religion can manifest in conflict over LST.

INTRODUCTION

Religion and spirituality take many forms and play a variety of roles in modern healthcare organisations.[1 2] For some patients and families, religion can be a source of support and/or a source of conflict.[2 3] Chapels and meditation rooms are a manifestation of religion in hospitals, and chaplains are available to assist patients and families when receiving medical care.[1 4 5] Previous studies have demonstrated that religiosity and religious coping are associated with wanting and receiving more aggressive treatment and are inversely related to having an advanced directive.[3 6–10] Some have suggested that religious doctrine, participation in a religious community, support from a higher power, a belief in miracles or the belief that do not resuscitate (DNR) is morally wrong may be reasons that religion is associated with choosing more aggressive treatment or wanting cardiopulmonary resuscitation (CPR).[9 11–13] Karches *et al*,[14] however, suggest that not all dimensions of religion may be associated with more aggressive treatment, and that prior studies used different measures of religion including religious affiliation, religiosity or religiousness and religious coping to assess these relationships. Geros-Willfond *et al*[15] also note the diversity in perspectives around religion and surrogate decision-making, suggesting that there are complexities around the ways in which religion and/or spirituality may shape preferences, decisions and assent around end-of-life treatment.

While many studies demonstrate that religion may lead families to continue treatment for patients at the end of life and/or select more aggressive treatments, it is unclear what mechanisms are at play in the relationship between religion and preferences around life-sustaining treatment (LST).[11] It is also unclear whether religion may play other roles in situations related to LST. For example, studies suggest that religion may be present in a variety of ways including as a source of support,[13] as inhibiting or facilitating an advanced directive,[6 14] as influencing decisions around CPR or as leading families to wait to make medical decisions in the hope that a miracle or a sign of God will occur.[3 15–17]

It is unknown to what extent religiously driven requests for more aggressive treatment generate conflict over LST. Religious beliefs have been at the centre of many high-profile cases involving conflict over LST, including Terri Shavio, Jahi McMath and Hassan Rasouli. Outside of anecdotal observation, however, the actual role of religion in conflict over LST, as opposed to merely pursuing more aggressive treatment, has been underexplored. It is also unclear how the presence of religion for patients and family members in cases of conflict affects the intensity of treatment, time to death or quality of death. Because ethics committees are often consulted to help mediate these conflicts, the ethics consultation experience provides a unique context in which to investigate these questions. This is a population enriched for difficult cases, and an exploration of the role of religion in this context may provide insight into the ways in which different dimensions of religion are related to preferences for aggressive treatment, guide decisions around LST and are central to continued conflict.

The purpose of this paper was to examine the different ways religion was present in cases involving conflict around LST, to consider when and how religion was a source of conflict in these situations, and to identify difference in sociodemographic and

clinical characteristics and outcomes in conflicts over LST that were religiously centred versus non-religiously centred. Because little is known about the role of religion in cases of conflict over LST, we sought to broadly examine the ways in which religion was present in these cases.

METHODS

This was a retrospective cohort study of ethics consultation cases for disagreement over LST referred to the (Optimum Care Committee) ethics committee (EC) at Massachusetts General Hospital between 1 January 2012 and 31 December 2014. The cases were identified from the EC research database as those in which there was disagreement between healthcare professionals and patients or their surrogates about starting, withholding or withdrawing a LST or medical interventions necessary to prevent or treat multiorgan dysfunction as previously described.[18] We collected sociodemographic, clinical and consultation characteristics as previously described.[19] The religious affiliation of the patient was abstracted from the demographic face sheet—which patients or surrogates reported at the time of their initial registration with the hospital—or from specific notes in the medical record.

We conducted a detailed review of the medical records of identified cases. One author (JB) read and collected information related to religion from clinical notes from the EC, chaplaincy, social work, palliative care and medical team discussions of goals of care. In addition, daily nursing progress notes and notes from subspecialty physicians were reviewed. Data were entered into REDCap (Research Electronic Data Capture), an online database for clinical research,[20] and were coded for mention or themes of religion in general. Each case was then grouped into one of two categories, 'religiously centred conflict' or 'non-religiously centred conflict', based on the information collected from the medical records. Coding and assessments were made independently by two authors (JB and WC), and differences in groupings were discussed before agreeing upon a category. We defined a 'religiously centred conflict' as a case in which religion was centrally involved in the conflict or generating disagreement between the patient/family and clinicians. In these cases, religion shaped the beliefs of the family and influenced them to take specific positions in the conflict regarding LST. A 'non-religiously centred conflict' included cases in which religion was not the primary reason for the conflict but was present in other ways in the conflict.

