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## Intercultural mediation at the end of life. Different perceptions of the same process

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### Abstract

The aim of this study was to identify the perceptions of palliative care professionals with regards to the management of patients from a different culture, and if there is a need to incorporate an intercultural mediator. To understand the influence of the intercultural mediator as a facilitator in the decision making of the patient and family at the end of life. The methodological approach is centered in pluralism, reinforced by triangulation of data and information. The intercultural mediator is crucial because they can provide light in a multitude of conflict situations caused by lack of knowledge about the patient's culture.

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### 1. Introduction

Death is a concept constructed by society. The fears, hopes and reactions that people have with regards to death are not instinctive attitudes, but learned within their culture. Every culture has a coherent vision that tries to explain and give meaning to the chaos that is death. The strategies that the patient uses to cope with this experience depends largely on the culture from which that person comes and on the cultural weight that dying represents in it. Although the individual's perception is associated with traditions, different concerns are found at the moment of planning the final days. If we want to be respectful to others, but also aim to exercise professional care, we must begin to understand the vision of the people we are with, how they think, how they perceive the moment surrounding death, what are their

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needs, its significance, what are the care practices of their culture, how they imagine the end of life and how they explain things that happen.

End of life care, as per Vivanco (2013), requires an approach of active compassion, comfort and support to patients dying of progressive or chronic conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and includes support for family and friends during the period of mourning. Cultural beliefs and practices are aspects that become relevant in care and decisions made in the process of dying; a review of the literature by the Catholic University of Chile (Rodríguez, 2005 & Gonzalez, Fernandez, Fuentes, & Medina, 2012), states that the approach of death involves considering values and practices of important cultural origin, it is necessary to foster an atmosphere where the expression of culture is supported and celebrated; preventing cultural clashes which disturb the patient and family and enabling care to be focused on the person.

Individuals are unique, valued in themselves until the time of their death. People's desires and needs must be respected. Some important components of the philosophy of palliative care can be influenced by culture in terms of beliefs, expectations and familiarity. These include: the perception of the patient and family as the core of care, physical aspects of care including symptom control, psychological support, the ethical dimension, decision making and care practices, expressions of mourning and rituals.

In order to provide quality care, it is necessary to ensure culturally competent care at the end of life; this concept was introduced into nursing discipline by Madeleine Leininger, when she founded the field of Transcultural Nursing in the mid-50s. Later, in the 60s, she defined it as the beliefs, values and lifestyles of a particular group that are learned and shared, and usually transmitted by intergenerational contact influencing the ways of thought and action (Leininger, 1995). According to the author, this definition allows us to understand the holistic dimension of a culture; this is important because culture shapes the way the person experiences health and disease (Spector, 2012).

Other important authors in the field of Transcultural Nursing either rely on the Leininger's definition, or (without naming her) offer various definitions of culture, addressing their own models and theories. This is the case of authors such as Larry Purnell and his model of cultural competence, Dula F. Pacquiao and his model of decision making, the Josepha Camphina-Bacote ethical performances culturally competent in care model, the theory of cultural traditions in health of Rachel Spector, the Gigger and Davidhizard model or the Toni Trypp-Reimer model (cited by Galao-Malo, Lillo, Casabona & Mora, 2005).

Except for Leininger, none of the revised theories take into account cultural competence at the end of life; this was one of the reasons why it was felt necessary to analyze these theoretical considerations in the healthcare field, and evaluate whether this philosophy, that is leading transcultural nursing, has a place in the daily life of professionals working with patients in their final stages.

In this paper, we explore the approach of diversity management at the end of life by palliative care professionals, what their needs and perceptions are, and their attitudes to the final journey of people from other cultures; also we intend to analyze what they perceive as necessary in the final care of people from other cultures; and if they know the signifiers and meanings of each culture.

This confrontation of perceptions can allow us to describe the position in which each one of us is, what we give to them, what we should give and if we truly are willing to do it.

## **2. Objectives**

To identify the perceptions of palliative care professionals with regards to the management of patients from a different culture, and if there is a need to incorporate an intercultural mediator. To understand the influence of the intercultural mediator as a facilitator in the decision making of the patient and family at the end of life.

