

Cultural Conceptualization of Hospice Palliative Care:
A Literature Synthesis
Final Report

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The role of culture is significant in Hospice Palliative Care (HPC), and how it is conceptualized and applied has enormous consequences for patients, families and Health Care Providers (HCP). Baker (2002) found that “collective research findings consistently suggest that choices involving end-of-life medical treatment decisions may be more related to ethnicity and culture than to age, education, socio-economic status, or other variables” (p. 34). It influences communication patterns, decision-making styles, responses to symptoms, treatment choices, and emotional expression at end of life (Valente, 2004; Werth et al, 2002). Cultural meanings of illness, suffering and dying shape the explanatory models that patients and HCP draw upon in their interactions with one another (Kleinman, 1988), and as Krakauer et al (2002) point out, “the process of dying, perhaps more than any other moment in the course of medical care, can accentuate cultural differences between patients, families and providers (p. 184). Accordingly, each cross-cultural encounter is more or less a “negotiation of difference” depending on the degree of cultural congruency between patients and their care providers (Dorazio-Migliore et al, 2005).

Studies show that when cultural differences are inadequately addressed, inferior care occurs. This is demonstrated by inequalities in utilization of, and access to, palliative care services; pain and symptom management; and location of death (Bruera, et al, 2002; Karim, Bailey, & Tunna, 2000; Krakauer et al, 2002; Ngo-Metzger, et al, 2003; Siriwardena & Clark, 2004). Therefore, to understand how culturally diverse patients and families conceptualize palliative care in pluralistic societies is especially necessary to “provide effective end of life care and . . . [to] alleviate pain and suffering” (Ward et al., 2004: 90-91). This is particularly important in Canada, which has an aging population comprised of many diverse ethnicities and cultures (Statistics Canada, 2006).

Purpose

Although the philosophy and practice norms of mainstream HPC have been well described in Canada by the Canadian Hospice Palliative Care Association (Ferris et al., 2002), there is no conceptual clarity regarding the meaning of HPC, or access to and utilization of it, among minority cultures and ethnicities. Various cultural definitions of

these concepts do exist, but there is limited understanding of the range and scope of their meanings, or their implications for end of life care goals and expectations. Therefore, the purpose of this project was to synthesize current literature regarding the conceptualization of HPC among culturally diverse populations and their corresponding experiences of access to, and utilization of, HPC services.

The decision to conduct a literature synthesis pertaining to this question reflects the importance generally of systematic reviews to evidence-based practice and policy in health care. The term ‘evidence-based medicine’ was “coined to describe an approach to practice that was explicitly grounded in the best evidence, usually in the form of well-conducted systematic reviews” (Dixon-Woods et al, 2006a: 29). Other scholars have emphasized that the full contribution of research will not be realized if individual studies merely accumulate without being synthesized in some way (Britten et al, 2002; Noblit & Hare, 1988; Sandelowski et al, 1997). As Estabrooks et al (1994) underline, the contribution of a synthesis “to theory construction is more powerful than any single study” alone (p. 505).

This review is part of a larger research project titled *Palliative Care in a Cross-Cultural Context: A New and Emerging Team (NET) for equitable and quality cancer care for culturally diverse populations*, which is funded by the Canadian Institutes of Health Research. The primary goal of this larger study is to investigate the intersection between culture and palliative care, and to advance understanding of its influence on health outcomes; this literature synthesis fits well within this mandate. Although there have been some literature reviews pertaining to culture and HPC (see Hsu, O'Connor, & Lee, 2005; Kwak & Haley, 2005; Payne et al, 2005; Jones, 2005; Johnson, Elbert-Avila & Tulskey, 2005), their focus has been on specific aspects of culture (eg., spiritual beliefs) in particular populations (eg. African Americans) rather than on the totality of the experience of cross-cultural care among minority groups. This literature synthesis explores the theoretical connections among a range of concepts that will provide a framework that can inform research questions and hypotheses about HPC access and service utilization among culturally diverse individuals and families. This knowledge can be used by practitioners and policy makers to facilitate the larger goal of promoting quality and equitable access to culturally appropriate palliative and end of life care.

Methods

Search Strategies

A systematic literature search was conducted to identify peer-reviewed literature published from 2001-2006 that discussed cultural dimensions of HPC. Eleven electronic databases were searched starting with Medline and CINAHL, which were followed by Ageline, Anthropology Plus, EMB Reviews, Embase, PsycARTICLES, PsycINFO, Social Work Abstracts, SocIndex, and Sociological Abstracts. Key concepts were sought using a combination of Medical Subject Headings (MeSH) such as *Palliative Care*, *Terminal Care*, *Hospice Care*, and *Cultural Diversity* with textwords such as *cultural competence*, *social and cultural barriers*, and *social and cultural exclusion* (see Appendix A for complete terms).

This search protocol yielded approximately 550 abstracts. The first two authors (HB & LA) applied inclusion and exclusion criteria to all of the abstracts independently; differences were resolved through discussion or consultation with the third author (AK). The involvement of two or more reviewers is a recommended way to increase the transparency of this process and to minimize error and bias (Coren & Fisher, 2006). Search activities that are systematic, explicit and reproducible contribute to the overall rigor of the search process (Booth, 2001).

Inclusion criteria captured articles that were written in English or French, reported on primary or secondary analysis of empirical data, were literature reviews, concept or theory papers, and were specific to Western countries. Opinion and editorial papers, as well as policy analyses, were excluded. Approximately 120 abstracts (Appendices B & C) met these criteria and were retrieved in full-text form. We cast a wide net at this stage with the awareness that a further critical review of the articles would eliminate those not relevant to the synthesis question.

After the articles were reviewed, 56 were retained (Appendix B). These included 30 empirical studies, of which there were 20 qualitative and 10 quantitative papers; 18 concept and theory articles that discussed a range of topics such as cultural competence, communication patterns and biomedical ethics; and 6 literature reviews, as noted above.

Of these articles, we decided to conduct a synthesis of the qualitative studies. There were several reasons for this decision. First, a mixed methods approach to data synthesis that incorporates both qualitative and quantitative studies requires parallel reviews that conclude with a third process that synthesizes their separate findings together. This is an advanced method of synthesis that is resource and time intensive (Coren & Fisher, 2006), and exceeded what was available to the research team.

Second, we chose to review the qualitative studies because we were primarily interested in understanding the perspectives of culturally diverse persons regarding HPC and the meanings they attach to it. Central to qualitative research designs is the goal of bringing the viewpoints of participants to the forefront, which is especially significant to understanding the experience of illness and people's responses to it. Qualitative research views such 'lay knowledge' as equal to other forms of knowledge in the determination and/or evaluation of the appropriateness of health care (Grypdonck, 2006; Popay, Rogers, & Williams, 1998), which is a position relevant to our synthesis goal. Furthermore, qualitative data is rich in detail, and its scope and depth can bring into focus perspectives pertaining to health care issues and processes that quantitative methods often are unable to delineate fully (Jones, 2005; Popay, Rogers, & Williams, 1998). In this way, qualitative data analysis offers a "conceptual development that constitutes a fresh contribution to the literature" (Britten et al, 2002).

