

Cultural Competence in End-of-Life Care: Terms, Definitions, and Conceptual Models from the British Literature

Natalie Evans, B.Sc., M.Sc.,¹ Arantza Meñaca, B.A., Ph.D.,¹ Jonathan Koffman, B.A., M.Sc., Ph.D.,²
Richard Harding, B.Sc., M.Sc., Ph.D., DipSW,² Irene J. Higginson, BMedSci, B.M., B.S., FFPHM, FRCP, Ph.D.,²
Robert Pool, B.A., M.A., Ph.D.,^{1,3} and Marjolein Gysels, B.A., M.A., Ph.D.^{1,2} on behalf of PRISMA

Abstract

Background: Cultural competency is increasingly recommended in policy and practice to improve end-of-life (EoL) care for minority ethnic groups in multicultural societies. It is imperative to critically analyze this approach to understand its underlying concepts.

Aim: Our aim was to appraise cultural competency approaches described in the British literature on EoL care and minority ethnic groups.

Design: This is a critical review. Articles on cultural competency were identified from a systematic review of the literature on minority ethnic groups and EoL care in the United Kingdom. Terms, definitions, and conceptual models of cultural competency approaches were identified and situated according to purpose, components, and origin. Content analysis of definitions and models was carried out to identify key components.

Results: One-hundred thirteen articles on minority ethnic groups and EoL care in the United Kingdom were identified. Over half ($n=60$) contained a term, definition, or model for cultural competency. In all, 17 terms, 17 definitions, and 8 models were identified. The most frequently used term was “culturally sensitive,” though “cultural competence” was defined more often. Definitions contained one or more of the components: “cognitive,” “implementation,” or “outcome.” Models were categorized for teaching or use in patient assessment. Approaches were predominantly of American origin.

Conclusions: The variety of terms, definitions, and models underpinning cultural competency approaches demonstrates a lack of conceptual clarity, and potentially complicates implementation. Further research is needed to compare the use of cultural competency approaches in diverse cultures and settings, and to assess the impact of such approaches on patient outcomes.

Introduction

Minority ethnic groups and end-of-life care

ETHNIC AND CULTURAL DIFFERENCES influence patterns of advanced disease, illness experiences, health care-seeking behavior, and the use of health care services. In light of increasing international evidence of low use of end-of-life (EoL) services by minority ethnic groups,^{1–6} it is critical to understand the influence of ethnicity and culture in the context of EoL care and current strategies to address inequalities.

In the United Kingdom, minority ethnic groups exhibit a disproportionately low use of EoL care services.^{2,3,7–11} Furthermore, substandard service provision has been reported by both health care professionals and service users from minority ethnic groups.^{12–17} In order to address these disparities the idea of “culturally competent” care has become increasingly popular, and a number of EoL care policy documents explicitly state the importance of sensitivity to cultural and religious differences, and the need for EoL care services to provide “culturally sensitive” care.^{18–22} Cultural competency training has also been identified as a priority for EoL care professionals.^{18,20–22}

¹Barcelona Centre for International Health Research (CRESIB), Hospital Clínic–Universitat de Barcelona, Barcelona, Spain.

²King’s College London, Department of Palliative Care, Policy, and Rehabilitation, School of Medicine, Cicely Saunders Institute, London, United Kingdom.

³Centre for Global Health and Inequality, University of Amsterdam, Amsterdam, the Netherlands.

Accepted March 11, 2012.

Ethnicity and culture

Defining ethnicity and culture is problematic, as there is no definitive definition for either concept. For the purposes of this article, ethnicity is understood as: "a subjectively felt sense of commonality based on the belief in common ancestry and shared culture."²³ Culture underpins constructions of ethnic identity. Culture is understood as "a system of shared ideas and meanings that underlie, influence and structure the ways in which people think and act in practical situations."²⁴ Both culture and ethnicity are largely self-defined and there is considerable overlap between the two. However, although ethnicity is by no means fixed, it is often seen as a less fluid aspect of a person's identity than culture due to its emphasis on common ancestry.²⁵ Everyone is influenced by their cultural background;²⁶ however, recommendations for the use of cultural competency approaches in United Kingdom policy concerning EoL care have only been made in reference to Britain's minority ethnic groups.

Cultural competency approaches

Cultural competency approaches originated in the United States in response to evidence that people from minority ethnic groups experience unequal access to care and face disparities in health care outcomes.²⁷ Much has been written about the causes of these disparities,^{28–30} the majority of which are undoubtedly due to socioeconomic disadvantages.^{28–30} Evidence, however, that patients with similar socioeconomic backgrounds, language ability, and health care needs receive different treatment and have differential health care outcomes related solely to their ethnicity led to the development of cultural competency approaches.²⁹ Such approaches are based on the premise that in order to meet the needs of diverse ethnic groups, health care professionals must provide care that is sensitive to patients' cultural contexts, and be aware of how health beliefs and behaviors can affect patients' and physicians' decision making.²⁹

Cultural competency approaches have their origin in transcultural nursing, pioneered by Leininger,³¹ who applied an anthropological perspective to patient assessment. Leininger's work stimulated a diversity of cultural competency approaches and associated conceptual models for their translation into practice, ranging from those widely applicable to all health care environments,^{32–36} to specialized approaches designed for specific medical settings.^{37,38} These approaches have been described using various terms (each with their own definition), such as "transcultural nursing," "cultural sensitivity," "cultural competency," and "cross-cultural care."²⁹ They are highly influential in the United States, and have been integrated into standard medical training.³⁹

