

ANSWERS
hope
family
trust

Culturally-sensitive End-of-Life Care Scoping Review

***KT Tools Project
Literature Review and Current State Assessment***

By: Dr. Judith Sixsmith and Mei Lin Fang

CANADIAN
Virtual Hospice



Portail CANADIEN EN SOINS
palliatifs



An initiative of / Une initiative de

CANADIAN PARTNERSHIP
AGAINST CANCER



PARTENARIAT CANADIEN
CONTRE LE CANCER

Production of this Literature Review has been made possible through financial support from the Canadian Partnership against Cancer and Health Canada.
The views expressed herein do not necessarily represent the views of Health Canada or the Canadian Partnership Against Cancer.

Annotated Bibliography: Culturally-sensitive End-of-Life Care Scoping Review (N=94)

Artsanitha, J., B. E. Mawn, et al. (2011). "Exploring the Palliative Care Needs of People Living in Thailand With End-Stage Renal Disease A Pilot Study." Journal of Hospice & Palliative Nursing **13**(6): 403-410.

This article describes the results of a pilot study that was undertaken as a needs assessment for the development of a home-based palliative care model for people living with end-stage renal disease (ESRD) in Thailand. Using the theory of uncertainty in illness as a guide, this mixed-methods study explored the palliative care needs of individuals with ESRD in Bangkok, Thailand. The study included 30 participants with ESRD, 39 family members, four community leaders, and four healthcare providers. The participants completed the revised Edmonton Symptom Assessment Scale, which provided descriptive data on nine symptoms commonly experienced among palliative care patients. In addition, focus group and in-person interviews were conducted with study participants. Four major themes emerged from the qualitative interviews that were congruent with the uncertainty in illness constructs: tremendous suffering, economic consequences, inadequate community support, and concern for the future. The participants suggested improvements in palliative home care from their unique cultural and spiritual perspectives. These findings will facilitate the development of a future intervention study that will examine the impact of a palliative care program for Thai persons living with ESRD.

Balboni, T. A., M. Balboni, et al. (2013). "Provision of Spiritual Support to Patients With Advanced Cancer by Religious Communities and Associations With Medical Care at the End of Life." Jama Internal Medicine **173**(12): 1109-1117.

Importance: Previous studies report associations between medical utilization at the end-of-life (EoL) and religious coping and spiritual support from the medical team. However, the influence of clergy and religious communities on EoL outcomes is unclear. Objective: To determine whether spiritual support from religious communities influences terminally ill patients' medical care and quality of life (QoL) near death. Design, Setting, and Participants: A US-based, multisite cohort study of 343 patients with advanced cancer enrolled from September 2002 through August 2008 and followed up (median duration, 116 days) until death. Baseline interviews assessed support of patients' spiritual needs by religious communities. End-of-life medical care in the final week included the following: hospice, aggressive EoL measures (care in an intensive care unit [ICU], resuscitation, or ventilation), and ICU death. Main Outcomes and Measures: End-of-life QoL was assessed by caregiver ratings of patient QoL in the last week of life. Multivariable regression analyses were performed on EoL care outcomes in relation to religious community spiritual support, controlling for confounding variables, and were repeated among high religious coping and racial/ethnic minority patients. Results: Patients reporting high spiritual support from religious communities (43%) were less likely to receive hospice (adjusted odds ratio [AOR], 0.37; 95% CI, 0.20-0.70 [P=.002]), more likely to receive aggressive EoL measures (AOR, 2.62; 95% CI, 1.14-6.06 [P=.02]), and more likely to die in an ICU (AOR, 5.22; 95% CI, 1.71-15.60 [P=.004]). Risks of receiving aggressive EoL interventions and ICU deaths were greater among high religious coping (AOR, 11.02; 95% CI, 2.83-42.89 [P<.001]; and AOR, 22.02; 95%

CI, 3.24-149.58 [P=.002]; respectively) and racial/ethnic minority patients (AOR, 8.03; 95% CI, 2.04-31.55 [P=.003]; and AOR, 11.21; 95% CI, 2.29-54.88 [P=.003]; respectively). Among patients well-supported by religious communities, receiving spiritual support from the medical team was associated with higher rates of hospice use (AOR, 2.37; 95% CI, 1.03-5.44 [P=.04]), fewer aggressive interventions (AOR, 0.23; 95% CI, 0.06-0.79 [P=.02]) and fewer ICU deaths (AOR, 0.19; 95% CI, 0.05-0.80 [P=.02]); and EoL discussions were associated with fewer aggressive interventions (AOR, 0.12; 95% CI, 0.02-0.63 [P=.01]). Conclusions and Relevance: Terminally ill patients who are well supported by religious communities access hospice care less and aggressive medical interventions more near death. Spiritual care and EoL discussions by the medical team may reduce aggressive treatment, highlighting spiritual care as a key component of EoL medical care guidelines.

Ball, C. G., P. Navsaria, et al. (2010). "The impact of country and culture on end-of-life care for injured patients: results from an international survey." Journal of Trauma **69**(6): 1323-1334.

BACKGROUND: Up to 20% of all trauma patients admitted to an intensive care unit die from their injuries. End-of-life decision making is a variable process that involves prognosis, predicted functional outcomes, personal beliefs, institutional resources, societal norms, and clinician experience. The goal of this study was to better understand end-of-life processes after major injury by comparing clinician viewpoints from various countries and cultures. **METHODS:** A clinician-based, 38-question international survey was used to characterize the impacts of medical, religious, social, and system factors on end-of-life care after trauma. **RESULTS:** A total of 419 clinicians from the United States (49%), Canada (19%), South Africa (11%), Europe (9%), Asia (8%), and Australasia (4%) completed the survey. In America, the admitting surgeon guided most end-of-life decisions (51%), when compared with all other countries (0-27%). The practice structure of American respondents also varied from other regions. Formal medical futility laws are rarely available (14-38%). Ethical consultation services are often accessible (29-98%), but rarely used (0-29%), and typically unhelpful (<30%). End-of-life decision making for patients with traumatic brain injuries varied extensively across regions with regard to the impact of patient age, Glasgow Coma Scale score, and clinician philosophy. Similar differences were observed for spinal cord injuries (age and functional level). The availability and use of "donation after cardiac death" also varied substantially between countries. **CONCLUSIONS:** In this unique study, geographic differences in religion, practice composition, decision-maker viewpoint, and institutional resources resulted in significant variation in end-of-life care after injury. These disparities reflect competing concepts (patient autonomy, distributive justice, and religion).

Blank, R. H. (2011). "End-of-Life Decision Making across Cultures." Journal of Law, Medicine & Ethics **39**(2): 201-214.

Even more so than in other areas of medicine, issues at the end of life elucidate the importance of religion and culture, as well as the role of the family and other social

structures, in how these issues are framed. This article presents an overview of the variation in end-of-life treatment issues across 12 highly disparate countries. It finds that many assumptions held in the western bioethics literature are not easily transferred to other cultural settings.

Bloomer, M. J. and A. Al-Mutair (2013). "Ensuring cultural sensitivity for Muslim patients in the Australian ICU: Considerations for care." Australian Critical Care **26**(4): 193-196.

Australia is a diverse and multicultural nation, made up of a population with a predominant Christian faith. Islam, the second largest religion in the world, has demonstrated significant growth in Australia in the last decade. Coming from various countries of origin and cultural backgrounds, Muslim beliefs can range from what is considered 'traditional' to very 'liberal'. It is neither possible nor practical for every intensive care clinician to have an intimate understanding of Islam and Muslim practices, and cultural variations amongst Muslims will mean that not all beliefs/practices will be applicable to all Muslims. However, being open and flexible in the way that care is provided and respectful of the needs of Muslim patients and their families is essential to providing culturally sensitive care. This discussion paper aims to describe the Islamic faith in terms of Islamic teachings, beliefs and common practices, considering how this impacts upon the perception of illness, the family unit and how it functions, decision-making and care preferences, particularly at the end of life in the intensive care unit.

Braun, U. K., M. E. Ford, et al. (2010). "The physician's professional role in end-of-life decision-making: voices of racially and ethnically diverse physicians." Patient Education & Counseling **80**(1): 3-9.

OBJECTIVE: Previous studies have shown racial/ethnic differences in preferences for end-of-life (EOL) care. We aimed to describe values and beliefs guiding physicians' EOL decision-making and explore the relationship between physicians' race/ethnicity and their decision-making. **METHODS:** Seven focus groups (3 Caucasian, 2 African American, 2 Hispanic) with internists and subspecialists (n=26) were conducted. Investigators independently analyzed transcripts, assigned codes, compared findings, reconciled differences, and developed themes. **RESULTS:** Four themes appeared to transcend physicians' race/ethnicity: (1) strong support for the physician's role; (2) responding to "unreasonable" requests; (3) organizational factors; and (4) physician training and comfort with discussing EOL care. Five themes physicians seemed to manage differently based on race/ethnicity: (1) preventing and reducing the burden of surrogate decision-making; (2) responding to requests for "doing everything;" (3) influence of physician-patient racial/ethnic concordance/discordance; (4) cultural differences concerning truth-telling; and (5) spirituality and religious beliefs. **CONCLUSIONS:** Physicians in our multi-racial/ethnic sample emphasized their commitment to their professional role in EOL decision-making. Implicitly invoking the professional virtue of self-effacement, they were able to identify racially/ethnically common and diverse ethical challenges of EOL decision-making. **PRACTICE IMPLICATIONS:** Physicians should use professional virtues to tailor the EOL decision-making process in response to patients' race/ethnicity, based on patients' preferences.

Brown, E., R. Patel, et al. (2013). "The Interface Between South Asian Culture and Palliative Care for Children, Young People, and Families-a Discussion Paper." Issues in Comprehensive Pediatric Nursing **36**(1/2): 120-143.

A fundamental element of quality healthcare is that provision is accessible to all users and culturally sensitive to them. However, there is evidence to suggest that there is inequity of provision across all cultures. Furthermore, there is a paucity of published research in the United Kingdom concerning palliative care for minority ethnic families with a life-threatened or life-limited child or young person. The article sets out to discuss the findings of a literature review and, drawing on current work by the Centre for Children and Families Applied Research at Coventry University under the leadership of Professor Jane Coad, to explore the interface between South Asian cultures and the experience of palliative care services of children, young peoples, and families. All families require a broad range of services which are appropriately delivered and accessible throughout the trajectory of their child's illness. The literature review findings reveal that how families understand concepts such as health and disease arise from the complex interaction between personal experience and cultural lifestyle including language, family values, and faith. There is an urgent need to involve South Asian families in research in order to provide a robust evidence-base on which to develop service provision so that care is matched to the unique needs of individuals concerned.

Bullock, K. (2006). "Social work series. Promoting advance directives among African Americans: a faith-based model." Journal of Palliative Medicine **9**(1): 183-195.

BACKGROUND: Studies show that African Americans are less likely than other ethnic groups to complete advance directives. However, what influences African Americans' decisions to complete or not complete advance directives is unclear. **METHODS:** Using a faith-based promotion model, 102 African Americans aged 55 years or older were recruited from local churches and community-based agencies to participate in a pilot study to promote advance care planning. Focus groups were used to collect data on participants' preferences for care, desire to make personal choices, values and attitudes, beliefs about death and dying, and advance directives. A standardized interview was used in the focus groups, and the data were organized and analyzed using NUDIST 4 software (QRS Software, Victoria, Australia). **RESULTS:** Three fourths of the participants refused to complete advance directives. The following factors influenced the participants' decisions about end-of-life care and completion of an advance directive: spirituality; view of suffering, death, and dying; social support networks; barriers to utilization; and mistrust of the health care system. **CONCLUSION:** The dissemination of information apprises individuals of their right to self-determine about their care, but educational efforts may not produce a significant change in behavior toward completion of advance care planning. Thus, ongoing efforts are needed to improve the trust that African Americans have in medical and health care providers.

Bushnaq, M. (2008). "Palliative care in Jordan: Culturally sensitive practice." Journal of Palliative Medicine **11**(10): 1292-1293.

In Jordan, based in the Islamic religion and cultural norms, people believe that no matter what you do, when your time comes to die, it is God's wish and your destiny.

Therefore, it is easy for the family to accept a do-not-resuscitate concept. And in the same way, they accepted the fact that it is the right of the patient to at least have some sense that his death is near, so that he could finish "unfinished business," in particular moral and religious duties, so that he may meet his lord free of sins. We present a case of a 52-year-old man presented with pallor, fatigue, and jaundice due to pancreatic cancer metastatic to the liver. He was a devout Muslim. After investigation, the oncologist decided there were no curative measures and he referred the patient to palliative care. At the time the palliative care team arrived in the patient's room, many family members were waiting outside the room with many questions. We asked the family to join us to see the patient together. We talked about his cancer, emphasizing that the goal now will be for symptom control and quality of life. The patient and the family were satisfied with this open discussion, and the patient was discharged home with our home palliative care service. Three weeks later the patient died at home peacefully. Thus, this case illustrates that approaches developed in Europe and the United States can be integrated into traditional Arab culture. We think its clear that values and principles of palliative care are the same everywhere, but the way we apply it needs to be tailored to local culture and norms.

Carr, D. (2011). "Racial Differences in End-of-Life Planning: Why Don't Blacks and Latinos Prepare for the Inevitable?" Omega: Journal of Death & Dying **63**(1): 1-20.

I evaluate the extent to which ethnic disparities in advance care planning reflect cultural and religious attitudes and experience with the painful deaths of loved ones. Data are from a sample of 293 chronically ill older adults who are seeking care at one of two large medical centers in urban New Jersey. Blacks and Hispanics are significantly less likely than Whites to have a living will, a durable power of attorney for health care (DPAHC), and to have discussed their end of life treatment preferences. Multivariate analyses reveal that the Black-White gap in advance care planning is largely accounted for by Blacks' belief that God controls the timing and nature of death. The Hispanic-White gap is partially accounted for by the belief that one's illness negatively affects one's family. Ethnic disparities are starkest for living will and DPAHC use, and less pronounced for discussions. Implications for policy and practice are discussed.