Finally, it is important to comment on the theory and concept papers found in the literature search. Currently, there is not consensus regarding the inclusion of non-empirical papers in syntheses, although many scholars recommend that summaries of information related to such papers should be reported separately from empirical studies (Coren & Fisher, 2006; Dixon-Woods et al, 2005; Kazanjian?). Although they may offer important and relevant knowledge, they are not grounded in empirical data and cannot be considered as 'evidence' of a particular experience (Coren & Fisher, 2006). Therefore, we chose not to include the theory and concept papers in this review because we were committed to synthesizing first hand perspectives about HPC from a range of people belonging to different ethnic and cultural groups.

Data Extraction and Appraisal

The next step in the review process entailed extracting information from each of the articles and conducting a detailed assessment of their methodological quality and relevance to the synthesis question. Each article was read in detail by two authors (HB & LA), who extracted information according to a data extraction template (Appendix D). Following this form, we collected a variety of information including research purpose and goals, characteristics of participants, and methods of data collection and analysis. The use of the template ensured that information from each study was extracted in a standard manner to ensure a consistent appraisal of relevance and quality. The primary findings of each study were also included in this template, which facilitated an easier synthesis of all the findings later. The template was formatted as a Microsoft Access file that was shared by both reviewers.

Because of the growing interest in qualitative inquiry, there has been a proliferation of guidelines for both doing and judging qualitative research (see Booth, 2001; Coren & Fisher, 2006; Dixon-Woods et al, 2005; Mays & Pope, 2000; Popay & Williams, 1998; Ryan, Coughlan, & Cronin, 2007. Dixon-Woods et al (2006a) note that there are now over 100 sets of quality checklists for qualitative research, which makes it impossible to identify one universal 'best' approach (Petticrew & Roberts, 2006). We based our data extraction template primarily on the appraisal questions developed by the Social Care Institute for Excellence (Coren & Fisher, 2006; Fisher et al, 2005), and added further criteria suggested by a variety of scholars and organizations (see for eg., Mays & Pope, 2000; Spencer et al, 2003; Critical Appraisal Skills Programme , 2002).

The primary criteria considered significant for inclusion in the synthesis focused on the strength and appropriateness of study design, the centrality of views of specific cultural and ethnic groups, the scope and depth of reporting and analysis, and the transferability of each study's findings. The studies were rated as 'strong', 'satisfactory', or 'not relevant' according to the extent that these criteria were met – that is, 'strong' studies met most of the criteria while 'satisfactory' studies met a third to a half of the criteria. We decided to synthesize the findings of the 'strong' papers and return to the 'satisfactory' papers if time and resources permitted.

The relevance of a study was given priority over its methodological quality to maximize the inclusion and contribution of a wide variety of papers at the level of concepts. Criteria were weighted in this manner because there is no hierarchy of study designs for qualitative research, and therefore, there was no logic to restrict inclusion choices to particular research approaches (Dixon-Woods et al, 2006b). Furthermore, there are wide variations in conceptions of good quality across the different research methods, and therefore, we allowed for some leeway in the assessment of quality so that important findings were not discounted for “surface mistakes” (Sandelowski et al., 1997: 368). Finally, the process of the synthesis itself involves ongoing judgments about the credibility and contributions of findings (Noblit & Hare, 1988).

In the end, we experienced reasonable consistency of appraisal with no discrepancies between the reviewers regarding which studies should be included or excluded in the synthesis. Most of the studies (18) were accepted because even ‘satisfactory’ papers were considered to have potentially high relevance. 2 studies were excluded because they did not pertain to the focus of the review. The appraisal process offered a useful format for screening out inappropriate papers, and it also provided a practical opportunity to organize key concepts from each of the studies for easier integration into the subsequent synthesis.

The Synthesis Process

Since the synthesis of qualitative studies is a relatively new activity, there are no standard protocols that are consistently followed in this process (Britten et al, 2002). Various approaches have been used that draw on different research methods such as those associated with case surveys (Yin, 1989), cross-case analysis (Miles & Huberman, 1994) and grounded theory (Strauss & Corbin, 1998). Another approach that was originally used in educational research is meta-ethnography, which was developed by Noblit and Hare (1988).

Meta-ethnography is grounded in the interpretivist paradigm of qualitative research, and it is likely the most well-developed method for synthesizing qualitative data (Campbell et al, 2003). Noblit and Hare (1988) describe the synthesis of qualitative findings as an interpretive and inductive process that aims to identify and connect related

concepts that have been described in the thematic findings of individual primary studies. The goal of meta ethnography is to better understand the meaning of social phenomena in their contexts rather than to quantify similar types of data related to them. Because the purpose of this synthesis was to develop an understanding of how minority populations conceptualize HPC, the interpretive perspective of meta ethnography provided a useful framework for this project.

We directly compared studies through a process of reciprocal translation of each of the studies into one another (Noblit & Hare, 1988). As Britten et al (2002) explain, the translation of findings into one another entails the “transfer [of] ideas, concepts and metaphors across different studies” (p. 210). We began this process with a detailed review of each study’s findings that had been previously compiled in the data extraction forms; we referred back to the original papers to check details and language as necessary for clarification. We identified key concepts and themes from each study and listed them on flip chart papers that we pinned to the walls. These represented different levels of interpretation, i.e., participant descriptions that are order 1 interpretations, and themes developed by the study authors that reflect order 2 interpretations (Coren & Fisher, 2006). The terminology we used to describe key concepts was mostly drawn directly from the language used in the individual papers in order to stay as close as possible to their original meanings.

As we reviewed the studies, we began to gradually identify recurring themes that emerged across them, and we made notes or drew arrows directly on the flip chart papers indicating their connections as they became evident. This was an iterative process of moving back and forth between each of the studies from which a line of argument was developed regarding the relationships among them (Noblit & Hare, 1988). We used the 2nd order interpretations as building blocks to construct several 3rd order concepts and themes that encompassed the original findings and simultaneously extended beyond them. Dixon-Woods et al (2006b) refer to these 3rd order interpretations as ‘synthetic constructs’ that are grounded in a body of evidence and emerge from a coherent interpretation of the whole of that evidence.

Findings

The majority of the studies were conducted in the United States (11) with the remainder occurring in the United Kingdom (3), Australia (2), Canada (1) and the Netherlands (1). Participants represented a wide range of ethnocultural groups including South Asians, Chinese, Latinos, Filipinos, African Americans, Moroccans and others. Several studies also included the perspectives of health care professionals such as nurses and social workers who provided direct services to minority patients and families.

Each of the studies identified different research questions and used different designs and methods to explore them (Table 1). Therefore, it was a time-intensive endeavor to identify and compare themes across this body of literature. Moreover, this process took extra time because the quality of reporting varied considerably across the papers. Additional effort was required to piece together information from design descriptions that were not clearly articulated, which has been a challenge noted by other reviewers as well (Campbell et al, 2003). In the end, we identified two sets of themes within the studies – the first related to the conceptualization of HPC among culturally diverse participants and the second related to barriers to utilization of HPC services.

