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Pain relief, spiritual needs, and family support: Three central areas in intercultural palliative care

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ABSTRACT

Objective: The purpose of this study was to draw out and coalesce the topic-specific information found in research literature regarding the provision of culturally sensitive palliative practice.

Method: This was a literature study and Gadamerian hermeneutic text analysis.

Results: It is more difficult to assess the level of pain in ethnic minority patients, and healthcare providers may become frustrated and interpret pain symptoms as fabrication. These patients are more likely to receive inadequate pain medication. Physical symptom management has become the priority in palliative care, but pain must also be viewed from the perspective of its social, cultural, and spiritual significance. Collectivist values may lead to an other-reliant and dependent coping style. This and religious demands may cause the family to rally around the patient. Many dying patients wish to be cared for at home by their families, but as the patient often has complex needs, the family may not be able to cope with the patient's care.

Significance of results: Formal education and in-service programs are needed for healthcare providers, together with empirical studies regarding how to achieve more culturally appropriate care in intercultural palliative practice. The immigrant population needs to be educated about cancer and the various kinds of palliative and hospice care offered in the society in which they now live.

KEYWORDS: Pain, Spirituality, Family, Culture, Palliative care

INTRODUCTION

Migration is a global phenomenon, causing a growing cultural heterogeneity within many societies. This fact challenges healthcare workers' ability to provide culturally sensitive and individually tailored palliative care. The aim of palliative care is to improve "the quality of life of patients and families who are affected by life-limiting illness, by providing pain and symptom relief and spiritual and psychosocial support from diagnosis to the end of life and bereavement" (Hospice Information Service, 2012). To succeed we must "acknowledge the importance of learning from each patient and family member what the illness, health care, dying and death means to them (and, by extension, their culture), reflecting on how their culture might interact with the health care system" (Chan et al., 2009, p. 120).

In this article we will discuss what culture-specific needs ethnic minority patients may have in the palliative stage of their lives, focusing on pain relief, spiritual needs, and family support. Although seemingly a separate issue, family support is vital for patients who are dying and in pain, and family support is often also crucial in relation to spiritual care. Spiritual and psychosocial factors are, furthermore, studied as separate phenomena, but also in relation to the patient's perception of and coping with pain. In addition to communication, these are, in our experience, among the most central aspects when working with ethnic minority patients. This is in line with Higginson et al. (2012) who found in an online survey of palliative care professionals across Europe and Africa that the most important questions in palliative and end-of-life care concern

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pain, symptoms, emotions, and family. As intercultural communication is examined by many authors (e.g., de Graaff & Francke, 2003; Dahl et al., 2006; Hanssen, 2010; Hanssen & Alpers, 2010), this topic will not be discussed in this text.

BACKGROUND

Koffman et al. (2008, p. 356) hold that "[c]ulture shapes the meanings we bring to the world, and this has relevance to understand the experience and cancer-related symptoms that challenges our views of the world as being purposeful and coherent." Also Leininger (1990; 1994), Papps and Ramsden (1996), Gerrish and Papadoupolos (1999) and other nurse theorists point to the importance of cultural competence, but also to the lack thereof. Andrews (1999) found that lack of cultural competency in healthcare providers may result in misdiagnosis, often with serious consequences. Quality improvement in healthcare delivery to culturally diverse populations is, therefore, a major concern.

Unless one realizes that patients may have a totally different understanding and expectations than those hailing from biomedical philosophy, and take this into consideration, patient teaching cannot be successful, which may impair treatment outcomes. Patients may, for example, experience illness as belonging to the spiritual or psychosocial aspects of their lives rather than being a somatic problem. A common characteristic of traditional medicine is a holistic understanding of human beings and their interaction with the environment and the universe. Barkwell (2005) claims that effective management of, for example, pain, "may well be compromised when cultural perspectives are ignored or discounted" by healthcare providers whose understanding of illness has little in common with their own (p. 455). Furthermore, if spiritual and psychosocial factors are not acknowledged, this will "invalidate other ways of knowing and understanding experiences of illness, death and dying, therefore invalidating the end-of-life experience of many people" (Muircroft et al., 2010, p. 119). Im et al. (2009) additionally hold that "it can be reasonably inferred that acculturation may influence the cancer pain experience of many ethnic minority cancer patients" (p. 359).