Chan, J. and J. Kayser-Jones (2005). "The experience of dying for Chinese nursing home residents: cultural considerations." Journal of Gerontological Nursing **31**(8): 26.

Given the increase of cultural diversity of the elderly population in the United States, there is a need for increased sensitivity of culturally diverse residents. Research on the care of terminally ill Chinese elderly individuals in nursing homes is limited. As part of a larger study on end-of-life care in nursing homes, data were obtained on 34 Chinese residents. Data were obtained through participant observation, event analysis, and in-depth interviews with residents and their families, nursing staff, and physicians. The process of providing care was observed from the time residents were identified as terminally ill until their death. The most significant factors

influencing the care Chinese residents received were communication barriers, dislike of Western food, and differing cultural beliefs and customs. These findings offer valuable information in helping to develop and implement interventions to improve the terminal care of Chinese elderly individuals in nursing homes.

Cheng, H.-W. B., C.-W. Li, et al. (2014). "Bringing Palliative Care into Geriatrics in a Chinese Culture Society-Results of a Collaborative Model between Palliative Medicine and Geriatrics Unit in Hong Kong." Journal of the American Geriatrics Society **62**(4): 779-781.

The article discusses research conducted to investigate the effectiveness of a collaborative model between palliative medicine and a geriatrics unit in Hong Kong, China. Researchers evaluated the model with 123 terminal adults. They found that only 2.7% of patients died at home and that there were several potential barriers to dying at home in Hong Kong, including crowded living environments, perceived threat to real estate value if death occurs at home and social and cultural taboos.

Cheraghi, M. A., S. Payne, et al. (2005). "Spiritual aspects of end-of-life care for Muslim patients: experiences from Iran." International Journal of Palliative Nursing **11**(9): 468-474.

The aim of this article is to describe the spiritual aspects of palliative care of Muslim patients based on experiences of end-of-life care in Iran. The religions of the world play a major part in the life cycle of their adherents, and most have rituals and beliefs concerning the care of dying people. For Muslims, death is believed to be not only the cessation of a complex set of biochemical processes, but also a belief that the spirit continues to live and dying is a passage from this world to the resurrection. The spirit is believed to be eternal and does not perish with death. According to Muslims' beliefs, reading of the Quran (the main religious text) can produce peace of mind in those who are near death. Nursing research has shown that the spiritual dimension of care infiltrates all aspects of nursing care. Palliative care nurses need to be informed about religious aspects of people around the world as a part of palliative care. This article indicates the methods of attending to spiritual care for Muslim patients based upon our experiences in Iran.

Chettih, M. (2012). "Turning the Lens Inward: Cultural Competence and Providers' Values in Health Care Decision Making." Gerontologist **52**(6): 739-747.

The population of older adults in the United States is growing in size and diversity, presenting challenges to health care providers and patients in the context of health care decision making (DM), including obtaining informed consent for treatment, advance care planning, and deliberations about end-of-life care options. Although existing literature addresses providers' need to attend to patients' cultural values and beliefs on these issues, less attention has been paid to how the corresponding values and beliefs of providers color the care they deliver and their assessments of older adults' DM capacity. The provider's challenge is to understand her own unacknowledged anxieties, prejudices, and fears around such charged issues as truth telling, individual agency, capacity, death and dying, and the value of life itself

and address their impact on the delivery of care. A social constructivist perspective and the clinical concept of cultural countertransference are proposed as aides in achieving this awareness and improving care. ABSTRACT FROM PUBLISHER (Copyright of Gerontologist is the property of Oxford University Press / USA and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.

Davidson, J. E., M. L. Boyer, et al. (2008). "Gap analysis of cultural and religious needs of hospitalized patients." Critical Care Nursing Quarterly **31**(2): 119-126.

PURPOSE: Identify patient and family needs specifically related to an in-hospital birth or death. This study aimed to perform a gap analysis between identified needs and current hospital practice, services, and resources. METHODS: With the IRB approval, and purposive sampling using the demographics of a community hospital plus subgroups from problematic cases. Twenty-two semistructured interviews were audiotaped, and 6 lectures and 2 panel discussions were videotaped.

Transcriptions were distributed to the research team and manually coded for gaps between current practices versus stated needs. Group process was used to form consensus regarding findings. PARTICIPANTS: The following subgroups were targeted: Muslim, Baha'i, Catholic, Protestant, Jewish, Buddhist, Mormon, Jehovah's Witness, Latino, Filipino, Chinese, African American. RESULTS: Gaps in available resources, such as prayer books, rugs, and compasses, were identified. Knowledge gaps included many issues such as the Muslim preference for decreasing sedatives at end of life to be able to recite the sacred prayer while dying. Practice issues such as respecting plain-clothed clergy, the impact of "rule-orientation" on family needs, and the universal need to call clergy early were identified.

del Río, N. (2010). "The influence of Latino ethnocultural factors on decision making at the end of life: Withholding and withdrawing artificial nutrition and hydration." Journal of Social Work in End-of-Life & Palliative Care **6**(3-4): 125-149.

In this article, the author reviews the legal precedents that underpin the policies and practices found in most medical settings in relation to artificial nutrition and hydration (ANH) as the context for exploring the end-of-life (EOL) care decision-making process of Latinos. The literature related to Latino beliefs and practices is reviewed. Specifically examined are the ways in which the values of familismo, filial duty, respect for authority figures, and personalismo play a major role in this group's decision-making process. Finally, the perspectives of ethicists who argue that Western bioethical approaches fail to recognize that cultural norms and values as well as religious convictions play a significant role in shaping moral deliberations, including the decision to withdraw ANH from individuals with a terminal illness, are explored. From a cross-cultural ethical perspective, it is important for health care

providers to understand that in a pluralistic society, patients and their families bring multiple models of healing and decision making to clinical encounters based on different cultural and religious values.

DeSanto-Madeya, S., M. Nilsson, et al. (2009). "Associations between United States acculturation and the end-of-life experience of caregivers of patients with advanced cancer." Journal of Palliative Medicine **12**(12): 1143-1149.

Background: Cultural beliefs and values influence treatment preferences for and experiences with end-of-life (EOL) care among racial and ethnic groups. Within-group variations, however, may exist based on level of acculturation. Objectives: To examine the extent to which EOL treatment factors (EOL treatment preferences and physician-caregiver communication) and select psychosocial factors (mental health, complementary therapies, and internal and external social support) differ based on the level of acculturation of caregivers of patients with advanced cancer. Methods: One hundred sixty-seven primary caregivers of patients with advanced cancer were interviewed as part of the multisite, prospective Coping with Cancer Study. Results: Caregivers who were less acculturated were more positively predisposed to use of a feeding tube at EOL (odds ratio [OR] 0.99 [p = 0.05]), were more likely to perceive that they received too much information from their doctors (OR 0.95 [p = 0.05]), were less likely to use mental health services (OR 1.03 [p = 0.003] and OR 1.02 [p = 0.02]), and desire additional services (OR 1.03 [p = 0.10] to 1.05 [p = 0.009]) than their more acculturated counterparts. Additionally, caregivers who were less acculturated cared for patients who were less likely to report having a living will (OR 1.03 [p = 0.0003]) or durable power of attorney for health care (OR 1.02 [p = 0.007]) than more acculturated caregivers. Caregivers who were less acculturated felt their religious and spiritual needs were supported by both the community (beta -0.28 [p = 0.0003]) and medical system (beta -0.38 [p < 0.0001]), had higher degrees of self-efficacy (beta -0.22 [p = 0.005]), and had stronger family relationships and support (beta -0.27 [p = 0.0004]). Conclusions: The level of acculturation of caregivers of patients with advanced cancer does contribute to differences in EOL preferences and EOL medical decision-making.

Deshpande, O., M. C. Reid, et al. (2005). "Attitudes of Asian-Indian Hindus toward end-of-life care." Journal of the American Geriatrics Society **53**(1): 131-135.

The population of older adults in the United States is increasing in cultural diversity. Thus, an appreciation of cultural perspectives regarding end-of-life care may benefit practicing physicians. This article addresses end-of-life care issues from the perspective of Hinduism--a faith embraced by a growing demographic of the U.S. population--and also reviews basic Hindu philosophical concepts salient to caring for patients at the end of life.

Donovan, R., A. Williams, et al. (2011). "The influence of culture on home-based family caregiving at end-of-life: A case study of Dutch reformed family care givers in Ontario, Canada." Social Science & Medicine **72**(3): 338-346.

Families are facing increased pressure to provide care to their terminally-ill or dying kin in the home. It is known that balancing care with other personal and social roles can adversely affect family caregivers' (FCGs) health, yet access to supportive services which can mitigate burden is often inadequate. Cultural factors are known

to shape the experience of caregiving: however, most research to date tends to neglect the experiences of FCGs from different cultural groups. This understanding is necessary to ensure that supportive services are both meaningful and culturally-appropriate. Using qualitative methods, we undertook longitudinal research with a sample of Dutch Reformed FCGs (n = 5) to understand their experiences of caregiving and bereavement. The results of the study are suggestive of a cultural specificity with respect to caregiving that impacts both responsibilities and reactions to care. Three themes were salient to this group as a cultural entity: cultural attitudes towards care, religious beliefs and coping, and culturally-informed care-seeking behaviours. These three themes were seen to be a function of their religious and ethnic identities and were reinforced by ties to the communities in which they resided. Cultural identity provided a framework through which to understand and make sense of the experience, while group membership provided access to networks of informal support. This research contributes to the geographical literature on care/caregiving by providing insight into the social, cultural and religious context of informal family caregiving with a population who live in close geographic proximity. On a practical level, this case study indicates the importance of considering how these factors may operate in other settings in order to implement timely and appropriate interventions to better support FCGs who are caring for their terminally-ill loved-ones at home.

Doorenbos, A. Z., T. Lindhorst, et al. (2010). "Development of a web-based educational intervention to improve cross-cultural communication among hospice providers." Journal of Social Work in End-of-Life & Palliative Care **6**(3/4): 236-255.

In this article, the authors describe the theoretical foundation, development, and content of a Web-based educational intervention to improve cross-cultural communication about end-of-life concerns and report on the preliminary evaluation of this intervention using a qualitative study design. The data were collected with non-structured questions in a convenience sample of 21 hospice providers. Participants reported that they found the training appropriate and useful. Participants also reported finding the online delivery convenient and the interactive format valuable. Improving the quality of cross-cultural patient-provider communication can contribute to reducing disparities at end-of-life.

Doorenbos, A. Z. and S. M. Schim (2004). "Cultural competence in hospice." American Journal of Hospice and Palliative Medicine **21**(1): 28-32.

Assessed cultural competence among hospice workers. Lack of cultural competence among hospice staff has been cited as a reason ethnic minorities access hospice significantly less often than whites. A sample of 113 hospice workers from a large multicounty hospice who were aged 21-75 (mean age 45) and from various disciplines completed the Cultural Competence Assessment (CCA). The CCA is a 38-item test that measures individual cultural awareness, cultural sensitivity, and cultural-competence behavior. Scores can range from 1 to 5, with higher scores representing higher levels of competence. Overall, the competence scores of respondents ranged from 2.3 to 4.8, with a mean of 3.9. Educational level and previous cultural-diversity training accounted for significantly higher scores. Analysis revealed that respondents with a high school education scored significantly

lower than respondents with bachelor degrees or graduate degrees. There were no significant differences in scores based on race, age, number of years providing hospice care, or number of ethnic groups with which the participant had experience.

Duffy, S. A., F. C. Jackson, et al. (2006). "Racial/ethnic preferences, sex preferences, and perceived discrimination related to end-of-life care." Journal of the American Geriatrics Society **54**(1): 150-157.

Investigated racial/ethnic preferences, sex preferences, and perceived discrimination related to end-of-life care. Ten focus groups and follow-up surveys were conducted to obtain in-depth information on end-of-life preferences among 73 adults aged 50-83 (mean age 67). The participants included Arab Muslims, Arab Christians, Hispanics, blacks, and whites. It was found that Arab Americans were in favor of making peace on earth and were against assisted suicide, extending life artificially, nursing homes, and telling the patient "bad news." Hispanic and black women were against assisted suicide and in favor of extending life, whereas the men in these groups felt the opposite. Hispanic women spoke of not wanting a feeding tube and would consider alternative medicine. Blacks were least opposed to nursing homes. For whites, it was important to have choices. When asked about discrimination related to end-of-life care, Muslim women spoke of cultural barriers, blacks spoke of inequities in the past, and whites spoke of age discrimination and abandonment when dying.

Edwards, A., N. Pang, et al. (2010). "The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: A meta-study of qualitative research." Palliative Medicine **24**(8): 753-770.

Spirituality and spiritual care are gaining increasing attention but their potential contribution to palliative care remains unclear. The aim of this study was to synthesize qualitative literature on spirituality and spiritual care at the end of life using a systematic ('meta-study') review. Eleven patient articles and eight with healthcare providers were included, incorporating data from 178 patients and 116 healthcare providers, mainly from elderly White and Judaeo-Christian origin patients with cancer. Spirituality principally focused on relationships, rather than just meaning making, and was given as a relationship. Spirituality was a broader term that may or may not encompass religion. A 'spirit to spirit' framework for spiritual care-giving respects individual personhood. This was achieved in the way physical care was given, by focusing on presence, journeying together, listening, connecting, creating openings, and engaging in reciprocal sharing. Affirmative relationships supported patients, enabling them to respond to their spiritual needs. The engagement of family caregivers in spiritual care appears underutilized. Relationships formed an integral part of spirituality as they were a spiritual need, caused spiritual distress when broken and were the way spiritual care was given. Barriers to spiritual care include lack of time, personal, cultural or institutional

factors, and professional educational needs. By addressing these, we may make an important contribution to the improvement of patient care towards the end of life.

