Annotated Bibliography:
Qualitative review of end-of-life and
ethnicity/race/diversity

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* Note: US or UK spellings are maintained throughout the bibliography to reflect the country of origin.

Anderson, J. M. (1986). "Ethnicity and illness experience: ideological structures and the health care delivery system." Social Science & Medicine 22(11): 1277-83.
This paper analyses the experiences of Anglo-Canadian and immigrant Chinese families with a chronically ill child by using the idea that the social organization and ideology of health care services generate particular illness experiences. Immigrant families find the ideology dissonant with their customs for managing illness. The disjuncture between practices often leads to non-compliance and ineffective treatment. Health professionals explain non-compliance by the obvious facts of cultural differences, but I argue that it should be understood by institutional practices that exclude families from participating in caretaking. I maintain that patients and families should be included in decisions that affect their lives. Pressures from government to economize by increasing home care services, and the increasing number of immigrants may force practitioners to negotiate culturally acceptable care with them.

Anonymous (1999). "Vaisnava Hindu and Ayurvedic Approaches to Caring for the Dying: An Interview with Henry T. Dom, PhD (Hari-dhama)." Innovations in End-of-Life Care.
Henry T. Dom is a practitioner of the ancient Vaisnava tradition of Hinduism. He earned his PhD in philosophy, writing a thesis on palliative and spiritual care in the Vaisnava-Hindu tradition at the Bhaktivedanta Research Institute for Vedic Studies, India and the University of Cape Town, South Africa. His perspective on the place of spirituality in palliative care is rooted in his own multi-cultural, multi-lingual background, his practice of Vaisnava Hinduism and familiarity with the principles and practice of Ayurvedic medicine in India, in addition to his experience over the past ten years working in London, England, with the elderly and those dying from AIDS, cancer and other diseases in nursing homes, hospitals, and hospices.

Anonymous (2003). Ian Anderson Continuing Education Program in End-of-life Care, Continuing Education and The Joint Centre for Bioethics, University of Toronto and The Temmy Latner Centre for Palliative Care, Mount Sinai Hospital, Toronto.
The Ian Anderson Continuing Education Program in End of Life care is a joint project of Continuing Education and The Joint Centre for Bioethics, University of Toronto and The Temmy Latner Centre for Palliative Care, Mount Sinai Hospital, Toronto. Its goal is to educate 10,000 primary care physicians and specialists across Canada over a five-year period to deal with issues surrounding death and dying. It also holds conferences relevant to dying in critical sectors including healthcare institutions and educators, media and government.

Antle, B. J., Cottingham, D., Ghelani, K., Gorman, E., Harrison, C., Martin, M., Rutka, J. (2002). Can we ease the burden? Preliminary findings from a qualitative study of parents' experiences with end-of-life decision making. 14th International Congress on Care of the Terminally Ill, Journal of Palliative Care.
The analysis contributes to the development of a framework for the development of best practices in quality end-of-life care for health care professionals participating in end-of-life decisions with families within a pediatric* setting.

Bailey, C., K. Froggatt, et al. (2002). "The nursing contribution to qualitative research in palliative care 1990-1999: a critical evaluation." Journal of Advanced Nursing 40(1): 48-60.
BACKGROUND: Qualitative research plays an important part in providing evidence for practice in nursing, and is gaining greater acceptance within medicine. However, questions remain about what criteria are most appropriate for evaluating qualitative research. To date,

little systematic evaluation of qualitative research in palliative care has been conducted. AIMS: This paper is based on a larger study in which we conducted a critical review of qualitative research in palliative care from nursing, medicine, specialist palliative care, sociology, death studies, medical anthropology, and gerontology journals published between 1990 and 1999. The aim of this paper is to present an account of the strengths and weaknesses of qualitative palliative care research in nursing, using data from this review. METHODS: In the larger study, 138 papers from 50 journals were reviewed critically using a tool developed to assess both content and quality; in one part of this tool reviewers recorded open-ended comments on the strengths and weaknesses of each paper. In this paper, we present a thematic analysis of reviewers' comments on a subgroup of 67 nursing papers from the main review, together with an analysis of comments on 29 papers from a comparison group of death studies, medical anthropology, and sociology journals. Patterns of positive and negative evaluation are identified and used to generate an account of strengths and weaknesses in qualitative palliative care research in nursing. FINDINGS: Over 40% of the subgroup of papers from nursing journals received positive comments on topic and quality of writing; around 30% received positive comments on contribution to understanding, practical value, and conceptual or theoretical issues. Less than 20% received positive comments on other critical dimensions. Over 40% of nursing papers received negative comments on the link between data, analysis, and findings, other aspects of method and theoretical and conceptual issues. A higher proportion of papers in the comparison group received positive comments on conceptual and theoretical issues and contribution to understanding. CONCLUSIONS: Nearly half the nursing papers reviewed were judged to be well written or to have a well-chosen topic. However, more than 40% of papers drew negative comments about key methods-related issues. Arguably therefore efforts to improve the quality of research evidence should focus on this area.

Baker, A. B. (1997). "Assumptions and Practice in Clinical Medical Ethics." Anaesthesia and Intensive Care 25(5): 528-534.
An orderly scheme of action is proposed to solve ethical problems in clinical medicine. This scheme depends on the understanding and discussion of the ethical assumptions that are involved in any dilemma. Six basic ethical assumptions (and their associated corollaries) are presented: Life, Autonomy, Beneficence, Equity, Truth and Law. These assumptions are dependent upon personal values and are therefore set in various hierarchical orders to permit case specific solutions.

Baker, M. E. (2002). "Economic, Political and Ethnic Influences on End-of-Life Decision-Making: A Decade in Review." Journal of Health and Social Policy 14(3): 27-40.
Implementation of the Patient Self Determination Act (PSDA) a decade ago has been followed by considerable research examining usage of advance directives among patient populations as well as among health care professionals. This article summarizes the history of end-of-life medical treatment options and provides a discussion of critical economic, political, and legal events that preceded passage of the PSDA. A review of the literature during the decade that followed is presented including research exploring ethnic factors in the completion of advance directives. Barriers to completing advance directives by minority populations are discussed and considerations for policy makers are provided.
KEYWORDS. Health care and minorities, poverty, living will, durable power of attorney for healthcare, end-of-life decision-making, advance directives

Barrett, R. K. (2001). Recommendations for Culturally Competent End-of-Life Care Giving, American Medical Association. 2003.
Barrett reviews two books, Counseling the Culturally Different: Theory and Practice (D. Sue, 1990) and Counseling American Minorities: A Cross-Cultural Perspective (D Atkinson, G. Morten & D.Sue, 1989) on the American Medical Association website (http://www.ama-assn.org.ama/pub/category/6824.html). In his review entitled, 'Recommendations for Culturally Competent End-of-Life Care Giving', Barrett synthesises recommendations from these two books. Issues discussed include: stereotyping, cultural self-awareness including

biases and value systems regarding care, comfort with multicultural differences in approaches to care, willingness to refer to caregivers who share the patients background, institutional barriers that prevent minorities from using care, and understanding and sensitivity to individual and group differences.

Bates, M. S. (1987). "Ethnicity and pain: a biocultural model." Social Science & Medicine 24(1): 47-50.
Zborowski's pioneering research in the 1950s noted ethnic differences in pain response. Subsequent clinical research has focused on ethnic variability in psychological, attitudinal and behavioral response but generally has ignored sociocultural influences on the perceptual component of pain. In light of Melzack and Wall's gate-control theory, it now appears that sociocultural factors may affect the psychophysiological processes of pain perception. This paper proposes that a biocultural model, which combines basic social learning and social comparison theories with certain aspects of the gate-control theory, will prove useful for studying and understanding cultural influences on human pain perception and response.

Bates, M. S., L. Rankin-Hill, et al. (1997). "The effects of the cultural context of health care on treatment of and response to chronic pain and illness." Social Science & Medicine 45(9): 1433-47.
Qualitative data from two studies in Puerto Rico and New England are used to show how cultural values, standards and beliefs in different health care contexts affect (1) health care professionals' responses to patients' problems, (2) the relationships between providers and patients, and (3) the patients' responses to chronic pain and illness. Influencing elements in the care setting include the world view of the relationship of mind and body in illness processes, the dominant values and standards regarding pain and illness behaviors and the degree of cooperation between the providers and other agencies the patient depends on for compensation, rehabilitation and health insurance. In the New England study, the biomedical world view of mind-body dualism was shared by providers and most patients, but this shared belief often contributed to substantial patient stress and alienation. In contrast, in the Puerto Rican study providers and patients often shared a view of mind-body integration in illness and valued treatments which addressed chronic pain as a biopsychosocial experience. In this setting, shared views and values contributed to more supportive patient-provider relationships, and patients thus experienced less treatment-related stress.

BBC-News (2003). Patients to decide treatment end, BBC News. 2003. Available from http://news.bbc.co.uk/go/pr/fr/-/2/hi/uk_news/england/2793973.stm
Hammersmith Hospitals NHS Trust in West London recently announced that it would be giving elderly patients a form called an Expression of Wishes in Healthcare. This is being done in order to allow patients to tell doctors when to stop treatment if they become so ill that they could not express their wishes.

Berger, J. T. (1998). "Culture and Ethnicity in Clinical Care." Archives of Internal Medicine 158(19): 2085-2092.
This commentary states that the American medical practice is influenced by the dominant culture. Advance directives, preferences for treatment, health beliefs, autopsy and organ donation, disclosure and truth telling, and physician's bias, behavior and background are analyzed in the context of different cultures and Berger discusses the compatibility, or lack thereof, with mainstream clinical care. The article aims to stimulate cultural and ethnic sensitivity among healthcare professionals to improve clinical care.

Black, J. (1987). "Broaden your mind about death and bereavement in certain groups in Britain." British Medical Journal 295(6597): 536-539.
"A collection of useful advice on topics that doctors need to know about but won't find in the medical textbooks". Includes Hinduism, Sikhism and Islam and covers Religious organisation, Imminent death, After death, Funeral arrangements, Mourning, Necropsies, Organ donation and transplants, Termination of pregnancy, Prenatal testing, Still births, and deaths of young children in each faith group.

Boulton, M., Fitzpatrick, R., Swinburn, C. (1996). "Qualitative research in health care: II. A structured review and evaluation of studies." Journal of Evaluative Clinical Practice 2(3): 171-9.
A hand search of the original papers in seven medical journals over 5 years was conducted in order to identify those reporting qualitative research. A total of 210 papers were initially identified, of which 70 used qualitative methods of both data collection and analysis. These papers were evaluated by the researchers using a checklist which specified the criteria of good practice. Overall, 2% of the original papers published in the journals reported qualitative studies. Papers were more frequently positively assessed in terms of having clear aims, reporting research for which a qualitative approach was appropriate and describing their methods of data collection. Papers were less frequently positively assessed in relation to issued of data analysis such as validity, reliability and providing representative supporting evidence. It is concluded that the full potential of qualitative research has yet to be realized in the field of health care.