## **3. Methodological strategy**

This section describes the methodology and technical design developed thus far, which is rooted in an approach of methodological pluralism, accompanied by triangulation of data and information, emphasizing the need for coherence between research methods and the object of study. Given the diversity of aspects we wanted to espouse, we have employed different social research strategies and techniques. Three types of methodological approach have been used to address the needs of palliate care professionals encountered during final journey of patients from different cultures,

as well as the ones perceived as necessary by cultural sources, responding to the objectives set out above.

Secondary sources: here we incorporated both bibliographic and administrative sources that allow us to briefly describe the organizational framework of the Andalusian health and social care system dedicated to palliative care, and studies/research on cultural diversity in health and methods of assessing this. In this case, we used both quantitative and qualitative approaches.

Primary sources: Our primary sources are supported by qualitative analysis; the bulk of the fieldwork data collection was based in in-depth interviews carried out with different types of people who could be classified into two categories:

I. Professional nurses who care for terminal and palliate care patients in the province of Huelva, both home care and specialized care (we selected a total of 7 professionals). In this subgroup interviews with people were carried out, consisting of what we might call two different profiles:

Nurse case managers from Huelva city, Huelva Costa and Huelva Condado-Campaña.

Palliative care professionals, both from support teams, and from the hospital unit

II. Intercultural Mediators from the most prevalent cultures: two informants were interviewed from sub-Saharan Africa, three other Maghrebi people and a girl from eastern Europe (although she is not practicing as a mediator at the moment but is aware of the culture).

The knowledge and experience gained after the completion of this first phase of interviews allowed us a closer look at the needs of foreign patients at the end of life, and how the dominant culture intervenes in the exercise of care.

For the selection of the respondents, rather than meet criteria for representative sampling (which made little sense for this research) we chose a theoretical sampling in order to approach people who might socially represent different discursive spaces regarding care at the end of life and issues arising from possible intercultural shocks.

The selection of informants from the group of intercultural mediators was originally developed with a theoretical perspective, but given the difficulty of locating them, we decided to use snowball sampling, which is based on the idea of social networking and consisted of gradually expanding the subjects in our field based on contacts provided by other subjects.

The number of selected participants was defined by the principle of speech saturation, i.e. collecting data from informants until the qualitative material ceases to provide new material.

The data analysis was performed using the Taylor-Bogdan model (1987): there is a phase of action-discovery (finding themes by examining data from all possible sources), one of coding (collection and analysis of all data referring to themes, ideas, concepts, interpretations and proposals) and a data relativization (interpreting it in the context of how it was collected). We used the software Atlas.ti.

## 4. Results

First, we will detail the coding of the categories listed by our professional nurse informants, we include those guidelines that a professional should follow when dealing with a patient from another culture in a terminal situation:

### 4.1. Migration project: etiology.

The professionals suggested the need to find out during the interview with the patient and the family (when it happens) why they emigrated, the time spent in our country and how well-adapted they are. "It is important to know why the country was chosen, how much the family depends on the patient and if they have social networks here to support them, because sometimes they care more about this than about their own disease process".

### 4.2. Migratory grief.

The need to identify the social networks that patients have in the host country, as well as their behaviour during the adaptation and final process, because it reduces the toll of their migratory grief initially and at the end. "Some patients tell us it was more difficult to explain to the family that they could not find work here, missing their loved ones and

lying to them on numerous occasions that this final process in itself".

#### *4.3. Spirituality.*

Each religion gives meaning to the lives of individuals from that culture, giving them a paradigm of life, in which they relate good and bad, what is normal and what is not, but we cannot confuse religion with spirituality because in some cultures religion makes them very spiritual in their coping process and see it as one more step in life, but in other cultures, spirituality does not depend on religion but on the philosophy of life of each individual. "Muslims like animists are patients who see death as the end of life, but Western culture sees it more as a punishment, it is necessary that the person processes this, and there are some cultures that promote that more than others".