Ellman, M. S., D. Schulman-Green, et al. (2012). "Using online learning and interactive simulation to teach spiritual and cultural aspects of palliative care to interprofessional students." Journal of Palliative Medicine **15**(11): 1240-1247.

Background: To meet the complex needs of patients with serious illness, health professional students require education in basics aspects of palliative care, including how to work collaboratively on an interprofessional team. **Objectives:** An educational program was created, implemented, and evaluated with students in medicine, nursing, chaplaincy, and social work. Five learning objectives emphasized spiritual, cultural, and interprofessional aspects of palliative care. **Design:** The program blended two sequential components: an online interactive, case-based learning module, and a live, dynamic simulation workshop. **Measurements:** Content analysis was used to analyze students' free-text responses to four reflections in the online case, as well as open-ended questions on students' post workshop questionnaires, which were also analyzed quantitatively. **Results:** Analysis of 217 students' free-text responses indicated that students of all professions recognized important issues beyond their own discipline, the roles of other professionals, and the value of team collaboration. Quantitative analysis of 309 questionnaires indicated that students of all professions perceived that the program met its five learning objectives (mean response values \geq 4 on a 5-point Likert scale), and highly rated the program and its two components for both educational quality and usefulness for future professional work (mean response values approximately \geq 4). **Conclusions:** This innovative interprofessional educational program combines online learning with live interactive simulation to teach professionally diverse students spiritual, cultural, and interprofessional aspects of palliative care. Despite the challenge of balanced professional representation, this innovative interprofessional educational program met its learning objectives, and may be transferable for use in other educational settings.

Evans, B. C. and E. Ume (2012). "Psychosocial, cultural, and spiritual health disparities in end-of-life and palliative care: Where we are and where we need to go." Nursing Outlook **60**(6): 370-375.

Although health disparities are well documented, the extent to which they affect end-of-life care is unknown. Limited research funding leads to sparse and often contradictory palliative care literature, with few studies on causal mechanisms. This article explores the psychosocial, cultural, and spiritual health disparities existing in palliative and end-of-life care with the goal of identifying future research needs. This article reports efforts to determine knowledge gaps related to health disparities in psychosocial, cultural, and spiritual aspects of end-of-life care in which the authors draw upon recent literature from multiple databases. Although few data are available, studies show that minorities make little use of hospice, often because of lack of knowledge about hospice or palliative care, family-centered cultures, and preferences for more aggressive end-of-life care than hospice allows. The authors conclude that future research should include a search for theoretical and causal mechanisms; prospective longitudinal investigations; diverse patients, conditions,

contexts, and settings; methodological diversity and rigor; and interdisciplinary, culturally sensitive interventions.

Evans, N., A. Meñaca, et al. (2012). "Systematic Review of the Primary Research on Minority Ethnic Groups and End-of-Life Care From the United Kingdom." Journal of Pain & Symptom Management **43**(2): 261-286.

CONTEXT: Patients from minority ethnic groups experience lower rates of referrals to end-of-life (EoL) care services, higher levels of dissatisfaction with services, and perceive some services as culturally inappropriate. OBJECTIVES: To systematically review original studies of minority ethnic groups and EoL care in the U.K. and appraise their quality. METHODS: Searches were carried out in 13 electronic databases, eight journals, reference lists, and the gray literature. Studies of minority ethnic groups and EoL care in the U.K. were included. Studies were graded for quality and key themes were identified. RESULTS: Forty-five studies met inclusion criteria. Study quality was good on average. Identified key themes included age structure; inequality by disease group; referrals; caregivers; place of care and death; awareness of services and communication; and cultural competency. Strategies described for the reduction of inequities were partial and reactive. The format of 10 studies prevented quality grading; these were, however, reviewed as they provided unique insights. Variations in terminology and sampling frames complicated comparison across studies. CONCLUSION: The results highlight the multiple and related factors that contribute to low service use and substandard quality of services experienced by minority ethnic groups, and the need for authors to clarify what they mean by "culturally competent" EoL care. The synthesis of diverse and disparate studies underpins a number of key recommendations for health care professionals and policymakers. Tackling these epidemiological, demographic, institutional, social, and cultural factors will require a systematic and organization-wide approach rather than the current piecemeal and reactive interventions.

Feldstein, B. D., M. Grudzen, et al. (2008). "Integrating spirituality and culture with end-of-life care in medical education." Clinical Gerontologist **31**(4): 71-82.

Describes experiences and challenges of introducing a curriculum on spirituality and multicultural literacy into the required Family Medicine Clerkship at Stanford University School of Medicine. The curriculum, presented to groups of 8-10 medical students during their required 4-week clerkship, consists of 4 hours of classroom instruction, directed reading, exercises performed in the clinic, and a written assignment at the end of the clerkship. It has been presented to approximately 500 students from a wide variety of backgrounds who have differing opinions about including spirituality in their role as a physician. The course is taught by a team that includes a former emergency room physician who is now a Jewish hospital chaplain, a family medicine educator and ethnogerontologist who had been a Catholic nun, and a family medicine educator with a background in psychology and Buddhism. The curriculum hopes to prepare students to identify patients' spirituality and sources of meaning as well as ways that spirituality and culture interrelate. Integrating spirituality and culture with end-of-life care into the fabric of the medical school curriculum is an essential step toward serving our increasingly multicultural

and multireligious society. (SW) (AgeLine Database, copyright 2008 EBSCO Publishing, Inc., all rights reserved)

Firth, S. (2005). "Diversities in approach to end-of-life care." Journal of Research in Nursing **10**(4): 455-457.

Comments on an article by K. Jones (see record [rid]2008-11716-006[/rid]). The main thrust of the paper is the recognition that many cultures have different concepts of the self, embedded in social relations. The primacy of the family over the individual, and the ethical commitment to protect the patient impacts on a whole range of issues, such as communication, disclosure and truth-telling, advance directives and decision-making. Such attitudes are common in Southern Europe as well as Africa, the Middle and Far East. Relatives may expect to make decisions on a patient's behalf, to maintain hope and quality of life. The author argues that exploring different approaches to the end-of-life enhances the dialogue on life and death in society as a whole. In the context of holistic care, spiritual and religious issues need to be explored openly and honestly as and when patients and families need them, not in ways that suit professionals. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

Gagliese, L., R. Nissim, et al. (2005). "Aging and cultural disparities in pain at the end of life." Geriatrics and Aging **8**(6): 34-36.

Discusses aging and cultural disparities in pain management at the end of life. Both older adults and minorities are at risk of undertreatment and mismanagement of pain. Caregivers report that many older adults are in pain before death, and doctors are often less willing to prescribe strong opioids to the dying. Underutilization of narcotics with older minority populations has also been reported. These findings are unacceptable for Canada, which has a rapidly aging population and is home to one of the most ethnically diverse cities in North America. Cultural disparities in end-of-life care may be part of a more general reduced quality of health care provided to minorities across a spectrum of interventions aimed at prevention, acute care, and chronic care. Another contribution to cultural disparities may be ethnic or race-based differences in preferences for end-of-life care; some evidence suggests that African Americans are more likely than European Americans to desire aggressive life support at the end of life. There is growing evidence for cultural and age differences in pain-related treatment seeking, access, and management. Other potential factors underlying age and cultural disparities include attitudes of health care providers, socioeconomic factors, and health care coverage. Suggested actions to address these concerns include cultural competence training programs for health care providers, education about end-of-life care options for patients and family caregivers, and research. (SW) (AgeLine Database, copyright 2005 EBSCO Publishing, Inc., all rights reserved)

Gerdner, L. A., D. Cha, et al. (2007). "Circle of life: end-of-life care and death rituals for Hmong-American elders." Journal of Gerontological Nursing **33**(5): 20-29.

Describes traditional spiritual beliefs related to life and death among Hmong

American older adults and the implications for nursing end-of-life and postmortem care. Information was acquired through invited field experiences in Hmong communities in Minnesota and Wisconsin. Published literature and consultation with Hmong elders were used to clarify and validate the authors' understanding. By tradition, the majority of Hmong practice a combination of animism (the belief that all components of the universe, both animate and inanimate, contain some form of life force or spirit) and ancestor worship. Even among Hmong who have converted to Christianity or another spiritual practice, many continue to practice animism and ancestor worship. Upon death, efforts of the survivors focus on assisting the soul on its journey to "yeeb ceeb" (the unseen world). Violations of prescribed funeral rituals negatively affect both the deceased and the surviving relatives. Living relatives assist the deceased in transcendence to the land of ancestors. In return, the deceased spirit guards and protects the living. The elaborate funerary rituals require a collaborative family effort. Nurses need to recognize and support the interdependence within the family and clan structure of the Hmong American community. At the same time, Hmong Americans are a heterogeneous group whose needs must be assessed individually. Nurses should use an open, nonjudgmental approach in discussing elder and family preferences specific to spiritual beliefs and practices related to end-of-life and postmortem care.

Gorospe, E. C. (2006). "Establishing palliative care for American Indians as a public health agenda." Internet Journal of Pain, Symptom Control & Palliative Care 4(2): 6p.

The circumstances of death in the United States have changed compared to the previous century because of successful public health programs. More Americans including ethnic minorities now suffer more from chronic lifestyle diseases. As a consequence, some minorities endure prolonged periods of debility, limited resources and culturally-inappropriate medical care. Although several studies have investigated health disparities among minorities with terminal illness, very few have addressed the end-of-life (EOL) issues of American Indians. Palliative care for American Indians may qualify as a public health agenda based on four criteria: (1) high burden of death and suffering, (2) major impact on individuals and society, (3) possibility for intervention and (4) involvement of socio-ecological determinants of health. As a public health issue, palliative care for American Indians requires multisectoral collaboration, community cooperation, involvement of public agencies, health care providers and the public health sector.

Graham, N., L. Gwyther, et al. (2013). "Traditional healers' views of the required processes for a "good death" among Xhosa patients pre- and post-death." Journal of Pain and Symptom Management 46(3): 386-394.

Context: South Africa faces enormous HIV-related mortality and increasing cancer incidence. Traditional healers are the preferred source of advice and care in Africa, and this is true for the large Xhosa ethnic group. Objectives: To provide more appropriate multidimensional, culturally suitable care at the end of life; this study aimed to identify the care needs and cultural practices of Xhosa patients and families at the end of life, from the perspective of traditional healers. Methods: The study design was qualitative and cross-sectional. The research took place in a 300 km radius around East London, Eastern Cape, South Africa. Interviewees were Xhosa individuals who were recognized by their communities as traditional healers.

Data from two focus groups and eight individual interviews were analyzed, using an inductive thematic approach. Results: Data were elicited around the facilitation of a good death in terms of care needs before death and important rituals after death. Care needs before death focused on relief of psychosocial suffering; the importance of the spoken word at the deathbed; and the importance of a relationship and spiritual connection at the end of life. There were broad similarities across the rituals described after death, but these rituals were recognized to differ according to family customs or the dying person's wishes. Conclusion: Awareness of potential needs at the end of life can assist clinicians to understand the choices of their patients and develop effective end-of-life care plans that improve the outcomes for patients and families.

Gutheil, I. A. and J. C. Heyman (2006). "'They don't want to hear us': Hispanic elders and adult children speak about end-of-life planning." Journal of Social Work in End-of-Life & Palliative Care **2**(1): 55-70.

This study used focus groups to understand Hispanic elders' and adult children's concerns about end-of-life planning. Ten older persons participated in the elders group, and ten adult children in a separate group. Themes in both groups included communication, control, burden, spirituality, religious issues, and importance of family relationships. Communication regarding end-of-life planning was of particular importance to both elders and adult children. The most striking indication of challenges in communication about end-of-life issues is insistence by both elders and adult children that their children/parents do not want to have these discussions.

Halm, M. A., R. Evans, et al. (2012). "Broadening cultural sensitivity at the end of life: an interprofessional education program incorporating critical reflection." Holistic Nursing Practice **26**(6): 335-349.

BACKGROUND/PROBLEM: End-of-life beliefs and practices are as varied as one's culture. Little is known about what interventions are effective in developing clinician's skills to deliver culturally sensitive end-of-life care. **PURPOSE:** Using a pre-post design, this pilot study aimed to evaluate the impact of a 2-stage educational program on enhancing clinician's knowledge and comfort in addressing and honoring diverse end-of-life care beliefs, as well as developing higher levels of cultural competence. **METHODS:** Twenty-four interprofessional team members practicing on a combined medical-surgical oncology unit attended an in-service session on the end-of-life care beliefs, practices, and preferences of the Latino, Russian, and Micronesian cultures and then participated in critical reflection sessions where culturally specific end-of-life care cases were discussed using a structured dialogue guide. Outcomes measured were cultural competence using the Intercultural Development Inventory, Frommelt Attitudes Toward Caring of the Dying, knowledge of cultural beliefs/traditions, and self-perceived comfort in providing culturally sensitive end-of-life care. **FINDINGS:** Collectively, the

Intercultural Development Inventory showed that the team's perceived cultural competence was at the level of "acceptance" whereas team's developmental orientation was "minimization," meaning that the team overestimated its cultural competence. The t tests showed no significant differences between pre-post attitude and knowledge scores ($P > .05$). Despite these findings, staffs' perceived level of understanding of end-of-life care beliefs, preferences, and practices of the Latino, Russian, and Micronesian cultures, as well as comfort and effectiveness in providing culturally sensitive end-of-life care, were higher after the in-service and critical reflection sessions ($P < .05$). CONCLUSION: This 2-stage educational program did not significantly advance the team along the intercultural development continuum, nor did it significantly change knowledge and attitudes, likely due to the small sample and that maturity in cultural competence, evolves over a longer period of time. Educational programs that incorporate critical reflection sessions that promote interprofessional dialogue and learning, however, are promising practices for advancing cultural competence that are worthy of more rigorous study.