It has been suggested, however, that the variety of terms, definitions, and conceptual models used has resulted in a conceptual vagueness.^{29,40–42} Furthermore, there is little agreement as to what should be included in cultural competency training programs, and there is little evidence that such approaches have any real effect on patients' health care outcomes.^{27,42,43}

The use of cultural competence approaches to address health care disparities has also raised a number of criticisms. There are concerns that such approaches can portray culture as fixed, static, or as a quantifiable variable, and can create

stereotypes.^{44,45} Culture can be presented as a barrier to be overcome, shifting the blame for low service use and poor health care outcomes onto the patient.⁴⁶ In addition, the approach has been said to ignore power differentials in the physician-patient encounter.⁴⁴

The concept of culturally competent health care is relatively new to the United Kingdom in comparison to the United States.⁴⁴ Furthermore, EoL care professionals have arrived relatively late to the debate surrounding equity of access and cultural competency in service delivery, even within the British context, due in part to the younger age structures of minority ethnic populations, and the relatively greater importance of non-malignant diseases for members of these groups.^{14,47}

Considering the recent commitments in British EoL health care policy to cultural competency approaches, and their growing popularity in British EoL care settings,^{18,20–22} it is imperative to subject it to critical analysis in order to understand the concepts it consists of and what these concepts represent. This article aims to explore cultural competency approaches in the British literature on EoL care and minority ethnic groups. Specific objectives include (1) to identify and examine terms and definitions used to describe approaches and associated conceptual models; and (2) to examine the constituent components of definitions and models and to situate them according to purpose and origin.

Methods

Search strategy

The identification of terms, definitions, and models was carried out in the context of a systematic review of the British literature on minority ethnic groups and EoL care. A detailed description of the systematic search procedure has been published elsewhere.⁴⁸ In summary, searches were carried out in 13 electronic databases, 8 journals, reference lists, and grey literature (Table 1).

Analysis

Full texts of included articles were examined for terms and definitions used to describe cultural competency approaches. Conceptual models were often referenced within the literature but not described. The version of the model cited and its supporting literature were obtained in full (via Internet searches). If more than one version of the same model was cited in the literature, the most recent version cited was analyzed.

Content analysis was used to categorize definition components. Definitions identified from the literature were the unit of analysis. Meaning units (words or phrases that relate to the same central meaning)⁴⁹ were identified, which were then abstracted into more general categories.^{49,50} Similarly, content analysis was used to categorize conceptual models' key components. The unit of analysis in this instance was the model itself.

Results

A total of 5882 citations were screened and 113 articles were found relating to minority ethnic groups and EoL care in the United Kingdom (13 reviews, 45 original studies, and 55 other articles). Just over half ($n = 60$) of the articles contained a term, definition, or model of a cultural competency approach.

TABLE 1. DATABASES AND HAND SEARCHES/SEARCH TERMS

<i>Databases (update search to mid-October 2010)</i>	<i>Search terms</i>	<i>Hand search of journals (update search to mid-October 2010)</i>
Web of Knowledge all databases (Web of Science with conference Proceedings 1899–2010; BIOSIS Previews 1969–2010; Inspec 1969–2010; MEDLINE 1950–2010; Journal Citation Reports 2000–2010); OVID (AMED 1985–2010; MEDLINE 1950–2010; PsycINFO 1806–2010; EMBASE 1980–2010); Cancerlit 1975–2010); ASSIA 1987–2010; CINAHL 1982–2010; Cochrane reviews 1996–2010; the NHS Ethnicity and Health Library ^a	("United Kingdom" OR UK OR Britain OR England OR Wales OR Scotland OR "Northern Ireland") AND (palliative OR terminal OR "end of life" OR end-of-life OR death OR dying OR "continu* care" OR "advance directive*" OR hospice* OR "supportive care") AND (cultur* OR intercultural OR cross-cultural OR transcultural OR ethnic* OR migrant* OR minorit* OR diversity OR Muslim* OR Jew* OR Christian* OR Sikh* OR Buddh* OR Hindu* OR India* OR Pakistan* OR black OR white OR Caribbean* OR Africa* OR Bangladesh* OR Irish OR British OR Chinese OR Asian*) ^b	European Journal of Palliative Care 1994–2010; International Journal of Palliative Nursing 1996–2010; Palliative Medicine 1987–2010; Journal of Palliative Care 1985–2010; Diversity in Health and Social Care 2004–2008 (Diversity in Health and Care 2008–2010; Omega 1970–2010; Mortality 1996–2010; Medical Anthropology Volume 21 2002–2010)

^aThe NHS Ethnicity and Health Library database was searched using the terms "palliative" and "end of life" only.

^bThe official classifications for ethnicity and religious affiliation used by the United Kingdom Office of National Statistics were included as search terms and the words cultur*, intercultural, cross-cultural, transcultural, ethnic*, migrant*, minorit*, and diversity were chosen in order to retrieve articles concerning cultural competence/sensitivity/humility and minority ethnic groups.

Terms

Seventeen different terms used to describe care that is sensitive to cultural differences were identified from the literature (Table 2). The most frequent term, "culturally sensitive," was used in a total of 43 articles (1995–2009), followed by "cultural competence," which appeared in 26 articles (1999–2009). The term "cultural competence" appeared more recently than the term "cultural sensitivity" (Table 2).