Table 1. Key Details of Studies

Authors/Date/ Country	Title	Design, Sample & Setting	Research Focus	Research Findings	Rating
Bonura et al. (2001); U.S. (42)	Culturally congruent end-of-life care for Jewish patients and their families	Open-ended interviews with professional care providers (11) and family members (5) in New Jersey who had experience with hospice care	To discover cultural influences in end-of-life care among Jewish people	Findings indicated the strong influence of cultural factors in caring; however, differences and similarities identified between professional and folkways of caring, and among Jewish families themselves	Strong
Born et al. (2004); U.S. (43)	Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos	Separate focus groups for African Americans (26) and Latinos (27) in large urban setting	To explore end-of-life care preferences and needs, and to determine how hospice services fulfill them	End-of-life care that emphasizes holistic well-being of patients and families, spiritual care, and family involvement was described as important aspects of hospice services	Strong

Authors/Date/ Country	Title	Design, Sample & Setting	Research Focus	Research Findings	Rating
Bowman & Singer (2001); Canada (53)	Chinese seniors' perspectives on end-of-life decisions	Semi-structured interviews with 40 healthy Chinese seniors, who were members of a Chinese community centre in Toronto; interviews conducted in Cantonese	To examine attitudes of Chinese seniors towards end-of-life decisions	End of life decisions based on factors of hope, suffering and burden, the future, emotional harmony, the life cycle, respect for doctors, and the family; a key finding was that participants were not favorably disposed to advance directives	Strong
Chan & Kayser-Jones (2005); U.S. (49)	The experience of dying for Chinese nursing home residents	Data collection strategies included event analysis, observations and in-depth interviews re:34 Chinese nursing home residents; interviews occurred with the residents, family members, and nursing home staff	This article is part of a larger study that investigated the clinical, environmental, social, and cultural factors influencing the care of terminally ill nursing home residents	Family involvement in care, traditional Chinese medicine, and spiritual beliefs were identified as central to health care generally, and to end-of-life care specifically	Strong
Chui et al. (2005); Australia (54)	Responses to advanced cancer: Chinese-Australians	Grounded theory approach; multiple semi-structured interviews with 11 Chinese-Australian participants with advancing cancer	To identify the impact of key aspects of Chinese culture on the responses of Chinese-Australians to their advanced cancer	Description of 'combat' response mode, which incorporated 5 culturally specific strategies: Chinese medicine, Chinese beliefs re: use of food, qi gong, feng shui, and ancestor worship; importance of accommodation of these practices highlighted	Strong
Diver et al. (2003); U.K. (57)	The palliative care needs of ethnic minority patients attending a daycare centre	Phenomenological study; semi-structured interviews with 4 ethnic minority patients in a hospice daycare in central England	To assess the culture-specific palliative care needs of ethnic minority patients	Participants expressed basic human needs rather than culture-specific ones; themes of acculturation and trying to 'fit in' emerged as partial explanations for this finding	Strong
Duffy et al. (2006); U.S. (45)	Racial/ethnic preferences, sex preferences, and perceived discrimination related to end-of-life care	10 focus groups that included Arab Christians, Arab Muslims, Hispanics, blacks, and whites (73) in Michigan; take-home survey re: end-of-life issues and demographics	To better understand end-of-life preferences and perceived discrimination of different racial/ethnic and sex groups	Concepts important to all groups included being comfortable, physician communication, having responsibilities taken care of, hope and optimism, and honoring spiritual beliefs	Strong

Authors/Date/ Country	Title	Design, Sample & Setting	Research Focus	Research Findings	Rating
Gelfand et al. (2001); U.S. (46)	Mexicans and care for the terminally ill: Family, hospice, and the church	10 focus groups in Arizona and Michigan: 8 focus groups of Mexican residents (65) and 2 focus groups of service providers (20)	To explore end-of-life attitudes toward hospice services among Mexicans in the U.S.	Attitudes toward palliative care among Mexican participants are intertwined with culturally based beliefs about the role of the family in caregiving, and religious or spiritual beliefs; focus on hope emphasized rather than discussions re: terminal condition; medicalized view of hospice care	Strong
Gelfand et al. (2004); U.S. (47)	Issues in hospice utilization by Mexicans	10 focus groups in Arizona and Michigan: 8 focus groups of Mexican residents (66) and 2 focus groups of service providers (20)	To examine factors that influence the use of hospice services by Mexicans, and desired characteristics of hospice staff	Hospice staff needs to understand Mexican culture (general and healing traditions), provide good care (know the illness), and encourage the patient	Strong
Jenkins et al. (2005); U.S. (50)	End-of-life care and African Americans: Voices from the community	Multiple meeting focus groups with African American adults who had experienced the death of a family member at home (FG1) or in hospital (FG2); also included 3 health care providers; average 5 participants per FG meeting	To expand knowledge about African American experiences about end of life care	Themes emerged re: positive communication, respect for spiritual beliefs, and interactions marked by compassion and warmth; needs and preferences at end of life are heterogeneous	Strong
Kagawa-Singer & Blackhall (2001); U.S. (56)	Negotiating cross-cultural issues at the end of the life	2 case studies: i) African-American couple in southern U.S., and ii) Chinese-American family in Hawaii; data collected through interviews re: 6 issues relevant to end-of-life care	To describe issues involved in cross-cultural care, and ways to negotiate differences among cultural beliefs, values and practices	Skilled use of cultural knowledge and communication techniques increases likelihood that cultural differences are negotiated and care is appropriate; cultural assessment tool described	Strong
McGrath et al. (2001); Australia (51)	Needs and experiences of non-English speaking hospice patients and families in an English-speaking country	3 focus groups that included 35 participants of Indian, Filipino, Chinese, Italian and Australian backgrounds in Queensland, Australia;	To examine the needs and experiences of non-English-speaking families in relation to hospice care	Hospice is a philosophy of care with a generic appeal across culture and ethnicity; the findings indicate that it is as important to focus on similarities across culture as to highlight differences	Strong

Authors/Date/ Country	Title	Design, Sample & Setting	Research Focus	Research Findings	Rating
Owens & Randhawa (2004); U.K. (48)	'It's different from my culture; they're very different': providing community based, 'culturally competent' care for South Asian people in the UK	Phenomenological study; semi-structured interviews with 10 community health care workers	To gain insight into the attitudes to, and experiences of, health care workers providing palliative care to South Asian patients	Health care workers put significant thought and effort into providing 'culturally competent' care based on a reflexive approach. The ability to critically evaluate the cultural needs of patients and families on an individual basis was viewed as important	Strong
Perkins et al. (2002); U.S. (52)	Cross-cultural similarities and differences in attitudes about advance care planning	Structured, open-ended interviews with Mexican-Americans, Euro-Americans and African-Americans inpatients on 2 general medicine wards in Texas	To describe relevant cultural attitudes to enable health care professionals to conduct culturally specific advance care planning	The 3 groups shared the view that a patient deserves a say in treatment and advance directives improve the chances that a patient's wishes will be followed; however, specific ethnic views were also identified that suggests that advance care planning must be tailored accordingly	Strong
Tong et al. (2003); U.S. (44)	What is a good death? Minority and non-minority perspectives	13 focus groups that included 95 White, Black, Hispanic and Asian participants in Connecticut; demographic questionnaire.	To identify common domains that characterize a good death for a range of community-dwelling individuals, and to describe differences that might exist between minority and non-minority viewpoints	10 common themes emerged as important to a good death among minority and non-minority groups; differences between non-minority and minority participants were apparent in the domains of spiritual care, cultural concerns and individualization; these related to mainstream biases and the tendency to stereotype	Strong

Themes Related to Conceptualization of HPC

Hospice palliative care is holistic care.

Many of the participants in these studies described HPC as holistic care that encompassed several components. First, pain and symptom control was identified as fundamental to end of life care (Bonura et al, 2001; Tong et al, 2003; Born et al, 2004; Duffy et al, 2005), and its importance was underlined by different participants:

“... nobody wants to suffer physically. Going out is tough enough as it is . . . I would like to have sufficient care where I wouldn't be physically suffering. (Minority participant, Tong et al, 2003: 170).
 “The last thing I would want to do is die in misery. I think pain control is 100% important (African American participant, Born et al, 2004: 251).

