Special Article

Culture Is a Priority for Research in End-of-Life Care in Europe: A Research Agenda

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Abstract
Context. Culture has a profound influence on our understanding of what is appropriate care for patients at the end of life (EoL), but the evidence base is largely nonexistent.

Objectives. An international workshop was organized to compile a research agenda for cultural issues in EoL research, and assess challenges and implications of the integration of the culture concept in different contexts.

Methods. Participant experts were identified from the expert network established through an Internet-based call for expertise on culture and EoL care and from meetings. The workshop comprised presentations of research priorities from country and disciplinary perspectives, and group discussions. Analysis used all data gathered in the workshop and applied standard qualitative techniques.

Results. Thirty experts participated in the workshop and identified the following priorities for cross-cultural research: 1) clarifying the concepts of culture and cultural competence; 2) defining EoL in a context of social and cultural

diversity, with a focus on concepts of EoL care and bioethics, experiences of receiving and giving EoL care, and care practices in different settings; and 3) developing appropriate methodologies and outcome measurements that address diversity.

   Conclusion. This first pan-European meeting compiled a research agenda, identifying key areas for future research focusing on culture, diversity, and their operationalization. This requires international and multidisciplinary collaboration, which is necessary in the current efforts to synthesize best practices in EoL care.   J Pain Symptom Manage 2012;44:285−294. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
End-of-life care, palliative care, research priorities, Europe, culture, collaboration

Introduction

   With the global challenge of an aging population, care at the end of life (EoL) is of growing importance.[1] However, EoL research is under-resourced and underdeveloped.[2] The World Health Organization recommends collaboration to strengthen EoL research.[3] Reflecting the Positive diveRsities of European prIorities for reSearch and Measurement in end-of-life cAre (PRISMA) is a European Commission-supported program consisting of a number of integrated work packages (WPs), which is the term used for "projects" in the Seventh Framework Program. PRISMA aimed to inform best practice and harmonize research in EoL care for cancer patients across Europe.[4] WPs undertake a broad range of actions that include establishing a collaborative research agenda informed by public and clinical priorities and drawing together best practice and resources for quality assurance in EOL care. PRISMA WP1 focused on the role of culture in EoL care.

   Culture affects perceptions of health, illness, and appropriate treatments, and it influences responses to symptoms, health care services, and death.[5,6] When patients, families, and health professionals are confronted with serious illness, limits to cure, and difficult decisions, cultural differences become especially salient. Related to this, cultural competence, which entails providing quality care to patients irrespective of race, ethnicity, culture, and language,[7] has become a key concept in EoL care, although it remains loosely defined.[8]

   Culture influences definitions of what the EoL is,[9,10] as well as our understanding of what constitutes appropriate EoL care,[11,12] how it is assessed,[13] evaluated and practiced,[14−16] and how care and illness are experienced.[17−19] Given an aging population with a growing demand for EoL care in increasingly multicultural communities, it is important to address culture through international exchange and collaboration.

   In May 2010, the PRISMA WP on culture and EoL care organized an international workshop to further explore these issues. This article presents the main conclusions from the workshop. The objectives of the workshop were: 1) to compile a research agenda for cultural issues in EoL care and 2) to assess the challenges and implications of taking culture into account in different care and research contexts.

Methods

The Context of the Workshop

   WP1 established an expert network through two meetings with recognized experts in the field and a call for expertise aimed at identifying and contacting the most prominent experts. During an initial meeting (May 2008, Amsterdam, The Netherlands), a small group of experts, comprising the members of the WP, and a selection of external Dutch experts were invited to set up the collaborative network. During the second meeting (May 2010, in Vic, Catalonia, Spain), international experts gave presentations and debated current issues relating to EoL care and culture. This second meeting comprised 1) a small, closed workshop on the first day, organized by the Barcelona Center

for International Health Research (CRESIB) and 2) a conference attended by 250 national and international delegates on the second day, jointly organized by CRESIB, the Institut Català d'Oncologia, and the University of Vic. This article reports on the research agenda compiled from the one-day workshop, but also takes account of the insights gained during the conference.

Workshop Participants

Participants for the workshop and conference were chosen from the experts identified through: 1) the call for expertise, 2) referral by other participants, 3) advertisements in online palliative care forums and newsletters, 4) national and regional palliative care associations in Europe, and 5) relevant conferences.