Bowman, K. W., D. K. Martin, et al. (2000). "Quality end-of-life care." Journal of Evaluation in Clinical Practice 6(1): 51-61.
Looking to the future, we must ultimately consider the quality of end-of-life care on a global level. Most of the world is still comprised of low to middle income countries whose end-of-life care may differ significantly from care in high income countries, such as Canada, the United States, and United Kingdom. Just as the World Health Organization's World Health Report compares indicators for a variety of other health care issues - such as infant mortality - so must we strive to establish indicators for end-of-life care. Understanding these challenges - and developing indicators for comparing end-of-life care in the health systems of various countries - is essential to reaching a state of health care that provides all dying patients and their families throughout the world with the respect, dignity and support they deserve.

Braun, K. L. and R. Nichols (1996). "Cultural issues in death and dying." Hawaii Medical Journal 55(12): 260-264.
Although all of us experience death, not all of us think about death or respond to death the same way. This study begins to explore how cultural traditions, education, and tenure in Hawaii impact views of advanced directives, organ donation, suicide, and euthanasia. This information is useful to physicians who need to engage patients and families in discussions about death and end-of-life decision making

Brownlee, A. (1978). "The family and health care: explorations in cross-cultural settings." Soc Work Health Care 4(2): 179-78.
This article discusses what a social worker or health practitioner should know about the family and its influence on health care among various ethnic groups, focusing first on basic information on family organization and interrelationships and then on the family's role during health care. The material is presented in a format designed to be useful to the practitioner in the field, discussing what important aspects of various topics the worker might investigate, why the information is important, and how to gather it.

Campbell, C. S. (1992). "Religious ethics and active euthanasia in a pluralistic society." Kennedy Institute of Ethics Journal 2(3): 253-77.
This article sets out a descriptive typology of religious perspectives on legalized euthanasia--political advocacy, individual conscience, silence, embedded opposition, and formal public opposition--and then examines the normative basis for these perspectives through the themes of sovereignty, stewardship, and the self. It also explores the public relevance of these religious perspectives for debates over legalized euthanasia, particularly in the realm of public policy. Ironically, the moral discourse of religious traditions on euthanasia may gain public relevance at the expense of its religious content. Nonetheless, religious traditions can provide a context of ultimacy and meaning to this debate, which is a condition for genuine pluralism. A table setting out the views of various denominations with regard to euthanasia is included.

Carrese, J. A., J. L. Mullaney, et al. (2002). "Planning for death but not serious future illness: qualitative study of housebound elderly patients." British Medical Journal 325(7356): 125-127.

Objective To understand how elderly patients think about and approach future illness and the end of life. Design Qualitative study conducted 1997-9. Setting Physician housecall programme affiliated to US university Participants 20 chronically ill housebound patients aged over 75 years who could participate in an interview. Participants identified through purposive and random sampling. Main outcome measures In-depth semistructured interviews lasting one to two hours. Results Sixteen people said that they did not think about the future or did not in general plan for the future. Nineteen were particularly reluctant to think about, discuss, or plan for serious future illness. Instead they described a "one day at a time," "what is to be will be" approach to life, preferring to "cross that bridge" when they got to it. Participants considered end of life matters to be in the hands of God, though 13 participants had made wills and 19 had funeral plans. Although some had completed advance directives, these were not well understood and were intended for use only when death was near and certain. Conclusions The elderly people inter-viewed for this study were resistant to planning in advance for the hypothetical future, particularly for serious illness when death is possible but not certain.

Clough, A. (2002). "Community care policy and end-of-life care: one patient's story." British Journal of Community Nursing 7(3): 153-158.

This article examines the effect of community care policy on the care of a young woman with a terminal illness from a minority ethnic group. Current NHS policy advocates collaboration between health and social care agencies to provide a seamless service for patients. The article considers aspects of interagency and interprofessional collaboration, teamwork and patient empowerment and analyses how beneficial these factors were in a patient's care. It also examines the concept of health promotion within the sphere of palliative care

Cohen, A. B., Koenig, M.D. (2002). "Spirituality in palliative care." Geriatric Times III(6).

Interest in religion and spirituality as a source of resilience in coping with serious physical illness has seen a dramatic increase in recent years (Koenig et al., 2001a, 2001b; Plante and Sherman, 2001). Health care professionals providing medical care to patients with serious illnesses should consider the roles that they can play in meeting patients' religious and spiritual needs. Compassionately addressing these issues may increase the health of patients and/or increase the comfort and meaning in the process of illness and the process of dying. We will focus our discussion on the Jewish and Christian traditions because those are the traditions with which we are most familiar; but, research is sorely needed on issues related to spirituality and medical outcomes in non-Judeo-Christian populations.

Conrad, P. (1994). "How ethnography can help bioethics." Bulletin of Medical Ethics No. 98: 13-8.

All too many debates in medical ethics take place remote from those involved in the issues as patient, family or careers. Ethicists have been slow to acknowledge the contribution that the various aspects of medical sociology, and ethnography in particular, could make to help inform those debates. This paper provides some useful examples of how ethnographic methods can broaden and deepen ethical discussion.

Crawley, L., R. Payne, et al. (2000). "Palliative and end-of-life care in the African American community." Journal of the American Medical Association 284(19): 2518-2521.

The Initiative to Improve Palliative and End-of-Life Care in the African American Community was formed to delineate historical, social, cultural, ethical, economic, legal, health policy, and medical issues that appear to affect African Americans' attitudes toward, acceptance of, access to, and utilization of palliative care and hospice services. In February 2000, an interdisciplinary working group of African American scholars and professionals met to begin

defining a research, education, and policy agenda for the improvement of end-of-life care for African American patients facing death. We offer this commentary to further this discussion.

Cunningham, M. E. (1994). "Afrocentrism and self-concept." Journal of the National Black Nurses Association 7(1): 15-24.
The promotion of healthy self-concept in clients is an important outcome in nursing practice. The nurse's own self-concept is also an important factor affecting one's ability to meet the needs of others. Several scholars who speak from an Afrocentric cultural base echo a warning about the potential deleterious effects on self-concept that can occur as a result of internalization of the perspectives of other cultures to the exclusion of perspectives from one's own culture. Proponent and opponent arguments have been articulated concerning the question, "Are there African American perspectives on biomedical ethics?" In this paper, the proponent view is supported, and the potential influence of Afrocentrism on self-concept is explored.

Dalla-Vorgia, P., K. Katsouyanni, et al. (1992). "Attitudes of a Mediterranean population to the truth-telling issue." Journal of Medical Ethics 18(2): 67-74.
The attitudes of the Greeks, a Mediterranean population, to the issue of telling the truth to the patient have been studied. There is no clear answer to the question: 'Do the Greeks wish to be informed of the nature of their illness?'. The answer is: 'It depends'. It depends on age, education, family status, occupation, place of birth and residence and on whether or not they are religious people. However, it does not depend on their sex--men and women have similar reactions to the issue of truth-telling. Although the present study shows lower percentages of those who wish to know the truth than studies on other populations, the conclusion is that, emphasising the need for good communication between doctors and patients, doctors should not lie, but should disclose to their patients the part of the truth they are ready to accept.

Davis, A. (1996). "Ethics and ethnicity: end-of-life decisions in four ethnic groups of cancer patients." Medical Law 15(3): 429-432.
In the United States, principled based ethics has molded bioethics to a large extent. These ethical principles, autonomy, non-maleficence, beneficence, veracity and fidelity used in clinical ethics have embedded in them values and assumptions. This research examined the end- of-life decisions made by or for patients who are Chinese-Americans, Black-Americans, Hispanic-Americans, and Anglo-Americans. Patients, their family care-givers and their health care professionals were interviewed. These interviews plus observations in the cancer clinic raise questions about these principles and asks whether, in an ethnically diverse culture, we need to reflect on ethical absolutes and ethical relativism

Department of Health (DOH) (2001). No Exclusion Clause Project. London, Department of Health (DoH). Available from http://www.doh.gov.uk/race_equality/noexclusion.htm
Race Equality in the Department of Health No Exclusion Clause Project: Opening doors to better palliative care services for people from culturally diverse communities.This project was designed to raise awareness amongst minority ethnic groups of the palliative care services and the potential benefits of accessing them. It also sought to raise awareness amongst the staff delivering the service of both the conscious and unconscious ways in which they discourage access.
The project was designed to develop in two phases:
   * Phase One - the establishment of community partnerships and the canvassing of user and professional views of the current service;
   * Phase Two - disseminating the findings and developing initiatives with providers to improve accessibility.
   The focus for this project was primarily on cancer services although it is intended that eventually other life limiting illnesses such as Motor Neurone Disease, AIDS and end-stage renal failure will also be included.

DeRoos, Y. S. (1995). "Ethnic Variations in Dying, Death and Grief: Diversity in Universality, Edited by Donald P. Irish, Kathleen F. Lundquist, and Vivian Jenkins Nelsen." Social Work 40(2): 276. Book review.

Doka, K. J., Editor (1998). Who We Are, How We Grieve. Washington, D.C., Hospice Foundation of America.
A compilation of cross-cultural essays on loss and grief with emphasis on ethnic, spiritual, class, and gender diversity in grieving. Includes a directory of resource organisations.

Dom, H. (2002). "Spiritual care and spirituality in the hospice movement." European Journal of Palliative Care 9(4): 156-159.
Without a deeper understanding of holistic care, we cannot recognize spiritual pain and the need to respond to it. Holistic care involves an appreciation of the term 'spirituality' and the ability to respond effectively to the spiritual needs of the individual. A person functions as a whole, and is composed of body, mind and spirit (soul). To function as an integrated whole, the individual must experience harmony among these components. Spiritual care aims to bring harmony and balance back into the life of the person who is suffering from long-term illness. However, spiritual care is not restricted to patients with a terminal illness, but is relevant to all those who feel that some aspect of themselves is lacking. [The author is a Western Monk in the Vaisnava tradition, working in London.]