METHODICAL APPROACH

Although this study is based on research articles, we can neither claim the necessary objectivity of outlook nor exhaustiveness of literature searches to claim that what is presented here is a review article (Sandelowski, 2008). The field of intercultural healthcare is too extensive for anyone to gain a complete overview. We have, however, conducted diligent literature searches for years. The most recent (August 2012–January 2013) was specifically driven by our research question, which is: What does international research tell us about the particular needs ethnic minority patients have concerning pain relief, existential and spiritual concerns, and family support in the palliative stage of their lives, and how are these needs met by healthcare personnel?

To answer this question, the search engines MEDLINE®, PubMed, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) were utilized, using key words such as culture and pain, culture/ethnicity/ethnic minorities and pain, intercultural/ transcultural/multicultural palliative care/nursing, culture and palliative care/nursing in various combinations, supplemented by more specific search words such as cancer, pain. Also, topic-specific journals have been searched to locate articles not found through the electronic search engines. Our searches have been limited to Scandinavian, English, and German literature.

Quite a few articles have been written on culture and pain, and we have found a copious body of international research literature concerning palliative care, but only a few of them are focused on ethnic minority patients. Little research has been reported on the experience of cancer among minority ethnic communities in the United Kingdom (Koffman et al., 2008), and we have so far only been able to find one such study from Scandinavia (Ekblad et al., 2000).

The research question has guided the literature research specific to this article, and also the selection of articles represented in this text. The purpose of this work has not been to compare various studies (Sandelowski, 2008), but to draw out and coalesce the topic-specific information found. In violation of systematic review practice, this text is interlaced with a few brief patient sketches to tie the discussion more closely in with clinical practice.

ANALYSIS

The texts found to be relevant to our study were analyzed according to a Gadamerien hermeneutic tradition. Interpretive analysis is a creative activity in which the researcher strives for depth of understanding (Gadamer, 1989). Gadamer holds that no understanding is possible without a pre-understanding of the phenomenon of interest, and that it is essential to visit these pre-understandings time and time again through a process of reflection. This causes the researcher's pre-understandings to change through the collection and interpretation of data.

The authors read and re-read the collected texts, all the while re-evaluating our conceptions and deepening our understanding. As we have ample foreknowledge through years of intercultural nursing studies and clinical experience, we did our best to avoid bias and being blinded by our pre-understanding. We tried to "remain open to the meaning of the other person or the text" (Gadamer, 1989, p. 268). Being two authors, we could discuss all aspects of our findings, which was helpful. Gadamer (1989) teaches us to be open and curious, communicate authentically, and realize that the fusion of horizons through the reading of texts leads to the creation of something new.

ETHICAL CONSIDERATIONS

The very brief clinical sketches presented in this text are void of personal or indeed traceable information. No ethical approval for their use has been sought.

RESULTS

Findings are focused on three main areas: Pain, existential and spiritual needs, and family support.

Pain

A main goal of palliative care is to relieve suffering caused by pain (World Health Organization, 1990). Pain is one of the main symptoms in the palliative stages of cancer, and often also the most feared. Koffman et al. (2008, p. 350) claim that the pain prevalence is "over 90% in the more advanced stages of the disease."

Cultural Perception and Expression of Pain

Within any ethnic group, pain must be viewed from the perspective of its psychological, social, cultural, and spiritual significance (Lasch, 2000; Koffman et al., 2003). Koffman et al.'s (2008) study of black Caribbean and white British cancer patients, for example, illustrates that pain may be closely related to a person's spirituality if perceived as a test of faith or as punishment. They particularly found this connection among the members of the black Caribbean community, and this perception of pain "appeared to be a clinical reflection of their strong religious faith in God" (p. 356).

Hobara (2005) describes Asian cultures as stoic regarding the expression of pain, whereas Dawes and Thoner (1996, p. 8) claim that "[i]n Asian cultures one generally expresses all kinds of pain openly, without any of the demands for self-control more common in western cultures." Such opposing views point to both intercultural differences, as Hobara writes about Japanese patients and Dawes and Thoner write about patients from the Indian subcontinent, and intracultural, or individual, variations.

An example of stoic suffering is the Native American Ojibway tradition of *blocking*, in which refusing to talk about or act on symptoms as long as possible is seen as protection against any serious or lethal course of a disease. The philosophy behind this blocking behavior is that language "does not merely describe reality, language shapes reality" (Barkwell, 2005, p. 462). Such behavior may be misconstrued as denial by majority culture health providers.