Definitions

Seventeen of the 60 included articles specifically defined the terms they used,^{13,25,42,45,47,51–62} with the first definition appearing in an article from 1998.⁴⁵ In contrast to the frequency with which the term "cultural sensitivity" appeared in the literature, the term was only specifically defined four times.^{51–54} "Cultural competence," however, was defined a total of eight times.^{13,42,47,56–60} "Cultural safety" was defined three times,^{25,47, 61} whereas the terms "culturally sensitive and appropriate care,"⁵⁵ "culturally appropriate care,"⁶² and "culturally proficient care,"⁴⁵ were all defined just once. All other terms were used without definition.

Content analysis was used to identify common components in the terms' definitions. Definitions contained both similarities and differences. Definitions were found to contain one or more of the following components: cognitive, implementation, or outcome (Table 3).

Analysis of definitions for terms that were defined more than once (e.g., cultural sensitivity, cultural competency, and cultural safety) revealed that the components categorized as "cognitive," "implementation," and "outcomes," appeared in one or more of the definitions for each term. However, the frequency with which the components appeared in definitions for the different terms varied. The

most frequent component of definitions for cultural sensitivity was "implementation" (i.e., the application of practical skills in order to achieve culturally sensitive care). In contrast, the most frequent component of the definitions for cultural competency was "cognitive." This component

TABLE 2. TERMS USED TO DESCRIBE CULTURAL COMPETENCY APPROACHES IN THE BRITISH LITERATURE ON MINORITY ETHNIC GROUPS AND END-OF-LIFE CARE

<i>Term used to describe a culturally competent approach</i>	<i>No. of articles in which the term appeared</i>	<i>Dates in which the articles were published</i>
Culturally sensitive care	43	1995–2005
Culturally competent care	26	1999–2009
Transcultural care	9	2002–2006
Cultural awareness	6	2000–2008
Culturally appropriate care	6	2002–2009
Culturally appropriate and sensitive care/appropriate and culturally sensitive care	5	1999–2009
Inter-cultural care	5	2001–2008
Multicultural care	4	2003, 2006
Cross-cultural care	4	1995–2007
Culturally responsive care	4	1998–2008
Culturally safe care	4	1999–2004
Culturally specific care	3	1995–2007
Culturally proficient care	1	1998
Culturally effective care	1	1998
Cultural pain and cultural care	1	1999
Ethnically and culturally sensitive care	1	2008
Ethnically sensitive care	1	2001

TABLE 3. CATEGORIZATION OF DEFINITIONS' COMPONENTS

Cognitive

The cognitive component encompasses the various changes in awareness, sensitivity, or understanding that form the basis of many definitions.

"Professionals should recognize and respect an individual's sense of identity in relation to decision-making, health and religious beliefs, family structure and how patients from ethnic minorities fit into their wider community."
Firth⁴⁷ in Ackroyd⁵²

"Health care professionals should aim to develop cultural competence, based on improved understanding rather than simply an increase in cultural knowledge."
Webb and Sergison⁶³ in Gatrad et al.⁵⁶

Implementation

The implementation component refers to the practical skills said to be needed in order to deliver culturally competent care.

"Cultural sensitivity in nursing is the provision of care that is sensitive to the needs of clients from all cultures.⁶⁴⁻⁶⁶ In practice this means providing services that meet the religious, dietary and linguistic requirements of patient groups, while retaining the principle of individualised care.^{67,68}"
Daddy et al.⁵¹

"Cultural competence is an evolving process that depends on self-awareness, knowledge and skills [...] It may also be seen as operating at three levels: developing self awareness, knowledge, development and application of skills."
McGee and Johnson⁵⁹

Outcome

The outcome component refers to the element of the definitions whereby service provision meets patients' specific needs.

"Cultural competence encompasses a set of values, behaviours, attitudes, knowledge, and skills which allow professionals to offer patient care which is respectful and inclusive of diverse cultural backgrounds."
Feser and Bon⁶⁹ in Payne et al.⁶⁰

"Culturally safe nursing practice involves actions which recognise, respect and nurture the unique cultural identity [...] and safely meet their needs, expectations, and rights."
Polascheck⁷⁰ in Oliviere²⁵

covered two important concepts: sensitivity to cultural differences, including awareness of one's own cultural background, and the acquisition of culturally-specific knowledge. Definitions for cultural safety, which originated in New Zealand, and is also popular in Australia,⁷⁰ all contained the "cognitive" and "implementation" components. However, unlike the definitions for cultural sensitivity and cultural competency, all of the definitions of cultural safety also included the component "outcome." The outcomes described were, without exception, patient-defined outcomes.

When references were given for definitions, just over half of the articles cited were from non-British publications (the United States,^{64,71,72} and New Zealand^{70,73-75}).

Models

Eight conceptual models of cultural competency were identified from 13 articles (Table 4). Six of these models came from the United States, whereas two came from the United Kingdom. Models fell into two categories: those designed for the teaching of cultural competence to health care professionals, and those designed for use in the assessment of patient cultural background (Table 4).