Dowd, S. B., V. L. Poole, et al. (1998). "Death, dying and grief in a transcultural context: application of the Giger and Davidhizar assessment model." Hospice Journal 13(4): 33-56.
One of the most challenging aspects of death education and grief counseling is providing care and education that is relevant to the cultural, racial, and ethnic needs of the client. Often appropriate responses are difficult due to the lack of a relevant model; otherwise practitioners tend to operate from facts collected in isolation. This article reports on an assessment model originally developed in nursing by Giger and Davidhizar and discusses its potential use in providing culturally relevant death education and grief counseling

Edassery, D. and S. K. Kuttierath (1998). "Spirituality in the secular sense." European Journal of Palliative Care 5(5): 165-167.
Addressing the spiritual needs of the patient has long been recognized as an integral part of palliative care. Since spirituality is usually considered to be linked to religious beliefs and since many people identify themselves with some religion, spiritual issues are generally regarded as the expression of an individual's internal conflicts and interactions. Thus, the sense of shame and guilt, fear of death or life after death, mistrust of God and disillusionment with religion have all been recognized as spiritual issues faced by patients with incurable diseases. Key point: An alternative secular approach to present model of spiritual care in palliative medicine is necessary. This approach should be compatible with existing religious spiritual care but at the same time should try to explore the spiritual realm of the patient and the carer at a deeper level. The issue spirituality in palliative car needs more attention and wider discussion.

Eisenbruch, M. (1984). "Cross-cultural aspects of bereavement. I: A conceptual framework for comparative analysis." Culture, Medicine and Psychiatry 8(3): 283-309.
This paper reviews some key conceptual questions in the study of cross-cultural aspects of bereavement. Six questions are reviewed in cross-cultural perspective: whether individuals in all societies share the same private experience and public expression of grief; whether the stages of grief occur in the same sequence and at the same rate in all cultures; the nature of the relationship between the individual's private grief and his public mourning; the reactions of children to death, and the reactions of adults to the death of children; the role of religious belief; and the possibility that an ethnic group can experience collective grief in response to uprooting.

Eisenbruch, M. (1984). "Cross-cultural aspects of bereavement. II: Ethnic and cultural variations in the development of bereavement practices." Culture, Medicine and Psychiatry 8(4): 315-47.
Despite a growing interest in bereavement in cross-cultural perspective, few reports have described a comparative analysis of bereavement. By examining the social contexts in the transformations of Western bereavement practices, structures common to bereavement in a range of cultures can be identified. The paper compares the contemporary bereavement practices of several ethnic and cultural groups in North America: Blacks; ethnic Chinese; Southeast Asian refugees; Haitians; Italians; Greeks; and Spanish-speaking groups. Consideration is given to the state of widowhood in different cultural systems. The impact of modernization among traditional societies demonstrates that even though Western technologies are incorporated into the procedures followed by these modernizing societies, the deep cultural code remains intact. Five questions require further clarification: is bereavement an illness, or a rite de passage and a normal life event? How widespread and useful are protective factors, such as group support, that facilitate successful resolution of grief? How effective are mourning practices of various ethnic groups in preventing "bad grief", and might some of these practices be beneficial if taken up by other ethnic groups? How can the Western health practitioner know that a bereaved person from an unfamiliar cultural group is suffering "bad grief"? How acceptable is Western grief counseling to non-Western clients?

Eisenbruch, M. (1990). "The cultural bereavement interview: a new clinical research approach for refugees." Psychiatric Clinics of North America 13(4): 715-35.
The large number of refugees in the world must cope with the loss of family and homeland. This paper proposes a new concept of cultural bereavement and presents a framework for its identification in the clinical interview with refugees. The cultural bereavement interview explores reactions to personal losses and to losses of both the social systems and the cultural meanings. Eleven areas are systematically explored, the first nine are indicators of bereavement and the tenth and eleventh are "antidotes" to cultural bereavement. The cultural bereavement interview can provide a clinical framework for exploring the patient's personal and cultural bereavement, clarify the "structure" of the patient's reactions to loss, complement the currently used psychiatric diagnostic categories, acknowledge the cultural system of meaning held by the patient, and provide information to be used in planning social supports or interventions.

Ekblad, S., A. Marttila, et al. (2000). "Cultural challenges in end-of-life care: reflections from focus groups' interviews with hospice staff in Stockholm." Journal of Advanced Nursing 31(3): 623-30.
Cultural challenges in end-of-life care: reflections from focus groups' interviews with hospice staff in Stockholm During the past few decades, Swedish society has changed from a society with a few ethnic groups to one with over a hundred groups of different ethnic backgrounds, languages and religions. As society is becoming increasingly multicultural, cultural issues are also becoming an important feature in health care, particularly in end-of-life care where the questions of existential nature are of great importance. However, cultural issues in health care, especially at hospices, have not been studied sufficiently in Sweden. The purpose of this study was to gather reflections about cultural issues among hospice staff after a 3-day seminar in multicultural end-of-life care, by using a qualitative focus groups method. The 19 participants (majority nurses) were divided into three groups, one per hospice unit. A discussion guide was developed with the following themes: 1) post-training experiences of working with patients with multicultural background; 2) experiences gained by participating in the course of multicultural end-of-life care; 3) post-training reflections about one's own culture; 4) ideas or thoughts regarding work with patients from other cultures arising from the training; and 5) the need for further training in multicultural end-of-life care. One of the study's main findings was that to better understand other cultures it is important to raise awareness about the staff's own culture and to pay attention to culture especially in the context of the individual. The findings from focus groups provide insight regarding the need for planning flexible training in cultural issues to match the needs of the staff at the hospice units studied.

Fetters, M. D. (1998). "The Family in Medical Decision Making: Japanese Perspectives." Journal of Clinical Ethics 9(2): 132-146.
There has been a recent flurry of discussion about the role of the family in medical decision making. This article uses a Japanese example to extend this discussion by illustrating the cultural influence on the perceived role of the family. In the Japanese culture, the family is recognized as the legitimate decision-making authority for both competent and incompetent patients. A framework for guiding US clinicians who are treating Japanese patients or patients from other collectivist cultures for whom respect for the autonomy of patients may not be a predominant paradigm is offered. Clinicians who feel pressure to operate in a framework of "family autonomy" that conflicts with the mainstream paradigm of respect for patients autonomy should find this discussion helpful.

Firth, S. (1988). "Death, dying and bereavement among British Hindus." Religion Today 5 nos.1and2: 4-7.
Describes some beliefs and attitudes, noting how these conflict with Western culture. Describes funeral practices of Punjabi Hindu and Sikh communities and provides some comment. (PAS)

Firth, S. (2001). Wider Horizons -- Care of the Dying in a Multicultural Society. London, National Council for Hospice and Specialist Palliative Care Services.
This report thoroughly reviews the recent literature about the use of palliative care services by people from ethnic minorities and places it in the wider context of debates about ethnicity and culture. The principle behind the document is to examine ways of improving services from the perspective of black and ethnic minorities themselves, not just to explore questions of uptake. Recommendations are made on good practice in the provision of care, training, and the future research agenda.

Frank, G., L. J. Blackhall, et al. (1998). "A discourse of relationships in bioethics: patient autonomy and end-of-life decision making among elderly Korean Americans." Medical Anthropology Quarterly 12(4): 403-23.
A two-year, multidisciplinary study (N = 800) was conducted on attitudes about end-of-life decision making among elderly individuals in four ethnic groups (African American, European American, Korean American, and Mexican American). On a quantitative survey, Korean Americans reported negative attitudes about the use of life-sustaining technology for themselves but positive attitudes about its use in general. This article reports on an interview with a 79-year-old typical Korean American respondent to explain the contradiction in the survey data. Expectations among elderly Korean Americans include protecting family members with a life-threatening illness from being informed of their diagnosis and prognosis, and doing everything to keep them alive. Two conclusions, one substantive and the other methodological, are drawn: First, the bioethics discourse on individual rights (patient autonomy) is insufficient to explain the preferences of many Korean Americans and must be supplemented with a discourse on relationships. Second, the rigorous use of qualitative, narrative methods clarifies quantitative data and should not be dismissed as "anecdotal."

Froggatt, K. A., Field, D., Bailey, C., Krishnasamy, M. (2002). "Qualitative Research in Palliative Care 1990 1999: A Descriptive Review." International Journal of Palliative Nursing (in press).
A collaborative, evaluative review of qualitative research in palliative care published between 1990 and 1999 had been conducted. Nearly 30,000 papers in 48 journals from specialist palliative care, oncology, death studies, medicine, nursing, gerontology, health and social sciences were examined. 138 papers (0.5%) tht reported qualitative research with a focus on palliative care in context of death, dying, or bereavement were identified from these journals. These papers were reviewed using a proforma designed by the group. This paper describes the review process, and the following findings: an assessment of the distribution of different forms of qualitative research in palliative care; the location of such papers; the focus of the research; and the research methodology and methods adopted.

Gaffin, J., Hill, D., Penso, D. (1996). "Opening doors: improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities. Commentary on palliative care." British Journal of Cancer Supplement 29: S51-3.
To put Council's project on improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities into context, palliative care will be defined, and the scope of palliative care services currently available in the UK outlined. Palliative care is the active total care of patients whose disease no longer responds to curative treatment. It is provided through a network of home-care, day-care, hospital support and hospital or hospice based in-patient services. These services are accessed mainly through GPs or hospital consultants and the extent to which people are referred depends on the knowledge of hospital consultants and GPs, and their perception of the value of the palliative care service to their patients. Council's project on improving access was supported by Cancer Relief Macmillan Fund and Help the Hospices as well as receiving a grant from the NHS Ethnic Minorities Unit. The report describes how the specialist palliative care services are currently provided in three areas with high minority ethnic populations and contains a series of recommendations around ethnic monitoring, equal opportunities strategies, staff training, communications and the provision of a more culturally sensitive service provision.

Goodkind, M. (2001). Crawley helps medical professionals see how race colors end-of-life issues. Stanford Report.
In a short report to help medical professionals see how race colours end-of-life issues, Goodkind describes African-American La Vera Crawley's experience with her mother's entry into hospice weeks before her death. Crawley explains: "Caregivers should understand that African-Americans often view palliative care from a tradition of struggling against death that dates back to the times of slavery and segregation, as well as from a predominantly Christian background that has roots in African religions"

Gramelspacher, G. P. (1999). Caring for the Dying Poor Project, Indiana University School of Medicine. 2003.
The 'Caring for the Dying Poor Project', based at Indiana University School of Medicine (http://shaw.medlib.iupui.edu/ethics/dyingpoor.html) and funded by the Open Society Institute, gathered descriptive, qualitative data on patients, families and care providers. It finds that the conditions of poverty and race significantly shape the end of life experience. The Project also finds great divergence between the point of view of providers and the community they serve. The Project developed, 'Uncovering the Hidden Faces of the Dying Poor', a home-based education programme for first and third year medical students and residents with a palliative and psychosocial focus.