The call for expertise was Internet-based and used a snowball approach to identify experts by including a request to recommend other relevant experts in this area. Although the call specified that we were looking for expertise in European settings, we also received recommendations from beyond Europe. Experts came from different backgrounds (academic, clinical, and nonclinical professionals).

A questionnaire was attached to the call for expertise and respondents were asked to complete five open questions on definitions of EoL care, EoL care in policy and practice, country-specific priorities, and culture-specific approaches to EoL. The response rate was 33% (168/511) of people who were sent the call by the WP1 team. This included the people identified by referral, but excluded the people who had seen the call through advertisement, or who were passed on the call by someone who was approached firsthand by the WP1 team.

On the basis of publications and questionnaire responses, five experts representing a mix of disciplines, expertise, and countries participating in the PRISMA project were invited to present their views on research priorities in culture and EoL care on the first day (for all participants, see Table 1). All other members of the expert network were invited to the conference on the second day.

Workshop Format

The workshop started with a series of presentations on the work conducted by the PRISMA WP1 team. This was followed by the five invited experts who had prepared presentations on research priorities in culture and EoL care. These presentations formed the basis for further discussion with the other participants.

This was followed by four parallel group sessions, during which themes based on the responses to the questionnaire and the main interests of PRISMA were discussed. The group sessions aimed to identify research priorities in the following areas: 1) EoL care in different cultural settings; 2) cultural competence and minority ethnic groups; 3) approaches to and methods for studying culture; and 4) outcome measures and culture. These four research areas were suggested by the WP1 team, and these areas were discussed and agreed on before the group sessions. Each group had a moderator and the discussions were audio recorded and then transcribed verbatim.

Analysis

We used all data gathered in the workshop for the analysis and applied standard qualitative techniques, such as indexing, coding, and constant comparison. Analysis was conducted within the context of the PRISMA team. Doubts about what was meant in the group discussions of the workshop were resolved by discussion among the team members and by checking with the people who had been involved in the group sessions.

Ethics Approval

Ethics approval was obtained for this WP of the PRISMA program from the Ethics Committee of the Fundacio Clinic in Barcelona.

Results

Thirty experts from 14 European institutions (Spain [13], U.K. [6], Belgium [3], The Netherlands [3], Germany [1], Norway [2], and Italy [2]) attended the workshop (Table 1), representing medical ethics, anthropology, sociology, clinical medicine, and epidemiology.

European Expert Views on Research Priorities

The priority areas that follow emerged from the expert presentations and group sessions. Although the focus of the individual presentations was on country priorities, the recommendations were generally applicable across Europe. These

Table 1
Full List of Participants, PRISMA WP1 Meeting on Culture and EoL Care

Name	Position	Affiliation
Albert Tuca	Palliative Care Support Group Coordinator	Institut Català d'Oncologia (Catalan Institute of Oncology)
Anna Novellas	Researcher	The "Qualy" Observatory/WHO Collaborating Center for Palliative Care Public Health Programs, Catalonia
Arantza Meñaca	Postdoctorate Research Fellow	CRESIB, Hospital Clínic—Universitat de Barcelona
Barbara Daveson	PRISMA Project Manager/Research Fellow	King's College London
Barbara Gomes	WP Lead "Public priorities and preferences," PRISMA	King's College London
Bettina Huesbo	Clinical Director	Bergen Red Cross Nursing Home
Chris Gastmans	Professor	Center for Biomedical Ethics and Law, Catholic University Leuven, Belgium
Claudia Bausewein	WP Lead "Measurement tools (POS and STAS)," PRISMA	Deutsche Gesellschaft für Palliativmedizin
Cristina Garzón	Palliative Care Research Coordinator	Institut Català d'Oncologia (Catalan Institute of Oncology)
Erin Andrew	Research Fellow	CRESIB, Hospital Clínic—Universitat de Barcelona
Franco Toscani	Scientific Director	Fondazione Lino Maestroni, Istituto di Ricerca in Medicina Palliativa, Cremona
Fuusje de Graaff	Researcher and Partner in MUTANT, a nonprofit agency	University of Amsterdam
Gwenda Albers	Junior Researcher	Vrije Universiteit Amsterdam
Irene Higginson	PRISMA Scientific Director	King's College London
Jonathan Koffman	Lecturer in Palliative Care & Sub Dean for Postgraduate Teaching in the School of Medicine	King's College London
Jose Espinosa	Researcher	The "Qualy" Observatory/WHO Collaborating Center for Palliative Care Public Health Programs, Catalonia
Josep M. Comelles	Professor	Universitat Rovira i Virgili (Tarragona)
Josep Porta	Head of Palliative Care Services	Institut Català d'Oncologia (Catalan Institute of Oncology)
Maria Pau González Gómez de Olmedo	Licenciada en Psicología. Especialista en Psicología Clínica… (Postgrado de antropologia social en Barcelona)	The "Qualy" Observatory/WHO Collaborating Center for Palliative Care Public Health Programs, Catalonia
Marjolein Gysels	WP Lead "Culture and End of Life Care," PRISMA	CRESIB, Hospital Clínic—Universitat de Barcelona
Natalie Evans	Research Fellow	CRESIB, Hospital Clínic—Universitat de Barcelona
Noel Derycke	WP Lead, "Final conference", PRISMA	Universiteit Antwerpen (UA), Belgium
Richard Harding	Scientific Director, PRISMA	King's College London
Robert Pool	Research Professor	CRESIB, Hospital Clínic—Universitat de Barcelona
Roeline Pasman	Senior Researcher	Vrije Universiteit Amsterdam
Silvia Finetti	Researcher	Fondazione Lino Maestroni, Istituto di Ricerca in Medicina Palliativa, Cremona
Stein Husebo	Director	Dignity Center—the Frail Old, Bergen Red Cross Nursing Home, Bergen, Norway
Tinne Smets	Communication Scientist	End-of-Life Care Research Group, Vrije Universiteit Brussels, Belgium
Xavier Gomez-Batiste	Director	The "Qualy" Observatory/WHO Collaborating Center for Palliative Care Public Health Programs, Catalonia
Yasmin Gunaratnam	Lecturer	Goldsmiths, University of London