Hanssen, I. and G. Pedersen (2013). "Pain relief, spiritual needs, and family support: Three central areas in intercultural palliative care." Palliative & Supportive Care **11**(6): 523-530.

Objective: The purpose of this study was to draw out and coalesce the topic-specific information found in research literature regarding the provision of culturally sensitive palliative practice. Method: This was a literature study and Gadamerian hermeneutic text analysis. Results: It is more difficult to assess the level of pain in ethnic minority patients, and healthcare providers may become frustrated and interpret pain symptoms as fabrication. These patients are more likely to receive inadequate pain medication. Physical symptom management has become the priority in palliative care, but pain must also be viewed from the perspective of its social, cultural, and spiritual significance. Collectivist values may lead to an other-reliant and dependent coping style. This and religious demands may cause the family to rally around the patient. Many dying patients wish to be cared for at home by their families, but as the patient often has complex needs, the family may not be able to cope with the patient's care. Significance of results: Formal education and in-service programs are needed for healthcare providers, together with empirical studies regarding how to achieve more culturally appropriate care in intercultural palliative practice. The immigrant population needs to be educated about cancer and the various kinds of palliative and hospice care offered in the society in which they now live.

Heyman, J. C. and I. A. Gutheil (2010). "Older Latinos' attitudes toward and comfort with end-of-life planning." Health & Social Work **35**(1): 17-26.

The purpose of this study was to determine which of two educational interventions delivered in Spanish would influence Latino elders' attitudes toward and comfort with end-of-life planning in comparison with a control group receiving only standard information routinely provided. Using a posttest-only control group design, elders receiving home care services who agreed to participate were randomly assigned to one of three groups: Conversación A; Conversación B, with culturally relevant material added; and a control group. A one-way multivariate analysis of variance was conducted to determine the effect on the two dependent variables: attitudes

toward end-of-life planning and comfort with end-of-life planning. Significant differences were found among the three groups on both outcome measures. Attitudes toward advance planning scores were significantly higher for both intervention groups compared with the control group. Although both intervention groups had higher comfort scores than the control group, only the Conversación A score was statistically different from that of the control group. The results of this study indicate that it may be possible to positively influence both attitudes toward and comfort with end-of-life planning among older Latinos receiving home care, through the use of a one-to-one protocol that is delivered in Spanish.

Ho, Z. J., L. K. Radha Krishna, et al. (2010). "Chinese familial tradition and Western influence: a case study in Singapore on decision making at the end of life." Journal of Pain & Symptom Management **40**(6): 932-937.

Decision making for an incompetent patient at the end of life is difficult for both family members and physicians alike. Often, palliative care teams are tasked with weaving through opinions, emotions, and goals in search for an amenable solution. Occasionally, these situations get challenging. We present the case of an elderly Chinese Singaporean with metastatic cancer, whose family and physicians had conflicting goals of care. The former was adamant on treating the patient's disease with an untested drug, whereas the latter aimed to treat his symptoms with more conventional medication. Drug-drug interactions prevented treatment with both. Beginning with a discussion of the patient's best interest, we delve into the Singaporean context to show how culture affects medical decision making. Confucianism and filial piety are the values on which this family's workings were based. In an analysis of what this entails, we attempt to explain the significant and assertive family involvement in the decision-making process and their insistence on using novel medications, having exhausted conventional interventions. Within this mix were Western influences, too. Through the Internet, family members have become more informed and empowered in decision making, wresting the traditional paternalistic role of physicians in favor of "patient autonomy." An understanding of such dynamic facets will help better tailor culturally appropriate approaches to such complex situations.

Hsu, C.-y., M. O'Connor, et al. (2009). "Understandings of death and dying for people of Chinese origin." Death Studies **33**(2): 153-174.

This article introduces the primary beliefs about ancestor worship, Taoism, Confucianism, Buddhism and traditional Chinese medicine that have influenced Chinese people for thousands of years, particularly in relation to death and dying. These cultures and traditions remain important for Chinese people wherever they live. Over a long period, Chinese people have integrated these philosophies and religions to form the basis of their culture and traditions. Although they agree that death is a natural part of the life span, a unique belief about death and dying has emerged among the Chinese from this integration. From this, the people find a significant definition of death and dying.

Huang, Y.-L., P. Yates, et al. (2009). "Factors influencing oncology nurses approaches to accommodating cultural needs in palliative care." Journal of Clinical Nursing **18**(24): 3421-3429.

Aims and objectives: The purpose of this study is to explore the social construction of cultural issues in palliative care amongst oncology nurses. **Background:** Australia is a nation composed of people from different cultural origins with diverse linguistic, spiritual, religious and social backgrounds. The challenge of working with an increasingly culturally diverse population is a common theme expressed by many healthcare professionals from a variety of countries. **Design:** Grounded theory was used to investigate the processes by which nurses provide nursing care to cancer patients from diverse cultural backgrounds. **Methods:** Semi-structured interviews with seven Australian oncology nurses provided the data for the study; the data was analysed using grounded theory data analysis techniques. **Results:** The core category emerging from the study was that of accommodating cultural needs. This paper focuses on describing the series of subcategories that were identified as factors which could influence the process by which nurses would accommodate cultural needs. These factors included nurses views and understandings of culture and cultural mores, their philosophy of cultural care, nurses previous experiences with people from other cultures and organisational approaches to culture and cultural care. **Conclusions:** This study demonstrated that previous experiences with people from other cultures and organisational approaches to culture and cultural care often influenced nurses views and understandings of culture and cultural mores and their beliefs, attitudes and behaviours in providing cultural care. **Relevance to clinical practice:** It is imperative to appreciate how nurses experiences with people from other cultures can be recognised and built upon or, if necessary, challenged. Furthermore, nurses cultural competence and experiences with people from other cultures need to be further investigated in clinical practice.

Jang, Y., D. A. Chiriboga, et al. (2010). "Willingness of Older Korean-American Adults to Use Hospice." Journal of the American Geriatrics Society **58**(2): 352-356.

Responding to an urgent need for more research on end-of-life concerns of racial and ethnic minorities, the present study explored predictors of willingness of older Korean-American adults (N=675) to use hospice. Guided by Andersen's behavioral health model, the study considered predisposing factors (age, sex, marital status, education), potential health needs (chronic conditions, functional disability), and enabling factors (health insurance, acculturation, prior awareness of hospice). Nearly three-quarters of the sample answered yes to the following statement and question, "Hospice is a program that helps people who are dying by making them feel comfortable and free of pain when they can no longer be cured of their disease. If you needed hospice services, would you use them?" A greater willingness was observed in younger persons (odds ratio (OR)=0.96, 95% confidence interval (CI)=0.93–0.98) and those with higher levels of education (OR=1.67, 95% CI=1.12–2.48), more chronic conditions (OR=1.23, 95% CI=1.05–1.44), health insurance (OR=0.59, 95% CI=0.37–0.94), higher levels of acculturation (OR=1.07, 95% CI=1.03–1.10), and prior awareness of hospice (OR=4.43, 95% CI=2.85–6.90). The present study highlights the role of prior awareness in shaping individuals' attitudes

toward services, calling attention to a need for community education and outreach programs for racial and ethnic minorities, with specific emphasis on dissemination of information and greater awareness of hospice services. ABSTRACT FROM AUTHOR (Copyright of Journal of the American Geriatrics Society is the property of Wiley-Blackwell and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.

Jenko, M. and S. R. Moffitt (2006). "Transcultural nursing principles." Journal of Hospice & Palliative Nursing **8**(3): 172-180.

Providing end-of-life care that is meaningful to each family, that honors a deep appreciation for the sanctity of human life, requires nurses to develop cultural competence. It is noted that many cultural variations exist in the dying process, in what is considered culturally meaningful, and in what constitutes a good death. Using transcultural nursing concepts as a theoretical base, this article will provide an overview to the hospice practitioner who might be unfamiliar with these concepts. Additionally, a framework is provided to assist with assessments and interventions in multicultural situations. Three specific ethical areas, germane to hospice care, are also discussed: (1) sharing bad news, (2) locus of decision making, and (3) advance directives. Throughout the article, numerous clinical examples are used to underscore the presented concepts.

Johnson, K. S., K. I. Elbert-Avila, et al. (2005). "The influence of spiritual beliefs and practices on the treatment preferences of African Americans: a review of the literature." Journal of the American Geriatrics Society **53**(4): 711-719.

Spirituality is an important part of African-American culture and is often cited as an explanation for the more-aggressive treatment preferences of some African Americans at the end of life. This paper reviews the literature on spiritual beliefs that may influence the treatment decisions of African Americans. Medline 1966 to February 2003, Psych Info 1872 to February 2003, and CINAHL 1982 to February 2003 were searched for studies exploring spiritual beliefs that may influence the treatment preferences of African Americans. All candidate papers were examined for quality, and data were extracted on study population, design, analysis, and results to identify recurrent themes. Forty studies met inclusion criteria. Recurrent themes describing spiritual beliefs that may influence the treatment preferences of African Americans throughout the course of illness include the following: spiritual beliefs and practices are a source of comfort, coping, and support and are the most effective way to influence healing; God is responsible for physical and spiritual health; and the doctor is God's instrument. Spiritual beliefs specifically addressing treatment preferences at the end of life include: only God has power to decide life and death, there are religious prohibitions against physician-assisted death or advance directives limiting life-sustaining treatments, and divine intervention and miracles occur. For some African Americans, spiritual beliefs are important in understanding and coping with illness and may provide a framework within which treatment decisions are made. Given the growing ethnic diversity of the United States, some understanding of the complexities of culture and spirituality is

essential for healthcare providers.

Jones, K. (2005). "Diversities in approach to end-of-life: A view from Britain of the qualitative literature." Journal of Research in Nursing **10**(4): 431-454.

Objective: To systematically investigate qualitative literature on end-of-life issues and ethnicity/race/diversity, employing qualitative methods and philosophical concepts. Design: A database of 119 references was compiled using a range of techniques, including information foraging theory. Qualitative principles, such as 'citation snowballing' and 'data saturation', were utilised to gather and consolidate the literature. A model of 'signal and noise' was employed to balance methodological rigour against the strength of the message itself in the literature included in the final review. Results: Existing reviews of qualitative literature on palliative care are minimal, with little mention of ethnicity/race/diversity; palliative care generally pays little attention to qualitative methods. Concepts of ethnicity/race/diversity are socially constructed and these extend to the literature on end-of-life. Changing terminology of palliative care reflects emerging and competing ways to talk about the care provided to dying patients. Conclusions: The 'cookbook' approach to diversity creates new myths or stereotypes, compounding this with inaccuracies or misunderstandings. Aspects other than formal religious beliefs are overlooked and not all members of an ethnic group will routinely follow the beliefs of a specific faith. Healthcare providers must recognise that the basic values, principles and assumptions of Western medicine and bioethics are themselves historically situated and culturally determined. The rights of families to medical knowledge and their roles in decision-making are just as valid, inalienable and crucial to the cultural belief systems of many ethnic minority communities as patient autonomy models are to Western medicine. A common theme emerging through the studies reviewed is a need for sensitivity to the varying expectations and mix of involvement of patients, practitioners and families in end-of-life care and the need for information-sharing and decision-making amongst them, along a continuum of health and social care constructed by synthesis and integration of models emerging through this review.

Jovanovic, M. (2012). "Cultural Competency and Diversity Among Hospice Palliative Care Volunteers." American Journal of Hospice and Palliative Medicine **29**(3): 165-170.

This case study examines the current state of cultural competence in hospice and palliative care in the Greater Toronto Area (GTA). Because of changing demographic trends and ethnic minorities underutilizing hospice palliative care services, this research examined the current state of culturally competent care in a hospice setting, and the challenges to providing culturally competent care in a hospice in the GTA. A case study was conducted with a hospice and included in-depth interviews with 14 hospice volunteers. The findings reveal that volunteers encountered cultural clashes when their level of cultural competency was weak.

Second, volunteers revealed there was a lack of adequate cultural competency training with their hospice, and finally, there was a lack of ethnic, cultural, and linguistic diversity among the hospice volunteers. ABSTRACT FROM PUBLISHER (Copyright of American Journal of Hospice & Palliative Medicine is the property of Sage Publications Inc. and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.

Kelley, A. S., N. S. Wenger, et al. (2010). "Opiniones: End-of-Life Care Preferences and Planning of Older Latinos." Journal of the American Geriatrics Society **58**(6): 1109-1116. OBJECTIVES: To measure end-of-life (EOL) care preferences and advance care planning (ACP) in older Latinos and to examine the relationship between culture-based attitudes and extent of ACP. DESIGN: Cross-sectional interview. SETTING: Twenty-two senior centers in greater Los Angeles. PARTICIPANTS: One hundred forty-seven Latinos aged 60 and older. MEASUREMENTS: EOL care preferences, extent of ACP, attitudes regarding patient autonomy, family-centered decision-making, trust in healthcare providers, and health and sociodemographic characteristics. RESULTS: If seriously ill, 84% of participants would prefer medical care focused on comfort rather than care focused on extending life, yet 47% had never discussed such preferences with their family or doctor, and 77% had no advance directive. Most participants favored family-centered decision making (64%) and limited patient autonomy (63%). Greater acculturation, education, and desire for autonomy were associated with having an advance directive (P-values <.03). Controlling for sociodemographic characteristics, greater acculturation (adjusted odds ratio (AOR)=1.6, 95% confidence interval (CI)=1.1–2.4) and preferring greater autonomy (AOR=1.6, 95% CI=1.1–2.3) were independently associated with having an advance directive. CONCLUSIONS: The majority of older Latinos studied preferred less-aggressive, comfort-focused EOL care, yet few had documented or communicated this preference. This discrepancy places older Latinos at risk of receiving high-intensity care inconsistent with their preferences. ABSTRACT FROM AUTHOR (Copyright of Journal of the American Geriatrics Society is the property of Wiley-Blackwell and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.