Cultural Expression of Pain and Healthcare

> Clinical example. "If they are given just a small injection, they are really affected by pain. I find that difficult to interpret."

More and Butow (2004) maintain that "cultural differences in emotional expression and stereotypes about pain . . . influence the clinician's interpretation and expectations regarding pain severity. This is possibly due to conscious and unconscious bias on the part of the clinician and patient, or subtle differences in cultural expressive cues (i.e., body language), since an individual can more readily recognize emotions expressed in the style to which they are accustomed." The extent to which healthcare providers are inclined to give prescribed p.r.n. pain medication is, for example, largely dependent upon their own cultural background and training (Cohen et al., 2005; Lovering, 2006).

Minority patients are more likely to receive inadequate doses of analgesics than are nonminority patients. Such "inequities have also been documented in nursing homes and cancer centers. Numerous studies document inadequate end-of-life care in minority populations" (Paice & O'Donnell, 2004, p. 192). Cancer pain is furthermore "much more likely to be inadequately assessed, treated, and controlled in minority patients" (p. 192). Other researchers have made similar observations (e.g., Green et al., 2003; Im et al., 2009; Chen et al., 2012).

It may be difficult to assess the level of pain in ethnic minority patients because they express pain differently than the majority population (Alpers & Hanssen, 2008). Several studies (Beck, 2000; Paice & O'Donnell, 2004; Cohen et al., 2005; Monivais & McNeill, 2007; Hanssen, 2010) indicate that it is difficult for nurses and other healthcare providers to understand ethnic minority patients' expression of pain, and that they easily become frustrated, even to the point where they may negate such patients' symptoms or interpret them as fabrication. And when it comes to patients who whine and complain too much according to the healthcare providers' standards, they may be seen as difficult to cope with, and may even lose their credibility with the healthcare workers. This is in keeping with Weissman et al. (2002, p. 1), who claim that "we are likely to provide more attentive and compassionate care to the patient who is stoic compared to the expressive patient. This is because the culture of pain in Western Civilization tends to honor the stoic person." According to Dias et al. (2012) stereotyping and prejudice may influence diagnoses, treatment prescriptions, and care given by healthcare personnel. Health care workers' negative attitudes have among other factors been associated with "lack of knowledge and competencies to deal with cultural diversity" (p. 2).

Existential and Spiritual Needs

According to the World Health Organization (WHO; 1990), a main goal of palliative care is to relieve suffering caused by spiritual problems. However, Western "biomedicine separates mind from body, the individual from component parts, the disease into constituent elements, the treatment into measurable segments, the practice of medicine into multiple specialities, and patients from their social relationships and culture" (Gaines & Davies-Floyd, 2003, quoted in Chan et al., 2009, p. 118). Thus, disease is assumed to be universal, and the pathological phenomena are better understood outside their cultural context, "separated from related people or objects and the emotions and meaning that patients associate with them" (Chan et al., 2009, p. 118).

As opposed to this reductionist understanding, patients may experience illness as spiritual or psychosocial aspects of life, something that tends to be excluded from the clinician's equation. Koffman et al. (2008), for example, found in their study that black Caribbeans tended to see pain as representing a trial or test of faith. "This meaning was associated with confirmation and strengthening of religious belief and loyalty to God" (p. 354). Another example is the Maori, who tend to hold to a four-faceted health construct: 1) spiritual aspects, 2) thoughts and feelings, 3) physical aspects, and 4) family and community aspects (Muircroft et al., 2010). "One study of the cancer journey taken by Maori patients highlights the importance of these aspects of culture, as well as the holistic aspects of health (. . .) that may be important for Maori. Participants expressed a need for 'navigators' to help patients and [the spirit] negotiate the health system, to ensure continuity of care, and to help make patients and [the spirit] aware of all of their entitlements" (Muircroft et al., 2010, p. 55).

Alpers and Hanssen (2008; 2009) found that many Norwegian healthcare providers have little knowledge about religions other than their own, aside from some superficial information about Islam. Firth (2001) suggests that access to palliative care services by minority ethnic groups is lower than one would expect from their proportion in the local community. According to Shanmugasundaram and O'Connor (2009, p. 8) this may be because potential users of, for example, hospices, may be anxious about not receiving appropriate spiritual and cultural care.

Is It Appropriate to Talk About It?

The American Institute of Medicine defines a good death as "free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Tong et al., 2003, p. 168). The strength of this definition is its universality. Its weakness is that existential and spiritual aspects are missing. In our experience it is of equal importance to focus on the spiritual needs of patients as on physical and other needs, as unmet spiritual needs may cause great suffering in both the patient and family.