In some cases, participants held a narrow view of HPC that entailed only medical and nursing activities related to symptom management such as giving injections to patients and changing their dressings (Gelfand et al, 2001; Gelfand et al, 2004; Owens & Randhawa, 2001).

However, in many studies HPC was described more broadly and included more than the management of physical needs. Participants also expressed that care activities that support patients to complete social and emotional tasks are crucial at the end of life and central to their well-being (Tong et al, 2003; Born, et al, 2004). Resolution of psychosocial concerns was linked to the experience of a peaceful death as one participant in a minority focus group study reflected: “it has been my experience that the people who had the most pain-free transitions have been people who . . . have not left any unfinished business or [have left] things in pretty good shape” (Tong et al, 2003: 172).

Additionally, the importance of acknowledging and honoring the religious and spiritual philosophies of palliative patients and families was highlighted as an essential aspect of end of life care (Born et al, 2004; Bonura et al, 2001; Chan & Kayser-Jones, 2005; Duffy et al, 2006; Gelfand et al, 2001; Jenkins et al, 2005; McGrath et al, 2001; Tong et al, 2003). Minority participants in Tong et al's (2003) study emphasized that spiritual care is as important as physical care at end of life. Participants spoke about

how spiritual beliefs and practices sustained patients and family members through the dying process and helped them cope with suffering and death by making meaning of these experiences (Born et al, 2004; Jenkins et al, 2005). Prayer was specifically identified in several studies as a supportive spiritual activity in end of life care (Born et al, 2004; Bonura et al, 2001; Gelfand et al, 2001).

African American and Latino participants in Jenkins et al's (2005) study reflected on how their relationship with God would influence their experience of distress or peace throughout the death and dying process. Therefore, addressing spiritual concerns at end of life is a primary task as an African American woman explained: "First of all, I'd like to know that I am ready for the other side, my soul is right. That would have to be the first thing" (Born et al, 2004:251). Spiritual beliefs and values about life and death also inform treatment choices and, therefore, HCP need to understand and be sensitive to them in order to establish appropriate care goals (Jenkins et al, 2005; Perkins et al, 2002). Unfortunately, some participants expressed their concerns that the spiritual aspects of dying were not adequately addressed in health care settings as illustrated in one respondent's story:

"I was [in the hospital] thirty-one days and the priest used to always come around to various people. But that priest, God bless him, he never said a word to me. And they didn't have [any] other person that came around and offered services all thirty-one days that I was there I think if [the priest] is going to do a service, hey, we all individuals, we all people, do it to everybody regardless" (Minority participant, Tong et al, 2003: 172).

The scope of holistic care is wide-ranging for many of the participants in these studies. It can be as basic as providing ethnically familiar foods and beverages such as rice soup and warm water to a Chinese patient (Chan & Kayser-Jones, 2005) or entail visiting and praying with dying persons who are religious (Bonura et al, 2001; Gelfand et al, 2003). Furthermore, some participants suggested that HPC should also address the needs of family and friends (Born et al, 2004; Bonura et al, 2001). As one Jewish woman described when her husband was dying, caring meant "the Jewish community coming together as a family and providing whatever is necessary to support the family [as a whole]" (Bonura, et al, 2001: 216). In some studies, the need to support professional caregivers was also acknowledged as a part of HPC (Bowman & Singer, 2001; Born et al,

2001). For many participants, the goal of HPC is to provide multi-faceted support to dying persons and those around them. As one Jewish hospice worker summarized, the “concept of hospice focuses on improving quality of life” on many levels to the various people involved (Bonura et al, 2001: 216).

The focus of holistic care and related expectations regarding the consequent quality of life of patients and family members can influence decisions about care goals, treatment choices and the best location of death (Perkins et al 2002; Tong et al, 2003; Chui et al, 2005). For example, in situations where improvement in quality of life was unlikely, some participants suggested that end of life care should be focused on facilitating a peaceful and natural death rather than maintaining life artificially: “[If] I’m bedridden, I’m in pain and there’s nothing else the doctor can do for me . . . he can put me on life support to just keep my chest pumping. I know I wouldn’t want it. I’d rather go peacefully (Minority participant, Tong et al, 2003: 171). In situations where improvement in functional ability might be possible, care could include complementary or alternative treatment choices as described by an elderly Chinese man with terminal kidney cancer: “I wanted acupuncture treatments to reduce the swelling in my legs, so that I would be able to walk better. But the Chinese doctor said it would not be a good idea for me to have acupuncture treatments and instead prescribed several packages of Chinese herbal tea for me to take.” (Chan & Kayser-Jones, 2005: 30). Finally, even though many ethnic participants expressed the desire to die at home in familiar surroundings with family and friends in attendance, the final decision about location of death would depend on whether adequate care could be provided at home by family members and/or the experience of a death at home would be too difficult for them (McGrath et al, 2001; Tong et al, 2003). Comments from several Italian family caregivers capture these concerns, for example when “the time comes, it is better to go to the hospital, as it is better to look after them [there]”, or “I could never have done that at home [provided end of life care] and stayed in that house” (McGrath, 2001: 308-309).

Regardless of ethnocultural background, there is a shared perception within many of these studies that the scope of end of life care should focus on the physical, emotional, social and spiritual needs of terminally ill individuals and their families. Another theme that emerges as central to such holistic care is the nature of the relationship between

palliative patients, family members and the health care professionals who provide care to them.

“Treat patients the way you would want to be treated”: Preferred qualities of HCP and relationships with them.

Participants from many of the studies reiterated the desire for end of life care to be provided with compassion, respect and warmth for patients and their families (Bonura et al, 2001; Born et al, 2004; Duffy et al, 2006; Gelfand et al, 2004; Jenkins et al, 2005). In Jenkins et al’s (2005) study that explored the experiences of African American family caregivers, participants identified specific actions such as making eye contact, using tone of voice and touching people to convey genuine care, sincerity and compassion. In these ways, the dignity of patients is enhanced and treating them with pity avoided. The importance of this approach by HCP is echoed by a Latina woman in Born et al’s (2004) study who stressed that good care “starts with the physicians and the nurses . . . even if they are short-staffed, if they treat the people with respect or kindness or even interest, that doesn’t cost any money” (p. 251). Other participants emphasized the need for care providers to get to know patients more intimately and to become more emotionally involved with them because dying patients should be treated “with love beyond all measure” (Jenkins et al, 2005).

Effective communication entails speaking to patients in language and terminology that is understandable to them, and to invite questions when comprehension is unclear (Jenkins et al, 2005). Additionally, some participants underlined the importance for HCP to listen carefully to their concerns at end of life: “I think it would make the families feel better if they felt the doctor and/or nurses were really understanding what was going on for them and that they were really willing to listen to what they want (Minority focus group, Tong et al, 2003). Conversely, when HCP are not communicating well, it “makes it more frustrating for the family . . . they don’t know what’s going on” (Minority focus group, Tong, et al 2003).