Ko, E. and C. S. Berkman (2010). "Role of children in end-of-life treatment planning among Korean American older adults." Journal of Social Work in End-of-Life & Palliative Care **6**(3/4): 164-184.

Three focus groups (n = 23) with Korean American older adults explored the role of culture in end-of-life decision making. No participants had completed an advance directive and few had discussed end-of-life treatment preferences. Focus group themes addressed: (a) whether children are resistant or receptive to discussing their parents' end-of-life treatment preferences; (b) whether the older adults or their children should make decisions about end-of-life treatment; (c) whether decision making should be the responsibility of the eldest son or of all the children; and (d) whether children would implement the parent's preferences for end-of-life treatment.

Understanding the role of children in end-of-life decision making among Korean American older adults is important for culturally competent care.

Ko, E., S. Roh, et al. (2013). "Do Older Korean Immigrants Engage in End-of-Life Communication?" Educational Gerontology **39**(8): 613-622.

End-of-life communication is an important process as it allows individuals' treatment preferences to be known, yet not every culture is receptive to such discussions. Planning for end-of-life care is not readily supported in Asian culture, and little is known about individuals' communication with family and health care professionals among older Korean immigrants related to end-of-life care. A cross-sectional study was conducted with 195 older Korean immigrants on end-of-life communication. Measures include end-of-life communication, attitudes toward end-of-life communication, perceived burden, number of adult children in the United States, health status, and sociodemographic variables. Overall, 21.9% (n=42) of participants reported to have discussed their end-of-life treatment preferences with others, primarily family members. Attitudes toward end-of-life discussions, perceived burden, religiosity, and the number of children in the U.S. significantly accounted for end-of-life communication. Culturally appropriate interventions are recommended to promote dialogue regarding treatment preferences among older adults, family, and health care professionals.

Kongsuwan, W., O. Chaipetch, et al. (2012). "Thai Buddhist families' perspective of a peaceful death in ICUs." Nursing in Critical Care **17**(3): 151-159.

Aim: To describe the concept of a peaceful death in intensive care units (ICUs) from the perspective of Thai Buddhist family members. Methods: This descriptive qualitative study was based on data generated from individual in-depth interviews of nine Thai Buddhist family members from the southern region of Thailand whose loved ones died in adult ICUs. Colaizzi's phenomenological approach was used to analyse the data. Rigour for the study was established by Lincoln and Guba's guidelines for qualitative research studies. Findings: Five core qualities emerged that made-up the concept of a peaceful death as described by Thai Buddhist family members who cared for their loved ones while they were dying in ICUs. These core qualities were 'knowing death was impending, preparing for a peaceful state of mind, not suffering, being with family members and not alone, and family members were not mourning'. Conclusion: Thai Buddhist family members described what they meant by a peaceful death. 'This was: preparing for a peaceful state of mind in knowing that one's impending death is not a situation of suffering or being alone, but rather a time of being with family members who are not yet mourning one's death.' The findings support that family members should participate in promoting a peaceful death for their loved ones dying in ICUs. Implications for practice: The five core qualities of a peaceful death reported in this study could be used as a framework for nurses to create nursing practice interventions for quality end-of-life care for Thai Buddhists.

Kristiansen, M., T. Irshad, et al. (2014). "The practice of hope: a longitudinal, multi-perspective qualitative study among South Asian Sikhs and Muslims with life-limiting illness in Scotland." Ethnicity & Health **19**(1): 1-19.

Objectives. We explored the role of faith and religious identities in shaping end of life experiences in South Asian Muslims and Sikhs with life-limiting illnesses.

Design. Secondary analysis of data from a longitudinal, multi-perspective qualitative study of the experience of life-limiting illness and access to palliative care services among South Asian Sikhs and Muslims in Scotland. Up to three semi-structured interviews were conducted with 25 participants, 15 family members and 20 health care professionals over a period of 18 months. Analysis was informed by Mattingly's theory on hope. Results. Hope emerged as a central construct in the accounts of illness constructed by the participants as they struggled to make sense of and uphold a meaningful life. Clinical encounters and, for some, religious beliefs served as sources of hope for participants. Hope unfolded as an active process that enabled them to live with the personal and in particular the social ramifications of their illness. Changing images of hope were formulated and reflected as illness progressed or treatments failed. These ranged from hoping for cure, prolonged life, the regaining of lost capabilities needed to fulfil social roles, or at times death when suffering and the consequences for the family became too hard to bear.

Conclusions. For those suffering from a life-limiting illness, sustaining hope is a complex challenge. The social character of hope is evident as it focuses on envisioning a life that is worth living, not only for oneself, but most importantly for social relations. Continuity in care at the end of life and a holistic approach is important in order to enable patients to articulate complex and changing notions of hope that at times are silenced within families, and for patients to feel confident in discussing the possible role of religious beliefs in shaping personal notions of hope.

Kwak, J. and W. E. Haley (2005). "Current research findings on end-of-life decision making among racially or ethnically diverse groups." Gerontologist **45**(5): 634-641.

Conducted a literature review on current research findings on end-of-life decision making among racially or ethnically diverse groups. Thirty-three empirical studies of American and Canadian samples that were printed between 1992 and 2003 were identified in which race or ethnicity was investigated as either a variable predicting treatment preferences or choices, where racial or ethnic groups were compared in their end-of-life decisions, or where the end-of-life decision making of a single minority group was studied in depth. A narrative review was conducted that identified 4 topical domains of study: advance directives; life support; disclosure and communication of diagnosis, prognosis, and preferences; and designation of primary decision makers. Results indicated that non-white racial or ethnic groups generally lacked knowledge of advance directives and were less likely than whites to support advance directives. African Americans were consistently found to prefer the use of life support; Asians and Hispanics were more likely to prefer family-centered decision making than other racial or ethnic groups. Variations within groups existed and were related to cultural values, demographic characteristics, level of acculturation, and knowledge of end-of-life treatment options. Although the studies were limited by methodological concerns such as lack of theoretical

framework and use of cross-sectional designs, identified differences in end-of-life decision-making preference and practice suggest that clinical care and policy should recognize the variety of values and preferences found among diverse racial or ethnic groups.

Kwak, J. and J. R. Salmon (2007). "Attitudes and preferences of Korean-American older adults and caregivers on end-of-life care." Journal of the American Geriatrics Society **55**(11): 1867-1872.

Examined social and cultural factors influencing views of Korean American older adults and caregivers on advance care planning and hospice care. Twenty older adults (mean age 68) and 16 caregivers (mean age 40) in west central Florida participated in 1 of 4 focus groups. Analysis of the focus group transcripts using modified grounded theory found diverse attitudes among Korean Americans toward end-of-life care and cultural and structural barriers to advance care planning and hospice use. Older adults and caregivers both expressed a lack of knowledge about advance care planning and hospice and agreed that the family would make the final decision about the end-of-life care, while acknowledging the challenge of initiating communications about treatment preferences. They interpreted the Korean value of filial piety to support both curative and palliative treatment. The traditional norm of home death and importance of physician communication influenced preferences for hospice and advance care planning, respectively. The results suggest that outreach and education efforts directed at Korean Americans should include development of culturally sensitive educational and communication tools and collaboration with ethnic community organizations and health care providers in the dissemination and education of these instruments.

Laguna, J., S. Enguídanos, et al. (2012). "Racial/Ethnic Minority Access to End-of-Life Care: A Conceptual Framework." Home Health Care Services Quarterly **31**(1): 60-83.

Minority underutilization of hospice care has been well-documented; however, explanations addressing disparities have failed to examine the scope of factors in operation. Drawing from previous health care access models, a framework is proposed in which access to end-of-life care results from an interaction between patient-level, system-level, and societal-level barriers with provider-level mediators. The proposed framework introduces an innovative mediating factor missing in previous models, provider personal characteristics, to better explain care access disparities. This article offers a synthesis of previous research and proposes a framework that is useful to researchers and clinicians working with minorities at end of life.

Liao, S. and R. J. Ackermann (2008). "Interdisciplinary end-of-life care in nursing homes." Clinical Gerontologist **31**(4): 83-96.

Discusses the barriers that exist to improving end-of-life (EOL) care in nursing

homes (NHs). Good EOL care is part of good palliative care, which by definition is interdisciplinary. Inherent to palliative care is the application of the biopsychosocial model to meet the comprehensive needs of the patient/family treatment unit. Such an approach may cause conflict in NHs, where the wishes of the resident must often yield to the schedule of the facility. Other barriers to good EOL care include cultural conflict between the facility and the hospice team, conflict between patients/families and staff, and regulator and reimbursement factors. Current EOL care in these facilities faces substantial challenges, including undermanagement of pain, dyspnea, and other symptoms; a clash of cultures between palliative/hospice teams and the nursing facility; and reimbursement policy that discourages the use of hospice. For ethnic minorities, these challenges are more striking. Education, better utilization of hospice, cooperation in quality improvement, and changes in reimbursement policy will lead to better care for NH residents.

Loike, J., M. Gillick, et al. (2010). "The Critical Role of Religion: Caring for the Dying Patient from an Orthodox Jewish Perspective." Journal of Palliative Medicine **13**(10): 1267-1271.

Background and objective: Culturally competent medical care for the dying patient by families and health care professionals is a challenging task especially when religious values, practices, and beliefs influence treatment decisions for patients at the end of life. This article describes end-of-life guidelines for hospital health care professionals caring for Orthodox Jewish patients and their families. Religious perspectives on advance directives, comfort care and pain control, nutrition and hydration, do not resuscitate/do not intubate (DNR/DNI), and extubation are often unfamiliar to the American medical community. Design: The guidelines for the care of the dying Orthodox Jewish patient were mutually agreed upon by the authors, recognized authorities in medicine, ethics, and Jewish law, who presented their perspectives during a 1-day symposium and who participated in an active working-group session. Conclusions: Care of the religious patient close to death is enormously complex especially when balancing religious obligations, the role of the rabbi, medical procedures, and personal preferences. These guidelines address from a religious perspective profound issues such as the definition of death, organ donation, and caring for the patient at life's end. The guidelines can be useful for any hospital that serves an Orthodox Jewish population.

McCormick, T. R., F. Hopp, et al. (2012). "Ethical and Spiritual Concerns Near the End of Life." Journal of Religion, Spirituality and Aging **24**(4): 301-313.

Case studies provide interesting windows into issues confronting patients in today's health care system. We present two cases from our clinical experiences involving spiritual and ethical issues arising in the care of patients facing life-threatening illnesses. We also present two methods that introduce ways of talking about spiritual and ethical issues, the HOPE mnemonic and a clinical ethics paradigm for organizing and analyzing ethical issues in the clinical context from a principled perspective. As growing numbers of older adults seek health care in the face of life-threatening illnesses, many will make decisions based upon values associated with their religious or spiritual beliefs. ABSTRACT FROM PUBLISHER (Copyright of Journal of Religion, Spirituality & Aging is the property of Taylor & Francis Ltd and

its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.

Mitchell, B. L. and L. C. Mitchell (2009). "Review of the literature on cultural competence and end-of-life treatment decisions: The role of the hospitalist." Journal of the National Medical Association **101**(9): 920-926.

Objective: To determine whether any associations exist between cultural (racial/ethnic, spiritual/religious) competence and end-of-life treatment decisions in hospitalized patients and the potential impact of those associations on hospitalists' provision of care. Data Sources and Methods: MEDLINE, PubMed, Embase, PsychInfo, and CINAHL databases were searched using the following search terms: cultural competence, race, ethnicity, minority, African American, Hispanic, end of life, palliative care, advanced care planning, inpatient, religion, spirituality, faith, hospitalist, and hospice. We identified studies in which spirituality/religion or race/ethnicity was used as a variable to study their potential impact on end-of-life treatment decisions in hospitalized patients. Results: In only 13 studies was spirituality/religion or race/ethnicity used to study its effect on end-of-life decisions in hospitalized patients. African American patients tended to prefer the use of life-sustaining treatments at the end of life, and race/ethnicity did not appear to affect decisions to withhold or withdraw certain types of life-sustaining technology. Specific spiritual needs were identified both within and outside organized religions when members of those religions were hospitalized at the end of life. Conclusions: End-of-life care may present unique challenges and opportunities in culturally discordant hospitalist-patient relationships. Culturally competent health care in an increasingly diverse population requires awareness of the importance of culture, particularly spirituality/religion and race/ethnicity, in the care of hospitalized patients at the end of life.

Moreira-Almeida, A. and H. G. Koenig (2006). "A cross-cultural study of spirituality, religion, and personal beliefs as components of quality of life." Social Science & Medicine **62**(6): 1486-1497.

This paper reports on an international study in 18 countries (n=5087) to observe how spirituality, religion and personal beliefs (SRPB) relate to quality of life (QoL). SRPB is assessed using the World Health Organization's QoL Instrument (the WHOQOL), where eight additional facets were included to more fully address these issues as they pertain to QoL, along with physical, social, psychological and environmental domains. The facets address issues such as inner peace, faith, hope and optimism, and spiritual connection. The results showed that SRPB was highly correlated with all of the WHOQOL domains ($p < 0.01$), although the strongest correlations were found with psychological and social domains and overall QoL. When all of the domain scores were entered into a stepwise hierarchical regression analysis, all of the domains contributed to overall quality of life (N=3636), explaining 65% of the variance. When this was repeated for those people who reported poor health (N=588), it was found that only four domains explain 52% of the variance. The first was the level of independence, followed by environment, SRPB and physical. Gender comparisons showed that despite showing lower scores for facets

in the psychological domain, such as negative feelings and poorer cognitions, women still reported greater feelings of spiritual connection and faith than men. Those with less education reported greater faith but were less hopeful. It is suggested that SRPB should be more routinely addressed in assessment of QoL, as it can make a substantial difference in QoL particularly for those who report very poor health or are at the end of their life.