Green, J. (1989). "Death with dignity: Islam." Nursing Times 85(5): 56-7.
Green's *Nursing Times* 1989 to 1992 series on 'Death with Dignity' that describes 13 religious belief systems and their approaches to dying and death as well as one paper on how to transport a body abroad for a funeral. The series is recapitulated in Green's (1993) compendium, "Death with dignity - Meeting the needs of patients in a multi-cultural society."

Green, J. (1989). "Death with dignity. Hinduism." Nursing Times 85(6): 50-1.

Green, J. (1989). "Death with dignity: Sikhism." Nursing Times 85(7): 56-7.

Green, J. (1989). "Death with dignity: Judaism." Nursing Times 85(8): 64-5.

Green, J. (1989). "Death with dignity: Buddhism." Nursing Times 85(9): 40-1.

Green, J. (1989). "Death with dignity: Baha'i faith." Nursing Times 85(10): 50-1.

Green, J. (1989). "Death with dignity: funerals abroad." Nursing Times 85(11): 63.

Green, J. (1992). "Death with dignity--Jehovah's Witnesses." Nursing Times 88(5): 36-7.

Green, J. (1992). "Death with dignity. Christianity." Nursing Times 88(3): 25-9.

Green, J. (1992). "Death with dignity. Christian Science." Nursing Times 88(4): 32-3.

Green, J. (1992). "Death with dignity. Rastafarianism." Nursing Times 88(9): 56-7.

Green, J. (1992). "Death with dignity--the Mormon Church." Nursing Times 88(6): 44-5.

Green, J. (1992). "Death with dignity. Zoroastrianism." Nursing Times 88(7): 44-5.

Green, J. (1992). "Death with dignity. The Afro-Caribbean community." Nursing Times 88(8): 50-1.

Green, J. (1993). Death with dignity - Meeting the needs of patients in a multi-cultural society. London, Nursing Times: 17.
Provides information and guidance on the requirements that different religions have for the care of the dying and the preparation of the dead. Religions discussed include Islam, Hinduism, Sikhism, Judaism, Buddhism and Baha'i Faith. Also included is advice on transporting a body abroad for a funeral.

Hedayat, K. M. and R. Pirzadeh (2001). "Issues in Islamic biomedical ethics: A primer for the pediatrician." Pediatrics 108(4): 965-971.
The United States is becoming increasingly pluralistic. Pediatricians must become familiar with the factors that affect the emotional, physical, and spiritual health of their patients that are outside the ken of the traditionally dominant value system. Although many articles have addressed the cultural and ethnic factors, very few have considered the impact of religion. Islam, as the largest and fastest-growing religion in the world, has adherents throughout the world, including the United States, with 50% of US Muslims being indigenous converts. Islam presents a complete moral, ethical, and medical framework that, while it sometimes concurs, at times diverges or even conflicts with the US secular ethical framework. This article introduces the pediatrician to the Islamic principles of ethics within the field of pediatric care and child-rearing. It demonstrates how these principles may impact outpatient and inpatient care. Special attention is also given to adolescent and end-of-life issues

Higginson, I. J., Sen-Gupta, G. J. A. (2000). "Place of Care in Advanced Cancer: A Qualitative Systematic Literature Review of Patient Preferences." Journal of Palliative Medicine 3(3): 287-300.
Background: It is commonly written that more patients wish to die at home than currently achieve this. However, the evidence for preferences for place of terminal care and death has not been systematically reviewed. Aim: To carry out a systematic literature review of the preferences for place of care and death among advanced cancer patients. Method: systematic database searches. Results: 18 studies identified. Conclusions: Home care is the most common preference, with inpatient hospice care as second preference in advanced illness. Study designs in this area need to be improved.

Higginson, I. J., I. Finlay, et al. (2002). "Do hospital-based palliative teams improve care for patients or families at the end of life?" Journal of Pain and Symptom Management 23(2): 96-106.
To determine whether hospital-based palliative care teams improve the process or outcomes of care for patients and families at the end of life, a systematic literature was performed employing a qualitative meta-synthesis and quantitative meta-analysis. Ten databases were searched. This was augmented by hand searching specific journals, contacting authors, and

examining the reference lists of all papers retrieved. Studies were included if they evaluated palliative care teams working in hospitals. Data were extracted by two independent reviewers. Studies were graded using two independent hierarchies of evidence. A Signal score was used to assess the relevance of publications. Two analyses were conducted. In a qualitative meta-synthesis data were extracted into standardized tables to compare relevant features and findings. In quantitative meta-analysis we calculated the effect size of each outcome (dividing the estimated mean difference or difference in proportions by the sample's standard deviation). Nine studies specifically examined the intervention of a hospital-based palliative care team or studies. A further four studies considered interventions that included a component of a hospital or support team, although the total intervention was broader. The nature of the interventions varied. The studies were usually in large teaching hospitals, in cities, and mainly in the United Kingdom. Outcomes considered symptoms quality of life, time in hospital, total length of time in palliative care, or professional changes, such as prescribing practices. Only one of the studies was a randomized controlled trial and this considered a hospital team as part of other services. Most method scores indicated limited research quality. Comparison groups were subject to bias and analyses were not adjusted for confounding variables. In addition, there were problems of attrition and small sample sizes. Nevertheless, to determine whether hospital-based palliative care teams improve the process or outcomes of care for patients and families at the end of life, a systematic literature review was performed employing a qualitative meta-synthesis and quantitative meta-analysis. Ten databases were searched. This was augmented by hand searching specific journals, contacting authors, and examining the reference lists of all papers retrieved. Studies were included if they evaluated palliative care teams working in hospitals. Data were extracted by two independent reviewers. Studies were graded using two independent hierarchies of evidence. A Signal score was used to assess the relevance of publications. Two analyses were conducted. In a qualitative meta-synthesis data were extracted into standardized tables to compare relevant features and findings. In quantitative meta- analysis we calculated the effect size of each outcome (dividing the estimated mean difference or difference in proportions by sample's standard deviation). Nine studies specifically examined the intervention that included a component of a hospital or support team, although the total intervention was broader. The nature of the interventions varied. The studies were usually in large teaching hospitals in cities, and mainly in the United Kingdom. Outcomes considered quality of life, time in hospital, total length of time in palliative care, or professional changes, such as prescribing practices. Only one of the studies was a randomized controlled trial and this considered a hospital team as part of other services. Most method scores indicated limited research quality. Comparison groups were subject to bias and the analyses were not adjusted for confounding variables. In addition, there were problems of attrition and small sample sizes. Nevertheless, all studies indicated a small positive effect of the hospital, except for one study in Italy, which documented deterioration in patient symptoms. The Signal scores indicated that the studies were relevant. No study compared different models of hospital team. This review suggests that hospital-based palliative care teams offer some benefits, although this finding should be interpreted with caution. The study designs need to be improved and different models of providing support at the end of life in hospital need comparison. Standardized outcome measures should be used in such research and in practice. (C) U.S. Cancer Pain Relief Committee, 2002.

Hill, D., Penso, D. (1995). Opening Doors: improving access to hospice and specialist palliative care services by members of the black and ethnic minority communities, National Council for Hospice and Specialist Palliative Care Services: 59.
Written in 1995, when it was evident that black and ethnic minority people were not utilising hospice and specialist palliative care services in proportion to their numbers. The report claimed that access was limited because of low referral rates, lack of knowledge and information about services, and because black and ethnic minorities preferred to care for dying patients at home. Low rates of cancer were seen as one reason for low uptake, but the figures were likely to have been inaccurate because of poor ethnic monitoring. When the services were utilised there were reported problems of communication and

misunderstandings over cultural, religious and gender issues. At the same time there were examples of imaginative attempts to provide a culturally sensitive service.

Ingleton, C., Seymour, J. E. (2001). "Analysing qualitative data: examples from two studies of end-of-life care." International Journal of Palliative Nursing 7(5): 227-33.
This article examines the analysis of qualitative data, identifying and explaining some key approaches which researchers may wish to use to contribute to the developing knowledge base of palliative nursing. Drawing on the work of Grbich (1999), practical examples from the authors' own studies of end-of-life care are used to illustrate some of the possibilities for analysing interview and observational data. The article concludes with an examination of the concept of 'rigour' in qualitative inquiry and suggests some practical ways of helping nurses who are new to palliative care research.

Irish, D. P., Lundquist, K. F., Jenkins Nelsen, V. (1993). Ethnic Variations in Dying, Death, and Grief. Washington D.C., Taylor and Francis.
This text is directed to those professionals who work in occupations related to death and dying, and includes illustrative examples of selected ethnic patterns and materials for personal reflection about death and dying and multicultural issues. Each of the ethnic chapters was prepared almost exclusively by representatives who share the cultural traditions they describe.

Jennings, B. (1994). "Cultural diversity meets end-of-life decision making." Volunteer Leader 35(4): 15.
In a diverse society, the sensitivity and mutual comprehension necessary for good patient/provider dialogue and good inter-professional relationships among the heath care team will be achieved only through a conscientious effort to recognize and value differences. If we take cultural diversity seriously, it will unmask the practices that create the illusion of respect and rights, and that can actually conceal cultural imperialism, and the imposition of power.

Jennings, B. (1999). Values Near the End of Lives: Grassroots Perspectives and Cultural Diversity on End-of-Life Care, New York State Partnership to Improve End-of-Life Care. Available from http://www.ahd.org/ahd/library/position/ValuesEnd.html
Americans are talking quietly about death and dying with their friends and neighbors. Efforts to improve end-of-life care at both the clinical and the policy levels need to begin by listening in on those grassroots conversations. One should not expect to find solutions there. And one need not look exclusively for the pulse of the voter or for interest group advocacy and demands. The grassroots level has something else above and beyond these overtly political messages for reformers, and that is a quiet, but cogent, value orientation. That orientation may reinforce some reform agendas, and it may conflict with others, but it is important for them all.

Kagawa-Singer, M. (1998). "The cultural context of death rituals and mourning practices." Oncology Nursing Forum 25(10): 1752-6.
PURPOSE/OBJECTIVES: To focus on the universal tasks of coping with the loss of a loved one and describe how various cultures have designed rituals to channel this grief. DATA SOURCES: Published articles, books, and clinical experience. DATA SYNTHESIS: Death is the final life transition and often is surrounded by culturally specific rituals to assist the bereaved in their expression of grief and mourning and in caring for the dying. These culturally unique rituals and mourning practices serve to facilitate completion of universal tasks of grief resolution and support the healing process. CONCLUSIONS: In developing an awareness and appreciation for the continuity of life for all patients and families, nurses must understand that variations among rituals and mourning practices surrounding death in different cultures provide a meaningful cultural context for patients, families, and friends. This context provides them with a sense of security and coherence as well as the emotional, social, and physical resources to navigate this final journey with integrity and peace of mind. IMPLICATIONS FOR NURSING PRACTICE: Nurses in the United States need to gain a

better understanding of the elements and patterns that make up a specific culture's beliefs and practices and integrate this information with an individual patient's and family's personal interpretations of their cultural heritage before prescribing one particular intervention to support the expression of grief and mourning of the bereaved. Culturally informed and tailored care increases the quality of care provided.

