



End-of-life care across Southern Europe: A critical review of cultural similarities and differences between Italy, Spain and Portugal

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Abstract

Evidence from a range of sources demonstrates that end-of-life (EoL) care practices and preferences vary across countries; culture is consistently one of the main explanations given for this. In order to understand how cultural factors are used to explain similarities and differences in EoL care between Spain, Italy and Portugal, database and hand searches were performed and cross-cutting core themes identified. Similarities included higher proportions of people who wished to die at home than actually died at home, a persistent trend for partial disclosure in Italy and Spain, low use of advance directives, and low incidence of all medical EoL decisions (with the exception of

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Abbreviations: ADs, advance directives; DNRs, do-not-resuscitate orders; EoL, end-of-life; ICUs, intensive care units.

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terminal sedation) compared to northern European countries. The role of religion and the importance of family ties were the two main cultural factors used to explain the similarities. Further research is needed in order to interpret the important differences that were also found. © 2011 Elsevier Ireland Ltd. All rights reserved.

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1. Introduction: different approaches to culture in EoL care

There is growing interest to integrate the cultural dimension in EoL care [1–3]. However, culture is a broad, multilayered concept [4–6] and the approach taken to understanding culture influences its potential contribution to improving EoL care. There are at least three different perspectives on the relationship between culture and medicine. These three perspectives can also be distinguished in the context of EoL care.

The most common approach links culture to the ways different groups of lay people understand and face health, illness and death: it is considered important to understand the *culture* of specific patient groups in order to improve their access, and adherence to medical services and treatments. This was the first approach to be used in medical anthropology and, nowadays, in western countries, it is mainly used to understand the behaviour of immigrant, minority and ethnic groups and is associated with clinical notions of 'cultural competence', 'cultural sensitivity' or 'cultural awareness' [7–9]. Nevertheless, it can also be associated with patients' other characteristics: illness related practices may also differ depending on age, gender, urban or rural origin, etc.

A second perspective, or group of perspectives, recognizes medicine itself as a cultural system with a specific understanding of disease, human body, and cure [4]. It also acknowledges the differences between specialties within medicine in the way they understand disease, treatment and care [10]. This is the perspective of those who explain palliative care as a 'new culture' within medicine [11], whose aim is to give total care to patients approaching EoL, and thus, differs from the main curative, death-denying approach of some other specialties.

Finally, a third perspective explores the geographic, social and cultural contexts of both patients and medical systems [12]. This approach is helpful in understanding why supposedly neutral, scientific and medical practices vary from place to place. This is the approach to culture applied in this article.

Evidence from a variety of sources suggests that many EoL care related practices, such as pain management [13], medical EoL decisions [14–16], and disclosure of life threatening diseases [17,18], vary across regions of the world, countries, or regions within countries. The influence of culture is consistently given as one of the main explanations for this variability [13–18]. In these comparisons, Italy, Spain, and Portugal are usually grouped together as part of 'Southern Europe' [19,20], the 'Mediterranean area' [21,22], or as representing 'Latin' [23], or 'Catholic' [14,24] culture. Other countries,

such as France and Greece, share some, but not all, of these characteristics. When grouped together, they are frequently contrasted with other sets of countries, such as those defined as 'Northern European', 'Anglo-Saxon' or 'Protestant'.

This article aims to understand how, in the literature, cultural factors are used to explain the similarities and differences between EoL care practices and preferences in Spain, Italy and Portugal. First, the preferences and practices in several EoL care domains in Italy, Spain and Portugal are synthesised, with a focus on the similarities and differences found between the three countries. Later, the explanatory potential and limits of the cultural factors, as they are used in the literature, are discussed. Throughout, special attention is given to qualitative research as a means to understand the role of culture in EoL care in different countries.

2. Design

This critical review of the literature was undertaken as part of the EU (FP7) supported PRISMA programme which aims to inform best practice and harmonise research in EoL care for cancer patients across Europe [25]. PRISMA incorporated a work package on the influence of culture on EoL care in different European countries.

Country-specific searches were performed in eight international and four Spanish databases (Table 1), using a set of search terms for the country, EoL care, and cultural factors. The search terms for cultural factors were chosen with the aim of retrieving articles concerning EoL care where cultural and social factors were sufficiently relevant to be referred to in the title, abstract, topic or key words, and articles which used qualitative, and particularly anthropological techniques (Table 1).

Reference searches were also undertaken using articles retrieved from database searches. In addition, key Spanish and Portuguese palliative care and cancer web pages, the Spanish medical anthropology bibliography compiled by Perdiguero and Comelles [26], and the abstracts from a number of Spanish and European medical anthropology conferences were also consulted (Table 1). Furthermore, a number of articles were recommended by experts participating in the PRISMA project's network of experts in cultural issues in EoL that was set up in parallel to the literature reviews. Articles in English, Spanish, Portuguese and Italian were included.

In the final selection of articles, original studies that focused on 'culture', operationalised as the perceptions, opinions, understandings, knowledge, preferences, attitudes, practices and behaviours of the different actors involved in

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