Morita, T., M. Kawa, et al. (2004). "Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan." Supportive Care in Cancer **12**(2): 137-140.

Background. Although alleviation of existential distress is important for terminally ill cancer patients, the concept of existential distress has not been fully understood. The aim of this study was to categorize existential concerns of Japanese terminally ill cancer patients and explore care strategies based on the categorizations.

Methods. A multicenter cross-sectional study in 88 terminally ill cancer patients receiving specialized inpatient palliative care was performed. The nurses explored patient existential concerns by asking several key questions, and recorded the answers that they considered typically described the patients' concerns. All statements recorded by the nurses were analyzed using content analysis methods.

Results. A total of 89 statements were subjected to analysis. The categories and their prevalence were: relationship-related concerns (22%; isolation, concerns about family preparation, conflicts in relationship), loss of control (16%; physical control, cognitive control, control over future), burden on others (4.5%), loss of continuity (10%; loss of role, loss of enjoyable activity, loss of being oneself), uncompleted life task (6.8%), hope/hopelessness (17%), and acceptance/preparation (25%).

Conclusions. Existential concerns of Japanese terminally ill cancer patients were categorized as relationship-related concerns, loss of control, burden on others, loss of continuity, uncompleted life task, hope/hopelessness, and acceptance/preparation. These themes seemed to encompass universal human suffering beyond cultural differences, and this conceptualization may contribute to the development of effective therapeutic interventions to alleviate existential distress.

Narayanasamy, A. (2007). "Palliative care and spirituality." Indian Journal of Palliative Care **13**(2): 32-41.

Critical junctures in patients' lives such as chronic illnesses and advanced diseases may leave the persons in a state of imbalance or disharmony of body, mind and spirit. With regard to spirituality and healing, there is a consensus in literature about the influence of spirituality on recovery and the ability to cope with and adjust to the varying and demanding states of health and illness. Empirical evidence suggests that spiritual support may act as an adjunct to the palliative care of those facing advanced diseases and end of life. In this article, the author draws from his

empirical work on spirituality and culture to develop a discourse on palliative care and spirituality in both secular and non-secular settings. In doing so, this paper offers some understanding into the concept of spirituality, spiritual needs and spiritual care interventions in palliative care in terms of empirical evidence. Responding to spiritual needs could be challenging, but at the same time it could be rewarding to both healthcare practitioner (HCP) and patient in that they may experience spiritual growth and development. Patients may derive great health benefits with improvements in their quality of life, resolutions and meaning and purpose in life. It is hoped that the strategies for spiritual support outlined in this paper serve as practical guidelines to HCPs for development of palliative care in South Asia.

Nath, S. B., K. B. Kirschman, et al. (2008). "Place called LIFE: exploring the advance care planning of African-American PACE enrollees." *Social Work in Health Care* **47**(3): 277-292.

Investigated the advance care planning of African Americans enrolled in the Programs of All-Inclusive Care for the Elderly (PACE). Data were collected between March 2004 and February 2005 for 18 African American PACE enrollees aged 57-86 (mean age 73.7) in a large eastern city, using medical record review and semistructured interviews. Review of verbalized and documented preferences for end-of-life (EOL) care among participants indicated that most preferred life-sustaining treatments. In addition, these PACE enrollees had limited information or understanding of the interventions and terminology associated with advance directives. Content analysis of interviews indicated that EOL decision making was influenced by the desire to maintain usual activities of daily living, to avoid burdening caregivers, and to remain in control of personal health care. Furthermore, participants relied on faith in God as central to medical decision making, believing ultimately that God controls the end of life.

Peng, N.-H., H.-L. Liu, et al. (2012). "Cultural practices and end-of-life decision making in the neonatal intensive care unit in Taiwan." *Journal of Transcultural Nursing* **23**(3): 320-326.

The purpose of this research was to describe conditions of decision making for dying infants and cultural effects on the process of infant death in the neonatal intensive care unit. A retrospective chart review was used in this research. Fifty charts were reviewed; the major cause of death for the research subjects was complications of prematurity (52%). Eighty-two percent of the charts documented a do not resuscitate order, and 16% of parents allowed discontinuation of ventilator support when they realized the futility of continued care. In 30 nursing records, parents and their dying infants were offered a quiet place in which to grieve. In 10

cases, nurses accompanied these parents and allowed them to express their emotions. Research findings showed great outward expression of religion at the time of death. Various cultural issues affected both the grieving process of the families and the dying process of their infants.

Perkins, H. S., J. D. Cortez, et al. (2009). "Cultural beliefs about a patient's right time to die: An exploratory study." Journal of General Internal Medicine **24**(11): 1240-1247.

Background: Generalist physicians must often counsel patients or their families about the right time to die, but feel ill-prepared to do so. Patient beliefs may help guide the discussions. Objective: Because little prior research addresses such beliefs, we investigated them in this exploratory, hypothesis-generating study. Design and Subjects: Anticipating culture as a key influence, we interviewed 26 Mexican Americans (MAs), 18 Euro-Americans (EAs), and 14 African Americans (AAs) and content-analyzed their responses. Main Results: Nearly all subjects regardless of ethnic group or gender said God determines (at least partially) a patient's right time to die, and serious disease signals it. Yet subjects differed by ethnic group over other signals for that time. Patient suffering and dependence on "artificial" life support signaled it for the MAs; patient acceptance of death signaled it for the EAs; and patient suffering and family presence at or before the death signaled it for the AAs. Subjects also differed by gender over other beliefs. In all ethnic groups more men than women said the time of death is unpredictable; but more women than men said the time of death is preset, and family suffering signals it. Furthermore, most MA women—but few others—explicitly declared that family have an important say in determining a patient's right time to die. No confounding occurred by religion. Conclusion: Americans may share some beliefs about the right time to die but differ by ethnic group or gender over other beliefs about that time. Quality end-of-life care requires accommodating such differences whenever reasonable.

Perry, E., J. Swartz, et al. (2005). "Peer mentoring: a culturally sensitive approach to end-of-life planning for long-term dialysis patients." American Journal of Kidney Diseases **46**(1): 111-119.

BACKGROUND: This study is designed to explore the impact of peer mentoring on end-of-life decision making. METHODS: A controlled randomized intervention study with 203 patients from 21 dialysis centers across Michigan explored the impact of peer mentors, dialysis patients trained to help other patients, on end-of-life planning. RESULTS: Communicating information on advance directives (ADs) through peer mentoring significantly influenced the completion of ADs overall compared with distributing standard printed material or no specific designed intervention. However, the influence was most prominent among African Americans, not only increasing actual completion of ADs ($P < 0.001$) and comfort discussing ADs ($P < 0.01$), but also improving subjective well-being ($P < 0.05$) and anxiety ($P <$

0.05) during the study period. These effects of peer mentoring did not appear among white patients, although printed material on ADs decreased reported suicidal ideation ($P < 0.05$). CONCLUSION: These results suggest the importance of addressing specific cultural factors in the process of AD education. Common practice assumes that printed materials are effective in educating patients about health care and decision making. However, peer mentoring, a relationship-centered person-to-person approach, may be more effective in some cultural groups because it partakes of oral, rather than written, traditions. Acknowledging cultural differences and tailoring our approach could be powerful in enhancing trust and participation and decreasing potential disparities in health care outcomes. Copyright © 2005 National Kidney Foundation, Inc.

Pesut, B. and S. Reimer-Kirkham (2010). "Situated clinical encounters in the negotiation of religious and spiritual plurality: A critical ethnography." International Journal of Nursing Studies **47**(7): 815-825.

Background: Despite increasingly diverse, globalized societies, little attention has been paid to the influence of religious and spiritual diversity on clinical encounters within healthcare. Objectives: The purpose of the study was to analyze the negotiation of religious and spiritual plurality in clinical encounters, and the social, gendered, cultural, historical, economic and political contexts that shape that negotiation. Design: Qualitative: critical ethnography. Settings: The study was conducted in Western Canada between 2006 and 2009. Data collection occurred on palliative, hospice, medical and renal in-patient units at two tertiary level hospitals and seven community hospitals. Participants: Participants were recruited through purposive sampling and snowball technique. Twenty healthcare professionals, seventeen spiritual care providers, sixteen patients and families and twelve administrators, representing diverse ethnicities and religious affiliations, took part in the study. Methods: Data collection included 65 in-depth interviews and over 150 h of participant observation. Results: Clinical encounters between care providers and recipients were shaped by how individual identities in relation to religion and spirituality were constructed. Importantly, these identities did not occur in isolation from other lines of social classification such as gender, race, and class. Negotiating difference was a process of seeing spirituality as a point of connection, eliciting the meaning systems of patients and creating safe spaces for the expression of that meaning. Conclusions: The complexity of religious and spiritual identity construction and negotiation raises important questions about language and about professional competence and boundaries in clinical encounters where religion and spirituality are relevant concerns.

Phua, J., A. C.-L. Kee, et al. (2011). "End-of-Life Care in the General Wards of a Singaporean Hospital: An Asian Perspective." Journal of Palliative Medicine **14**(12): 1296-1301.

Background: Despite international differences in cultural perspectives on end-of-life issues, little is known of the care for the dying in the general wards of acute hospitals in Asia. Methods: We performed a retrospective medical chart review of all 683 adult patients who died without intensive care unit (ICU) admission in our Singaporean hospital in 2007. We first evaluated the prevalence of do-not-

resuscitate (DNR) orders and orders for or against life-sustaining therapies; second, if such orders were discussed with the patients and/or family members; and third, the actual treatments provided before death. Results: There were DNR orders for 66.2% of patients and neither commitment for DNR nor cardiopulmonary resuscitation (CPR) for 28.1%. Orders to limit life-sustaining therapies, including ICU admission, intubation, and vasopressors/inotropes were infrequent. Only 6.2% of the alert and conversant patients with DNR orders were involved in discussions on these orders. In contrast, such discussions with their family members occurred 82.9% of the time. Interventions in the last 24 hours of life included CPR (9.4%), intubation (6.4%), vasopressors/inotropes (14.8%), tube feeding (24.7%), and antibiotics (44.9%). Analgesia was provided in 29.1% of patients. Conclusions: There was a lack of commitment by doctors on orders for DNR/CPR and to limit life-sustaining therapies, infrequent discussions with patients on end-of-life decisions, and excessive burdensome interventions with inadequate palliative care for the dying. These findings may reflect certain Asian cultural biases. More work is required to improve our quality of end-of-life care.

Puchalski, C. M., R. E. Dorff, et al. (2004). "Spirituality, religion, and healing in palliative care." Clinics in Geriatric Medicine **20**(4): 689-714.

In end-of-life care, attending to spiritual needs ensures that a dying patient has the opportunity to find meaning in the midst of suffering and to have the opportunity for love, compassion, and partnership in their final journey. This article summarizes some of the beliefs and traditions from Judaism, Islam, and Christianity that affect people as they face their own dying and mortality. People who do not participate in any formal religion also have a drive to find meaning in the midst of suffering and dying. They may find this in personal ways. This article presents some practical tools to help clinicians address and respect spiritual and religious issues of patients. It is crucial that our culture and our systems of care for the dying include a spiritual approach so that dying can be meaningful and even filled with hope.

Rao, A. S., O. M. Desphande, et al. (2008). "Elderly Indo-Caribbean Hindus and end-of-life care: a community-based exploratory study." Journal of the American Geriatrics Society **56**(6): 1129-1133.

Surveyed older Indo-Caribbean Hindu people attending a senior center in Queens, New York, about end-of-life care (EOLC). The 44 participants aged 65-84 (mean age 71.1), regular attendees at the center and mostly from Guyana, completed a semistructured interview on demographics, clinical status, functional ability (instrumental activities of daily living), and psychosocial status (Geriatric Depression Scale Short Version and Lubben Social Network Scale). Previously validated scales were used to collect data on acculturation, religiosity, and EOLC beliefs. Participants were socially connected, moderately acculturated, and religious. Scores on the Ethnicity and Attitudes Towards EOLC Survey indicated negative beliefs about life-sustaining or prolonging technology and positive attitudes about advance care directives (ACDs), truth-telling, and family involvement. The number of ACDs that had been completed and knowledge about ACDs was low; only 3 participants possessed a living will, and only 4 possessed a health care proxy. Study participants expressed attitudes and beliefs regarding EOLC similar to those

of other ethnic older adults.

Reese, D. J. (2011). "Proposal for a University-Community-Hospice Partnership to Address Organizational Barriers to Cultural Competence." American Journal of Hospice and Palliative Medicine **28**(1): 22-26.

Models of culturally competent hospice services have been developed, but they are not generally being used. This article describes a participatory action research project which is addressing organizational barriers to cultural competence through a university-community-hospice partnership. The intervention plan is to develop a connection with the African American community, increasing community knowledge, and hospice staff cultural competence through a social work student field placement. It is hoped that, if successful, this model will be replicated to address the problem of African American utilization and access to hospice. ABSTRACT FROM PUBLISHER (Copyright of American Journal of Hospice & Palliative Medicine is the property of Sage Publications Inc. and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.

Reese, D. J., E. Melton, et al. (2004). "Programmatic barriers to providing culturally competent end-of-life care." American Journal of Hospice and Palliative Medicine **21**(5): 357-364.