#### *4.4. Coping strategies: individuals/family.*

In this category the family organization, the patriarchs or matriarchs, and how these roles are positioned within each family are very important issues, this is an important cultural component. "We are used to living with machismo, not challenging it, and we use the role of our culture where women can ask for information and decide, we will not allow it to be a male decision". "Depending on the family dynamics we must know how to mediate with them to embolden each family member to express themselves, this is very different depending on the different cultures", "(the family organization...) also influences their coping strategies when the family depends on them financially, there is no gender distinction".

#### *4.5. Conspiracy of silence.*

The conspiracy of silence is a cultural component of communication which is increasingly apparent in our work and much depends on the patient-professional relationship and the skill of professionals. We have to be very careful when undertaking the communication of bad news and not only with the language problem, even with patients who speak Spanish there is a cultural component that must be considered. "I deal with conspiracies in the same way independent of culture, I do the best for the patient". "The most important thing is to allow the patient to express himself and the family should help him, I will not do what the family tells me to". "I do not need anyone to help me give bad news".

#### *4.6. Practices and rituals in death.*

We need to know the rituals that the other culture performs at the funeral and post-mortem care and we must respect it. "For me it is irrelevant if he has to look to Mecca, what I do is be with him so that he can die in peace," "everyone needs to feel in peace at the final moment, I do not do more because I do not know the rites of each of them (culture), but I would value learning them".

#### *4.7. Culture of health professionals.*

Professionals who accompany the final process must have sensitivity when caring for the patient from another culture, because of the need be properly aware of our cultural prejudices that determine our behaviour during interaction with the other.

#### *4.8. Religion: education, paradigm, philosophy of life, gender, work, health-disease process.*

In Western culture we find patients have an increasingly tangible tendency to believe in this final process but have not been practicing throughout their life. "Women are more religious than men and young people are less religious than older people". "There are two types of patients, practicing believers and nonbelievers on the one hand and non-practicing believers, agnostics, etc., on the other, the least anxious individuals during the process of dying are practicing believers and non-believers".

With regards to the data obtained from the cultural sources and intercultural mediators, we found results relating to pain management: culture can influence the acceptance of the expression of physical pain, how to express the pain, the meaning given to physical pain and suffering. In many cases there is prejudice against the use of opioid analgesics for fear that the mind is altered or can create addiction, which is frowned upon. In this context physical touch becomes important. It is essential to consider who can touch whom and in what context (in some cultures men cannot touch women), which hand is used (some cultures use the right and left hand for different functions), if you can touch to provide emotional support, if they need the presence of a family member or not. Physical privacy, for example, can be crucial for the elderly in certain cultures. It is salient for Muslims to face Mecca. With regards to nutrition, it is important to consider the types of food that can be eaten, who can prepare and serve food and in what way, the usual practice in the process of eating. As for grooming practices, bathing formats, hygiene and cleanliness and eventually other complementary therapies: plants, massages, rituals, prayers, songs, and others can be significant.

With reference to communication, intercultural mediators consider the cultural value of reporting bad news, telling the truth to an older adult about an incurable disease may be one of the most problematic areas of care. For some cultures we should not tell the truth to the elderly since it only serves to upset them and make them lose hope. It also depends on the individual family.

When a language is not shared it can prove a big obstacle. Not all cultures talk and share emotions in the same way. There are also differences in non-verbal communication. Even speaking the same language, when this is the second language for both, you may even be saying the same words, but with a different psychological content or meaning.

Family and friends may have different roles depending on their culture. For example: who has the authority, what is expected of the gender, who makes the decisions, who can participate in family gatherings. Cultures have diverse expectations about the quality of care of health workers and social service providers.

## 5. Conclusions

As we have seen in the results, during the process of caring for others the professional adopts an ethnocentric stance, with the desire to care, but without being aware of their own cultural convictions restricting their care. The figure of the intercultural mediator is crucial for culturally competent care at the end of life, they can provide light in a multitude of conflict situations caused by lack of knowledge about the patient's culture.

Cultural competence is required in palliative care; we must learn from people of diverse cultures, their lifestyles, their context, their feelings, their concerns, their beliefs, practices and values. It is essential to obtain knowledge through research and carry the outcomes over into nursing practice and advance towards cross-cultural nursing. Intercultural mediation is a tool that we can use to facilitate communication with our patients, and we should encourage its implementation in health institutions to promote culturally competent intervention in the field of palliative care.

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