PRISMA = reflecting the Positive diveRsities of European prIorities for reSearch and Measurement in end-of-life cAre; WP = work package; EoL = end of life.

areas are a mapping of the themes from the group discussions and based on the participants' experiences in their daily work. The themes are summarized under the predetermined areas and this stays close to the raw data of the discussions. In the Discussion section of this article and in the tables, the priorities and the way they are layered and linked are the result of the inductive approach we took to the data, separate from the original predetermined areas. This led to a fresh view of how all suggested aspects of culture and EoL care are related, and how this is informed by the rationales and benefits of the priorities.

Cultural Competence and Ethnic Minorities

The concept of cultural competence was developed to enable health care providers to better respond to cultural diversity in practice.[20] Although existing cultural competence models are often not applicable in practice because of their complexity, participants stressed the importance of attention to cultural identifications and practices, consistent with the holistic approach at the EoL.

Holistic Conceptualization. The understanding of ethnicity as involving complex biopsychosocial processes is underdeveloped. This includes understanding how the cumulative problems of illness; economic, social, and linguistic marginalization; and racism affect palliative care experiences and needs. Interdisciplinary, multimethod research on culture and ethnicity is needed, with greater attention to the conceptualization and meanings of key categories such as "ethnicity" and "culture."

The Concept of Cultural Competence. Although used in a variety of ways, the term connotes an overly rationalist model of practice that does not acknowledge the relational and emotional dimensions of care and professional vulnerability,[10] uncertainty and doubt. Perhaps a new term is needed.

Recording of Ethnicity and Other Relevant Cultural Data in Key Data Sets and in Service Utilization. It is necessary to work with service providers to improve the collection of quantitative and qualitative ethnicity-related data.

Sharing of Information/Good Practice as a Basis to Develop an Evidence Base. A national palliative care and culture resource should be developed, with information on service initiatives (e.g., liaison/bilingual posts, multicultural education, and case studies).

Diversity in Changing Environments

The nature of cultural diversity in different countries varies and changes as a result of migration, aging and cultural mixing. For example, generational differences can signify different experiences of cultural integration, social inequalities, language use and cultural/spiritual identifications. Because these variations cannot

always be covered by the concept of ethnicity, there is a need for an evidence base informed by more multifactorial and longitudinal analyses of cultural diversity.

Aging Populations. Aging populations entail an increasing burden of chronic illness. Older people are, therefore, a priority for future research, and dementia in particular needs more attention. It is important to have a better evidence base for long-term care settings that are also sites of death. Communication and care preferences, including advance care planning, are priorities to be studied in these settings. Insight in these areas will form the basis for the further development of caring concepts, competence, and resources allowing the frail old to live and die with dignity.