Teaching. Content analysis of teaching models resulted in the same abstract components as those identified for the definitions: "cognitive" (sensitivity, knowledge, awareness, understanding, and caring), "implementation" (skills), and "outcome" (competence). In addition, all teaching models contained the term "cultural competence" in the title. These models emphasized that the development of cultural competency is a process, and visual representations often had overlapping or interlinked components to emphasize the non-linear nature of the development of "cultural competency." The model developed by the British researchers Papadopoulos et al.⁷⁶ was the most frequently cited in the literature.

Cultural assessment. A number of models designed for the assessment of patient cultural background were identified. These models showed greater variation than those for the teaching of cultural competency, providing schematic frameworks for the description of cultural background. Components were so diverse that categorization was meaningless. All of these models were American in origin.

There was, however, some overlap between models designed for teaching cultural competence and those focused on the assessment of patient cultural background. Some models designed primarily to elucidate specific cultural information assumed, implicitly or explicitly, that the accumulation of culturally-specific knowledge would lead to culturally-competent health care professionals.^{77,78} In addition, sensitivity, respect, and awareness of one's own cultural background were often given as underlying assumptions (such as in the "meta-paradigm" of Giger and Davidhizer's model,^{79,80} the "theoretical premises" of Leninger's model,^{77,81} and the "explicit assumptions" of Purnell's model).^{78,82}

Discussion

Various terms, definitions, and conceptual models for "cultural competency" approaches were found in the British literature on minority ethnic groups and EoL care. The term "cultural sensitivity" was the first to appear in the literature, and was found in the largest number of articles. The term "cultural competency," in contrast, appeared more recently, following its popularity of use in the United States,⁹² and was the term that was most frequently defined, reflecting more recent calls for conceptual clarity.^{29,40-42}

Content analysis revealed that definitions consisted of three components: cognitive, implementation, or outcome. Definitions for the term "cultural sensitivity" focused more frequently on implementation, and those for "cultural competency" focused more on cognitive change, whereas definitions of "cultural safety" placed greater emphasis on outcomes of care. In contrast to cultural sensitivity and cultural competency, cultural safety is said to recognize the

TABLE 4. CONCEPTUAL MODELS OF CULTURAL COMPETENCY APPROACHES

<i>Model of cultural competency</i>	<i>Main model components</i>	<i>Type of model</i>	<i>Origin</i>	<i>Articles in which the model is cited</i>
The Model of Cultural Competency Campinha-Bacote ⁸³	Sensitivity, skills, knowledge, encounters and desire	Teaching model	United States	McGee et al. ⁵⁹
A Model of Culturally Competent Health Care Practice Papadopoulos et al. ⁷⁶	Awareness, knowledge, sensitivity and competence	Teaching model	United Kingdom	Oliviere ²⁵ Firth ⁴⁷ Payne et al. ⁶⁰ Gunaratnam ⁵⁸ Gunaratnam ⁴² Gunaratnam ⁸⁴
Taxonomy for Culturally Competent Care Lister ⁸⁵	Awareness, knowledge, understanding, sensitivity and competence	Teaching model	United Kingdom	Somerville ⁸⁶
Model for the Development of Culturally Competent Community Care Kim-Godwin et al. ⁸⁷	Caring, sensitivity, knowledge, and skills; cultural competency was only part of the model, which also included the health care system and outcomes	Teaching model	United States	Gunaratnam ⁵⁸ Gunaratnam ⁴²
Transcultural Model Giger and Davidhizar ⁷⁹	Communication, space, social organization, time, environmental factors, and biological variations	Cultural assessment model	United States	McCaffery-Boyle ⁴⁵ Gatrad et al. ⁸⁸
Four-step Approach to Providing Culturally Sensitive Patient Teaching Kittler and Sucher ⁸⁹	A four-step process of self-evaluation, pre-interview research, in-depth interviewing, and unbiased data analysis	Cultural assessment model	United States	McCaffery-Boyle ⁴⁵
Model of Cultural Competence Purnell and Paulanka ⁷⁸	Communication; overview/heritage; family roles and organization; workforce issues; bio-cultural ecology; high-risk behaviors; nutrition, pregnancy, and childbearing practices; death rituals; spirituality; health care practices; and health care practitioner concepts	Cultural assessment model	United States	Jack et al. ⁵⁴
Sunshine Model Leininger ⁷⁷	Worldview, cultural, and social structure dimensions, environmental context, language and ethno-history, influences, types of care, adaptation, and culturally congruent care	Cultural assessment model	United States	O'Neill ⁹⁰ Diver et al. ⁹¹ McCaffery-Boyle ⁴⁵

position of groups in society, and the influence of the social structures in which personal interactions take place, with an emphasis on patient-defined outcomes of care.⁷⁰

Two types of models were identified from the literature: those designed for the teaching of cultural competency and those designed for the cultural assessment of patient cultural background. Content analysis of the teaching model components resulted in the same categories as content analysis of term definitions, highlighting the importance of cognitive change (encompassing increased awareness, sensitivity, and knowledge improvement), implementation, and patient-defined outcomes in the development of culturally-competent health care professionals.

Models conceived as cultural assessment tools showed greater variation, providing schematics for the collection of culturally-specific information. These were the most complex models, which attempted to include all factors influencing the patient-health care professional encounter. Often the value of a conceptual model lies in its ability to transmit complex ideas simply. However, patient assessment models are complex, and relegate important concepts such as cultural awareness, sensitivity, and respect, to the models' underlying assumptions or supporting material, and this may limit the usefulness of such models in practice. Models for patient cultural assessment often anticipated, implicitly or explicitly, that gaining culturally-

specific knowledge would lead to culturally-competent health care professionals.

