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Attitudes About and Preferences for End-of-Life Care in Persons of the Reform Jewish Faith

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ATTITUDES ABOUT AND PREFERENCES FOR END-OF-LIFE CARE IN PERSONS OF THE REFORM JEWISH FAITH

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INTRODUCTION

Decisions made toward the end-of-life (EOL) are heavily influenced by religion and spirituality (Broeckaert, 2011; Clarfield, Gordon, Markwell & Alibhai, 2003) and are considered emotionally and politically charged (Sachedina, 2005) for patients, their loved ones, and for health care providers. Guidelines used in health care facilities may not be evidence-based and may represent religious traditions not preferred by individual Jewish persons and/or their families at end-of-life. Knowing the complexities of end-of-life care that include the diverse and oftentimes very sensitive issues involved, health care providers must be at least somewhat knowledgeable about these issues so that the culture and spiritual faith of persons in the last days of their lives can be honored. Studies regarding Jewish end-of-life preferences for care are extremely scarce, and none could be located regarding those of the Jewish faith who live in Texas, specifically those of the Reform sect.

STUDY PURPOSE

To determine the attitudes about and preferences for care in persons of the Reform Jewish faith.

RESEARCH QUESTIONS

What are the attitudes about and preferences for care in persons of the Reform Jewish faith regarding pain management, conflict resolution, disclosure, life sustaining measures, and spiritual issues?

What are the attitudes of Reform Jewish persons regarding the most important concerns in the last days of life?

BACKGROUND

Spiritual faiths vary significantly regarding end-of-life care, loss and bereavement. Health care professionals must acknowledge and respect these unique traditions in order to provide the best quality care for their patients and their respective families at this very sensitive and vulnerable time of life. Other groups include Orthodox, Conservative and Secular Judaism (Bulow et. al, 2008). The main principles of Judaism include having one powerful God who created the universe who communicated his commandments through Moses that is written in the Torah. The Torah contains "Halacha" which are Jewish laws regarding commitments, obligations, duties and commandments that are priority over individuals pleasures (Pastoral Care Leadership and Practice Group of Healthcare, 2009). Basic core principles of Halacha regarding end-of-life care for Judaism include 3 main principles, 1) under no circumstances may life be intentionally shortened 2) aging, illness and death are a natural part of life and 3) patient's quality of life should always be improved constantly (Goldsand et. al, 2001). However despite the goal to maximize living, there is no obligation to actively prolong the pain and suffering of a dying patient or to lengthen such a patient's life (Bulow et. al, 2008). All individuals should die with dignity around family members and loved ones (Kinzbrunner, 2004).

After death, the body should be treated with respect. Conservative, Reform, and certain small sectors of the Orthodox Jews permit autopsy and organ donation. However, cremation is either prohibited or discouraged (Popovsky, 2007). Jewish funerals are comprised of different practices and customs. Each community differs in the way they practiced with influences from Jewish tradition, local law and regulations, and cemetery rules, but there are key concepts that are practiced by all Jews. For example, funerals should not be held on Shabbat or during Jewish holidays. Traditionally, burials must take place 24 hours after death, however, Reformed Jews acknowledge that modern Jewish families are spread out around the country, so it might be necessary to delay the burial a day or two until all of the mourners can arrive (Black, http://www.reformjudaism.org/what-expect-jewish-funeral).

Studies regarding end-of-life care for the Jewish population in the United States are extremely scarce. Anecdotal evidence through clinical practice of the study authors reflect significant diversity within spiritual groups. Guidelines used by clinical facilities are often written by spiritual leaders or may reflect information that does not accurately reflect best practice regarding end-of-life care for the person and family. This study explored qualitatively the attitudes about and preferences for care in persons of the Reform Jewish faith.

METHODS

Design: Qualitative descriptive
Sampling: Purposive, networking, snowballing. Inclusion criteria: Must be of Reform Jewish faith for at least one year; 45 years old or over.
Settings: Tyler, Fort Worth, and Dallas, Texas
Data Collection: Interviews (individual & focus groups per participant preference); field notes. The open-ended interview guide consisted of questions about pain management, life sustaining measures, conflict resolution, truth telling, and special concerns and preferences for the last days and hours of life.
Data Analysis: Krippendorf's (2004) method of thematic data analysis was applied to the data to "(make) replicable and valid inferences from texts…to the contexts of their use" (p. 18). Transcripts were read and abstracted on four levels.