Kagawa-Singer, M. and L. J. Blackhall (2001). "Negotiating cross-cultural issues at the end of life: "You got to go where he lives"." Journal of the American Medical Association 286(23): 2993-3001.
Culture fundamentally shapes how individuals make meaning out of illness, suffering, and dying. With increasing diversity in the United States, encounters between patients and physicians of different backgrounds are becoming more common. Thus the risk for cross-cultural misunderstandings surrounding care at the end of life is also increasing. Studies have shown cultural differences in attitudes toward truth telling, life-prolonging technology, and decision-making styles at the end of life. Using 2 case studies of patients, one of an African American couple in the southern United States and the other of a Chinese-American family in Hawaii, we outline some of the major issues involved in cross-cultural care and indicate how the patient, family, and clinician can navigate among differing cultural beliefs, values, and practices. Skilled use of cross-cultural understanding and communication techniques increases the likelihood that both the process and outcomes of care are satisfactory for all involved

Karnik, A. M. (2002). "End-of-life issues and the do-not-resuscitate order - Who gives the order and what influences the decision?" Chest 121(3): 683-686.
The decisions pertaining to end-of-life care obviously would be made by the physician in consultation with the patient and the family. The physician, however, needs to remember that there are numerous factors that influence the patient and families' attitudes and decisions in this regard. Some of the strongest factors seem to be the underlying disease and its prognosis, and race or ethnicity.

Klessig, J. (1992). "The effect of values and culture on life-support decisions." Western Journal of Medicine 157(3): 316-22.
Withdrawing life support is always difficult. When patients and health professionals are from different ethnic backgrounds, value systems that form the basis for such decisions may conflict. Many cultural groups do not place the same emphasis on patient autonomy and self-determination that Western society does and find the idea of terminating life support offensive. Although physicians should never assume patients will respond in a particular way because of their ethnic background, issues of life support should be discussed in a culturally sensitive way. African-American, Chinese, Jewish, Iranian, Filipino, Mexican-American, and Korean patients were surveyed about their views on life support. The findings reported here, although not meant to be definitive, should add to health professionals' understanding about diverse beliefs around life-and-death issues. By becoming aware of this diversity of beliefs, health professionals can avoid the damage to the physician-patient relationship caused by conflicting value systems.

Knebel, A. R. (2002). "Research initiatives to improve end-of-life care." Geriatric Times III(6).
Many agencies within the U.S. Department of Health and Human Services (HHS) are interested in improving the care of people who have life-limiting conditions and who are approaching the end of life. Under the leadership of the National Institute of Nursing Research (NINR) at the National Institutes of Health (NIH), and in collaboration with other HHS agencies, several research initiatives have been sponsored. The HHS agencies involved in these activities are listed in a Table.

Kobylarz, F. A., J. M. Heath, et al. (2002). "The ETHNIC(S) mnemonic: A clinical tool for ethnogeriatric education." Journal of the American Geriatrics Society 50(9): 1582-1589.
Geriatrics healthcare providers need to be aware of the effect that culture has on establishing treatment priorities, influencing adherence, and addressing end-of-life care issues for older patients and their caregivers. The mnemonic ETHNIC(S) (Explanation, Treatment, Healers, Negotiate, Intervention, Collaborate, Spirituality/Seniors) presented in this article provides a framework that practitioners can use in providing culturally appropriate geriatric care. ETHNIC(S) can serve as a clinically applicable tool for eliciting and negotiating cultural issues during healthcare encounters and as a new instructional strategy to be incorporated into ethnogeriatric curricula for all healthcare disciplines

Koenig, B. A. and J. Gates-Williams (1995). "Understanding Cultural Difference in Caring for Dying Patients." Western Journal of Medicine 163(3): 244.
Experiences of illness and death, as well as beliefs about the appropriate role of healers, are profoundly influenced by patients' cultural background. As the United States becomes increasingly diverse, cultural difference is a central feature of many clinical interactions. Knowledge about how patients experience and express pain, maintain hope in the face of a poor prognosis, and respond to grief and loss will aid health care professionals. Many patients' or families' beliefs about appropriate end-of-life care are easily accommodated in routine clinical practice. Desires about the care of the body after death, for example, generally do not threaten deeply held values of medical science. Because expected deaths are increasingly the result of explicit negotiation about limiting or discontinuing therapies, however, the likelihood of serious moral disputes and overt conflict increases. We suggest a way to assess cultural variation in end-of-life care, arguing that culture is only meaningful when interpreted in the context of a patient's unique history, family constellation, and socioeconomic status. Efforts to use racial or ethnic background as simplistic, straightforward predictors of beliefs or behavior will lead to harmful stereotyping of patients and culturally insensitive care for the dying.

Koffman, J., Higginson, I.J. (2000). " Minority ethnic groups and our healthier nation." Journal of Public Health Medicine 22: 245- 246. [Comment, Letter; In English; England]

Koffman, J. and I. J. Higginson (2001). "Accounts of carers' satisfaction with health care at the end of life: a comparison of first generation black Caribbeans and white patients with advanced disease." Palliative Medicine 15(4): 337-45.
While much research has described experiences at the end of life, no studies have explored the black Caribbean perspective. This paper compares the final year of life of first generation black Caribbeans and white patients with advanced disease in an inner London health authority, focusing on their satisfaction with service provision in both primary care and acute settings using face-to face interviews with carers of deceased patients. Of the 106 black Caribbean patients and 110 white deceased patients identified as dying during the study period 50 interviews per ethnic group were conducted with family members or close friends, a response rate of 47% and 45%. Even though examples of excellent and good care were cited, a larger proportion of negative satisfaction ratings of health care was recorded among respondents representing black Caribbean patients. This was true for all health care settings, particularly primary care, but less so for specialist palliative care nurses. However, few black Caribbean patients accessed specialist palliative care nurses or hospices. Qualitative data provided a deeper insight into the black Caribbean experience care at the end of life. We recommend that where examples of best practice in palliative care and culturally sensitive provision are evident they be extended to more health care professionals through education and training. Access to specialist palliative care services needs to be improved.

Krakauer, E. L., C. Crenner, et al. (2002). "Barriers to optimum end-of-life care for minority patients." Journal of the American Geriatrics Society 50(1): 182-190.
Although major efforts are underway to improve end-of-life care, there is growing evidence that improvements are not being experienced by those at particularly high risk for inadequate care: minority patients. Ethnic disparities in access to end- of-life care have been found that

reflect disparities in access to many other kinds of care. Additional barriers to optimum end-of-life care for minority patients include insensitivity to cultural differences in attitudes toward death and end-of-life care and understandable mistrust of the healthcare system due to the history of racism in medicine. These barriers can be categorized as institutional, cultural, and individual. Efforts to better understand and remove each type of barrier are needed. Such efforts should include quality assurance programs to better assess inequalities in access to end-of-life care, political action to address inadequate health insurance and access to medical school for minorities, and undergraduate and continuing medical education in cultural sensitivity

Larson, D. B., S. S. Larson, et al. (2002). "Mortality and religion/spirituality: a brief review of the research." Annals of Pharmacotherapy 36(6): 1090-8.
Over the past decades, quantitative research has increasingly studied potential links between religious/spiritual involvement and mortality among various types of study populations, including regional, national, and international community samples, as well as patient populations in the US. This article provides an overview of findings regarding these various study populations and the potential relevance of religious/spiritual involvement to longevity.

Leichtentritt, R. D. and K. D. Rettig (2001). "Values Underlying End-of-Life Decisions: A Qualitative Approach." Health and Social Work 26(3): 150-159.
The purpose of the study was to reveal the values that would receive priority attention when considering end-of-life decisions. Nineteen elderly Israelis and their 28 family members participated in individual interviews that were analyzed using a hermeneutic phenomenological method. Analysis of the transcripts indicated that participants considered a unique set of value priorities that raised different considerations in each of four domains of life: physical-biological, social-psychological, familial, and societal. Three transcendent values crossed all four domains: dignity, quality of life, and quality of death. These value considerations are useful information for social workers who consult patients and family members at times of end-of-life decisions. 1 Figure, 31 References. (Original Abstract - amended)

Masri, C., C. A. Farrell, et al. (2000). "Decision making and end-of-life care in critically ill children." Journal of Palliative Care 16: S45-S52.
Objectives: 1) To comment on the medical literature on decision making regarding end-of-life therapy, 2) to analyze the data on disagreement about such therapy, including palliative care, and withholding and withdrawal practices for critically ill children in the pediatric intensive care unit (PICU), and 3) to make some general recommendations. Data sources and study selection: All papers published in peer-reviewed journals, and all chapters on end-of-life therapy, or on conflict between parents and caregivers about end-of-life decisions in the PICU were retrieved. Results: We found three case series, three systematic descriptive studies, two qualitative studies, four surveys, and many legal opinions, editorials, reviews, guidelines, and book chapters. The main determinants of end-of-life decisions are the child's age, premorbid cognitive condition and functional status, pain or discomfort, probability of survival, and quality of life. Risk factors in persistent conflict between parents and caregivers about end-of-life care include a grave underlying condition or an unexpected and severe event. Conclusion: Making decisions about end-of-life care is a frequent event in the PICU. Children may need both intensive care and palliative care concurrently at different stages of their illness. Disagreements are more likely to be resolved if the root cause of the conflict is better understood.

McGrath, P., Yates, P., Clinton, M., Hart, G. (1999). ""What should I say?": qualitative findings on dilemmas in palliative care nursing." Hospice Journal 14(2): 17-33.
The nursing literature suggests that talking and listening to patients about issues associated with death and dying, is both important and difficult, and may be improved with training. This discussion presents the results of recent nursing research to confirm, and elaborate on, this theme. In this research participants touched on many central issues in communicating with

patients that included articulating a sense of discomfort and inadequacy about the whole process, detailing the innumerable blocks to open communication [e.g., interference, denial, unrealistic optimism, resistance, collusion and anger] and sharing their sense of success and failure. The insights of nurses who participated in this research testify to the ongoing need to prioritize the development of nursing skills and support in this challenging but important area.