The assumption that the acquisition of knowledge about different cultural groups can lead to cultural competence has been described as a “fact-file” or “cookbook” approach.^{46,93} Fact-file approaches have been criticized for framing the needs of patients from minority ethnic groups in “culturalist” terms, and providing health care professionals with a false sense of competence, which is far removed from the reality of providing care for patients from diverse cultural backgrounds.^{46,84}

The various terms, definitions, and models identified reveal a need for researchers to provide conceptual clarity when referring to “cultural competency” or “cultural sensitivity,” in order to provide a framework for implementation and for outcomes to be measured. A lack of clarity regarding definitions and underlying conceptual models can lead to difficulties in operationalizing the concept for training purposes and in evaluation.

Definitions and models of cultural competency were either of American origin or highly influenced by the American approach to cultural competency. Although two models of British origin were identified, including the model most frequently cited in the literature, neither of these models’ components differed significantly from those of the American models, and cannot be characterized as a specifically British approach. The term “cultural safety,” which originated in New Zealand, and which addresses social inequities and differentials in power-relations between patients and health care professionals, was defined three times. However, no conceptual models were identified for its translation into practice. The predominance of American models is perhaps inevitable, reflecting the origin of both the concept and the majority of models in current use. More cross-country research, however, is recommended in order to compare the use, and any adaptation, of such approaches in diverse cultural settings and in different health care systems. Furthermore, it is critical to assess the impact of cultural competency approaches on patient outcomes.

No model specifically designed for the EoL care setting was identified. Ideally, EoL care is patient-led, individualized, and addresses a patient’s “physical, emotional, social and spiritual” needs.⁹⁴ The recent focus on including a patient’s “cultural” needs is significant, and is supported by evidence of inequalities in care related to ethnicity. While proponents of cultural competency approaches acknowledge the institutional, social, and political influences that drive inequalities, these multiple and interconnected influences are not always addressed in EoL care policy.⁹⁵ End-of-life care policy in the United Kingdom recognizes the need for cultural competency and sensitivity in care, but there is little mention of other causes of low service use among minority ethnic groups.⁹⁵ This raises the question of whether enthusiasm for cultural competency approaches in policy represents a way to address disparities at a service level rather than addressing more complicated causes of inequalities. Indeed, Culley⁹⁷ and Gunaratnam⁹⁶ suggest that simplistic conceptualizations of cultural competency divert attention from more challenging problems, such as inequality and institutional racism in health care services. On the other hand, Johnson emphasizes the need for fair and equal access to EoL care services in order to reduce inequalities in health care.²⁶

Limitations

This article does not attempt to give an exhaustive account of all terms, definitions, or conceptual models of cultural competency. Rather it explores how the concept has translated in a specific body of literature: the literature on minority ethnic groups and EoL care in the United Kingdom.

Conclusions

The wide variety of terms, definitions, and conceptual models for cultural competency approaches identified from the British literature are confusing and reveal a lack of clarity as to what such approaches consist of and how they can be implemented. Any call for consensus would, however, be premature; “cultural competency” in health care is a relatively new concept, and diversity in opinion regarding what the approach consists of and how it should be implemented can lead to better understanding and the development of theory. A more pressing issue than consensus is clarity; when researchers and policymakers discuss the need for such approaches, they must be clear about what they mean, and should preferably cite the definition and conceptual framework they adhere to.

The palliative care movement has assumed a leading role in addressing the health and social care needs of patients and families facing the inevitability of death. It has only been recently that attention has focused on the importance of providing care for increasingly diverse societies. This has now become an increasingly important demographic imperative in many developed countries.

This article has shown that just over half of all articles on minority ethnic groups and EoL care referred to cultural competency approaches. As cultural competency approaches become more popular in the United Kingdom and other countries, comparison of how these approaches are adapted in different cultures and settings can aid the development of theory. Furthermore, it is crucial to ensure that enthusiasm for cultural competency approaches does not divert attention from other causes of inequalities.

Acknowledgments

PRISMA is funded by the European Commission’s Seventh Framework Programme (contract number: Health-F2-2008-201655), with the overall aim to coordinate high-quality international research into end-of-life cancer care. PRISMA aims to provide evidence and guidance on best practices to ensure that research can measure and improve outcomes for patients and families. PRISMA’s activities aim to reflect the preferences and cultural diversities of citizens, the clinical priorities of clinicians, and appropriately measure multidimensional outcomes across settings where end-of-life care is delivered. Principal Investigator: Richard Harding. Scientific Director: Irene J. Higginson. In recognition of the collaborative nature of PRISMA, the authors thank the following PRISMA members: Gwenda Albers, Barbara Antunes, Ana Barros Pinto, Claudia Bausewein, Dorothee Bechinger-English, Hamid Benalia, Lucy Bradley, Lucas Ceulemans, Barbara A. Daveson, Luc Deliens, Noël Derycke, Martine de Vlieger, Let Dillen, Julia Downing, Michael Echteld, Dagny Faksvåg Haugen, Lindsay Flood, Nancy Gikaara, Barbara Gomes, Sue Hall, Stein Kaasa, Pedro Lopes Ferreira, Johan

Menten, Natalia Monteiro Calanzani, Fliss Murtagh, Bregje Onwuteaka-Philipsen, Roeline Pasman, Francesca Pettenati, Tony Powell, Miel Ribbe, Katrin Sigurdardottir, Steffen Simon, Franco Toscani, Bart van den Eynden, Jenny van der Steen, Paul Vanden Berghe, and Trudie van Iersel.

