



GRIGORE T. POPA UNIVERSITY OF
MEDICINE AND PHARMACY IASI

**SOCIAL, PSYCHOLOGICAL,
SPIRITUAL AND CULTURAL NEEDS IN
THE CONTEXT OF PALIATIVE CARE
IN ROMANIA**

Ph.D. THESIS
ABSTRACT

Ph.D. candidate: Cristina SAVA (căs. CHIRILĂ)

Scientific advisor: Vasile ASTĂRĂSTOAE, M.D., Ph.D.,
Professor

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This PhD. thesis includes:

- The state of knowledge structured into 2 chapters with a total number of 31 pages
- The personal contribution divided into 2 chapters with a total number of 131 pages
- PhD. bibliography with 170 references
- An annex of 60 pages
- 2 figures in Chapter II
- 74 tables inserted as follows: Chapter II - 2 tables, Chapter III - 28 tables, Annex - 44 tables

NOTE: The current abstract contains only a selective bibliography.

Keywords: palliative care, social needs, psychological needs, spiritual needs, cultural needs, cultural assessment, cultural competence.

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1. INTRODUCTION

The incidence of diseases with limited life expectancy demands not only to provide an optimal legal framework for running and organizing palliative care services but also to study the impact of end-stage disease on the affected individuals. This impact is also expressed as social, psychological, spiritual and cultural needs.

Correlating the experience and good practices worldwide in the palliative field with the reality of the national healthcare system is a fair way to promote interculturality. Identity awareness can be achieved by formulating a paradigm that values specificity through a culturally competent approach.

2. STATE OF KNOWLEDGE

The current understanding of the dissertation topic focuses on the research of five most relevant subject areas: palliative care worldwide; palliative care in Romania; theoretical aspects and broad meaning of needs with respect to palliative needs; a review of the literature on social, psychological, spiritual and cultural needs; monographic analysis particular to the local context.

3. PERSONAL CONTRIBUTION

3.1. Research goals

This study was interested in exploring the social, psychological, spiritual and cultural needs associated with the current palliative context within Romania. The focus was also on specific manifestations related to the subjective reality of patients, families, medical staff and other team members involved in palliative care services.

3.2. Aims of the study

General objectives: analyzing current specific needs of patients, family and staff involved in providing palliative care and associating them with action measures and strategies adapted to the palliative context in Romania.

Specific objectives: investigating social, psychological, spiritual and cultural needs and defining methods for acquiring the cultural competence triad (awareness, diversity, sensitivity).

3.3. Material and methods

3.3.1. Study design

The study design has used methodologies of qualitative research. Data were analysed in two stages of research: the main research - data-based research (Grounded Theory) and the secondary research - the narrative analysis of selected reports.

The main methodological tools included the semi-structured interview and the standardized interview with open-ended questions. The participants were interviewed only once, individually (face-to-face or in some cases as written responses sent by e-mail), main and complementary. The secondary methodological tools were as follows: document analysis for recording demographic information (medical records and other available documents, such as identification papers, certificates of employment, social investigations), informal conversation, used as a means to initiate interaction with selected individuals from the target groups and to obtain the required demographic data that were not collected through secondary data analysis and observation.

3.3.2. Study population

The individuals in the study groups were selected as follows:

- target group 1 was selected from the patients registered in the palliative care ward of the Regional Institute of Oncology (IRO) Iasi;
- target group 2 was selected from families of patients registered in the palliative care ward of IRO Iasi;
- target group 3 included employees of IRO Iasi, healthcare workers involved in palliative care provided to patients in target group 1;
- target group 4 included medical professionals who are working both for IRO Iasi and for the medical school, but are active in disciplines other than palliative care, with the purpose of

acquiring different perspectives on the concept of cultural competence.

3.3.3. *Inclusion and exclusion criteria*

Inclusion criteria:

Eligibility in the target group 1: patients registered in the palliative care ward of IRO Iasi, of Romanian ethnicity and orthodox religion who were recruited to assess their specific ethnic and spiritual identity, which may be useful for a future interethnic comparative study, having the cognitive and physical ability to participate in an interview (according to the assessment of the coordinating physician of the palliative care ward), who gave their consent to participate in the study.

Eligibility in the target group 2: members of the families of patients registered in the palliative care ward of IRO Iasi, of Romanian ethnicity and orthodox religion (the inclusion criteria assume that the needs are specific to the native cultural environment, a comparative ethnic and / or religious study would be a suggestion for further research), aged over 18 years old, who gave their consent to participate in the study.