Although direct communication with HCP was identified as an important part of HPC, there were different perspectives among participants across the studies regarding the type and extent of information they wished to discuss with their care providers. Some

participants stated that they wanted full and truthful information about their diagnosis, prognosis and treatment options (Born et al, 2004; Jenkins et al, 2005; Perkins, et al, 2002; Tong et al, 2003). This was viewed as important so that individuals could make appropriate treatment decisions and complete outstanding affairs in their lives. An African American participant explained that this could either mean deciding “to beat this thing” or “to get right with Jesus” (Jenkins et al, 2005). Mexican and Arab participants in Perkins et al’s study (2002) indicated that it was important to fix relationships, say goodbye and prepare for the next life. It was also important for family members to be proactively informed by HCP about what to expect in terms of disease progression so that they could provide appropriate and relevant care to their loved ones: “on top of keeping them [patients] comfortable, keeping the whole family comfortable on what exactly is going on with them and what we can do to make them feel better in their last days” is helpful (African American woman, Born et al, 2004).

Nevertheless, some study participants believed that HCP should not tell patients that they are dying (Chan & Kayser-Jones, 2005; Gelfand et al, 2001; Gelfand et al, 2004; Duffy et al 2006; McGrath et al, 2001). They expressed concerns that such information would take away hope and tempt fate. As one Filipino woman stated, “we don’t speak of death because we are superstitious and somehow feel if we speak it, we will evoke it” (McGrath et al, 2001: 307). This was reiterated by a Chinese social worker who remarked that “it’s very difficult with Chinese people because they don’t want you to talk about death. They’re superstitious and think it’s bad luck if you talk about death” (Chan, 2005:30). The Indian, Filipino, Italian and Chinese participants in McGrath et al’s study (2001) described the “Western way” of directly informing people about their prognosis as “too abrupt”, “terrifying” and “blunt” (p. 307). Some Arab participants stated that they would avoid the words “death” or “cancer”, and disclose only some pieces of medical information to an ill family member so as to protect them from bad news: “I said not the whole picture – just half the picture – because she cannot handle it” (Duffy et al, 2005: 153). However, these same participants revealed an internal dissonance regarding this approach. Although they wished to limit information shared with family members who were ill, they did indicate that they personally would want to be told their diagnosis and prognosis so that they could complete their affairs on earth and prepare for heaven.

Alternatively, some participants suggested that interactions with patients and families should focus on hope, encouragement and optimism (Born et al, 2004; Gelfand et al, 2001; Gelfand et al, 2004). A Mexican American participant suggested that it was important for hospice staff to emphasize these attitudes: “Don’t tell the patient that he is ill. Make the person feel happy so he is not sad, continue ahead, give the person energy, and make him know that we are all alive and that he still has to continue ahead (Gelfand et al, 2004: 11). Mexican American participants in Gelfand et al’s (2001) previous study suggested that this focus should also be highlighted with family members because discussions about a patient’s terminal condition was not viewed as supportive to them. This approach creates a dilemma for many HCP providers because of the value placed on truth-telling in Western medicine.

Finally, some participants spoke about how highly they valued the knowledge and expertise of their HCP (Bonura et al, 2001; Bowman & Singer, 2001; Gelfand et al, 2001; Gelfand et al, 2004; Kagawa-Singer & Blackhall, 2001; McGrath et al., 2001). It is important for HCP to know the illness of a patient well so that bad care does not occur (Gelfand et al, 2004). Some of the Jewish participants in Bonura et al’s (2001) study spoke about the importance of seeking input from HCP with the most knowledge and expertise. As one rabbi stated, “this explains why Jewish people may continue to seek many opinions, in search of unanswered questions and delivery of the highest level of care” (p. 216). Some Chinese participants indicated a similar respect for the knowledge of physicians and highlighted this in combination with the moral duty of doctors to provide the best care to patients (Bowman & Singer, 2001).

The qualifications and experiences of HCP were identified in several studies as more important than their ethnic or racial congruency with their patients (Gelfand et al, 2004; Kagawa-Singer & Blackhall, 2001; McGrath et al., 2001). As one African American woman stated, “because [an African American] doctor is the same nationality as myself, that causes me to want to trust him more, because he could relate better . . . that helps, but like I said, as long as I know he’s qualified, it would make a difference [whether he is African American or not] (Kagawa-Singer & Blackhall, 2001: 2995). Similarly, the quality of hospice volunteers in terms of their helpfulness was considered more important than their ethnicity (McGrath et al, 2001).

Preempting burdens.

A theme that translated across many studies was the concern of becoming a burden to one's family at end of life (Born et al, 2005; Bowman & Singer, 2001; Jenkins et al, 2005; Perkins et al, 2002; Tong et al, 2003; Duffy et al, 2005). The participants in Tong et al's (2003) study identified three types of burdens related to end of life care that included physical caregiving burdens, responsibilities for making difficult treatment choices, and financial stressors. They emphasized the importance of avoiding these difficulties by adequately preparing for death by arranging one's affairs in advance. As one participant stated, "I just don't want to be a burden to my kids. That's why the best thing for you to do is make arrangements . . ." (Tong et al, 2003: 171). The Chinese participants in Bowman & Singer's (2001) study expressed worry about becoming an even greater burden – that is, not only to their families, but also to their professional caregivers and to society as a whole.

For some individuals, a tension arose between their desire to die at home and their concern for the welfare of their family caregivers (Born et al, 2005; Jenkins et al, 2005). Participants who had been caregivers previously expressed this dilemma most often. As one participant stated, "I'd rather not be in a nursing home, but I wouldn't want family care [either]. I wouldn't want to burden my family" (Born et al, 2005: 250). Participants in this study agreed that effective HPC must include the provision of support to family caregivers that includes respite care from physical duties as well as psychosocial support to cope with the grief of losing a loved one. An African American woman reflected on the experience of her sister: "I feel that caregivers themselves deserve a break. I feel my sister carried all the burden for about two or three years now. So that's what I wanted to speak on. The people that are the caregivers, where do they get a break? When you want to scream, where do you go?" (Born et al, 2005: 250). Arab participants expressed the least worry about becoming burdensome to their families, perhaps because they viewed their network of support as more extensive than just their immediate family – as one participant pointed out, "the whole neighborhood is involved when someone is dying" (Duffy et al, 2005: 153).

Implicit to this theme is the recognition that the experience of death and dying affects not only patients, but their formal and informal caregivers as well. Therefore, many of the participants in these studies believed that HPC should include services that adequately equip family members and friends to care for their loved ones both in the short and long term. In addition, they conveyed the idea that HPC should include direct assistance to individuals to complete their affairs early on, and to consider different options for end of life care. These care strategies are ways to avoid the experience of becoming burdensome at the end of one's life, which is a worry shared by many.

Themes Related to Barriers to HPC

The paradox of familial duty and obligation.

Many of the studies' participants from diverse ethnic and cultural backgrounds shared the perspective that it is the duty of families to care for their members at the end of life (Born et al, 2005; Bonura et al, 2001; Bowman & Singer, 2001; Chan & Kayser-Jones, 2005; de Graaf & Francke, 2003; Duffy et al, 2005; Gelfand et al, 2001; Jenkins et al, 2005; Kagawa-Singer & Blackhall, 2001; Kramer & Auer, 2005; McGrath et al, 2001). There was a strong expression of filial obligation and tradition of sacrificing personal needs in the service of family. As one Latina woman explained regarding the decision to care for an ill parent: "That's the way it is in our families. It's like, if you can do it (care for a sick parent), then you do it. If you can't, then you're going to leave your job, or whatever. But our family comes first. Our parents come first" (Born et al, 2005: 250). Many participants believed that family care would enable their loved ones to die in dignity.

