



Journal of Nursing

Revista de Enfermagem

UFPE On Line

ISSN: 1981-8963

ORIGINAL ARTICLE

COMFORT IN PATIENTS WITH NO CHANCE OF CURE - WHAT DOES IT MEAN?

CONFORTO EM PACIENTES FORA DE POSSIBILIDADES DE CURA - QUE SIGNIFICADO?

CONFORT EN PACIENTES SIN POSIBILIDADES DE CURA - ¿QUÉ SIGNIFICA?

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ABSTRACT

Objective: to identify the meaning for nurses to provide comfort care for patients that are without possibilities of cure in a health institution in Lisbon. **Method:** a descriptive, exploratory study with qualitative approach with discourse analysis of the subjects, on the question: How does a nurse experience the process of providing comfort care for patients without any chance of cure? Data collection was performed by means of recorded interviews, with signature of Free and Clarified Term of Consent, conducted between January and April 2010, with twenty nurses in service for the Medical and Surgical Hospital of Lisbon, as authorized by the Ethics Committee of the institution. **Results:** two categories emerged: personal experience and professional requirement; conflicting points. **Conclusion:** the focus of providing comfort in patients with no possibility of cure is rooted in the interpersonal relationship between nurse and patient at the end of life, thus guiding the activities of the nurses to a level of excellence. It appears that the influencing factors are enhanced by the human condition and the tenuous preparation of people involved to face death. It is necessary to enhance training in the various grade levels. **Descriptors:** Nursing Care; Comfort; Terminal Care.

RESUMO

Objetivo: identificar o significado para enfermeiros da prestação de cuidados de conforto a pacientes fora de possibilidades de cura. **Método:** estudo descritivo, exploratório, de abordagem qualitativa, com análise de discurso dos sujeitos, a partir da questão "Como é que o Enfermeiro vivencia o processo de prestação de cuidados de conforto em pacientes fora de possibilidades de cura?" A coleta de dados foi realizada por meio de entrevistas gravadas, com vinte enfermeiros do serviço de Medicina e Cirurgia de um Hospital de Lisboa. **Resultados:** após análise das informações emergiram duas categorias: 1) experiência pessoal e exigência profissional 2) eixos conflitantes. **Conclusão:** o foco da prestação de conforto em pacientes fora de possibilidades de cura encontra-se alicerçado na relação interpessoal entre Enfermeiro e pacientes em fim de vida, norteando assim as intervenções dos Enfermeiros para um nível de excelência. É necessário potenciar a formação nos vários níveis de graduação. **Descritores:** Enfermagem; Cuidados de Conforto; Assistência Terminal.

RESUMEN

Objetivo: identificar el significado para los enfermeros de la prestación de cuidados paliativos a pacientes sin posibilidades de cura. **Método:** estudio descriptivo, exploratorio, de abordaje cualitativo, con análisis de discurso de los sujetos, a partir de la pregunta << ¿Cómo experimenta el Enfermero el proceso de proporcionar atención paliativa a los pacientes sin posibilidad de cura? La recogida de datos fue realizada a través de entrevistas grabadas, con veinte enfermeros del Servicio de Medicina y Cirugía de un Hospital de Lisboa. **Resultados:** tras el análisis de la información surgieron dos categorías: 1) experiencia personal y exigencia profesional 2) ejes conflictivos. **Conclusión:** el foco de la prestación de cuidados paliativos a pacientes sin posibilidades de cura está basado en la relación interpersonal entre Enfermero y pacientes en el final de la vida, orientando así las intervenciones de enfermería hacia un nivel de excelencia. Es necesario potenciar la formación en los distintos niveles del grado. **Descriptores:** Enfermería; Cuidados de Comodidad/Cuidados Paliativos; Atención Terminal.