McGrath, P. (2002). "Qualitative findings on the experience of end-of-life care for hematological malignancies." American Journal of Hospice & Palliative Care 19(2): 103-11.
There is a loud silence in the literature on the issues related to palliative care for hematological malignancies. This article presents information that begins to address that silence. The limited research that is available indicates that, to date, patients with a hematological malignancy and their families received scant attention with regards to the provision of palliative care. The findings presented in this article demonstrates that families are enduring considerable hardship and are left with much emotional pain and many unresolved issues when such care is not offered. It is hoped that the findings presented in this article will be used for developing effective strategies to ensure that patients with hematological malignancies and their families, no less than any others, can be afforded the dignity and respect that the appropriate provision of palliative services ensures.

Mishara, B. L. (1993). "Thanatology Research from Quebec: A Different Emphasis." Omega 27(1): 91.
Researchers must be acutely aware of the emotional, environmental, and cultural context of studies as well as the dynamic interactions which are continually changing this context. This characterization of a major trend in French-speaking research in Quebec is well exemplified by the series of lectures on Death, Distress, and Solidarity that gave rise to the articles published in this special issue of Omega. The contributors have attempted to in corporate the best aspects of European critical thinking within an interdisciplinary and contextual approach, showing clear awareness of the socio-political forces that affect our relationship with mortality. The author illustrates some of his points by discussing the Kurosawa film, 'Ikuru', which recounts the transformation of an obsessive bureaucrat after he learns that he has terminal cancer.

Mitchell, G. K. (2002). "How well do general practitioners deliver palliative care? A systematic review." Palliative Medicine 16(6): 457-64.
General practitioners (GPs) deliver the majority of palliative care to patients in the last year of life. This article seeks to examine the nature of GP care, perceptions of the GPs themselves and others of that care, the adequacy of palliative care training, issues relating to accessibility of GPs to palliative care patients, and strategies that may be of use in encouraging more effective delivery of palliative care by GPs. Medline and PubMed databases from 1966 to 2000 were searched, and 135 references identified. Sixty-six of these described studies relevant to GP palliative care. GPs value this part of their work. Most of the time, patients appreciate the contribution the GP makes to palliative care particularly if the GP is accessible, takes time to listen, allows patient and carer to ventilate their feelings, and is seen to be making efforts made regarding symptom relief. However, reports from bereaved relatives suggest that palliative care is performed less well in the community than in other settings. GPs express discomfort about their competence to perform palliative care adequately. They tend to miss symptoms which are not treatable by them, or which are less common. However, with appropriate specialist support and facilities, GPs have been shown to deliver sound and effective care. GP comfort working with specialist teams increases with exposure to this form of patient management, as does the understanding of the potential other team members have in contributing to the care of the patient. Formal arrangements engaging GPs to work with specialist teams have been shown to improve functional outcomes, patient satisfaction, improve effective use of resources and improve effective physician behaviour in other areas of medicine. Efforts by specialist services to develop formal involvement of GPs in the care of individual patients, may be an effective method of improving GP palliative care skills and appreciation of the roles specialist services can play.

Mitty, E. L. (2001). "Ethnicity and end-of-life decision-making." Reflections on Nursing Leadership 27(1): 28-31, 46.
Emphasizes that we can never assume that all members of the group act the same or share the same beliefs and that preconceived cultural or ethnic assumptions may be problematic. Proposes a culturally sensitive approach.

Moadel, A., C. Morgan, et al. (1999). "Seeking meaning and hope: self-reported spiritual and existential needs among an ethnically-diverse cancer patient population." Psychooncology 8(5): 378-85.
Spiritual beliefs and practices are believed to promote adjustment to cancer through their effect on existential concerns, including one's personal search for the meaning of life and death, and hope. This study sought to identify the nature, prevalence, and correlates of spiritual/existential needs among an ethnically-diverse, urban sample of cancer patients (n=248). Patients indicated wanting help with: overcoming my fears (51%), finding hope (42%), finding meaning in life (40%), finding spiritual resources (39%); or someone to talk to about: finding peace of mind (43%), the meaning of life (28%), and dying and death (25%). Patients (n=71) reporting five or more spiritual/existential needs were more likely to be of Hispanic (61%) or African-American (41%) ethnicity (vs. 25% White; p<0.001), more recently diagnosed (mean=25.6 vs. 43.7 months; p<0.02), and unmarried (49% vs. 34%; p<0.05), compared with those (n=123) reporting two or fewer needs. Treatment status, cancer site, education, gender, age, and religion were not associated with level of needs endorsement. Discriminant analysis found minority status to be the best predictor of high needs endorsement, providing 65% correct classification, p<0.001. Implications for the development and delivery of spiritual/existential interventions in a multi-ethnic oncology setting are discussed.

Moore, C. D. and S. R. Sherman (1999). "Factors that influence elders' decisions to formulate advance directives." Journal of Gerontological Social Work 31(1/2): 21-39.
Nine minority and 11 white low-income community-dwelling senior adults participated in semi-structured qualitative interviews regarding end-of-life decisions. They were asked to discuss the role of their own evaluations and beliefs and their perceptions of the influence of significant others in their decisions to complete advance directives. Religious affiliation and a measure of religiosity were also examined. The participants overwhelmingly evaluated the completion of advance directives as positive, but many reported that discussing end-of-life issues with their children was difficult. Depth of religious belief figured prominently in medical treatment planning for some participants, particularly the minority seniors. (Original abstract - amended)

Mount, J. (2001). Palliative Care Services for Different Ethnic Groups Proceedings of a Seminar held in December 2000, National Council for Hospice and Specialist Palliative Care Services: 23.
An earlier report, 'Opening Doors' findings identified a need for hospices and palliative care services to provide culturally sensitive services in respect of language, religion, spiritual and dietary need, and for particular attention to be given to providing appropriate and accessible information to those communities. Recommendations for purchasers and providers were made. This report reviews progress to date.

Mouton, C. P., Lewis,R.M.,Miles,T.P.,Talamantes,M.A.,Espino,D.V. (2001). "Ethnic Considerations in End-of-Life Care." Geriatric Times II(2): 1-8.
Discusses ethnic disparities in perceptions about advance directives, palliative and hospice care, and physician-assisted suicide as well as problems that can arise between a patient and physician of the same ethnic background.

Muller, J. H. and B. Desmond (1992). "Ethical dilemmas in a cross-cultural context. A Chinese example." Western Journal of Medicine 157(3): 323-7.
Considerable attention is now being given to ethical conflicts raised by such issues as the disclosure of diagnosis and prognosis, the role of the family in making medical decisions, and the withholding or withdrawing of treatment of terminally ill patients. Already complicated, these issues take on added complexity in contexts where medical professionals and patients have differing cultural beliefs and practices. Ethical dilemmas that develop in multicultural settings have been largely unaddressed. Through the analysis of a case involving the hospital admission and death of a Chinese woman with metastatic lung cancer, we examine some of these dilemmas and their effect on the patient, family, and physicians. Many issues were raised by this case regarding the relationships among ethnic background, bioethics, and medical care.

Murray, S. A., K. Boyd, et al. (2002). "Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community." British Medical Journal 325(7370): 929.
OBJECTIVE: To compare the illness trajectories, needs, and service use of patients with cancer and those with advanced non-malignant disease. DESIGN: Qualitative interviews every three months for up to one year with patients, their carers, and key professional carers. Two multidisciplinary focus groups. SETTING: Community based. PARTICIPANTS: 20 patients with inoperable lung cancer and 20 patients with advanced cardiac failure and their main informal and professional carers. MAIN OUTCOME MEASURES: Perspectives of patients and carers about their needs and available services. RESULTS: 219 qualitative interviews were carried out. Patients with cardiac failure had a different illness trajectory from the more linear and predictable course of patients with lung cancer. Patients with cardiac failure also had less information about and poorer understanding of their condition and prognosis and were less involved in decision making. The prime concern of patients with lung cancer and their carers was facing death. Frustration, progressive losses, social isolation, and the stress of balancing and monitoring a complex medication regimen dominated the lives of patients with cardiac failure. More health and social services including financial benefits were available to those with lung cancer, although they were not always used effectively. Cardiac patients received less health, social, and palliative care services, and care was often poorly coordinated. CONCLUSIONS: Care for people with advanced progressive illnesses is currently prioritised by diagnosis rather than need. End of life care for patients with advanced cardiac failure and other non-malignant diseases should be proactive and designed to meet their specific needs.

Nunez Olarte, J. M. and D. G. Guillen (2001). "Cultural issues and ethical dilemmas in palliative and end-of-life care in Spain." Cancer Control 8(1): 46-54.
BACKGROUND: The concept of palliative care differs according to cultures and traditions. In Spain, palliative care programs have expanded in recent years. The European Commission Research Project in Palliative Care Ethics has sponsored ongoing research to analyze and clarify the conceptual differences in providing palliative care to patients in European countries with diverse cultures and backgrounds. METHODS: The authors present key ethical issues in clinical practice in palliative and end-of-life care in Spain and how these issues are influenced by Spanish culture. They discuss typical characteristics of the Spanish conceptual approach to palliative care, which might be relevant in an even larger Latin palliative care context. RESULTS: The cultural tradition in Spain influences attitudes toward euthanasia, sedation, the definition of terminality, care in the last 48 hours of life, diagnosis disclosure, and information. The overall care of terminally ill patients with an Hispanic background includes not only the treatment of disease, but also the recognition and respect of their traditions and culture. CONCLUSIONS: The Spanish palliative care movement has shifted its focus from starting new programs to consolidating and expanding the training of the professionals already working in the existing programs. Although there is a general consensus that a new philosophy of care is needed, the interpretation and application of this general philosophy are different in diverse sociocultural contexts

Olarte, J. M. N. and D. G. Guillen (2001). "Cultural Issues and Ethical Dilemmas in Palliative and End-of-Life Care in Spain." Cancer Control 8(1): 46-54.
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Pachter, L. M. (1994). "Culture and clinical care. Folk illness beliefs and behaviors and their implications for health care delivery." JAMA-Journal of the American Medical Association 271(9): 690-4.
This article presents an approach to the evaluation of patient-held beliefs and behaviors that may not be concordant with those of biomedicine. Physicians and patients often hold discrepant models of health and illness that may affect the effectiveness of communication during the clinical visit. An extreme example of such a discrepancy exists when the patient feels that he or she has an illness that is not defined within the biomedical paradigm. These are commonly referred to as folk illnesses. An example of such an illness is provided in order to discuss the effects of folk beliefs on patient-held perceptions of health and sickness, treatment-seeking behavior, clinical care, and physician-patient communication. Guidelines for addressing clinical issues surrounding folk beliefs and behaviors in a culturally sensitive way are discussed.