Author Disclosure Statement

No competing financial interests exist.

References

- De Graaff F, Francke A: Home care for terminally ill Turks and Moroccans and their families in the Netherlands: carers' experiences and factors influencing ease of access and use of services. *Int J Nurs Studies* 2003;40:797-805.
- Fountain A: Ethnic minorities and palliative care in Derby. *Palliat Med* 1999;13:161-162.
- Fraser LK, Fleming T, Miller M, Draper ES, McKinney PA, Parslow RC: Palliative care discharge from paediatric intensive care units in Great Britain. *Palliat Med* 2010;24:608-615.
- McGrath P, Holewa H, Kail-Buckley S: "They should come out here...": Research findings on lack of local palliative care services for Australian aboriginal people. *Am J Hospice Palliat Med* 2007;24:105.
- The National Hospice and Palliative Care Organization (NHPCO): Facts and figures on hospice care in America. www.nhpco.org/files/public/Statistics_Research/Hospice_Facts_Figures_Oct-2010.pdf. (Last accessed September 2011).
- Crawley LV, Payne R, Bolden J, Payne T, Washington P, Williams S: Palliative and end-of-life care in the African American community. *JAMA* 2000;284:2518.
- Ahmed N, Bestall J, Ahmedzai S, Payne S, Clark D, Noble B: Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliat Med* 2004;18:525.
- Hill D, Penso D: Opening Doors: Improving Access To Hospice And Specialist Palliative Care Services By Members Of The Black And Ethnic Minority Communities: National Council for Hospice and Specialist Palliative Care Services; 1995.
- Karim K, Bailey M, Tunna K: Nonwhite ethnicity and the provision of specialist palliative care services: factors affecting doctors' referral patterns. *Palliat Med* 2000;14:471.
- Rees W: Immigrants and the hospice. *Health Trends* 1986;18:89-91.
- Silcocks PBS, Rashid A, Culley L, Smith L: Inequality even in terminal illness? *Eur J Cancer* 2001;37(Suppl 2):S1-S126.
- Randhawa G, Owens A, Fitches R, Khan Z: Communication in the development of culturally competent palliative care services in the UK: a case study. *Int J Palliat Nurs* 2003;9:24-31.
- Spruyt O: Community-based palliative care for Bangladeshi patients in east London. Accounts of bereaved carers. *Palliat Med* 1999;13:119-129.
- Owens A, Randhawa G: 'It's different from my culture; they're very different': providing community-based, 'culturally competent' palliative care for South Asian people in the UK. *Health Social Care Community* 2004;12:414-421.
- Worth A, Irshad T, Bhopal R, Brown D, Lawton J, Grant E, Murray S, Kendall M, Adam J, Gardee R, Sheikh A: Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. *Br Med J* 2009;338:183.
- Gunaratnam Y: 'We mustn't judge people... but': staff dilemmas in dealing with racial harassment amongst hospice service users. *Sociol Health Illness* 2001;23:65-84.
- Gunaratnam Y: Eating into multiculturalism: hospice staff and service users talk food, 'race', ethnicity, culture and identity. *Crit Social Policy* 2001;21:287.
- Department of Health: End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life; 2008.
- General Medical Council. Treatment and care towards the end of life: good practice in decision making. Available at: www.gmc-uk.org/End_of_life.pdf_32486688.pdf. (Last accessed September 2011).
- Department of Health: Cancer Reform Strategy; 2007.
- House of Commons Health Committee: Palliative Care Fourth Report of the Session Volume 12004. Available at: www.publications.parliament.uk/pa/cm200304/cmselect/cmhealth/454/45402.htm. (Last accessed September 2011).
- Gysels M, Higginson I, Rajasekaran M, Davies E, Harding R: Improving Supportive and Palliative Care for Adults with Cancer, 2004. Available at: www.nice.org.uk/nicemedia/pdf/csgspmanual.pdf. (Last accessed February 2010).
- Wimmer A: The making and unmaking of ethnic boundaries: a multilevel process theory. *Am J Sociol* 2008;113:987-1022.
- Keesing RM, Strathern A: *Cultural Anthropology: A Contemporary Perspective*. New York: Holt, Rinehart and Winston, 1976.
- Oliviere D: Culture and ethnicity. *Eur J Palliat Care* 1999;6:53-56.
- Johnson M: End of life care in ethnic minorities: Providers need to overcome their fear of dealing with people from different backgrounds. *BMJ* 2009;338:489.
- Betancourt J, Green A, Carrillo J, Park E: Cultural competence and health care disparities: key perspectives and trends. *Health Aff* 2005;24:499.
- Mutchler J, Burr J: Racial differences in health and health care service utilization in later life: the effect of socioeconomic status. *J Health Social Behav* 1991;32:342-356.
- Betancourt J, Green A, Carrillo J, Ananeh-Firempong O: Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Rep* 2003;118:293.
- Fiscella K, Franks P, Gold M, Clancy C: Inequality in quality: addressing socioeconomic, racial, and ethnic disparities in health care. *JAMA* 2000;283:2579.
- Leininger M: *Transcultural Nursing: Concepts, Theories, and Practices*. New York: Wiley, 1978.
- Campinha-Bacote J: A model and instrument for addressing cultural competence in health care. *J Nurs Education* 1999;38:203.
- Purnell LD, Paulanka BJ: Purnell's model for cultural competence. In: Purnell LD, Paulanka BJ, (eds): *Transcultural Health Care: A Culturally Competent Approach*. Philadelphia: FA Davis, 1998, pp. 1-6.
- LaFromboise T, Foster S: Cross-cultural training: Scientist-practitioner model and methods. *Counseling Psychologist* 1992;20:472.
- Cross TL, Bazxon BJ, Dennis KW, Isaacs MR: Towards a culturally competent system of care. A monograph on effective services for minority children who are severely emotionally disturbed. Washington, DC: National Institute of Mental Health, Child and Adolescent Service System Program; 1989.