Eligibility in the target group 3: medical and non-medical personnel working for IRO Iasi, who are involved in the provision of palliative care, who gave their consent to participate in the study.

Eligibility in the target group 4: medical professionals who are working both for IRO Iasi and for the medical school, but are active in areas other than palliative care, who gave their consent to participate in the study.

Exclusion criteria: refusal to participate in the study, choosing to withdraw from the study and age less than 18 years for family members who participated in the interviews.

3.3.4. *Ethical considerations*

The study was conducted:

- with the approval of the Research Ethics Committee of IRO Iasi;
- after obtaining the informed consent of study participants;

- after informing participants about the research process, the purpose, the procedures used and the use of the data obtained from them.

Participation in the survey was voluntary and the patients were assured that they have the right to withdraw at any moment from the study without experiencing negative repercussions while receiving medical care and their personal data are protected through anonymity.

3.3.5. *Sample size*

The methodology of data-based research requires the sampling to be theoretical, which means that the number of interviews to be taken was not given from the start. Finally, 7 patients were recruited for the semi-structured interview. 11 healthcare workers (3 doctors, 7 nurses, 1 physiotherapist, 1 psychologist) were selected for the main structured interviews, 1 non-medical attendant (priest), 7 family members and 7 members of the teaching staff of the medical school for a complementary structured interview conducted in order to saturate the data needed for the final theoretical model.

3.3.6. *Selected variables*

The variables selected for the target group 1 (patients) were as follows: gender (male, female), age (18–29, 30–49, 50–69, 70+), educational level (elementary school, middle school, high school, professional school, university), marital status (married, single, cohabiting, divorced, widowed), socio-economic status (no income, low income, no health insurance), profession, occupational status (employed, self-employed, retired, out of work, unemployed), the diagnosis made known to the patient, the social network (living alone, living with his / her spouse / cohabiting partner, living with family / other people). The variables selected for the target group 2 were the following: relationship with the patient (parent, child, partner, relatives, others). The variables selected for the target group 3 were the role played within the palliative care team, professional

experience. The position occupied within IRO was considered in the target group 4.

3.3.7. Data collection

3.3.7.1. Instruments for data collection

3.3.7.1.1. Literature review as reference point for the interview guides

Several electronic databases (e.g. Pubmed Medline, Embase, Ovid Medline, EBSCO) were searched using keywords related to palliative care.

The main tools for assessing the needs used worldwide were selected and described. They were used for a content analysis that helped identify the social, psychological and spiritual needs, as they appear in the cross-cultural context. The selected articles were read in full text and the words or phrases regarding the previously mentioned needs were identified and underlined, so that a list of subjects was made. The interview guides were based on the literature review, which has provided valuable additional information on cultural specificity, all the more because of the lack of research associating palliative care with the cultural approach.

In developing the interview guides, six further methods and studies relevant to the scope of the present study were added to the tool items: Sherman's review on the needs of palliative care recipients, the MINI interview (The McGill Illness Narrative Interview), Bradshaw's Taxonomy of Need, the RISK model, Michael Quinn Patton's qualitative evaluation checklist and the method of controlled comparison described by Fred Eggan.

Four sets of questions were developed for each target group: interview guide for the target group 1 (patients), structured interview administered to the target group 2 (patients' families), structured interview for the target group 3 (medical and non-medical personnel - doctors, nurses, physiotherapist, psychologist, priest), structured interview for the target group 4 (medical personnel - teaching staff of the medical school).

3.4. Results

3.4.1. *Qualitative data analysis*

In order to carry out a qualitative data analysis, the interview was followed by a full transcription of data from audio recordings. The text was categorised into areas relevant for the next stages and data were assigned for the different types of analysis used. The data analysis itself followed two methodological approaches specific to qualitative research: the main procedure was data-based research (Grounded Theory) and the secondary method was the analysis of narrative fragments.

3.4.1.1. *Data-based research (Grounded Theory)*

The following epistemological models were considered: the grounded theory of Glaser and Strauss (1967), the grounded theory revised by Glaser in 1992 and the constructivist grounded theory of Charmaz (2006).

The methodological design has an exploratory nature, as the theory was gradually developed based on data collected on the ground according to the research objectives. Sampling was theoretical and interviewing was carried out without establishing in advance an exact number of interviews.

Besides the first three models, an additional data collection stage was required for the saturation of the explanatory theory and for supporting the interpretative approach of the final model. Another characteristic of this type of research is the triangulation of data sources, which means addressing the same type of question to several categories of subjects (in this case, patients, medical and non-medical staff and patients' families, in order to increase the credibility of the developed final models, due to the usual lack of statistical validity of the data obtained by quantitative analysis.