However, this commitment to care for a dying family member can preclude the utilization of formal HPC services. For example, Latino, Chinese, Turkish and Moroccan participants from different studies spoke about the embarrassment, shame, and sense of failure that is evoked by accepting outside help (de Graaf & Francke, 2003; Gelfand et al, 2001; Kagawa-Singer & Blackhall, 2001; McGrath et al, 2001). Decisions about using home care services or admission to a hospice can become issues of face for many ethnic groups. As one Chinese woman stated, "I think one of the reasons that Asians are

resistant to hospice is that it feels like a failure on the part of the caretaker . . . to take care. It seems almost like giving up or admitting that the caretakers can no longer take care of their own” (Kagawa-Singer & Blackhall, 2001: 2998).

The ability of families to care adequately for a sick relative does not always match the reality of their situations. However, traditions within the model of family-centered decision making may fail to recognize a family’s limited capacity to provide end of life care. For example, decisions to assume care for a family member may be determined by family leaders (often men), who are not directly involved in the day to day care (often women), and, therefore, are unaware of the demands associated with it (de Graaf & Francke, 2003; Duffy et al, 2005; Kramer & Auer, 2005; McGrath et al, 2001). A young Moroccan mother of six spoke about how her extended family expected her to care for her sick mother-in-law without outside help – “I feel like a social worker and a little nurse at the same time (de Graaf & Francke, 2003: 802). A HCP in Kramer and Auer’s (2005) study spoke about how barriers to utilization of HPC services arose because of the traditional decision-making norms followed by an Asian family with whom she was working: “Family in U.S. deferred to family in Asia to make decisions . . . [they] believed placement [in hospice] was culturally inappropriate even though [the] daughter could not cope with demands of caregiving . . . [the] oldest son should have made decisions but was not available” (p. 658).

Of course, not all ethnic families adhere so closely to traditions of familial piety. Participants in some studies spoke about the importance of family involvement in end of life care, but also acknowledged the pressures of doing so and the need for outside assistance (Diver et al, 2003; McGrath et al, 2001). In Diver et al’s (2003) study, an Asian participant spoke about the benefits of hospice care and contradicted the cultural stereotype of the extended Asian family who must ‘look after their own’: “My oldest son . . . he is trying to help a little bit, when I need an important something [the hospice helps], because he’s working and has a family. Therefore, I don’t have to ask all the time. . .” (Diver et al, 2003: 394). Unfortunately, some HCP still retain assumptions that ethnic families are large enough and capable enough to care for an ill family member. These perceptions have been linked with failures to refer palliative patients to HPC services in the community (de Graaf & Francke, 2003; Owens & Randhawa, 2004).

“I don’t know what you mean”: How communication and language barriers limit hospice palliative care.

In HPC “communication is the pinnacle of everything” (Service Provider, (Randhawa et al, 2003: 27). Efforts to provide excellent care at end of life can be markedly compromised by language differences and communication problems. Many participants in different studies identified how their inability to speak the dominant language was an obstacle in accessing and utilizing HPC services (Born et al, 2005; Chan & Kayser-Jones, 2005; de Graaf & Francke, 2003; Gelfand et al, 2004; McGrath et al, 2001; Randhawa et al, 2003). This can be immediately problematic for palliative patients who are unable to communicate their physical needs to their care providers. For example, Chan & Kayser-Jones (2005) found that suboptimal management of symptoms such as pain and dyspnea occurred for Chinese nursing home residents who were unable to speak English. Similarly, a Latino participant spoke about the challenge of effectively meeting the needs of a family member who did not speak English in a hospital where no care providers spoke Spanish: “How can they make her feel comfortable when they don’t understand what she is saying? . . . when I went to the hospital where she had surgery not too long ago, she was in a lot of pain and the nurses that come around, they wouldn’t know what to do” (Born et al, 2005: 252). Many of the study participants who were professional care providers echoed the same concern (Chan & Kayser-Jones, 2005; Kramer & Auer, 2005; Owens & Randhawa, 2004; Randhawa et al, 2003). They described how language barriers impeded their ability to fully assess the needs of palliative patients and their families and deliver holistic care to them.

Additionally, patients and families may have a limited understanding of a diagnosis and prognosis because of language differences. Some participants described how they learned about their own, or a relative’s illness, in an ad hoc fashion from different HCP, and garnered only a partial comprehension of how it would progress (Randhawa et al, 2004). Consequently, they did not know what additional services to request or which ones were available to them. For example, Moroccan and Turkish immigrants in the Netherlands identified how their inability to speak or read Dutch limited their access to and use of home care (de Graaf & Francke, 2003). Minority

participants in McGrath et al's (2001) Australian study echoed the same experience because of their lack of fluency in English. One participant added a further observation about limited utilization of health care service, that is, "without the ability to communicate in English, they wouldn't know how to use it, even if they know about it" (McGrath et al, 2001: 309).

The result of not understanding the seriousness of an illness or the services available can limit the ability of patients and families to assert their preferred choices for end of life care. This was sadly illustrated in an interview with a Moroccan man:

He just thinks it's sad. He really regrets the fact that his mother didn't die at home, surrounded by her family. He says: "The doctor might have known, that this woman didn't have long to live anymore, and why couldn't he inform the family" [about the fact this woman might have died at home with the aid of home care services]. (Interpreter rendering the words of a Moroccan participant whose mother died at the hospital without any of her family). (de Graaf & Francke, 2003: 800).

Other participants voiced a similar sense of disempowerment in enacting their desires for care because of language barriers (McGrath et al, 2001). Some Latino participants suggested that language differences result in discrimination against minority patients, which diminishes the quality of care provided to them (Born et al, 2004).

Effective communication is not only about language proficiency, however. It entails a broader understanding of a patient's cultural beliefs, values and practices. Some HCP reflected that their inability "to make [patients] comfortable" stemmed not only from linguistic limitations, but also from an insufficient understanding of their cultural and religious background (Owens and Randhawa, 2004; Randhawa et al, 2004). Patients and family members identified this same limitation from their perspective. They also felt that HCP did not always understand their cultures and, therefore, failed to adequately meet some of their cultural needs (Tong et al, 2003). A Muslim participant underlined the importance of learning about religious traditions regarding the treatment of a body after death: "The people who are taking care [of the dying], they look like they don't know anything about what's behind our culture ... This happened in a funeral home, [they] didn't know how to take care of the body to be cremated" (Tong et al, 2003: 172). Some participants reported that HPC staff did not directly ask them about their cultural

traditions and neither did they offer cultural information about themselves (Diver et al, 2003), which may contribute to ongoing misunderstandings.

Different ways to address the challenges of communicating with minority patients and families were suggested by some of the participants in different studies. Some Hindu and Muslim respondents recommended that more HPC workers needed to be recruited from “their community” because they would speak their languages and have an insider understanding of their cultural and religious beliefs (Randhawa et al, 2003: 27). The idea that HCP should be able to speak the language of their patients and families was reiterated by participants in other studies as well (Born et al, 2004; Gelfand et al, 2004; McGrath et al, 2001). They suggested that the ability to speak an ethnic language could build therapeutic relationships more effectively and quickly. This perspective is partially based on the notion that some emotional and spiritual issues that arise at end of life are more easily discussed in one’s ethnic language. An Italian participant captured this idea eloquently in his description of the dying process: “when the person is dying and things come out, it is really from the heart and heart talk is Italian, not in English ... what comes from the heart comes in your own language” (McGrath et al, 2001: 309). Finally, various professional care providers suggested that the development of culturally appropriate concepts and assessment tools could also facilitate an exchange of information that would promote the use of relevant and appropriate HPC services (Kramer and Auer, 2005).