Statistical analysis

We used descriptive statistics to provide means and SDs, medians and IQRs, and percentages of selected variables. We used χ^2 tests and t-tests (for normally distributed variables) or Wilcoxon rank-sum tests (for non-normally distributed variables) to compare selected clinical and sociodemographic variables between patients whose conflict over LST was and was not religiously centred. We used similar tests to evaluate whether patients whose conflict over LST were more likely to be hospitalised in an intensive care unit, to be receiving artificial nutrition/hydration or mechanical ventilation, to have an earlier time from admission to EC consultation, or a longer time from consultation to death or discharge. All analyses were performed using Stata (V.14, Stata, College Station, Texas, USA). The Institutional Research Board at Massachusetts General Hospital approved this study.

RESULTS

There were 95 cases involving conflict over LST in the EC database included in the sample. Sociodemographic, clinical and consultation characteristics of the study cohort are listed in table 1. The majority of the sample was Judeo-Christian, which included patients who were Catholic (49.5%); other Christians (28.4%) such as Protestant, Pentecostal, Seventh Day Adventist, Orthodox Christian, Coptic Christian, Greek Orthodox, Assembly of God, Russian Orthodox, Armenian Orthodox; and Jewish (8.4%). A majority of patients (61.1%) were hospitalised

Table 1 Sociodemographic, clinical and consultation characteristics of study cohort

Age, mean±SD	66.8±16.8
Female sex, n (%)	39 (41.1)
Religious affiliation, n (%)	
Catholic	47 (49.5)
Christian*	14 (14.7)
Pentecostal	3 (3.2)
Seventh Day Adventist	2 (2.1)
Armenian Orthodox	1 (1.0)
Assembly of God	1 (1.0)
Coptic Christian	1 (1.0)
Protestant	2 (2.1)
Greek Orthodox	1 (1.0)
Jehovah's Witness	1 (1.0)
Mormon	1 (1.0)
Orthodox Christian	1 (1.0)
Russian Orthodox	1 (1.0)
Jewish	8 (8.4)
None	3 (3.2)
Unknown	4 (4.2)
Hindu	2 (2.1)
Buddhist	1 (1.0)
Muslim	1 (1.0)
Non-white race, n (%)	37 (38.9)
Non-English primary language, n (%)	20 (21.1)
Born outside of the USA	37 (38.9)
Low income, n (%)	11 (11.6)
Underinsured, n (%)	23 (24.2)
Complete dependence prior to admission, n (%)	33 (34.7)
Number of admission comorbidities, n (%)	3 (2–4)
Oncological diagnosis, n (%)	30 (31.6)
Hospitalised in an intensive care unit, n (%)	58 (61.1)
Number of LST, median (IQR)	3 (1–4)
Absent or fluctuating decision-making capacity, n (%)	81 (85.3)
Formal healthcare proxy, n (%)	62 (65.3)
Time from admission to consultation, median (IQR)	11 (5–20.5)
Consulting service	
Internal medicine	57 (60.0)
Surgery	16 (16.8)
Neurology/neurosurgery	10 (10.5)
Anaesthesia	5 (5.3)
Palliative care	5 (5.3)
Other	2 (2.1)
Religion central to conflict over LST, n (%)	24 (25.2)
Mention of miracles, n (%)	18 (18.9)
Mention of 'in God's hands', n (%)	25 (26.3)
Religion as a coping mechanism (positive and negative), n (%)	62 (65.3)
More than two ethics consultation meetings, n (%)	40 (42.1)
In-hospital death, n (%)	53 (55.8)

*Some patients were identified as Christian without a specific denomination.
The category 'Christian' does not include those who self-identified with a specific Christian denomination as listed below.
LST, life-sustaining treatment.

in an intensive care unit, and almost a third (31.6%) had an oncological diagnosis. Most of the patients lacked decision-making capacity (85.3%), but only 65.3% had a formal health-care proxy.

Role of religion

Religion was mentioned in a variety of ways in most of the cases reviewed. By analysing inductively how religion was present in these cases, we identified three main ways religion was present, sometimes simultaneously. These included religion (1) as a source of coping for patients and/or families including through discussion or mention of miracles and through discourse around support and intervention from a higher being, (2) via the visits from chaplains and (3) as central to conflict about LST.