The process of theoretical development was mainly inductive. The cycles of induction were consecutive, until the final theoretical model was developed. The first induction was an open or initial coding, the second induction was the axial coding (theoretical, as in the model revised by Glaser in 2004), and the third induction was the selective coding, a stage focused on identifying central and

secondary categories and on establishing relationships between categories, which make up the developed theory.

3.4.1.2. *Open coding (data summary)*

The open coding, also called by some authors initial, conceptual or thematic coding, was carried out in two simultaneous stages: conceptualization and summary of data. Coding on questions was used for conceptualization, according to the scale developed by Williams and Johnson, in which each question addressed is associated with all the answers of the respondents, as extracted from the *in vivo* text of interviews (previously transcribed from audio recordings). This text was analyzed line by line and reduced to the semantic content of the question (Annex 1).

3.4.1.3. *Axial coding*

The second induction called axial coding was achieved by tabulating the answers of the respondents according to 3 main thematic axes: needs as reported by healthcare workers, needs as reported by patients' families, needs as reported by patients and 4 secondary axes: patient's needs, needs of the patients' families, needs related to the social system and needs associated with the healthcare system.

Following the primary data analysis, two thematic axes were added later: needs with respect to cultural assessment and needs with respect to cultural competence. The transcripts of the summarized *in vivo* semantic structures were associated with codes, memos and the inductive application of primary and secondary categories.

The most common semantic categories found in the respondents' discourse were similarly tabulated to allow for response comparison from different points of view. The primary categories identified were subsequently associated with the types of needs specified in the first place: social, psychological, spiritual and cultural needs, in addition to which there are two related categories, physical needs and needs seen from a holistic perspective. Identifying categories and relationships between concepts and categories, the initial meaning of data, the relation to the existing

literature make the transition to the next level of generalization which is the selective coding.

3.4.1.4. *Selective coding*

As with open coding and axial coding, the identified codes, memos and secondary categories have been gradually classified as primary or central categories. The central categories established for the existing data were customized to the informative research areas: social, psychological, spiritual and cultural needs plus categories related to them: physical, holistic needs, ethical and legal issues, actions to be taken and recommended approach.

By using selective coding, the respondents' answers were classified according to the established central and secondary categories, as follows:

Social needs	Information needs		
	Counseling needs		
	Needs for social interaction		
	Material and financial needs		
	Instrumental needs		
	Social support needs		
Psychological needs	Attitudinal needs		
	Emotional needs		
	Existential needs		
	Behavioral needs		
	Communication needs		
	Coping mechanisms		
	Needs for psychological / psychiatric support		
Spiritual needs	The importance of faith (religiosity)		
	Attitude towards death		
	The perspective of the faithful		
	The perspective of the unbelievers		
	The problem of conversion		
	Religious conscience (guilt, remorse, moral influence)		
	The need for spiritual support		
Cultural	From the	Demographic	Residential status

needs	perspective of cultural assessment	data	Age
			Educational level
			Occupation
		Attitudes, beliefs and practices related to health, illness, suffering and death	Beliefs on disease
			The presumed cause of the disease
			The approach of traditional medicine
			Prejudices
			Describing the structure and characteristics of the family
			Participation in religious rituals
			Performing mortuary rituals
	Place of death		
	From the perspective of cultural competence	Cultural diversity	The role of ethical values and legal regulations
			The importance of the patient's faith and rite
			Attitude towards alternative medicine
			Representations and prejudices
		Cultural awareness	Communication barriers
			Educational barriers
			Socio-economic barriers
			Barriers related to origin
			Barriers related to religion
			Barriers related to ethnicity
			Gender barriers
			Other barriers (patient's mental status, degree of resilience, presence of associated organic dysfunctions, ignorance of existing barriers, different perceptions, lack of empathy)
The importance of ethical issues			
Medical staff training			
Cultural sensitivity	Doctors' attitudes		
	Doctors' skills		

		Cultural competence	As reflected in the daily practices and behaviors of the healthcare workers
			Increased patient compliance and accountability
			More efficient management

3.4.2. *Narrative data analysis*

Narrative analysis is characteristic for qualitative research. It was applied by including interview questions with the purpose of obtaining narrative sequences that could complete the overall picture of needs.