> Clinical example. The patient knows he only has a few weeks or months to live, but does not speak about this to his family.

Khoshrouy-Sefat (1985) claims that death is not to be discussed with Muslim patients, whereas Sheikh and Gatrad (2000) hold that death is not a taboo subject in Muslim communities. Spiritual peace is primary at the time of death for Hindus and Buddhists (DeMartinis, 1998), and it is important to Buddhists to know, as they need to consciously prepare themselves for their impending death (Forrest, 1983).

For many ethnic minority patients, it is important to be surrounded by family when death approaches. This is the case for Muslims, for example, as prayers and verses from the Quran are to be recited (Sheikh & Gatrad, 2000). Furthermore, Hindu "[f]amily members are likely to be present in large numbers as death nears. Chanting and prayer incense and various rituals are part of the process" (Shanmugasundaram & O'Connor, 2009, p. 7). It is important that healthcare providers facilitate this. If family members are not able to be present and perform important rituals it may cause great suffering both for the patient and the family.

As needs will vary among individuals, whether because of or independent of religious background, healthcare providers need to be prepared to talk openly about death, and at the same time be sensitive to whether the patient wants to talk about it or not. One of the interviewees in Gunaratnam's (2007) study described his practice in this regard as "walking a fine line" between cultural knowledge and openness.

> Clinical example. A Muslim woman is hospitalized with cancer pain, extensive physical problems, and anxiety. It is very important to her and her family to pray and read aloud from the Quran.

Holloway (2006) claims that healthcare providers are familiar with the assessment of physical, emotional, and social needs but may be less comfortable taking account of a patient's spirituality and religious needs, although they are increasingly required to do so. According to Todd and Baldwin (2006) physical symptom management has become the priority in palliative care, as the physical aspects of palliative care are less daunting than the intricate complexities associated with emotional and spiritual suffering. They hold that there has not been a parallel advancement in the areas of alleviation of emotional and spiritual suffering as has been made regarding physical suffering. Statements such as "you don't want to offend but you don't want to appear ignorant either," illustrates, in our experience, why spiritual or religious subjects are often not approached by healthcare providers. If you do not ask you avoid offending patients, but you also give them little or no opportunity to express the spiritual needs that often are present when facing serious illness and death.

Holloway (2006) points out that it is not enough to be knowledgeable about and sensitive to issues associated with particular religions and cultural contexts. Healthcare providers have to be sensitive to the beliefs of the individual and also be able to recognize the spiritual needs expressed by persons who only have a loose affiliation to any particular faith system or with a humanist spirituality. One needs, for example, to realize that hailing from a predominantly Muslim country does not necessarily mean that the patient is a Muslim. Furthermore, all members of a family may not belong to the same religion. It is important to ask the patient about his beliefs and philosophy of life.

Family Support

Shanmugasundaram and O'Connor (2009, p. 4) point out that "[o]ne of the fundamental principles of palliative care is that the patient and family together are the unit of care." Furthermore, "[p]atient and family satisfaction should include the patient's peace of mind, the family's perception of the patient's care and comfort, the decision making process, the care received, both by the patient and the family, and the extent to which opportunities were provided to complete life in a meaningful way. The time spent by patient and family should be treasured and not simply tolerable" (Shanmugasundaram & O'Connor, 2009, p. 4).

Family Members' Caring Role

National cultures may be divided into being mainly individualistic or collectivistic. In individualistic societies "the ties between individuals are loose: everyone is expected to look after himself or herself and his or her immediate family," whereas in collectivistic societies, people "are integrated into strong, cohesive ingroups, which . . . protect them in exchange for unquestioning loyalty" (Hofstede, 1991, p. 51).

Family support is of vital importance to any dying patient, but collectivist values may create a very different patient to work with than will the individualistic values of independence and autonomy (Hanssen 2004), and tend to lead to an other-reliant and dependent coping style. As to this, Bhanumathi (1983) describes cultures as "passivity" or "activity' centered." She suggests that illness behavior is affected by whether the patient comes from the one or the other.

> Clinical example. Although the patient is hospitalized, friends and family want to nurse the patient themselves.