Coping

Religion was often a source of coping for patients and families, providing hope, strength and meaning in difficult situations around end-of-life treatment. These included cases in which religious or spiritual beliefs, practices or communities were helpful for patients and families in getting through a difficult situation. For example, a psychiatry nursing note about a visit with a patient who identified as a Seventh Day Adventist stated, 'We talked briefly about her religious faith, things she enjoys doing when she is well …. Identifies here [sic] religious faith and talking to God as her main source of support and coping'. Even if the conflict around LST was not necessarily driven by religious convictions, many patients and families mentioned support from religious beliefs or faith as helping them cope with their present situation.

Belief in miracles

One aspect of religious coping present in the data was a belief in miracles. Families used the discourse around belief in miracles and the hope for a miraculous recovery for the patient, which were mentioned in 18 (18.9%) of the cases we reviewed. A belief in miracles seemed to be a source of coping and making sense of these difficult situations for patients and/or families. Oftentimes, religious beliefs in miracles were situated in a certain cultural context with which the family identified, as some families tried to hold on to their faith as defining them and separating them from the medical team. One social worker described her discussion with a patient's wife after a team meeting, noting that 'she continues to pray and hope for a miracle. She said this is what her culture believes in'. Similarly, a chaplain noted a different family's belief in miracles with regard to the patient's treatment, writing, 'Mother and family has a deep faith in God's ability to perform miracles: "God saved [patient] for a reason: he will bring her back to us I'm sure."' A belief in miracles or divine intervention often meant that families anxiously, and often persistently, held hope that the patient would recover against all odds.

'In God's hands'

Religion was also mentioned through talk of the situation being 'in God's hands' in 25 (26.3%) of the cases. This discourse was used as a coping mechanism and value system to negotiate how to proceed with further medical treatment. For example, one palliative care note from a family meeting stated,

> Family expressed their understanding that [patient] was dying …. They want to continue current level of care and let God decide when it is [patient's] time to die. They referred to a 'natural death' several times and also said that they would 'not pull the plug.'

In this case, the family made sense of the situation by drawing on their belief in an ultimate power other than themselves or the medical team.

Chaplaincy visits

Visits by hospital chaplains were another way in which religion was present in these cases. Chaplains were involved in some capacity in 65 cases (68.4%). These visits were requested by the care team or by the family or patient. The purpose of these visits was to provide support and spiritual care to patients and families, often in the form of providing a religious ritual or to pray with patients and/or family members: 'Prayed with the grieving family, offered patient the Sacrament of the Sick, end of life Catholic prayers and offered family spiritual support'. Chaplains also assisted patients and families in understanding end-of-life care and discussed decisions around goals of care. The following chaplaincy note demonstrated a review of this Catholic patient's life as well as an increased acceptance due to chaplaincy intervention:

> Patient tearfully sharing, 'I have a big decision to make. Do I want to go on or do I want to die?' Much life review including stories of her children …. Patient states she believes that God will call her when it is her time …. When asked what God answers when she prays about this decision she states, 'God will take me when I'm called.' In prayer together, we asked God to reveal and guide patient how she wants to live. Imposition of ashes. After prayer patient states, 'I have had a good life, I am blessed. I am ready for God to take me.'

Religion as central to the conflict

In a quarter of cases, we found religion to be central to conflict around LST (25.2%). In other words, religion shaped beliefs and oriented families to their own positions in disagreement with clinicians. We focused on these cases because they consume disproportionate amounts of healthcare providers' time and because the literature portrays religion as particularly relevant and problematic around discussions of LST.

We found no significant differences between those cases that were religiously centred versus those that were not religiously centred in terms of age, sex, insurance status, number of LST or the number of comorbidities on admission (table 2). Religion was more likely to be central to the conflict among cases involving patients who were non-white (62.5% vs 31.0%, p=.008),

Table 2 Sociodemographic and clinical differences between patients with and without religiously centred conflict over LST

Characteristic	Not religiously centred (n=71)	Religiously centred (n=24)	p Value
Age>65, n (%)	42 (59.2)	10 (41.7)	0.16
Female, n (%)	30 (42.3)	9 (37.5)	0.81
Non-white race, n (%)	22 (31.0)	15 (62.5)	0.008
Non-English primary language, n (%)	10 (13.1)	10 (41.7)	0.008
Born outside the USA, n (%)	22 (31.0)	15 (62.5)	0.006
Low income, n (%)	5 (7.0)	6 (25.0)	0.03
Underinsured, n (%)	15 (21.1)	8 (33.3)	0.27
Number of admission comorbidities, n (median)	3	4	0.70
Complete dependence prior to admission, n (%)	27 (38.0)	6 (25.0)	0.32

LST, life-sustaining treatment.

did not speak English as a primary language (41.7% vs 13.1%, p=.008), were born outside the USA (62.5% vs 31.0%, p=.006) and were with low income (25.0% vs 7.0%, p=.03). Chaplains were present in 19 of the 24 cases (79.2%) in which religion drove the conflict.