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INTRODUCTION

According to theoretical studies, despite conceptualization of nursing care being different, they are all unanimous while considering that the care provided follows the human being from conception to death, thus some of them highlight the importance of nursing care for terminal patients. The negativity inherent in the word 'terminal' originated today in the expression "with no chance of cure", so this expression is also used throughout the study. Thus, the condition of absence of curative treatment available for specific patient requires a set of care methods, known as comfort care for the person without any chance of cure, and they should definitely ensure human dignity.

Given the proposed theme, it becomes essential to contextualize the historical path of death and the processes of dying, as well as to analyze how the concept of comfort has been studied by several theoretical studies of nursing. Such attitude allows to review the main focus of the study - the end of life and comfort care.

The knowledge of death and issues around it reveal how different and changeable was, throughout history, its relationship with humanity. The place of death has been neither simple nor stable. One of the biggest changes in the twentieth century was that the hospital became the most common place of death instead of the family house. The hospital began as a place dedicated for cure, and quickly became a normal place of consummated death.¹ This practice of avoiding imminent death (at home) also includes the attempt to maintain people unaware during the terminal phase, towards the severity of the disease and the proximity of death, which requires significant changes in family rituals of saying goodbye at the time of death. Sometimes a person dies unaware they will die, or in some cases, unable to express they are aware they will die. The silence often becomes the most common attitude in confronting death. Advances in medical and health science of the twentieth century have imposed numerous barriers, and without them life (or any expression of it) cannot exist. Death was extended as ultimate limit to the human being. It became an obstacle to life, which must be overcome. Death creates fear, in a way that, sometimes the reference to the word is synonymous of the aggravation of it. The western view of death is marked by fears, anxieties and anguish. Basically, death remains the most unknown fact. One knows when someone is dead, but it ignores what

dying is about, as seen from inside.²

Nursing care can sometimes be full of defense attitudes by nurses, since the human condition drags their own fear of death into care giving, preventing them to relate to the person who is dying which becomes an obstacle for the care process.

While it is true that all humans will experience death sooner or later, its discovery is assumed as the antithesis of life. After all, death is not surprising, but the bright and sharp insight that death is the future. And the unavoidable certainty that the future is deadly does not eliminate unpredictability. This way, recognition of being a mortal is the anthropological expression, since dying is a human condition and death is a full part life - and therefore the meaning of death is within the meaning of life.²

Thoughts about death and feelings inherent to it influence how each person experiences the process of death. In this context, the nurse faces new challenges in his confrontation with the constant sense of life and death. However, death is not a subject freely thought. It is both an imperative of life and the outcome of certain situations that determine the end of it.

Providing care to people with no chance of cure is a confrontation of the nurse with the challenge of understanding death, involving issues of subjective analysis and on the other hand, directs the research within the care of comfort.

The word comfort is daily used in different contexts of nursing care. The concept is often related to the physical dimension of the person, however provides, in the nursing literature, a broader outline.

In references carried out in the literature in the early twentieth century, comfort was assumed to be the primary goal of nursing. The focus towards discomfort in order to understand the comfort and the measures implemented by nurses to relieve the distress of patients goes against the core of nursing. In this sense, comfort may be considered the last health status, and this way being recognized as a goal of nursing.³

Several authors such as Ida Orlando, Callista Roy, Hildegard Peplau, Jean Watson, Madeleine Leininger, Josephine Paterson, Loretta Zderad, Joan Hamilton, Janice Morse and Katharine Kolcaba contributed from the second half of the twentieth century, not only for the growth of discipline, but also to clarify the concept of comfort, in order to be considered one of the major goals of nursing.