Patrick, D. L., R. A. Engelberg, et al. (2001). "Evaluating the quality of dying and death." Journal of Pain and Symptom Management 22(3): 717-726.
We propose a model for evaluating the quality of dying and death based on concepts elicited from literature review, qualitative interviews with persons with and without chronic and terminal conditions, and consideration of desirable measurement properties. We define quality of dying and death as the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others. Expected level of agreement is modified by circumstances surrounding death that may prevent following patient's Prior Preferences. Qualitative data analysis yielded six conceptual domains: Symptoms and personal care, preparation for death, moment of death, family, treatment preferences, and whole person concerns. These domains encompass 31 aspects that can be rated by patients and others as to their importance prior to death and assessed by significant others or clinicians after death to assess the quality of the dying experience. The proposed model uses personal preferences about the dying experience to inform evaluation of this experience by others after death. This operational definition will guide validation of after-death reports of the quality of dying experience and evaluation of interventions to improve quality of end-of-life care. (C) U.S. Cancer Pain Relief Committee, 2001.

Payne, S., F. Sheldon, et al. (2002). "Differences in understanding of specialist palliative care amongst service providers and commissioners in South London." Palliative Medicine 16(5): 395-402.

This paper describes a study that sought to identify service providers' and commissioners' understanding of specialist palliative care within the context of changing service provision in one area of South London. Using a formative evaluation framework, we examined the views of 44 providers and commissioners from statutory and voluntary health and social care services about their understanding of specialist palliative care services and, in particular, the remit of current service provision delivered by a Marie Curie Centre. Face-to-face audiotaped semi-structured interviews were conducted. A qualitative thematic analysis highlighted a number of issues including a lack of consensus about definitions of palliative care, ambivalence about referral procedures, and a lack of role clarity between specialist and generalist palliative care providers. The study took place within the real world context of changing services and economic pressures. This raises methodological issues about how services are evaluated and what terminology is used to describe end-of-life care. The study findings confirm that confusion about terminology and referral criteria remain major issues for clinical workers and organizations seeking to access services.

Petit de Mange, E. (1998). "The story of Rabbia, a dying person." Holistic Nursing Practice 13(1): 76-81.

Many nurses report that caring for the dying and the dead is the most difficult situation they face. Several factors contribute to this anxiety: inexperience, sociocultural influences, and the lack of education about death. Current nursing practice in caring for the dying is philosophically steeped in the Western medical model. From this viewpoint, death is considered an enemy, and its occurrence implies that the practitioner has failed. The article explores how nursing care of the dying and dead is influenced by multicultural dimensions: Western medicine, societal norms, and religious beliefs. The nursing care of a dying American Muslim woman is compared with the care provided by the patient's family and religious community.

Pfeifer, M. P., Sidorov, J. E. (1993). "End-of Life Discussions between Patients and Physicians - a Qualitative-Analysis." Clinical Research 41(2): A585-A585.

Discussions about end-of-life care are often difficult and discomforting and occur less frequently than patients prefer. Interviews with 43 primary care physicians and 47 ambulatory out patient. Conclude that patients prefer end-of-life discussions earlier and with greater honesty than physicians perceive.

Pfeifer, M. P., Sidorov, J. E., Smith, A. C., Boero, J. F. Evans, A. T., Settle, M. B., Adelman, H. M., Wallach, P. M., Crnkovich, D., Halbritter, K. A., Johnston, S., Layson, R., Obrien, M. E., McNutt, R. A. (1994). "The Discussion of End-of-Life Medical-Care by Primary-Care Patients and Physicians - a Multicenter Study Using Structured Qualitative Interviews." Journal of General Internal Medicine 9(2): 82-88.

Objectives: To identify primary care patients' and physicians' beliefs, attitudes, preferences, and expectations regarding discussions of end-of-life medical fare, and to identify factors limiting the quality and frequency of these discussions. Design: Descriptive study using audiotaped, structured, qualitative interviews. Setting: Ambulatory care clinics and offices at eight medical centers in six states. Participants: Forty-three primary care physicians and 47 ambulatory outpatients. Results: The patients expressed strong feelings about having end-of-life discussions early in their medical courses while they were competent. They desired straightforward and honest discussions and were less concerned than the physicians about damaging hope. The patients wanted their physicians to play central roles in discussions and both the patients and the physicians noted the impact of the patient-physician relationship on these discussions. The patients desired information focusing more on expected outcomes than on medical processes. The physicians expressed feelings of ambiguity when their desire to save lives clashed with their belief that aggressive life-sustaining treatments were futile. The physicians described their roles in end-of-life discussions in five major categories: lifesaver, neutral scientist, guide, counselor, and intimate confidant. The physicians

considered living wills excellent "icebreakers" for starting discussions but of limited utility otherwise. Conclusions: Patients prefer end-of-life discussions earlier and with greater honesty than physicians may perceive. These discussions are inseparably linked with the patient-physician relationship. physicians can better address patients' desires in end-of-Life discussions by altering their timing, content, and delivery.

Raholm, M. B., Lindholm, L. Eriksson, K. (2002). "Grasping the essence of the spiritual dimension reflected through the horizon of suffering: an interpretative research synthesis." Australian Journal of Holistic Nursing 9(1): 4-13.
The purpose of this research synthesis was to describe the essence of the spiritual dimension reflected through the horizon of suffering. The material reviewed consisted of 18 articles published between 1989 and 2000 in caring and nursing journals. A depth in the interpretation of the texts was discovered where four different themes emerged: undemanding communion, confirmation of dignity, the dialectic of suffering, and the creation of coherence of meaning.

Randhawa G., O. A., Fitches R., Khan Z. (2003). "Communication in the development of culturally competent palliative care services in the UK: a case study." International Journal of Palliative Nursing 9(1): 24-31.
Research suggests that many minority ethnic patients who receive palliative care in the UK are satisfied with the service they are given. However, various studies have revealed that minority ethnic groups' experiences of care are far from perfect. The most significant problem for these patients centres on communication. This article presents some results from an exploratory study, commissioned by Luton Health Action Zone, to explore the role of communication in delivering effective palliative care services to South Asians living in Luton. Overall, it was found that the services provided are, in most cases, valued and seen as being effective. However, as the service providers who were interviewed readily recognized, there were areas where improvements could be made. The main issues were found to be the need to inform South Asian populations of the availability of palliative care services and the need to improve communication between patients and service providers. This article describes the communication problems that service providers and users face. It also identifies possible policy improvements aimed at developing the 'cultural competency' of services.

Romero, L. J., R. D. Lindeman, et al. (1997). "Influence of ethnicity on advance directives and end-of-life decisions." Jama-Journal of the American Medical Association 277(4): 298-299. [letter]

Rosenfeld, K. E., N. S. Wenger, et al. (2000). "End-of-life decision making: a qualitative study of elderly individuals." Journal of General Internal Medicine 15(9): 620-5.
OBJECTIVE: To identify the desired features of end-of-life medical decision making from the perspective of elderly individuals. DESIGN: Qualitative study using in-depth interviews and analysis from a phenomenologic perspective. SETTING: A senior center and a multilevel retirement community in Los Angeles. PARTICIPANTS: Twenty-one elderly informants (mean age 83 years) representing a spectrum of functional status and prior experiences with end-of-life decision making. MAIN RESULTS: Informants were concerned primarily with the outcomes of serious illness rather than the medical interventions that might be used, and defined treatments as desirable to the extent they could return the patient to his or her valued life activities. Advanced age was a relevant consideration in decision making, guided by concerns about personal losses and the meaning of having lived a "full life." Decision-making authority was granted both to physicians (for their technical expertise) and family members (for their concern for the patient's interests), and shifted from physician to family as the patient's prognosis for functional recovery became grim. Expressions of care, both by patients and family members, were often important contributors to end-of-life treatment decisions. CONCLUSIONS: These findings suggest that advance directives and physician-patient discussions that focus on acceptable health states and valued life activities may be better suited to patients' end-of-life care goals than those that focus on specific medical interventions, such as cardiopulmonary resuscitation. We propose a model of collaborative

surrogate decision making by families and physicians that encourages physicians to assume responsibility for recommending treatment plans, including the provision or withholding of specific life-sustaining treatments, when such recommendations are consistent with patients' and families' goals for care.

Seymour, J., G. Bellamy, et al. (2002). "Using focus groups to explore older people's attitudes to end of life care." Ageing and Society 22(4): 517-26.
Reports on the methodological and ethical issues that were encountered when using focus groups to explore older people's knowledge, beliefs and risk perceptions about the use of innovative health technologies in end of life care. Older people drawn from community organisations in Sheffield, England, took part in discussions about the application of 'life prolonging' and 'comfort care' technologies during serious illness and impending death. Offers a reflective account of the management of recruitment and informed consent, and of the issues that arose when facilitating group discussions of potentially distressing material. Concludes with a brief account of the steps that were taken to enhance the 'credibility' of the data. (Original abstract)

Seymour, J. E. and C. Ingleton (1999). "Ethical issues in qualitative research at the end of life." International Journal of Palliative Nursing 5(2): 65-73.
Aim: The objective of this study was to outline some of the reasons why palliative care patients are seen to be vulnerable as research participants. Method The author conducted a literature review to ascertain whether or not palliative care patients should be involved in research. Results: The author found that the case for involving patients who are receiving palliative care in research is overwhelming, but that the protection of these patients must be an integral part of the research. Conclusion: The research design should essentially incorporate the same aims as the palliative care philosophy: patient autonomy, open awareness, holism, respect and collaboration.

Siegler, E. L. and B. W. Levin (2000). "Physician-older patient communication at the end of life." Clinics in Geriatric Medicine 16(1): 175-+.
Communication with dying patients and their families requires special skills to assist them in this extremely stressful period. This article begins with a case that illustrates many of the challenges of communicating with the dying. It then reviews the literature about communication with older patients at the end of life, focusing on physician-patient discussions, decision-making, advance directives, and cultural factors. The article concludes with a practical discussion of problems that physicians may encounter when working with older patients at the end of life and their families and recommendations to improve communication

Smyth, A., Riedl, M., Kimura, R., Olick, R., Siegler, M. (1997). "End of life decisions in amyotrophic lateral sclerosis: a cross-cultural perspective." Journal of Neurology Science 152 Suppl 1: S93-6.
In an era where life-sustaining technology offers physicians unprecedented powers to prolong survival in terminal illness, the question of how end of life decisions are made has become a major subject of study and debate. Amyotrophic lateral sclerosis (ALS) is a disease in which physical ability declines while mental capacity most often remains intact. Since most patients with ALS die of respiratory failure, a distinguishing feature of this disease is whether a patient is offered and accepts a chance to go on long-term mechanical ventilation. This unusual feature makes ALS a compelling model for studying end of life decisions in different countries. This paper reviews the literature and presents preliminary data on how end of life decisions in ALS are made in the US, Great Britain, and Japan. We address this issue by examining how cultural differences in truth-telling and informed consent, societal differences in attitudes toward the use of artificial life support, and legal differences in the role and status of advance directives in each country influenced decisions in the following three groups of patients: (1) the mentally competent; (2) mentally incompetent patients who previously completed advance directives when competent; and (3) mentally incompetent patients who have not provided advance guidance about their wishes.