Bhanumathi claims that in the passivity-oriented Indian culture, the patient submits passively to treatment given by family members or healthcare workers, whereas in an activity-oriented culture, such as that of the United States, patients try to move out of the "sick role" as soon as possible. Bhanumathi's "passivity" and "activity" centered cultures seem to correspond quite well with the cultures Hofstede (1991) has named "collectivistic" and "individualistic," respectively.

Both other-reliance and religious demands may cause the family to rally around the patient. At times one may find that whereas healthcare providers may find that the patient's need of rest takes precedence because of the patient's condition, family members may find that the patient needs constant family presence based on intra-family loyalty, empathy with "their" patient, and a need to stay in close touch with and support their ill family member (Hanssen, 2004).

A women in her 70s communicated to a district nurse that there were too many people milling around her at home, and that she wanted to go to the hospital (Pedersen, 2006). This illustrates that not all ethnic minority patients want to be cared for by their family, or die at home. For some, the security that the hospital represents is an important factor in achieving a peaceful death. It may, however, be difficult for the patient to communicate this to their family members.

However, many dying patients with ethnic minority backgrounds wish to be cared for at home by their families (Firth, 2001; de Graaff & Francke, 2003). Even when offered help from district nurses, patient and family often want to manage the caregiving themselves or choose to receive as little help as possible. This is because to care for dying relatives at home "is a matter of honor and integrity for many families of different cultures: failure to do so creates stigma and loss of face" (Shanmugasundaram & O'Connor 2009, p. 4).

> Clinical examples. A decision of home nursing care is made on discharge, but a few days later the patient states that she does not need help; there are recurring readmissions thereafter.

A man in need of total care. He wishes to be cared for at home, but the family cannot cope; there are frequent hospital readmissions.

As the palliative patient often has complex needs, it is often too much for the family to manage on their own. The consequence tends to be frequent hospital readmissions when the family cannot cope. As a result, the patient often dies in the hospital. Henley and Schott (quoted in Philips & Taylor, 2012, p. 26) hold that "the most vulnerable people are least likely to die in their chosen place, with evidence suggesting that patients from black and minority ethnic communities are most likely to die in hospital."

When the patient is receiving family care at home, the responsibility is often shouldered by one particular – most often female – member of the family. Although the main carer may feel the responsibility to be too great, the rest of the family may ignore this (Firth, 2001; de Graaff & Francke, 2003). Caregivers may feel inadequate and insecure; become socially isolated (Shanmugasundaram & O'Connor, 2009); and experience a decrease in sense of coherence, spirituality, and religious coping (Khanjari et al., 2012), and through this, increased health risk (Corà et al., 2012).

Filial duty is an important aspect of a collectivistic society's morality. In-group obligations are intrinsic facets of any collectivistic society's "honor code" or set of rules group members are expected to follow (Wikan, 2003). A person's honor depends on the collective's evaluation of that person's acts, and to act in conflict with the honor code creates public disapproval, dishonor, and shame. Strong filial duty and moral obligation toward ill family members may create a feeling of shame if one is unable to cope with the situation at home. It is important to be perceptive to whether the carer needs more help and support from home care nurses, irrespective of the carer's actively communicating such needs. Shanmugasundaram and O'Connor (2009, p. 4) point out that "[a]s families struggle to be caregivers of the dying, they must also struggle with their impending loss, their changing roles and relationships, watching a loved one suffer both physically and emotionally, and dealing with their own concerns about their abilities to be caregivers." They therefore need support to be able to give the support the patient needs spiritually, psychosocially, and physically.

CONCLUSION

Healthcare providers working with ethnic minority patients need help and support to be able to give physical and spiritual care in accordance with excellent professional standards, and to meet the patients' cultural and religious needs and expectations. Research shows that healthcare providers need formal education and in-service programs as well as support in their everyday work (Alpers & Hanssen, 2008; 2009). It is also necessary to empirically study how to achieve more culturally appropriate and sensitive care in intercultural palliative practice.

Also, the immigrant population needs to be educated about cancer and the various kinds of palliative care and hospice care offered in the society in which they now live. This may make it more socially acceptable for family carers of patients gravely ill from cancer to solicit professional care for their loved one (Shanmugasundaram & O'Connor, 2009).

And not the least, one needs to remember that "there are no cultural facts, only cultural possibilities, and . . . as much as there is inter-group variation there may be important intra-group variations in behaviors and belief around needs and health related experiences" (Iliffe & Manthorpe, 2004, p. 288). Every patient, therefore, needs to be respected as an individual, and not expected to think and act according to the healthcare providers' "cultural" expectations.

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