36. Green J: *Cultural Awareness in the Human Services*. Upper Saddle River, NJ: Prentice Hall, 1982.
37. Kittler PG, Sucher K: Diet counseling in a multicultural society. *Diabetes Educator* 1990;16:127.
38. Sadowsky G, Taffe R, Gutkin T, Wise S: Development of the multicultural counseling inventory: A self-report measure of multicultural competencies. *J Counseling Psychol* 1994;41:137.
39. Kripalani S, Bussey-Jones J, Katz M, Genao I: A prescription for cultural competence in medical education. *J Gen Intern Med* 2006;21:1116–1120.
40. Kumas-Tan Z, Beagan B, Loppie C, MacLeod A, Frank B: Measures of cultural competence: examining hidden assumptions. *Academic Med* 2007;82:548.
41. Seeleman C, Suurmond J, Stronks K: Cultural competence: a conceptual framework for teaching and learning. *Med Ed* 2009;43:229–237.
42. Gunaratnam Y: From competence to vulnerability: Care, ethics, and elders from racialized minorities. *Mortality* 2008;13:24–41.
43. Brach C, Fraser I: Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Med Care Res Rev* 2000;57(Suppl 1):181.
44. Price K, Cortis J: The way forward for transcultural nursing. *Nurse Ed Today* 2000;20:233–243.
45. McCaffery-Boyle D: The cultural context of dying from cancer. *Int J Palliat Nurs* 1998;4:70–85.
46. Gunaratnam Y: Culture is not enough: a critique of multiculturalism in palliative care. In: *Death, Gender and Ethnicity*. London: Routledge, 1997.
47. Firth S: *Wider Horizons: Care of the Dying in a Multicultural Society*. National Council for Hospice and Specialist Palliative Care Services; 2001.
48. Evans N, Meñaca A, Andrew EVW, Koffman J, Harding R, Higginson IJ, Pool R, Gysels M, PRISMA: Systematic review of the primary research on minority ethnic groups and end-of-life care from the UK. *J Pain Symptom Manage* 2012;43:261–286.
49. Graneheim U, Lundman B: Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Ed Today* 2004;24:105–112.
50. Elo S, Kyngäs H: The qualitative content analysis process. *J Advanced Nurs* 2008;62:107–115.
51. Daddy J, Clegg A: Cultural sensitivity: a practical approach to improving services. *Nurs Stand* 2001;15:39–40.
52. Ackroyd R: Audit of referrals to a hospital palliative care team: role of the bilingual health-care worker. *Int J Palliat Nurs* 2003;9:352–357.
53. Dunckley M, Hughes R, Addington-Hall J, Higginson IJ: Language translation of outcome measurement tools: views of health professionals. *Int J Palliative Nurs* 2003;9:49–55.
54. Jack CM, Penny L, Nazar W: Effective palliative care for minority ethnic groups: the role of a liaison worker. *Int J Palliat Nurs* 2001;7:375–380.
55. Molassiotis A: Supportive and palliative care for patients from ethnic minorities in Europe: do we suffer from institutional racism? *Eur J Oncol Nurs* 2004;8:290–292.
56. Gatrads R, Choudhury P, Brown E, Sheikh A: Palliative care for Hindus. *Int J Palliat Nurs* 2003;9:442–448.
57. Nyatanga B: Cultural competence: a noble idea in a changing world. *Int J Palliat Nurs* 2008;14:315.
58. Gunaratnam Y: Intercultural palliative care: do we need cultural competence? *Int J Palliat Nurs* 2007;13:470.
59. McGee P, Johnson M: Developing culturally competent services in palliative care: management perspectives. In: Gatrads R, Brown E, Sheikh A, (eds): *Palliative Care for South Asians: Muslims, Hindus and Sikhs*. London: Quay Books, 2007.
60. Payne S, Chapman A, Holloway M, Seymour JE, Chau R: Chinese community views: Promoting cultural competence in palliative care. *J Palliat Care* 2005;21:111–116.
61. Randhawa G, Owens A: Palliative care for minority ethnic groups. *Eur J Palliat Care* 2004;11.
62. Sarhill N, Mahmoud F, Walsh D: Muslim beliefs regarding death and bereavement. *Eur J Palliat Care* 2003;10:34–37.
63. Webb E, Sergison M: Evaluation of cultural competence and antiracism training in child health services. *Arch Dis Childhood* 2003;88:291.
64. Leininger M: Culture care theory, research, and practice. *Nurs Sci Quarterly* 1996;9:71.
65. Archibald G: The needs of South Asians with a terminal illness. *Prof Nurse* 2000;15:316–319.
66. Swan E: *Equal care for all*. Nursing Standard (Royal College of Nursing, Great Britain: 1987) 1999;13:42.
67. Vydelingum V: South Asian patients' lived experience of acute care in an English hospital: a phenomenological study. *J Advanced Nurs* 2000;32:100–107.
68. Gerrish K: Individualized care: its conceptualization and practice within a multiethnic society. *J Advanced Nurs* 2000;32:91–99.
69. Feser L, Bon B: Enhancing cultural competence in palliative care: perspective of an elderly Chinese community in Calgary. *J Palliat Care* 2003;19:133.
70. Polaschek NR: Cultural safety: a new concept in nursing people of different ethnicities. *J Advanced Nurs* 1998;27:452–457.
71. Jones M, Cason C, Bond M: Cultural attitudes, knowledge, and skills of a health workforce. *J Transcultural Nurs* 2004;15:283.
72. Leininger M: Response to Cooney article, "a comparative analysis of transcultural nursing and cultural safety". *Nurs Praxis NZ* 1996;11:13.
73. Coup A: Cultural safety and culturally congruent care: a comparative analysis of Irihapeti Ramsden's and Madeleine Leininger's educational projects for practice. *Nurs Praxis NZ* 1996;11:4.
74. Ramsden I: *Kawawhakaruru Hau: Cultural Safety in New Zealand*. Wellington: Ministry of Education, 1990.
75. Ramsden I: *Kawawhakaruru Hau, cultural safety in nursing education in Aotearoa*. *Nurs Praxis* 1993;8:4–10.
76. Papadopoulos I, Tilki M, Taylor G: *Transcultural Care: A Guide for Health Care Professionals*. Salisbury: Quay Books, 1998.
77. Leininger M: Leininger's theory of nursing: Cultural care diversity and universality. *Nurs Sci Quarterly* 1988;1:152.
78. Purnell LD, Paulanka BJ: *Transcultural Health Care: A Culturally Competent Approach*. Philadelphia: FA Davis, 1998.
79. Giger J, Davidhizar R: *Transcultural Nursing: Assessment and Intervention*. St. Louis: Mosby-YearBook, 1995.
80. Giger J, Davidhizar R: The Giger and Davidhizar transcultural assessment model. *J Transcultural Nurs* 2002;13:185.
81. Leininger M: Culture care theory: A major contribution to advance transcultural nursing knowledge and practices. *J Transcultural Nurs* 2002;13:189.
82. Purnell LD: A description of the Purnell model for cultural competence. *J Transcultural Nurs* 2000;11:40.
83. Campinha-Bacote J: *The Process of Cultural Competence in the Delivery of Healthcare Services: a Culturally Competent Model of*