The theory of Transcultural Care⁴ as well as the theory of Human Care⁵ explain what is nursing, also including the sense of comfort. Leninguer identified comfort as a major construct of the taxonomy of caring, which is the utmost importance that this is evaluated in the respective cultural context making it possible to provide quality care, holistic care.⁴

In Watson's Caring Theory, comfort is described as a condition that interferes in the development of internal and external person.⁵ Comfort is an external variable that nurses can control. The comfort provided by the nurse shall be more effective. It is considered that activities of comfort may be supportive, protective or corrective of personal development. Socio-cultural comfort measures were identified as related to habits, behaviors, cultural values, family life and social class of the patient, recognizing that knowledge and respect for the spiritual meaning given to life by each person can be extremely comforting.⁶ The transpersonal care allows humanity to collectively move towards greater harmony with the mind, body, spirit, himself, with others and with nature.⁵⁻⁶

Kolcaba, contemporary theory, concerned with this assessment, considers comfort as a state in which basic human needs are met concerning relief, tranquility and transcendence in four contexts of experience: physical, psycho-spiritual, sociocultural and environmental.⁷⁻⁹

Although it is agreed that comfort is central to nursing and to the action of nurses, there are different perspectives within the various theories of nursing, especially in the conception of Watson, Leininger and Kolcaba. In the Theory of Watson and Leininger Caring assumes a central importance and comfort is a component of caring. Leininger and Watson consider comfort as a component of caring.^{4, 6} Kolcaba agrees that nursing intervention is the action of comfort and that comfort is the result of such intervention. However, he believes that studying the process of comfort without evaluating the results is an incomplete exercise and shall therefore have an underlying process of conceptualization and functionality.^{7,9}

Whereas the last stage of life is full of intense moments, often associated with suffering, and that professionals are not accordingly prepared to deal with death, it becomes relevant to know the meaning of comfort for nurses, arising the need to prepare them to face the process of comfort and death. Thus, this study aims to

prepare the professional how to deal with emotions in relation to patients with no chance of cure.

Driven by the need to understand the questions relating to comfort in the last stage of life, all efforts are invested in this area, defining the object of study to provide comfort to people at the end of their life.

OBJECTIVE

- To identify the meaning for nurses to provide comfort care to patients with no chance of cure.

METHOD

In order to reach this objective, it is chosen to study with a qualitative, descriptive and exploratory approach, considering that this type of study applies best to handle the questions raised. Qualitative research is concerned with the meaning each person gives to their experiences, seeking to go deeper, to see beyond what is allowed to see outside, trying to understand what they experience, how they interpret their experiences and how they structure the social world they live.¹⁰

The scenarios of the study were a surgery service and a medical service of a public hospital in Lisbon, as they are key sectors where nurses often experience situations to provide comfort care to patients with no chance of cure. The period for data collection corresponded the months from January to April 2010. It was defined the following inclusion criteria: (1) minimum two years of professional experience in the area, (2) experience the phenomenon under study and (3) accept the audio recording of the interview. For data collection followed a script of semi-structured interview following guiding question: How is the process of providing comfort care for patients with no chance of cure experienced? The criterion of data saturation criterion was used for defining the sample, since this occurs when the information transmitted by the subjects of study becomes redundant or repetitive.¹⁰

The interviews were recorded using an audio device, in a reserved area ensuring privacy for the process. After data collection, a systematization of the transcribed text was carried out, reviewing data with the technique of content analysis, which is a set of techniques of communication analysis that uses systematic procedures and objectives of description of the content of messages.¹¹ The systematization of data was carried out aiming the pre-analysis, followed by material investigation and the treatment and

interpretation of results.

This procedure allowed the identification of expressions of each speech, seeking for similar and divergent points, going through grouping of the most important issues. In order to ensure anonymity of the subjects, the letter E was used followed by the number corresponding to the order of the interview. Ethical observances were followed for research involving human beings, according to the Declaration of Helsinki ¹², ensuring the ethical general principles of research, data confidentiality, voluntary participation of the subjects, their anonymity and respect for autonomy of the person, using for this purpose the Free and Clarified Term of

Consent.

RESULTS AND DISCUSSION

The group consisted of 20 nurses, from which 15 were females. Half were married and were aged between 25 years and 41 years, with an average of 29.5 years old. Results are presented from theoretical reference and several transcripts, where the body of the study discussion emerged in two categories: ‘personal experience and professional requirement’ and ‘conflicting points’. In each of the categories, in different lines, several sub-categories were identified (Figure 1).