Examined barriers within the health care system to providing culturally competent end-of-life care. A sample of 22 directors of hospice and palliative care programs in a southeastern state were interviewed by telephone using quantitative and qualitative questions about cultural diversity attitudes and estimates regarding the diversity of the patients, staff, and volunteers in their programs. Results indicate that directors overestimated how well programs are doing in meeting the needs of diverse groups but were very interested in implementing cultural diversity training for their staff. Those who were more concerned about such issues had recruited more diverse volunteers into their programs. The presence of diverse staff or volunteers predicted a more diverse patient population. A number of efforts were underway to develop cultural competence and provide culturally competent care; however, several directors reported no efforts in this direction. Programmatic barriers to providing culturally competent end-of-life care include language barriers, lack of awareness of cultural diversity issues, and lack of access to and contacts within diverse communities. It is concluded that directors should provide leadership in their agencies in welcoming diversity. (SW)

Reiner, S. M. (2007). "Religious and spiritual beliefs: an avenue to explore end-of-life issues." Adultspan Journal **6**(2): 111-118.

Reviews the literature on the relationship between spirituality/religion and how people respond in the face of impending death. Spiritual and religious beliefs are associated with protecting against depression, despair, hastened death, and suicidal ideation; these beliefs can also assist people in making sense of terminal illness, easing emotional burden, and reducing fear of death. Recognition of the value of religious and spiritual beliefs of clients can provide counselors with a

wealth of information and an avenue to explore end-of-life issues. There are many therapies that counselors and clients can choose from when working together on end-of-life issues that incorporate their religious and spiritual beliefs, including dignity psychotherapy, meaning-centered psychotherapy, logotherapy, and life review.

Saccomano, S. J. and G. A. Abbatiello (2014). "Cultural Considerations at the end of life." Nurse Practitioner **39**(2): 24-32.

Abstract: It is important for nurse practitioners to understand their patients' cultural backgrounds to provide competent care at the end of life. Understanding the concepts of various cultures can keep the lines of communication open and help providers elicit the necessary information to make the end-of-life experience as comfortable as possible.

Salman, K. and R. Zouha (2010). "Considering faith within culture when caring for the terminally ill Muslim patient and family." Journal of Hospice & Palliative Nursing **12**(3): 156-165.

Nursing is a caring profession that strives to deliver holistic care regardless of patients' cultural differences, values, and religious faith. The current health system in the United States was developed to meet the needs of the dominant cultural groups, despite the fact that the United States is the most diverse country in the world. Nurses and other healthcare professionals cannot assume that common cultural values or a standard care plan is applicable to all people. An important aspect of promoting culturally competent care is the careful examination of religious faiths. The Islamic faith is considered a culture and philosophy of life, which characterizes Muslims from other faiths and cultures. For Muslims, at the death bed, spirituality and religious faith are the only empowering sources that help them to face death. To deliver effective culturally congruent care to a terminally ill Muslim patient, the Islamic rituals must be carried out in a way that recognizes and respects the cultural differences of this particular population.

Samanta, J. (2013). "Equality for followers of South Asian religions in end-of-life care." Nursing Ethics **20**(4): 382-391.

Significant minority populations confer richness and diversity to British society. Responsive end-of-life care is a universal need that has ascended the public agenda following myriad reports of inadequate provision. Nevertheless, the potential exists for unwitting discrimination when caring for terminally ill patients on the basis of their religion or faith. Recent implementation of the Equality Act 2010, together with the government and professional initiatives, promises to positively impact upon this area of contemporary relevance and concern, although the extent to which facilitative policies can truly enhance patient care will depend upon how these are translated into care at the bedside. The contributions of health professionals will be central in meeting the challenges and seizing the opportunities for meeting the religion and faith interests of patients of South Asian descent.

Schim, S. M., A. Z. Doorenbos, et al. (2006). "Enhancing Cultural Competence Among Hospice Staff." American Journal of Hospice & Palliative Medicine **23**(5): 404-411.

A critical component in making hospice and palliative care services accessible and acceptable to diverse communities is preparation of all providers to enhance cultural competence. This article reports a study designed to test an educational intervention aimed at expanding cultural awareness, sensitivity, and competence with a multidisciplinary and multilevel team of hospice workers. The purpose of this quasi-experimental, longitudinal, crossover design was to test the effects of an educational intervention for multidisciplinary hospice providers. Findings demonstrated that even with a modest face-to-face intervention, cultural competence scores were significantly greater after the educational intervention for participants in both groups. Although the intervention proved successful at enhancing cultural competence scores among diverse types of hospice workers, limitations and logistic insights gained from this pilot suggest the need for examination of alternative methods of program delivery.

Seale, C. (2010). "The role of doctors' religious faith and ethnicity in taking ethically controversial decisions during end-of-life care." Journal of Medical Ethics **36**(11): 677-682. BACKGROUND AND AIMS: The prevalence of religious faith among doctors and its relationship with decision-making in end-of-life care is not well documented. The impact of ethnic differences on this is also poorly understood. This study compares ethnicity and religious faith in the medical and general UK populations, and reports on their associations with ethically controversial decisions taken when providing care to dying patients. METHOD: A postal survey of 3733 UK medical practitioners, of whom 2923 reported on the care of their last patient who died. FINDINGS: Specialists in care of the elderly were somewhat more likely to be Hindu or Muslim than other doctors; palliative care specialists were somewhat more likely to be Christian, religious and 'white' than others. Ethnicity was largely unrelated to rates of reporting ethically controversial decisions. Independently of speciality, doctors who described themselves as non-religious were more likely than others to report having given continuous deep sedation until death, having taken decisions they expected or partly intended to end life, and to have discussed these decisions with patients judged to have the capacity to participate in discussions. Speciality was independently related to wide variations in the reporting of decisions taken with some intent to end life, with doctors in 'other hospital' specialities being almost 10 times as likely to report this when compared with palliative medicine specialists, regardless of religious faith. CONCLUSIONS: Greater acknowledgement of the relationship of doctors' values with clinical decision-making is advocated.

Sharma, R. K. and S. M. Dy (2011). "Cross-Cultural Communication and Use of the Family Meeting in Palliative Care." American Journal of Hospice and Palliative Medicine **28**(6): 437-444.

Terminally-ill patients and their families often report poor communication and limited understanding of the patient's diagnosis, prognosis, and treatment plan; these deficits can be exacerbated by cross-cultural issues. Although family meetings are frequently recommended to facilitate provider-family communication, a more structured, evidence-based approach to their use may improve outcomes. Drawing on research and guidelines from critical care, palliative care, and cross-cultural communication, we propose a framework for conducting family meetings with

consideration for cross-cultural issues.

Shubha, R. (2007). "End-of-life care in the Indian context: the need for cultural sensitivity." Indian Journal of Palliative Care **13**(2): 59-64.

End-of-life care requires dealing with challenging issues along various dimensions - physical, psychological, social and cultural. In addition to physical care, the importance of mental healthcare for patients at the end of life is now clearly recognised. However, there is much less awareness about the cultural factors that are involved in end-of-life care. Sensitivity to these factors is essential to providing high quality care and satisfaction to patients. In India, patients come from varied backgrounds. Their end-of-life needs differ according to their belief systems and values relating to life and death in general. In turn, these are influenced by the position they occupy along various dimensions, such as class, religion, caste, community, language, gender, to name a few. Moreover, cultural variations in attitudes and values have important practical implications for individuals making crucial medical decisions. It is therefore important for medical, paramedical and mental health professionals to be cognizant of these factors so as to provide effective and satisfying end-of-life care to patients. This paper discusses some of the issues in providing culture-sensitive care, using examples from the Indian context.

Singh, A. and M. Freeman (2011). "The important role for nurses in supporting the Asian Hindu patient and family at end of life: providing culturally sensitive end-of-life care." Canadian Oncology Nursing Journal **21**(1): 46-47.

As cultural ecology of Canada evolves with daily arrival of new immigrants, Canadians welcome them and feel very proud of preserving their multicultural heritage. As minority groups, especially South Asian Hindus, continue to grow, there is a need to understand their cultural perspectives and accommodate their cultural preferences for end-of-life care. This article addresses end-of-life care from a point of view of Hindu culture and religion and provides a brief overview of their beliefs and rituals related to it. This article also guides nurses to understand diverse Hindu cultural practices and beliefs to help support their patients and families at this difficult time of life.

Siriwardena, A. N. and D. H. Clark (2004). "End-of-life care for ethnic minority groups." Clinical Cornerstone **6**(1): 43-48.

Death and dying are profound events that bring into focus important ethical and medical questions for all patients, whatever their cultural background. For ethnic minority groups and their families, specific issues or barriers may arise related to culturally appropriate health care practices, cultural or religious differences, diverse health beliefs, and access to services for care and support during end-of-life conditions. National policy and local initiatives in both the United States and the United Kingdom support the development of services that address the care of ethnic minorities. This article examines end-of-life care for ethnic minority groups.

Siriwardena, A. N. and D. H. Clark (2010). "End-of-life care for ethnic minority groups..."

Clinical Cornerstone®. 2004;6(1):43-49." Clinical Cornerstone **10**(1): 7-13.

Death and dying are profound events that bring into focus important ethical and medical questions for all patients, whatever their cultural background. For ethnic minority groups and their families, specific issues or barriers may arise related to culturally appropriate health care practices, cultural or religious differences, diverse health beliefs, and access to services for care and support during end-of-life conditions. National policy and local initiatives in both the United States and the United Kingdom support the development of services that address the care of ethnic minorities. This article examines end-of-life care for ethnic minority groups.

Smith, A. K., E. P. McCarthy, et al. (2008). "Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences." Journal of Clinical Oncology **26**(25): 4131-4137.

PURPOSE Despite well-documented racial and ethnic differences in advance care planning (ACP), we know little about why these differences exist. This study tested proposed mediators of racial/ethnic differences in ACP. **PATIENTS AND METHODS** We studied 312 non-Hispanic white, 83 non-Hispanic black, and 73 Hispanic patients with advanced cancer in the Coping with Cancer study, a federally funded multisite prospective cohort study designed to examine racial/ethnic disparities in ACP and end-of-life care. We assessed the impact of terminal illness acknowledgment, religiousness, and treatment preferences on racial/ethnic differences in ACP. **Results** Compared with white patients, black and Hispanic patients were less likely to have an ACP (white patients, 80%; black patients, 47%; Hispanic patients, 47%) and more likely to want life-prolonging care even if he or she had only a few days left to live (white patients, 14%; black patients, 45%; Hispanic patients, 34%) and to consider religion very important (white patients, 44%; black patients, 88%; Hispanic patients, 73%; all $P < .001$, comparison of black or Hispanic patients with white patients). Hispanic patients were less likely and black patients marginally less likely to acknowledge their terminally ill status (white patients, 39% v Hispanic patients, 11%; $P < .001$; white v black patients, 27%; $P = .05$). Racial/ethnic differences in ACP persisted after adjustment for clinical and demographic factors, terminal illness acknowledgment, religiousness, and treatment preferences (has ACP, black v white patients, adjusted relative risk, 0.64 [95% CI, 0.49 to 0.83]; Hispanic v white patients, 0.65 [95% CI, 0.47 to 0.89]). **CONCLUSION** Although black and Hispanic patients are less likely to consider themselves terminally ill and more likely to want intensive treatment, these factors did not explain observed disparities in ACP.

Smith, S. H. (2004). "End-of-life care decision-making processes of African American families: implications for culturally-sensitive social work practice." Journal of Ethnic and Cultural Diversity in Social Work **13**(2): 1-23.

Investigated end-of-life care decision making among African American families. A total of 46 adults aged 40 and over (mean age 65) from 15 African American families, who had an elderly relative (65 years of age or over) die following 2 weeks or more of care in a hospice or an acute or long term care facility, completed qualitative interviews. Most participants identified themselves as Methodists (89%)

or Baptists (10%) and 41% of the participants were adult children of their deceased relatives, while 15% were spouses and 24% siblings. Family participants' end-of-life care decisions were characterized in thematic patterns focusing on the primacy of the dying family member's wishes, inclusion of family members in the decision-making process, maximization of treatment options, and religious influences. Five families interviewed identified social workers as helpful in making end-of-life care decisions concerning their dying older adult relatives. Results suggest that many families felt that they received too little information or did not fully understand the information received from health care professionals, indicating a need for a broader role for social workers.

Sneesby, L., R. Satchell, et al. (2011). "Death and dying in Australia: perceptions of a Sudanese community." Journal of Advanced Nursing **67**(12): 2696-2702.

Aims. The aims of this study were to obtain information to support Palliative Care healthcare workers to meet the needs of the Sudanese population in death, dying, and bereavement. **Background.** Australia is a multicultural society and healthcare workers are faced with increasing numbers and diversity of immigrants to whom healthcare professionals strive to provide quality health care. **Methods.** A qualitative interpretive approach was used with data collected from a sample of 15 participants during focus group discussions. Data were collected in 2008-2009, transcribed and analysed. **Results.** The main themes and ideas identified in the dialogues were analysed under five main headings - Communication issues including disclosure and consent; Concepts of disease and illness; Attitudes towards medical treatments; Customs surrounding death, dying and bereavement; and Spiritual and religious issues. **Conclusion.** The cultures and traditions of African countries vary widely; this study provides a snapshot of the views of a Sudanese African community about death and dying in Australia.

Taxis, J. C., T. Keller, et al. (2008). "Mexican Americans and hospice care: culture, control, and communication." Journal of Hospice & Palliative Nursing **10**(3): 133-141.

Hispanic/Latinos are the fastest growing ethnic minority group in the US and the most unlikely of any racial/ethnic group to use hospice services for end-of-life (EOL) care. The construction of healthcare systems that are culturally compatible for an increasingly diverse population, particularly at the EOL when cultural perspectives are central to the decision making process, is an urgent yet complex task. This qualitative study, conducted in two locations in the southwest part of the US explored the attitudes and experiences of Mexican Americans that influence decisions about EOL care and participation in hospice programs. The key findings include the need for (a) effective incorporation of the family with its cultural and spiritual values, (b) careful negotiation of the fluctuating need for the patient and family to both maintain and release control in EOL care, and (c) culturally and linguistically consistent communication. Recommendations for hospice care staff and administrators are offered.