RESULTS

Demographics

Sampling was done until data saturation was achieved. Sixteen persons were interviewed and included ten females, six males, ranging in age from 45 to 77, with the average being 63 years. All but three of the participants had been Jewish all or most of their lives, and the other three had converted from Christianity to Reform Jewish 2, 9 and 25 years ago. All except four had college degrees, and current/past occupations included nursing, engineering/software, social work, law, education, journalism. Three only stated retired, and two were rabbis, and one was a cantor and hospital chaplain. Themes are listed in the order of their dominance as reflected in the responses.

Life Sustaining Measures

For responses about life sustaining measures (LSM), participants were given a hypothetical scenario upon which they would respond to whether or not they would accept enteral nutrition. Three major themes evolved out of the responses: Conditional (acceptance, refusal, other) Absolutely Not!, and Ambivalence. The conditional theme included various reasons they would accept LSM, which included ability to perform basic activities of daily living, younger ages due to increased hope for recovery, holding out for a miracle, ability to enjoy isolated aspects of life, organ function, "buying time" to find a cure, to communicate with children, honoring of wishes, and completion of important tasks. One of the reasons for LSM refusal included intractable or severe pain or illness. Many were emphatic regarding no LSM, and some insisted their wishes for no LSM be adhered to despite that they may not be congruent with religious beliefs.

Conflict Resolution

Four themes highlighted conflict resolution responses. Participants were asked if there was disagreement among family about LSM or similar for a loved one who could not make their own decision, how would it be resolved? Themes of Decision Maker, Anticipatory Conflict, Planning/Communication, and Trust vs Mistrust reflected participant responses. Decision Maker alluded to designation of a person who would make those decisions. Most of the time the decision maker was the spouse, and when not so, designees included an external person, oldest child, or the child living closer to or overseeing the care of the person: "often then parents will move to where one of the children is… so I think it's kind of who's overseeing, you know." Participants also were adamant that this was their decision, and no one else's and their wishes must be adhere to: "It's my decision, not my kids' decision…It really is…." Anticipatory conflict was mentioned often, especially when estrangement was an issue, or when several children were involved. Integral to this was the importance of planning and communication, with one of the participants acknowledging that advance planning and communication can prevent conflict and facilitate honoring of wishes. Trust vs mistrust dealt with rabbis the participants did not know well and with family members who were not trusted to honor wishes.

Truth Telling

Truth telling, or disclosure or a poor prognosis, reflected 5 themes: Transparency, Purposeful Disclosure, and Darkness of Truth, Uncertainty, Hidden Truth. Transparency reflected responses that advocated for whole truth regardless of the circumstances, and that honesty facilitated a peaceful death. Purposeful disclosure would be done to see if disclosure may heal estranged relationships and facilitate honoring of wishes. One participant said her mother and brother would not tell her the truth, but her father would. Darkness of Truth was when participants felt the truth would lead to hopelessness and despair: "…with my dad…once he knew that there was no hope, he went down so fast. I mean, it killed him. It killed him just knowing, he just gave up."