The cases in which religion was central to the conflict over LST differed in content by the ways religion was present in the conflict. Some cases involved a strong belief in miracles or insistence that decisions are 'in God's hands', indicating a belief in God's power over and above the power of the medical team. One nurse wrote about the role of a family's religion in making choices about medical treatment for the patient, noting, 'Their faith is very important to them and affects their decision making. [Husband] referred to miracles that are performed that are not explained by science'. In addition, religious doctrine and disagreements or misunderstandings about religious teachings on medical treatment are other ways religion was central to the conflict. For example, one family's understanding of Catholic teachings and end-of-life care led them to the conflict over the patient's nutrition:

> They stated that it is against the Catholic Church for a patient to refuse nutrition. They stated that [chaplain, a priest] is 'wrong' about the Catholic teaching on the right to refuse nutrition, even when it is burdensome to the patient. They stated that the doctors and others are pressuring [patient] into refusing a [gastric feeding tube].

Strong religious and cultural notions and beliefs that differed from dominant American medical perspectives were another dimension of religiously centred conflict. In one ethics consult note, the physician viewed religion as central to the conflict for a patient who identified as a Coptic Christian: '[Physician] believes that religious factors influence the son's stance to continue treatment for his father, as well as a socio-cultural disconnect, where perceptions of hospital care and hospice care are differently understood'. A chaplaincy note described one Armenian Orthodox family's differences about treatment as based on their religious and cultural beliefs:

> Patient's wife often cited what is done 'in my country' as reference points in describing what she and her family wants for the patient. Patient's wife said that she and her children are 'mad' following the meeting. Patient's wife and family said in her country 'they give medicine to the sick person until they get better.' God has the final decision as to whether someone is healed or not.

This note demonstrates that culturally influenced experiences of healthcare outside the USA are often present in non-American families' considerations of end-of-life care.

Religiously centred conflict outcomes

There was no difference in the number of LST, hospitalisation in the intensive care unit, or utilisation of artificial nutrition, hydration or mechanical ventilation in patients with religiously versus non-religiously centred conflict (table 3). Consults for religiously centred conflict did not occur earlier than non-religiously centred conflict, and there was no difference in in-hospital mortality or time to death or discharge between patients with religiously versus non-religiously centred conflict.

Table 3 Clinical, consultation and disposition differences between patients with and without religiously centred conflict over LST

Characteristic	Not religiously centred (n=71)	Religiously centred (n=24)	p Value
Number of LST, n (median)	2	3	0.54
Hospitalised in an intensive care unit, n (%)	45 (63.4)	13 (54.2)	0.47
Receiving artificial nutrition/ hydration, n (%)	30 (42.3)	14 (58.3)	0.24
Receiving mechanical ventilation, n (%)	36 (50.7)	11 (45.8)	0.81
Time to consult, d (median)	12	7	0.67
In-hospital mortality, n (%)	42 (59.1)	11 (45.8)	0.34
Time to death or discharge, d (median)	8	11	0.17

LST, life-sustaining treatment.

DISCUSSION

Despite the data that religiously affiliated patients and surrogates pursue more aggressive interventions during critical illness, the role of religion in cases of conflict over LST has been underdescribed. Our primary findings in this retrospective investigation of 3 years of ethics consultation were: (1) that religion is present in a number of ways in these populations, including a central factor of the conflict in a quarter of cases; (2) that when religion is central to conflict, there is a specific constellation of sociodemographic factors that are often present; (3) that patients with religiously centred conflict over LST do not receive more interventions than patients with other types of conflict.

The findings from this study confirm findings from other studies that religion is an important factor in decision-making because of the idea that God is in control or that the situation is 'in God's hands'.[15 21] There is complexity around the locus of control when clinicians ask surrogates to make decisions, but there is a belief that the decision is not that of the clinicians to make. Additionally, death and dying is often experienced as a spiritual more than a medical event.[22] The data demonstrate that religious teachings about end-of-life care may be influential in shaping patients' and families' orientation and preferences to medical treatment, which has also been previously reported.[11] As Jahn Kassim and Alias[16], p. 7 state, 'religion and religious traditions serve two primary functions, namely the provision of a set of core beliefs about life events and the establishment of an ethical foundation for clinical decision making'. As demonstrated in the data, families used religion as a value system to inform their decision-making or to affirm their choices about medical treatment. Oftentimes, families invoked religious beliefs to assert power or to resist the medical model in situations in which they may have felt powerless.