Sommerville, J. (2001). "Palliative care: the experience of informal carers within the Bangladeshi community." International Journal of Palliative Nursing 7(5): 240-247.
Optimal palliative care cannot be realized unless nurses have a full understanding of what the patient's family is experiencing. There is a gap in nursing knowledge related to informal care and ethnic minorities. The aim of this retrospective qualitative exploratory study was to investigate the experiences of Bangladeshi informal carers living in the UK, associated with caring for a dying relative. Semi-structured interviews using an interpreter were carried out and patient notes were examined. Four categories emerged from the data: caring, support, communication, and home and family. In addition to the demand and stresses caused by their relative's symptoms and the knowledge that they were dying, the Bangladeshi carers experienced communication barriers, isolation and anxieties regarding visas and housing - yet all were uncomplaining about their situation. Palliative care nurses working with Bangladeshi families need to be aware of the additional stresses that these families may experience and be able to offer strategies to enable them to cope with them.

Sullivan, K. E., P. C. Hebert, et al. (1996). "What do physicians tell patients with end-stage COPD about intubation and mechanical ventilation?" Chest 109(1): 258-264.
Background: At some point in time, many patients with end-stage COPD require intubation and mechanical ventilation (MV) to sustain life. MV decisions are most effective when the patient and physician have discussed the options in advance. The purpose of this study was to examine how the physician perceives the decision-making process. Methods: Fifteen respirologists were interviewed to elicit information regarding intubation and MV, and the exchange of information between patients and physicians. Emergent themes were coded using a qualitative approach and were verified by a blinded researcher. Results: Respondents included ten academic and five community- based respirologists from seven hospitals. Most physicians were men with between 4 and 37 years experience. Narratives were very similar in content and seemed well rehearsed. Approach and delivery, however, were unique to each physician. Fourteen respirologists emphasized the importance of knowing patients as individuals prior to initiating this discussion. This period of familiarization often dictated when the physician believed the ventilation discussion is appropriate. Individual physician comfort also appeared to affect the timing of the discussion. Physicians discussed the many elements that make the MV discussion difficult for physicians and patients. Intubation details included a tube being placed down. the throat, the discomfort associated with the tube, the inability to speak, and the availability of pain reducing medication. All physicians discussed the possibility of death with their patients, although many preferred euphemisms in initial discussions. All physicians indicated that intubation is presented as the patient's choice. However, all but one physician commonly framed their discussions in order to influence patient choice. The positive or negative framing seemed contingent on the physician's expectations for that patient. Conclusions: Our interviews demonstrated considerable agreement between physicians about the content and timing of the intubation MV discussion. Physicians all agreed that knowing the patient and his or her situation was important in determining the timing of the intubation and MV discussion. Practice style and individual physician comfort with end-of- life decisions may influence the timing of the discussion and possibly the number of patients who are finally approached. All physicians advocated a shared decision-making approach, but they strongly influence the deliberation process. Thus, the decision-making model seemed to be physician driven in this study.

Suresh, R., Liu,M.,Kupfer,Y., Tessler,S. (2000). "Ethnic variations regarding end-of-life utilization of medical resources." Critical Care Medicine 28(12): 110.
Physicians frequently recommend discontinuation of life support when the prognosis for a good functional outcome is poor. Conflicts between the patient and physician may reflect cultural differences. ...Conclusions: Utilization of supportive measures at the end-of-life varies considerably amongst different ethnic groups.

Teno, J. M., V. A. Casey, et al. (2001). "Patient-focused, family-centered end-of-life medical care: Views of the guidelines and bereaved family members." Journal of Pain and Symptom Management 22(3): 738-751.
A fundamental barrier to improving the quality of medical care at the end of life is the lack of measurement tools. The Toolkit of Instruments to Measure End of Life Care (TIME) aims to fill that void by creating measurement tools that capture the patient and family perspective. To develop a conceptual model for a retrospective survey of bereaved family members that incorporates both professional and family perspectives on what constitutes good care at the end of life, a qualitative literature review of existing professional guidelines and six focus groups with bereaved family members from, acute care hospitals (n = 2), nursing homes (n = 2), and hospice/VNA home health services (n = 2) was performed. The focus groups were held in Arizona, New York, and Massachusetts and included 42 bereaved family members/friends contacted 3-12 months from the time of patients death. Domains of care that define quality end-of-life care were defined. Focus group participants defined high quality medical care as: 1) providing dying persons with desired physical comfort; 2) helping dying persons control decisions about medical care and daily routines; 3) relieving family members of the burden of being present at all times to advocate for their loved one; 4) educating family members so they felt confident to care for their loved ones at home, and 5) providing family members with emotional support both before and after the patient's death. The qualitative literature review yielded similar results, except that the professional guidelines did not mention the advocacy burden felt by families. These two sources provided the foundation for a conceptual model of patient-focused, family-centered medical care and a new tool for surveying bereaved family members. Views of bereaved family members' stories and professional guidelines help to identify key domains of quality of end-of- life care. A new survey instrument provides a way to in corporate the perspectives of bereaved family members in measuring the quality of end-of-life care. (C) U.S. Cancer Pain Relief Committee, 2001.

Teno, J. M., M. J. Field, et al. (2001). "Preface: The road taken and to be traveled in improving end-of-life care." Journal of Pain and Symptom Management 22(3): 713-6.
The prevailing health care culture considers death as simply a failure and assigns a low priority to end-of-life care. The Toolkit of Instruments to Measure End-of-Life Care is explained in this issue as a multidisciplinary tool developed by clinicians and researchers suited to the purposes of research, accountability, and quality improvement in end-of-life care. Four articles outline work on new measurement tools.

Thibault, J. (2003). "How Can Health Care Professionals Meet the Spiritual Needs of Dying Older Patients?" Geriatric Times I(4).
Few studies have evaluated the quality of life during an older person's dying process. Most of the existing data have been gleaned from dying patients of all ages and have focused on the effects of pain control, comfort measures and the use of life-sustaining interventions. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) and the Hospitalized Elderly Longitudinal Project (HELP)-initiated in 1989 and 1994 respectively-were designed to assess current practice and to improve end-of-life care of elderly and seriously ill hospitalized patients. Joanne Lynn, M.D., and colleagues (1997) analyzed the databases in search of descriptions of the experiences of older dying patients as perceived by family members. They concluded that older adults' experience of dying continues to be characterized by inadequate pain control and psychological discomfort, and they support the notion of hospice's early involvement and the adoption of a hospice-like philosophy of care by the health care system.

Ventres, W., M. Nichter, et al. (1993). "Limitation of medical care: an ethnographic analysis." Journal of Clinical Ethics 4(2): 134-45.
This ethnographic study has shown how one attempt to apply ethical principles through a routine procedure failed to fit the clinical context and, in the two cases studied, served to counteract the very foundation these principles were based on--that patients or their families have the right to determine life-and-death decisions regarding code status. The results

suggest that the use of well-meaning forms that are intended to facilitate decision making can, in the absence of appropriate guidelines, routinize the doctor-patient discourse to meet bureaucratic needs, narrowing rather than expanding understanding and communication. Bioethical principles implemented in abstraction, apart from the complex intricacies of the doctor-patient-family relationship and the sociocultural influences upon which this relationship is dependent, may be counter-productive to patient interests. As bioethicists and clinicians work to implement the demands of the Patient Self-Determination Act, they will undoubtedly try to forestall legal problems, assure ethical consistency, facilitate auditing, and promote documentation by creating forms. They may look to create inventories, such as the Limitation of Medical Care form described here, or turn to other, less explicit, means of documentation. This study suggests that, in these efforts, genuine attention should be given to patient concerns, not just to the ethical or institutional needs of medicine. This shift in focus from outcome to process can enhance patient and clinician satisfaction, help resolve difficulties in reaching consensus between involved decision makers, and return the power in DNR decision making to patients and families.

Waters, C. M. (2000). "End-of-life care directives among African Americans: lessons learned--a need for community-centered discussion and education." Journal of Community Health Nursing 17(1): 25-37.
African Americans appear to be less likely to know about advance directives and, even if known, to complete them. This small, exploratory study used a community-centered educational group discussion to assess African Americans' knowledge, attitudes, and utilization of end-of-life care directives before the occurrence of a health crisis. McNemar and paired t tests were computed to detect immediate changes in participants' initial and final perceptions about advance directives before and after the group discussion. Findings indicated further education is needed to clarify the terms used for advance directives. African Americans rely on a family-centered approach to end-of-life decision making, especially in the absence of written advance directives. They are open to community forums to discuss end-of-life care choices if presented the opportunity. Culture plays an essential role in this issue. There is a need for community health nurses to develop community-based educational programs that are not a "one-size-fits-all" approach.

Werth, J. L., D. Blevins, et al. (2002). "The Influence of Cultural Diversity on End-of-Life Care and Decisions." American Behavioral Scientist 46(2): 204-219.
The heath care system in the United States is based on specific cultural beliefs that are sometimes inappropriate with groups that have different belief systems. These cultural differences can be seen in various end-of-life situations. To familiarize providers with some of the ways that culture can influence end-of-life care and decisions, the authors focus on the following three individual characteristics shown to be important in the literature: age, ethnicity, and gender. The article contains a broad overview of the (a) documented differences in the cultural interpretations of the ethical meta principles (e.g., autonomy and respect), (b) provision of medical service in general and pain management in particular to different groups, and (c) attitudes toward various end-of-life interventions and the use of advance directives. Finally, the authors summarize guidelines for making end-of-life care more culturally sensitive, which emphasize that each person must be interacted with as a unique individual.

Wilkes, L. (1998). "Palliative care nursing research: trends from 1987 to 1996." International Journal of Palliative Nursing 4(3): 128-134.
Nursing research in palliative care is becoming ever more important as cost-effectiveness and evidence-based practice become mandatory in the workplace. A search of Cinahl and Medline databases and the content pages of the International Journal of Palliative Nursing, Palliative Medicine and the Journal of Palliative Care provided 180 articles relating to nursing research in palliative care over the past decade. On reviewing the abstracts emerging trends show that nurses are becoming more focused on service delivery and there is evidence of their participation in particular aspects of patient and family care. In particular they are conducting more quantitative research on patient outcomes especially in areas where nurses

can have an effect on care outcomes, e.g. complementary therapies, psychosocial support and non-pharmaceutical symptom control. These trends must continue in order to cement the nurse's place in palliative care.