DISCUSSION

CONCEPT	RESULT THEMES	LITERATURE FINDINGS
Conflict Resolution	Decision Maker Planning/Communication Anticipatory Conflict Trust vs. Mistrust	Clinicians should ask Jewish patients whether they want to consult with family members and their rabbi regarding advance directives. Rabbis are consulted for advance directives or power of attorney to insure that Jewish law is incorporated and adhered to when making end-of-life decisions (Kinzbrunner, 2004). The rabbi would speak with the doctor in charge of the individual's condition to gain more knowledge and provide the best-informed options for the individual (Dorff, 2005).
Truth Telling	Transparency Purposeful Disclosure Uncertainty and Ambivalence Hidden Truth Darkness of Truth	Traditionally, it was decided that truth may be reserved from an individual if it is believed that it will be harmful (Kinzbrunner, 2004). Jewish elders believe that hope and healing are connected. Thus justifies their means in believing that it is permissible to withhold truth so long as it promotes sustenance of hope in condition. However now in the modern age, evidences suggest that participation of the individual in his/her treatment improves their treatment outcomes so a shift towards truth telling is observed more (Popovsky, 2007).
Pain	Unconditional Pain Relief Balanced Pain Relief Conditional Pain Relief Death Over Pain	Unremitting suffering is considered even worse than death in Jewish law (Greenberger, 2015). It is obligatory in Jewish law to treat physical and emotional pain and suffering. If pain and suffering are unceasing, treatments and procedures that are prolonging life may be removed (Kinzbrunner, 2004).
Life Sustaining Measures	Conditional Absolutely Not! Ambivalence	**Life Support and Procedures** Jewish law provides an emphasis on the notion that individuals cannot end life prematurely. For this reason, it is generally forbidden to withdraw life support and/or other procedures that enable the individual to continue living. (Kinzbrunner, 2004). However, some scholars of the Jewish law do allow and even obligate not using these life-prolonging procedures when the individuals are terminally ill (Greenberger, 2015). **Artificial Nutrition and Hydration** Artificial nutrition and hydration are considered basic necessities, not medical interventions, thus individuals should be provided despite being terminally ill. However, if the individual refuses after multiple attempts, their wishes should be respected because autonomy and dying with dignity is a priority (Kinzbrunner, 2004).
Most Important in the Last Days	Peace and Comfort Respect my Faith (Spiritual) Presence Last Breath	**Presence of Visitors** Jewish law and tradition obligates *hippur holim* – visiting the sick as it is a part of the commandments to *love your neighbor as yourself*. Presence of visitors are important as they enable the sick individual to talk about his/her illness, make sure that a will has been prepared, occupy the individual in different conversations involving politics, sports, etc., and accompany him/her in prayer (Dorff, 2005). **Attitudes on End-of-Life Care** Jewish attitudes on end-of-life care are centered on shared decision-making between patients and family on current circumstance instead of planning on what may happen in the future. Jews put an emphasis on dying with dignity and peace surrounded by family with enough time to give final salutations to their children (Kinzbrunner, 2004). During the last days, Reform Jews might consult a rabbi, however, the information that they gather from the rabbi are not treated as authoritative law but instead merely as guidance in addressing their expertise in Jewish tradition (Dorff, 2005). **Fear, Despair and Lack of Hope** Fear is an overwhelming and alarming response to a Jewish individual who is seriously ill which is why Judaism places treatment of fear on the same level as medical needs. Despair and lack of hope regarding physical health and worth of life are also common spiritual needs that need to be alleviated in terminally ill Jewish patients (Schutz, Baddarni & Bar-Sela, 2011). **Palliative Care** Some Jewish patients and families might refuse palliative care because it can be seen as losing hope in healing. This is interpreted as lack of faith in God and his healing capabilities (Schutz, Baddarni & Bar-Sela, 2011).

Pain and Suffering

Participants were asked two broad questions about acknowledging and accepting pain medication if asked, and taking pain medication if it resulted in loss of communication ability. Unconditional Pain Relief, Balanced Pain Relief (BPR), Conditional Pain Relief and Death Over Pain were the 4 emerging themes. With some exceptions, there seemed to be a general sense of free acceptance of pain medication, and acknowledgement of pain if asked. Conditional Pain Relief meant that pain medication would be acceptable under certain conditions, including unfinished business, severe pain only, and special life events. Balanced Pain Relief dealt primarily with the balancing of some pain relief in order to have a level of cognition and ability to communicate or do other important activities. Death over Pain reflected statements that death or shortening of life would be preferable over pain, this was also a condition cited to legitimize physician-assisted or prescribed suicide. One participant, in recalling a deceased friend stated: "I think if someone's in pain and they want to end it, they ought to be able…", and "I'd rather die in peace than die in pain."

Most Important in the Last Days

Participants were asked what the most important concerns or issues they had in the last very few days or hours of life, and elicited four overriding themes: Peace and Comfort, Respect My Faith, Presence, and Last Breath. Peace and Comfort encompassed not only physical comfort, but also peace of mind regarding family and unfinished business. Knowing family would be taken care of and at peace was important. A social worker familiar with issues about ineffective pain management in healthcare feared she would suffer due to a provider's fear of opioids: "I would have a fear of, oh, [my] suffering, prolonged for the sake of… don't want to be made to stay here because somebody else is afraid of (giving me) morphine or…". Issues relating to one's religious and spiritual needs emerged under Respect My Faith. While varying preferences for spiritual needs were expressed, the prevailing opinions of the participants dealt with the need to acknowledge, be somewhat familiar with, and to respect their Jewish faith. While discussing who she wanted at her bedside, one woman stated: "I do not want my Christian relatives and friends coming and trying to convert me at the last moment." Regarding prayer, some felt it acceptable for a Christian to say a "generic" prayer as long as "Jesus" or related terms were excluded from the prayer. Presence referred to not being alone and identification of specific persons they wanted at their bedside, as well as the presence of the sounds of people interacting and music. Last Breath designated responses about desired locations for dying.

IMPLICATIONS & CONCLUSIONS

The quality of end of life care depends on attitudes, knowledge a skills of health care providers. This study reflected much variati within the Reform group regarding the multi-faceted and compl issue of end of life care preferences. It is profoundly critical t health care providers are cognizant of the uniqueness of variations within a particular religious group and not m assumptions about their belief systems. Inquiries made in sensiti compassionate and caring ways regarding patient and family nee especially within the context of religious and spiritual needs, m be implemented to facilitate a peaceful death with dignity.