Lack of awareness of hospice palliative care services.

In some studies, lack of knowledge of HPC services was identified as a primary reason why palliative patients and families did not access them (Born et al, 2004; McGrath et al, 2001; Gelfand et al, 2004; Jenkins et al, 2005). One African American man remarked that “when you mention hospice to people, they don’t know what the hell you’re talking about. What is hospice, really?” (Born et al, 2004: 252). Other participants pointed out that minority patients and families are not only unaware of the range of HPC services, but also about eligibility criteria, costs for services, and who will pay for them.

As noted above, lack of awareness of palliative resources is linked to language differences. However, some participants emphasized that they did not know about HPC

services because they were never informed about them – “we didn’t know about hospices ... no doctor told us” (McGrath et al, 2001: 307). Therefore, they used the health care resources already known to them and never benefited from specific HPC ones. Some participants suggested that access to and use of services could be significantly improved through a centralized dissemination process of referral information. An African American man suggested the following:

“Let’s say a person comes to the hospital, and you know he’s terminal. You know he’s going to have a whole lot of problems. Isn’t there someone who’s supposed to explain all this to you and let you know exactly what forms of help you could get and where you can get counseling or education? It seems like that should be done automatically (Born et al, 2004: 252).

No coverage, no service.

Another barrier identified in two studies was the high cost of health care services (Born et al, 2004; Gelfand et al, 2004). Perhaps it is not surprising that both of these studies reflect the experiences of American minorities in the context of privatized health care. Participants reported that lack of health insurance and limited personal incomes affected their access to health care generally. As one Latino man stated, “most of us that don’t have insurance, we don’t go to the hospitals because of the expenses” (Born et al, 2004: 252). Some Mexican American participants expressed the same worries about the costs of hospice care, which subsequently inhibited their pursuit and use of them (Gelfand et al, 2004).

Mistrust of the health care system.

The theme of mistrust emerged in several studies, and was identified primarily by African American and Latino participants as a barrier to their utilization of HPC services (Born et al, 2004; Gelfand et al, 2004; Kagawa-Singer & Blackhall, 2001; Kramer & Auer, 2005; Perkins et al, 2002). Many participants related their suspicion of health care services to historic injustices and current prejudices and discrimination. Others suggested that HCP providers were motivated more by money rather than a genuine desire to help people. In Perkins et al’s (2002) study, many of the African American participants indicated that they did not believe that the health care system serves patients well. As

one African American man explained, “We’re Black. These White folks won’t help, and that’s the mind set. I was reading an article in the paper the other day about health care among the African American community. They are less likely to get proper care (Born et al, 2004: 253). This belief can contribute to a significant misunderstanding about the purpose of HPC as reflected in a social worker’s experience with an African American family: “the mom was dying and pretty much wanted to be left alone but ... [her] daughters ... saw comfort care as racially motivated to end her life” (Kramer & Auer, 2005).

Gelfand et al (2004) suggested that the reluctance of Mexican Americans to seek hospice services might also be linked to past negative discriminatory experiences. Additionally, some expressed fears related to their immigration status and the worry that HCP would disclose this information to employers and other authorities. These concerns are highlighted by comments made in a focus group regarding interviews with hospice workers:

They shouldn’t ask so many questions. If they want to help, help. That’s all. Because many times the people get scared. “Hey, do you have legal documents?” “Hey, how long have you been living in the U.S.?” “Hey, where are you from?” “Hey, what did your grandmother die of?” It’s because these things really scare people.”

Exactly, do you think I am going to give you my information so that you can go right to my boss? For me, I’d better not (Gelfand et al, 2004: 9).

Understandably, mistrust and skepticism about the agenda and motivation of HCP will inhibit utilization of health care services generally, and HPC services specifically, by some minority groups.

Discussion

The translation of these study findings into one another generated these concepts of HPC and the various barriers to utilization of it. They emerged out of a dynamic back and forth process of immersion into the individual studies and stepping out again to

interpret them collectively as a related single entity. Not all studies addressed each of the themes identified, although there was much crossover for some of them.

Many of the findings that described the barriers that deter access to and utilization of HPC are likely not surprising to many readers. Certainly, the challenges associated with language differences make it very difficult for minority patients to convey their needs, and for HCP to accurately assess and understand them. Furthermore, delivery of adequate and relevant HPC services also depends on an appropriate comprehension of a patient's cultural beliefs, values and practices – a body of knowledge that goes beyond linguistic capabilities. Interestingly, the ways in which traditions associated with familial duties to care for dying family members can block utilization of HPC services is an unexpected outcome of an otherwise admirable commitment. An additional impediment is added when HCP hold similar expectations about family obligations and withhold referrals to formal resources because of them. These different factors contributed to situations where patients and families lacked awareness of HPC services, which prevented them from using them when they were most needed. The barriers of mistrust in the health care system and lack of coverage within it are specific to the experiences of minority participants in the United States. However, these obstacles may reflect experiences of ethnic minorities in similar socioeconomic situations in other Western countries.

In regard to the conceptualization of HPC, there was significant data generated that described a holistic understanding of it. This depiction of HPC encompasses the physical, emotional, social and spiritual aspects of death and dying for individuals and their families. The importance of spiritual beliefs and practices was especially highlighted in these findings. These different facets of end of life experiences are linked to notions of quality of life, and its subsequent influence on treatment choices and care goals.

Many of the studies also presented comprehensive descriptions of expectations regarding desired characteristics of HPC professionals, and the ways in which they should interact with palliative patients. HCP who demonstrate excellent knowledge and expertise about end of life care, and who are respectful, genuine and compassionate with patients and families represent the ideal care provider. Although clear and consistent

communication with HCP was commonly regarded as an important part of HPC, there were different ideas about how much information about diagnosis and prognosis should be shared with a terminally ill person. In situations where participants argued that information should be withheld or edited, the primary rationale expressed was that full disclosure of a terminal diagnosis would deplete a person's hope and hasten the dying process. Finally, participants in several studies asserted that HPC should include a range of resources and services that alleviate the potential burdens associated with end of life care.

This conceptualization of HPC by minority populations is significant because much of it is consistent with the philosophy of care espoused by mainstream HPC organizations. For example, the Canadian Hospice Palliative Care Association (2002) has delineated principles and norms of practice that are holistic in focus, and which aim to maximize quality of life at end of life through pain and symptom management, psychosocial and spiritual support, and compassionate communication. Furthermore, HPC has been described as patient and family centred with the goal of effectively meeting individual and collective needs according to the particular context of each patient and family during the dying process and bereavement. These similarities were noted by some of the authors of these studies as well (Born et al, 2004; Diver et al, 2003; McGrath et al, 2001). The synthesis of this knowledge suggests that the scope of HPC is relatively generic across culture and ethnicity with more similarities than differences. This may explain the themes in Diver et al's (2003) study of ethnic patients in a hospice day program, which reflected a predominance of basic human needs shared by the participants rather than culturally specific ones. As a participant in McGrath et al's (2001) study stated, "I don't think we are really too much different - we are putting too much emphasis on our ethnic group" (p. 311).