Cultural Differences Between Countries and Regions. In some European countries, sociocultural issues in EoL care are relatively underresearched (e.g., Spain). As well, there are clear differences between the Mediterranean and the Anglo-Saxon traditions that need to be understood. These relate to areas such as ethical decision-making processes in spiritual and religious issues, family presence, caregiving, decision making and autonomy at the EoL, the organization of care for the dying, and palliative sedation.

Religious Identity in Pluralist Societies. Religious identity in pluralist societies can lead to polarized views, which, as is the case in Belgium, may determine approaches to appropriate EoL care. It is, therefore, important to carry out comparative analyses of EoL policies of national ethics committees with a special focus on the role of culture and religious identity in EoL care.

Advance Directives in Multicultural Settings. In Western society, respect for autonomy and a rejection of paternalism is important. Advance directives aim to promote patient autonomy at the EoL, but to what extent is the concept of autonomy culturally specific, and what are the culturally defined limits of patients' autonomy? Analysis of advance directive documents from different countries could identify their sensitivity to different cultural aspects of EoL care and the relative importance of autonomy.

Outcome Measurement

The concept of culture needs to be operationalized in relation to outcome measurement, especially given the current activity regarding the development of outcome measurement instruments in EoL care. The Palliative Care Outcome Scale (POS) is a widely used measurement tool that has been developed for patients in different settings and contains 10 core items covering physical, psychological, and spiritual domains.[21] This is one of several outcome measures in palliative care that aims to capture an overarching view of what is assessed, over the different domains that constitute palliative care, including both patient and carer needs and with attention to quality of care and quality of death and dying. Comparative research on variation in the interpretation of the POS, as well as similar instruments, would be useful. Also, an analysis of how such outcome measures have been adapted in various settings could shed light on how they have been adjusted and on associated successes and failures.

Translating and Adapting Palliative Care Outcome Measures to Different Cultural Settings. Key terms and concepts in outcome measures are sometimes difficult to interpret in different cultures and translation of terms may be problematic, for example, differences between the Argentinean and Spanish POS.[22] In some cultures, although the language is the same, the questionnaire may need adaptation, for example, the African Palliative Care Association's POS.[13] Further challenges emerge when patients are not fluent in the main language of the tool and ad hoc translations are necessary.

The Effects of Cultural Competence on Outcomes. There is uncertainty whether cultural competence can improve EoL care, and evidence is needed on how the cultural identity of patients, families, and providers can impact on outcomes. Particularly useful to understand is which aspects of someone's cultural identity could form a barrier to or enhance care, which can then inform ways to improve the access to and appropriateness of services. More insight is needed in differences between and within patient groups in how to measure outcomes, in their expression of symptoms, and how this can best be integrated into assessment tools.

Methodology

Equating culture with ethnicity is one way in which stereotypes are created.[23–25] In surveys, cultural identity is often determined on the basis of questions about nationality, country of birth, or country of parents' birth, but this may not reflect the respondent's actual self-identity, beliefs, or worldview. Suitable approaches to studying culture should be developed, as they are relevant to all other priority areas identified.

Developing Innovative Methods Capable of Capturing the Complexity of Cultural Effects at the EoL. Approaches developed in anthropology, involving participant observation, could identify how culture "works" in practice in EoL situations. This research could be part of a mixed methods approach with an iterative design and might focus on one particular issue and compare it in different settings.

Methods tailored to the specific challenges of researching EoL care need to be developed to take into account the sensitivities at the EoL, where participants often have limited time, strong emotions, and fluctuating capabilities.

Discussion

There is growing awareness of the need for evidence in EoL care,[26–29] and this has led to increasing research activity in clinical practice and the way services are organized and managed. Despite the importance of the role of culture, it has never been explicitly included in European initiatives to strategically address research needs. This is related to the practical demands of an emerging field of health care and to the biomedical model in health research.[30] Meanwhile, the influence of context on treatment remains poorly understood, and research is needed to clarify this.[31] A recent study showing the benefit of palliative care in addition to standard oncologic care underscores the importance of addressing context.[32] Modest progress has been made in the study of culture in EoL care, and the three broad lines of investigation, which the research agenda relates to, need to be pursued to enhance the effectiveness of care at the EoL (summarized in Table 2).