- Care, 4th ed., 2003. www.transculturalcare.net. (Last accessed July 2010).
84. Gunaratnam Y: Care, artistry and what might be. *Ethnicity Inequalities Health Social Care* 2008;1:9–17.
 85. Lister P: A taxonomy for developing cultural competence. *Nurse Ed Today* 1999;19:313–318.
 86. Somerville J: The paradox of palliative care nursing across cultural boundaries. *Int J Palliat Nurs* 2007;13:580.
 87. Kim-Godwin Y, Clarke P, Barton L: A model for the delivery of culturally competent community care. *J Advanced Nurs* 2001;35:918–925.
 88. Gatrads AR, Sheikh A: Palliative care for Muslims and issues before death. *Int J Palliat Nurs* 2002;8:526–531.
 89. Kittler PG, Sucher C: Diet counseling in a multicultural society. *Diabetes Educator* 1990;16:127–131.
 90. O'Neill A: Cultural issues in palliative care. *Eur Palliat Care* 1995;2:127–131.
 91. Diver F, Molassiotis A, Weeks L: The palliative care needs of ethnic minority patients attending a day-care centre: a qualitative study. *Int J Palliat Nurs* 2003;9:389–396.
 92. Saha S, Beach M, Cooper L: Patient centeredness, cultural competence and healthcare quality. *J Natl Med Assn* 2008; 100:1275.
 93. Jones K: Diversities in approach to end-of-life: A view from Britain of the qualitative literature. *J Res Nurs* 2005;10:431.
 94. World Health Organization: WHO Definition of Palliative Care. www.who.int/cancer/palliative/definition/en/, 2011; www.who.int/cancer/palliative/definition/en/. (Last accessed February 2011).
 95. Evans N, Meñaca A, Andrew E, Koffman J, Harding R, Higginson IJ, Pool R, Gysels M, PRISMA: Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life care strategy. *BMC Health Services Res* 2011;11:141.
 96. Gunaratnam Y: Implications of the Stephen Lawrence Inquiry for palliative care. *Int J Palliat Nurs* 2000;6:147–149.
 97. Culley L: A critique of multiculturalism in health care: the challenge for nurse education. *J Advanced Nurs* 1996;23: 564–570.

Address correspondence to:

Natalie Evans, B.Sc., M.Sc.

Barcelona Centre for International Health Research (CRESIB)

Hospital Clínic–Universitat de Barcelona

C/ Rosselló 132 Sobre ático

08036 Barcelona, Spain

E-mail: n.evans@vumc.nl