Moreover, the compilation of individual 'factfiles' of characteristics of cultural and ethnic groups does not reflect the frequent diversity within them – an important observation discussed in several studies (Diver et al, 2003; Duffy et al, 2006; Jenkins et al, 2005; Owens & Randhawa, 2004; Tong et al, 2003). Some participants spoke about the changing nature of cultures and the "messy" realities of multicultural identities (Owens & Randhawa, 2003). Several studies pointed to the process of acculturation as

one of the reasons for shifting cultural hybridity within pluralistic societies (Diver et al, 2003; Owens & Randhawa, 2003; Randhawa et al, 2003). For example, second generation immigrants often do not face the same communication challenges in health care as those experienced by their parents because they have learned the language of mainstream society and incorporated some of its cultural practices (Randhawa et al, 2003). Another participant in a day hospice spoke about his deliberate decision to try “fitting in” by placing his ethnic culture into the background: “my culture is fine, but I’m not there anymore. I am here and so I must fit in ... If I was to have my culture here ([at the hospice] I would appear ungrateful ... No, this is not difficult, I’ve lived here a long time” (Diver et al, 2003: 395).

The recognition that end of life care needs cut across ethnic and cultural groups, coupled with the awareness that there is often significant heterogeneity within them, supports an argument for HPC based on individual assessments rather than on static and essentialized information about ethnocultural backgrounds. This approach would promote an openness and curiosity about patients and families that is not constrained by preconceived cultural notions. From this position, patients and families emerge more readily as the experts of their own culture, while HCP shift their focus to seeking an understanding of what that means to them.

Future research that explores the implications of these concepts can lead to a better understanding of individual patient and family needs at end of life in the context of the fluidity of their cultures. This can facilitate exploration and risk-taking that expands practice into more imaginative directions. Deliberately assuming a clinical position of ‘not-knowing’ establishes a non-threatening tone for engagement with culturally diverse patients and families, which can enhance communication, build trust and facilitate access to appropriate care. Future inquiries should also examine the personal and professional cultural beliefs and biases of HCP and the ways in which they influence cross-cultural interactions. This understanding will promote the exploration of both similarities and differences between the cultures of patients and health care professionals regarding HPC, which can then frame the negotiation of mutual goals of care at end of life.

This synthesis does not offer a final conceptualization of HPC among culturally diverse patients and families, or list all the barriers to access to and utilization of it. We

did not include a review of grey literature or a search of citations referenced in these studies because of time and resource limitations so undoubtedly research papers have been missed. Nonetheless, we were able to review a significant number of qualitative studies, and consider their findings cohesively. This synthesized knowledge provides a robust conceptual framework to develop research questions and hypotheses about appropriate and relevant end of life care for culturally diverse individuals and their families.

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Appendix A
Search Terminology

MeSH	Textwords
<ul style="list-style-type: none"> • Palliative Care • Terminal Care • Hospice Care • Anthropology, Cultural • Ethnopsychology • Cross-cultural Comparison • Culture • Cultural Characteristics • Cultural Deprivation • Cultural Diversity • Ethnic Groups • Refugees 	<ul style="list-style-type: none"> • palliative • terminal: adj2 care • hospice • end-of-life care • refugee* • immigrant* • cultural competence • (social or cultural) adj1 (barrier: or exclusion) • (socially or culturally) adj1 (excluded)

Appendix B

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Appendix D

Data Extraction Template

Publication details

Author(s):

Year:

Title of paper:

Title of publication (book, journal, report):

Vol., Issue, Pages:

Country:

Study Purpose

Research purpose and/or question(s):

- Is the purpose/question(s) clear?

Literature review completed:

- Is the research purpose/question(s) situated in the context of existing knowledge?

Study Design & Methods

Study date & duration:

Theoretical/conceptual framework for research:

- Was a particular theory referred to or conceptual model used for the research?

Context:

Study site(s):

- Details of setting (eg. rural/urban), context and key characteristics.
- Target population
 - Who were the participants and why were they selected as most appropriate to provide the type of knowledge sought by the study?

Ethics Approval:

Sampling:

Recruitment procedures:

- Are they clearly outlined?

Number of participants

Characteristics of participants

Exclusions

- Include refusals and explanations as to why people chose not to take part.

Data collection:

Methods of data collection:

- Are they clearly described?
- Did author(s) justify methods chosen?
- If different sources were used, what were they?

Modification of methods:

- Were methods modified? If so, how and why?

Who collected the data?

How was data recorded?

- Were interviews done? Were these taped (audio/video) and transcribed? Were field notes taken?

Were any specific research tools used?

Data Analysis:

Methods of data analysis:

- What were the methods?
- Are the methods clearly described?

Is there a description of how categories, themes and/or concepts were generated?

Are findings explicit and clearly summarised?

- Are tables used?

Is there sufficient data to support the findings?

Limitations:

- Are limitations and/or strengths of the study identified and discussed?

Is there discussion for and against the researcher(s)' arguments or perspective?

Relevance and Quality of the Study

Relevance:

- Is the focus of the study relevant to the synthesis question?
- Is the context of the study relevant?
- Is the sample of participants relevant?
- Are outcomes relevant?
 - Are they relevant to practice, policy, theory, and/or literature?

Quality:

Strength of design:

- Are the research purpose and/or questions clear?
- How appropriate was the research design and methods for answering the questions posed in the study?
 - Did the author(s) discuss how they decided which methods to use?
 - Would a different method have been more appropriate?
 - Note that open or semi-structured interviews are often more effective in collecting rich and descriptive data compared to structured questioning. Similarly, face to face interviews are better than telephone interviews.

Centrality of views:

Are the views of: i) specific cultural groups or ii) Health Care Providers (HCP) who work with culturally diverse patients and/or families central to the study:

- Is the centrality of these views evident in the description of the purpose/question(s) and methods of the study?
 - Note that stronger studies would aim to discover cultural group members' views, or those of HCP, in their own words.
- Were participative methods, or methods for building trust/rapport with the participants, used?
 - An example of a method used for building trust/rapport is when the same interviewer is used for follow-up interviews with the participants.
- Does the study build on previously reported studies of cultural group members' views, or those of HCP?

Quality of analysis and reporting:

- Is “thick” description used?
 - Are findings and concepts richly described?
 - Are relationships between concepts investigated and described?
- Are negative cases sought and discussed?
- Are direct quotes used to support interpretations?
- Does the quality of information appear to adequately reflect the selection and composition of the sample?
- Is there a description of contextual factors that might have influenced the findings?
- How well does the sample of participants address that which the study purpose intended to investigate?
- How clearly are findings linked to the purpose of the study?

Transferability:

- Are findings described “thickly” enough to provide sufficient information to judge the “fit” between two contexts?
- Is the context or setting adequately described so that the reader could relate the findings to other settings?
- Did the authors discuss whether or how findings can be transferred to other populations or settings, or how else the research might be used?

Appraisal outcome

Based on the above appraisal, is the study deemed to be:

- strong (the majority of criteria are answered affirmatively or met)?
- weak (less than half of the criteria are answered affirmatively or met)?
- excluded (minimal or no criteria are answered affirmatively or met)?

If the studies are appraised as “strong”, go on to the next section. If deemed “weak”, go on to the next section only if enough time/resources are available to do so. “Excluded” studies stop here.

Outcomes & results

Details of outcomes/findings:

Order 1 Interpretation: Participant responses and descriptions (in most studies, this information is integrated in 'Order 2' findings as noted below, and can be included there):

Order 2 Interpretation: The author(s)' conclusions:

- What are the categories, themes, and/or concepts that emerge from the data?

The information collected at this point will be used for the final synthesis, which includes the development of 3rd order interpretations that emerge out of the categories, themes and/or concepts identified at the level of order 2.