The first priority is clarification of the concept of culture.[7,33] Equating culture with ethnicity does not capture existing diversity in

Table 2
Research Priorities for Culture and EoL Care

Priority Area	Domain	Rationale	Benefit/Outcome
Culture			
Understanding of culture: theoretical and applied	• Concept of cultural competence • Alternative concepts • Uses of culture (ideologic, critical approaches) • Classifications • Recording of ethnicity data	To explore approaches conducive to mutuality and inclusiveness and identify barriers	Avoids the replication of problematic (insufficiently underpinned) interventions Questions routinized behavior Enhances the acceptability of services and successful communication
End-of-life care			
Experiences of receiving and giving of EoL care in all conditions, and including families	• The elderly • Dementia • Support networks • Role of spirituality	To explore the scope of EoL care and its responsibilities consistent with contemporary societal developments and diversity	Retains the holistic approach in EoL care and avoids fragmentation into disease-specific EoL care specialisms
Concepts central to or pervading EoL care	• Dignity • Good death/good life before death • Autonomy/heteronomy • Vulnerability	To develop clarity regarding definitions, boundaries, and purpose of EoL care as an emergent health care field	Promotes awareness of the specificity of EoL care vis-à-vis the medical goal of cure Allows for the building of an ethics suitable for EoL care
Practices in and interactions between diverse settings	• Social and cultural backgrounds • Service models • Positioning in relation to mainstream health care • Policy environment • Public perceptions and media	To uncover: • Norms and values • Assumptions • Motivations • Expectations	Facilitates intercultural exchange, transparency, and makes best practice examples available
Research			
Outcome measurement	• Impact of culture on outcomes • Impact of measurement on care	To operationalize the concerns relating to culture in EoL care	Provides valid research and assessment tools in EoL care
Methodology	• Long-term, in-depth methods • Mixed methods designs • Comparative studies focused on a specific topic of interest • Questioning of traditional classifications • Narrative approaches	To reach those areas that established study designs cannot and to develop approaches that can work with sensitive issues and impaired functioning	Provides valid methods for research

EoL = end of life.

contemporary societies, and reducing it to personal beliefs has little explanatory value. The further clarification of culture in EoL care will ensure that cultural differences in needs and wants deriving from individual, family, or community cultural contexts are recognized so that responsive care can be provided. This includes a rethinking of cultural competence and whether alternative notions are more appropriate.[34] This requires empirical evidence.

Second, a cultural approach, recognizing diversity and change, is needed to examine the definitions, boundaries, and purpose of EoL care. Concepts central to EoL care, such as dignity or good death, are not yet fully understood from diverse cultural perspectives. EoL care is based on concepts derived from Western bioethics, such as autonomy and quality of life, and these need to be situated if their use in EoL care is to be culturally appropriate.

Empirical evidence on experiences of receiving and providing care at the EoL in all conditions and in diverse settings will help to determine definitions of EoL and the scope of EoL care. Also, practices in and interactions between diverse institutional settings need to be

documented to gain insight into the underlying institutional cultures and value structures and how these affect care. This evidence is relevant for the development of quality indicators in EoL care.[35] Cultural issues such as the organization, values, and roles of providers are central to the quality of care that patients experience.[36]

Third, to operationalize the issues relating to culture in EoL care, there needs to be more focus on outcome measurement and methodologies to study culture. In outcome measurement, recent findings show that rigor alone cannot achieve meaningful results.[37] For the development of valid measures in research and practice, the effect of culture on outcomes, and of measurement on care, needs to be studied. Also, conversely, to study the effects of culture on outcomes and of measurements on care, valid measures must be developed. Mixed research designs, combining quantitative and qualitative methods, including ethnographic methods in particular, are needed to address the complexity of cultural effects on EoL care and the sensitivities related to patient and provider populations with varying levels of competence.

The priorities are interrelated, with the abstract notions of culture and EoL care informing operationalization and the applied approaches feeding back into the understanding of concepts of culture and EoL care.

Studies of different patient groups from various settings (e.g., long-term care) are needed to find ways to adequately deliver EoL care in diverse populations.[38] In this light, the focus on aging that emerged from the workshop is important, with more people living longer and needing appropriate care.

The barriers to conducting research on culture and EoL care are the same as those outlined for the clinical priorities,[39] where a lack of recognition for EoL care is responsible for a lack of funding. Social science is doubly affected, as the medical funding bodies tend to overlook the relevance of the wider sociocultural context and its potential role in improving care at the EoL. Multidisciplinary collaboration can contribute to developing this area of research, to which this WP within the PRISMA project has given the incentive by setting up a network of expertise, bringing experts together to give direction to this field, and creating several channels to exchange ideas and ensure collaboration in the future.

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