The belief in miracles as being influential in medical decision-making has been noted in previous studies.[3 15 17 23] Other studies have demonstrated the association between religious coping and the preference of aggressive care,[3 13] and our study extends these findings by demonstrating the different ways religious coping may play a role in discussions around LST, even in cases in which there is no religiously centred conflict. The importance of chaplains in assessing how religious beliefs contribute to positive or negative coping, as well as in providing supportive spiritual care and in assisting families in making sense of difficult hospitalisations at end of life, and in helping patients and families move to acceptance has also been noted elsewhere.[1 4]

The cases in which the conflict over LST was motivated by religion also point to the challenges for clinicians in providing the most optimum care possible and avoiding harm to patients while also respecting the patient's and/or family's wishes about medical treatment. Ethics consultants and members of the medical team navigated these boundaries by listening

compassionately to the viewpoints of patients and surrogates while also working collaboratively to provide high quality care. Such considerations are important when providing care to patients and their families who may have strong religious beliefs that inform their perspectives and choices around medical treatment. We note, however, that both religiously centred and non-religiously centred cases received the same number of LST, medical nutrition and hydration, mechanical ventilation and had similar mortality. This suggests that the presence of religious considerations in the conflict does not, in and of itself, determine the outcomes of these cases.

Patients who were among the group of religiously centred conflicts were more likely to be non-white, not speak English as a primary language, born outside the USA and be with low income, which may suggest a cultural component to the role of religion in conflict over LST, potentially mediated by distrust in the health system.[24] It may also be possible that these patients and families who have concerns over withdrawal of LST are more likely to use religious language to express their discomfort or conflict. Alternatively, it may be that patients and families who are white and born in the USA may express their desire for ongoing LST in non-religious terms because of a perception that clinicians will be more responsive to non-religious requests. Studies suggest that race, ethnicity and culture play a unique role in end-of-life decision-making and preferences and call for more research on cultural diversity and preferences for end of life.[25 26] The data from this study may suggest that stated religious beliefs may be a mechanism for framing convictions and wishes in a way that surrogates believe is more likely to evoke a particular response among clinicians, although more detailed prospective work is needed to investigate this hypothesis.

LIMITATIONS

Our study has several limitations. First, it was a retrospective review conducted in a single hospital, limiting the generalisability of our findings. Second, because we focused on the written medical records, our data do not directly include the perspectives of patients and families. This research, however, will form the foundation for an ongoing prospective project exploring the role of religion in ethics consultation cases, including discussions and interviews with all stakeholders involved. Third, we relied on information from the medical charts on religious affiliation and do not have information on patients' and families' perspectives of their own religiosity or spirituality. We were specifically unable to identify patients or surrogates who identify themselves as spiritual but not religious. Fourth, we restricted our sample to patients whose ethics consult was for disagreement or conflict over LST among the patient, family and healthcare providers. Therefore, the different ways religion was present among these cases may not be generalisable to all patient populations whose conflict over LST did not require ethics consultation. Fifth, although we were able to identify some sociodemographic differences between patients whose ethics consultation for conflict over LST was and was not religiously centred, we did not have sufficient numbers of cases to conduct a meaningful multivariate model to separate the significant variables in our bivariate analysis. A larger sample will be required to expand on these findings and to detect small effect sizes in individual populations.

CONCLUSION

The data from this study demonstrate that while religion can be a source of conflict over LST, religion also plays a variety of roles in discussions in these situations. It is important for clinicians to recognise that religion can also be a source of support for patients and families through coping and making sense of the hospitalisation. While there is often concern about the presence of religion in cases involving LST, our study shows the positive role that religion can play in helping families cope with these situations and also demonstrates that religion does not necessarily increase interventions or use of LST. Finally, visits from chaplains may be helpful for patients and families in reaching an acceptance of the situation and also important for clinicians in understanding the perspectives of patient and surrogate viewpoints.

Contributors AC, WC, ER and AZ initiated the collaborative project. JB collected the descriptive data, and JB and WC coded the data. AC ran the statistical analyses. All authors contributed to the drafting and revising of the paper.

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Notes