Thomas, R., D. M. Wilson, et al. (2008). "A literature review of preferences for end-of-life care in developed countries by individuals with different cultural affiliations and ethnicity." Journal of Hospice & Palliative Nursing **10**(3): 142-163.

Anticipatory decision making about end-of-life care is predominantly a North American concept. Researchers investigated four themes: advance directives, life support, communication, and decision making. Substantial differences exist among cultural groups in the percentages with living wills/advance directives, and they are less frequent for those with family-centered decision making or with less trust in the healthcare system. African Americans prefer life support more than Asian Americans or European Americans. Cultural groups vary in their preferences about communicating terminal diagnoses. Non-English-speaking patients perceive communication as a barrier to care. Mexican Americans, Korean Americans, and Canadian First Nations emphasize family-based decision making at the end of life, and European Americans emphasize patient autonomy.

True, G., E. J. Phipps, et al. (2005). "Treatment preferences and advance care planning at end of life: The role of ethnicity and spiritual coping in cancer patients." Annals of Behavioral Medicine **30**(2): 174-179.

Background: Although studies have reported ethnic differences in approaches to end of life, the role of spiritual beliefs is less well understood. Purpose: This study investigated differences between African American and White patients with cancer in their use of spirituality to cope with their cancer and examined the role of spiritual coping in preferences at end-of-life. Methods: The authors analyzed data from interviews with 68 African American and White patients with an advanced stage of lung or colon cancer between December 1999 and June 2001. Results: Similar high percentages of African American and White patients reported being "moderately to very spiritual" and "moderately to very religious." African American patients were more likely to report using spirituality to cope with their cancer as compared to their White counterparts ($p = .002$). Patients who reported belief in divine intervention were less likely to have a living will ($p = .007$). Belief in divine intervention, turning to higher power for strength, support and guidance, and using spirituality to cope with cancer were associated with preference for cardiopulmonary resuscitation, mechanical ventilation, and hospitalization in a near-death scenario. Conclusions: It was found that patients with cancer who used spiritual coping to a greater extent were less likely to have a living will and more likely to desire life-sustaining measures. If efforts aimed at improving end-of-life care are to be successful, they must take into account the complex interplay of ethnicity and spirituality as they shape patients' views and preferences around end of life.

van Wijmen, M. P. S., M. L. Rurup, et al. (2010). "Advance directives in the Netherlands: an empirical contribution to the exploration of a cross-cultural perspective on advance directives." Bioethics **24**(3): 118-126.

Research Objective: This study focuses on ADs in the Netherlands and introduces a cross-cultural perspective by comparing it with other countries. Methods: A questionnaire was sent to a panel comprising 1621 people representative of the Dutch population. The response was 86%. Results: 95% of the respondents didn't

have an AD, and 24% of these were not familiar with the idea of drawing up an AD. Most of those familiar with ADs knew about the Advanced Euthanasia Directive (AED, 64%). Both low education and the presence of a religious conviction that plays an important role in one's life increase the chance of not wanting to draw up an AD. Also not having experienced a request for euthanasia from someone else, and the inconceivability of asking for euthanasia yourself, increase the chance of not wanting to draw up an AD. Discussion: This study shows that the subjects of palliative care and end-of-life-decision-making were very much dominated by the issue of euthanasia in the Netherlands. The AED was the best known AD; and factors that can be linked to euthanasia play an important role in whether or not people choose to draw up an AD. This differentiates the Netherlands from other countries and, when it comes to ADs, the global differences between countries and cultures are still so large that the highest possible goals, at this moment in time, are observing and possibly learning from other cultural settings.

Venkatasalu, M. R., J. E. Seymour, et al. (2014). "Dying at home: A qualitative study of the perspectives of older South Asians living in the United Kingdom." Palliative Medicine **28**(3): 264-272.

Background: South Asians constitute the single largest ethnic minority group in the United Kingdom, yet little is known about their perspectives on, and experiences of, end-of-life care. Aim: To explore beliefs, attitudes and expectations expressed by older South Asians living in East London about dying at home. Design: A qualitative study using focus groups and semi-structured interviews. Data were analysed using a constructivist grounded theory approach. Setting/participants: Five focus groups and 29 in-depth semi-structured interviews were conducted with a total of 55 older adults (24 men and 31 women) aged between 52 and 78 years. Participants from six South Asian ethnic groups were recruited via 11 local community organisations. Results: Two key themes were identified. The theme of 'reconsidering the homeland' draws on the notion of 'diaspora' to help understand why for many participants, the physical place of death was perceived as less important than the opportunity to carry out cultural and religious practices surrounding death. The second theme 'home as a haven' describes participants' accounts of how their home is a place in which it is possible to perform various cultural and religious rituals. Cultural and religious practices were often seen as essential to achieving a peaceful death and honouring religious and filial duties. Conclusions: Older people of South Asian ethnicity living in East London perceive home as more than a physical location for dying relatives. They make efforts to adhere, and also adapt, to important social and cultural values relating to death and dying as part of the wider challenge of living in an emigrant society.

Wesley, C., K. Tunney, et al. (2004). "Educational needs of hospice social workers: spiritual assessment and interventions with diverse populations." American Journal of Hospice and Palliative Medicine **21**(1): 40-46.

Analyzed the roles and educational needs of hospice social workers regarding assessment and intervention in spirituality, religion, and diversity of their patients. Seven male and 55 female social workers (mean age 47) who had spent an average of 7 years in hospice social work responded to a mail survey on the roles and needs of hospice social workers in religion, spirituality, and diversity. The

instrument included 31 closed and 3 open-ended narrative questions. The results suggest that spiritual care is shared among hospice team members and that most social workers feel comfortable in addressing these issues. However, role conflict and role ambiguity also exist. Respondents often felt ill-prepared to deal with complex faith-based conflicts related to diversity. They saw themselves in need of assessment models and interventions for end-of-life decision making regarding assisted suicide and euthanasia. Recommendations for social work practice, education, and research are provided.

Wiener, L., D. G. McConnell, et al. (2013). "Cultural and religious considerations in pediatric palliative care." *Palliative & Supportive Care* 11(1): 47-67.

OBJECTIVE: A growing multicultural society presents healthcare providers with a difficult task of providing appropriate care for individuals who have different life experiences, beliefs, value systems, religions, languages, and notions of healthcare. This is especially vital when end-of-life care is needed during childhood. There is a dearth of literature addressing cultural considerations in the pediatric palliative care field. As members of a specific culture often do not ascribe to the same religious traditions, the purpose of this article was to explore and review how culture and religion informs and shapes pediatric palliative care. **METHOD:** Comprehensive literature searches were completed through an online search of nine databases for articles published between 1980 and 2011: PsychINFO, MEDLINE(R), Journal of Citation Reports-Science Edition, Embase, Scopus, CINAHL(R), Social Sciences Citation Index (SSCI), EBSCO, and Ovid. Key terms included: culture, transcultural, spiritual, international, ethnic, customs or religion AND end-of-life, palliative care, death, dying, cancer, or hospice, and children, pediatrics, or pediatric oncology. Reference lists in the retrieved articles were examined for additional studies that fit the inclusion criteria, and relevant articles were included for review. In addition, web-based searches of specific journals were conducted. These included, but were not limited to: Qualitative Health Research, Psycho-Oncology, Journal of Psychosocial Oncology, Journal of Pediatric Psychology, Journal of Pediatric Health Care, Journal of Pediatric Oncology Nursing, Omega, Social Work in Health Care, and Journal of Palliative Medicine. **RESULTS:** Thirty-seven articles met eligibility criteria. From these, seven distinct themes emerged that have implications for pediatric palliative care. These include the role of culture in decision-making, faith and the involvement of clergy, communication (spoken and unspoken language), communicating to children about death (truth telling), the meaning of pain and suffering, the meaning of death and dying, and location of end-of-life care. **SIGNIFICANCE OF RESULTS:** The review of the literature provides insight into the influence of religion and how culture informs lifestyle and shapes the experiences of illness, pain, and end-of-life care. Recommendations for providing culturally sensitive end-of-life care are offered through the framework outlined in the Initiative for Pediatric Palliative Care Quality Improvement Project of 2002. Cultural traditions are dynamic, never static, and cannot be generalized to all families. Guidelines to aid in approaches to palliative

care are provided, and providers are encouraged to define these important differences for each family under their care.

Wong, M. and S. W. Chan (2007). "The experiences of Chinese family members of terminally ill patients -- a qualitative study." Journal of Clinical Nursing **16**(12): 2357-2364.

AIM: To describe and understand the experiences of Chinese family members of terminally ill patients during the end of life process in a palliative care unit.

BACKGROUND: Palliative care aims to provide care to dying patients and their family members. Skillful interventions are necessary to help family members cope with the impending death of the patient and maintain their emotional equilibrium.

Hence, it is important to understand the experiences of family members of palliative care.

DESIGN: A phenomenological study was conducted. Data were collected by semi-structured interviews. We interviewed a purposive sample of 20 family members of terminally ill patients in a palliative care unit in Hong Kong. The data were analysed following Colaizzi's phenomenological methodology.

RESULTS: Family members experienced anticipatory grief, with reactions that included anger, unease, sadness and helplessness. This was particularly acute when the patient was first admitted to the palliative care unit. However, the family members quickly accepted the reality and committed themselves to the care of the patient, seeking informational and emotional support from the nurses. The families wanted to be assured that the patient had been offered good care and suffered no pain. It was considered important to be with the patient during the dying process.

CONCLUSION: This study demonstrated that Chinese family members were committed to the care of the patients in the palliative care unit. Cultural beliefs played a part in influencing family emotions and concerns.

RELEVANCE TO CLINICAL PRACTICE: This study offers a direction for family interventions that acknowledge the reactions of family members to the admission of a patient to a palliative care unit. It highlights that families need active informational and emotional support from nurses.

Worth, A., T. Irshad, et al. (2009). "Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: Prospective longitudinal qualitative study." BMJ: British Medical Journal **338**(7693): 1-19.

Objectives: To examine the care experiences of South Asian Sikh and Muslim patients in Scotland with life limiting illness and their families and to understand the reasons for any difficulties with access to services and how these might be overcome.

Design: Prospective, longitudinal, qualitative design using in-depth interviews.

Setting: Central Scotland. Participants: 25 purposively selected South Asian Sikh and Muslim patients, 18 family carers, and 20 key health professionals.

Results: 92 interviews took place. Most services struggled to deliver responsive, culturally appropriate care. Barriers to accessing effective end of life care included resource constrained services; institutional and, occasionally, personal racial and religious discrimination; limited awareness and understanding among South Asian people of the role of hospices; and difficulty discussing death. The most vulnerable patients, including recent migrants and those with poor English language skills, with no family advocate, and dying of non-malignant diseases were at particularly high risk of inadequate care. Conclusions: Despite a robust Scottish diversity policy,

services for South Asian Sikh and Muslim patients with life limiting illness were wanting in many key areas. Active case management of the most vulnerable patients and carers, and "real time" support, from where professionals can obtain advice specific to an individual patient and family, are the approaches most likely to instigate noticeable improvements in access to high quality end of life care. Improving access to palliative care for all, particularly those with non-malignant illnesses, as well as focusing on the specific needs of ethnic minority groups, is required.

Yapp, K. A. (2012). "Culture and End-of-Life Care: An Epidemiological Evaluation of Physicians." American Journal of Hospice and Palliative Medicine **29**(2): 106-111.

Beneficence is a fundamental concept of medicine, which embodies the notion above all, do no harm. While this principle illustrates the health care professional's duty to contribute to the patient's welfare, the principle becomes convoluted when the wishes of the patient directly conflict with that of the physician. The purpose of the study was to determine the degree to which cultural beliefs influence a physician's decision to introduce the concept of hospice to terminally ill patients. This phenomenological study explored the perceptions of 14 physicians practicing medicine in Mercer County, New Jersey. Analysis of the textual data revealed the following 5 themes: (a) physician personal perspectives, (b) physician perspectives on culture, (c) perspectives on hospice care, (d) communication with patients, and (e) training and experience. ABSTRACT FROM PUBLISHER (Copyright of American Journal of Hospice & Palliative Medicine is the property of Sage Publications Inc. and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.

Zaide, G. B., R. Pekmezaris, et al. (2013). "Ethnicity, race, and advance directives in an inpatient palliative care consultation service." Palliative & Supportive Care **11**(1): 5-11.

Objective: Although race and ethnic background are known to be important factors in the completion of advance directives, there is a dearth of literature specifically investigating the effect of race and ethnicity on advance directive completion rate after palliative care consultation (PCC). Method: A chart review of all patients seen by the PCC service in an academic hospital over a 9-month period was performed. Data were compiled using gender, race, ethnicity, religion, and primary diagnosis. For this study, advance directives were defined as: "Do Not Resuscitate" (DNR) and/or "Do Not Intubate" (DNI). Results: Of the 400 medical records reviewed, 57% of patients were female and 71.3% documented their religion as Christian. The most common documented diagnosis was cancer (39.5%). Forty-seven percent reported their race as white. White patients completed more advance directives than did nonwhite patients both before (25.67% vs. 12.68%) and after (59.36% vs. 40.84%) PCC. There was a significantly higher proportion of whites who signed an advance directive after a PCC than of nonwhites ($p = 0.021$); of the 139 whites who did not have an advance directive at admission, 63 signed an advance directive after a PCC compared with 186/60 nonwhites (45% vs. 32%, respectively, $p = 0.021$). Further analysis revealed that African Americans differed from whites in the likelihood of advance directive execution rates pre-PCC, but not post-PCC. Significance of results: This study demonstrates the impact of a PCC on the

completion of advance directives, on both whites and nonwhites. The PCC Intervention significantly reduced differences between whites and African Americans in completing advance directives, which have been consistently documented in the end-of-life literature.