The analytical abstraction was achieved in this case by dividing the interviews into narrative sequences and creating titles for each sequence through the identification of sequential themes. The central stories were accounts of the medical personnel and of the patients' families on topics with the greatest emotional impact and a short exercise of rating the needs performed by patients.

In the second stage of the sequential analysis, the answers were grouped according to the categories of respondents and correlated with the psychological, social, spiritual and cultural relevance of the content.

3.5. Discussions

The discussion section highlighted the particular features of the Romanian context of palliative care, while also addressing issues not included in the research objectives (and illustrating the phenomenon of *serendipity*) that fall into categories seen as related and similar, such as physical needs, needs considered from a holistic perspective, ethical and legal issues, ethical issues, the action strategies and the approach suited to the palliative care services and to the healthcare system.

3.5.1. *Study limitations*

The study limitations derive from the very limits of qualitative research itself, which takes into consideration above all the validity of the obtained results. It is difficult to assess the objectivity of the achieved results, since the results cannot be generalized, as they are specific to the study group, due to the fact that the qualitative research requires an in-depth analysis of the study population. Other limiting aspects of the study were the small number of enrolled subjects, as compared with the larger groups used in quantitative research, the subjectivity of the researcher and certain methodological characteristics such as the inclusion in the study of a group that was comprised solely of cancer patients from a single institution.

In some cases, a limiting factor was a lack of trust in the interview method expressed mainly by members of patient's families, many of them refusing to participate for this reason. Other sources of bias were the formalization imposed by interviewing, the stage fright caused by the lack of experience with audio recording and healthcare workers' assumption that the answers will be judged or compared with the responses of others. Moreover, the single interview method provides a variable amount of information depending on circumstantial factors such as the general context, the location of the interview, the mental and physical state of the interviewee and how the aim of the study was perceived.

3.5.2. *Original contribution*

The research is thorough and qualitative in nature, which allowed for the analysis of issues that have not been yet considered, such as the needs specific to the current palliative context within Romania, which were estimated by multidimensional analysis and from different perspectives, and the optimal measures to be taken, according to the stakeholders involved in the palliative care process. There are very few doctoral theses in Romania in the field of palliative care. Literature search has yielded systematic reviews and meta-analyses of different needs in palliative care, but no exploratory studies have been found, which makes the present research different.

The significance of this study is also due to the number of respondents (33 in total, with at least 7 in each category: patients, family, medical staff), which is a significant number for qualitative research. An additional contribution was the methodological approach, as the data resulting from coding specific to data-based research (Grounded Theory) could be used as a starting point for further quantitative or comparative research.

Given the existing context of interethnic mobility, the analysis of the concepts of cultural evaluation and cultural competence within the context of the Romanian healthcare system and finding ways to use them in the training and practice of medical personnel are also important research questions which have not been addressed until now.

4. CONCLUSIONS

1. Understanding the needs of palliative care is essential for creating an optimal care plan and implementing an efficient management with real and up-to-date information.
2. The interdependence of needs backs up the importance of holistic interdisciplinary approach towards needs, while emphasizing the major role of the team in the palliative care services.
3. The development / validation of tools for assessing physical, social, psychological, spiritual and cultural needs and customizing them for several types of respondents are important for recognizing and ordering the needs characteristic to the Romanian healthcare system.
4. The analyzed descriptive aspects require the issuance / change of legal norms, so that the needs of all participants in palliative care are met (e.g. adequate services and facilities for patients, support for families not only while nursing, but also during the mourning period, post-discharge multidisciplinary follow-up of patients).
5. The difficulties of interviewing patients during end-stage disease is an argument for making a complex and multidimensional assessment in the early phase of the disease, followed by monitoring the patient, which ensures an ethically valid approach, but also an updated and readily available record for the transfer between different locations or levels of care within the healthcare system.

6. The particular importance given by respondents to resilience make the ability to cope with stress a central theme of research.
7. The concept of cultural competence involves opportunities for inclusion and professional advancement during the training and practice of healthcare workers, as a sign of a policy of inclusion and non-discrimination favored by a society characterized by increased migration.
8. Spirituality and culture shape the other types of needs, which is why the survey of patients and the self-evaluation of medical professionals regarding cultural competence have a positive impact on the organization of the care process.
9. The presence of communication barriers and ethnic disparities, as reported by respondents, recommends organizing training programs for medical professionals in communication skills and interethnic relations / multiculturalism.
10. The case studies, the narrative analysis and the life narrative provide a better understanding of the existing needs, which is why teaching these methods during the training programs for healthcare workers could be a means of improving the quality standards of palliative care in Romania.

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