Category	Sub-category	Speeches
Personal experience and professional requirement	Satisfaction of needs and desires	E3, E4, E8, E17
	Experience feelings and emotions	E1, E3, E8, E16
	Monitoring	E2, E11, E12
	Emotional Involvement	E4, E18
	Professional and personal responsibility	E9, E19
Conflicting points	Environment	E5, E6, E10, E11
	Family presence and participation	E3, E9, E15
	Training	E2, E5, E18
	Difficulty in dealing with death	E7, E14, E20

Figure 1. Presentation of categories, sub-categories and speech of nurses

• **Category 1: Personal experience and professional requirement**

The positive motivational and emotional states are a necessary condition for an action performed in complex contexts. Self-esteem and satisfaction with life in general is a condition to enable nurses to engage with enthusiasm and effectiveness in their social environment and their work. Caring for others, nurses shall have a positive subjective evaluation of themselves.¹³

The analysis of the expressed speeches direct your attention to the satisfaction of needs and desires not only of the patient / family as well as the nurse. People with no chance of cure transmit for the nurse their physiological needs, needs for safety, autonomy and achievement. Providing comfort care at the end of life creates in the nurses the expectation of feelings related to personal accomplishment and the hope of developing inner feelings, also minimizing the fear of facing death (their own and of others).

Someone who is about to die soon confronts us with our condition of humans and of finite. This usually makes us wish to know ourselves better, and continually question: what do I want to do and to be before dying? (E3)

When providing comfort care it is necessary to be aware of many things. The presence of people the patient likes, photographs, flowers, etc... Either let the patient talk

about what he expects we can do with him before dying. (E4)

Comforting is to satisfy the patient’s needs. Thinking about their desires, no matter how ‘small’ they may seem to us. (E8)

Comforting a person who knows who is about to die can be very difficult or very easy. There are examples of everything: how to help a patient to say goodbye to a loved one, or enable him to go to a particular site. All of this is comforting. (E17)

Comfort care before death about to be announced can often be a reflection of a relationship with patients / families, but also as a way to protect the professionals due to the need to break the paradigm related to death. Thus, the guideline ranges from difficult to escape the sense of failure to serenity of humanization at the end of life, culminating with a ‘good death’ .¹⁴ Providing comfort care means for nurses participating in this study, to experience feelings and emotions such as impotence (before death); guilt; frustration, compassion, peace, serenity and inner calm, and on the other hand arises inner confrontation so they are aware of the several needs of comfort expressed by patients / families, as well as inner confrontation given to them by the process of dying.

The patient in his last stage of life and his family triggers lots of emotions, often difficult to cope with. I think peace is what best

defines it. (E1)

Comforting patients at the end of life begins as a confrontation with frustration, certain impotence, but that's just the beginning, because then what remains is peace of getting the patient alive with loved ones. (E13)

The comfort of patients at the end of life is a patchwork of feelings and emotions that fill us inwardly and gives us strength day by day. (E16)

I feel happy when a patient dies peacefully, it is a sign that our care reached an essential point - comfort. (E16)

Centered in caring within the existential dimension of man in his plenitude, and at the same time away from technology, nurses feel strong while dealing with a patient with no chance of cure, they often feel part of the final walk of the patient, together with the experience of living in the last stage of life.¹⁴

The same way nurses seek for knowledge and skills for the development of nursing techniques for physical care, they also maintain the same concern about skills appointed to behaviors and skills related to the functions of contact, such as touch, look, distances, physical locations, time, act of listening and means of communication.¹⁵

Monitoring was expressed by the statements of nurses. Caring for a terminal patient is caring for a person alive, even if it is a life headed for death. So, monitoring the other who suffers in your way, does not stop the suffering itself but avoids or minimizes loneliness that is usually present at the time of death. However, nurses emphasize that monitoring a patient with no chance of cure is complex, demanding and difficult. 'Being with' the patient who is dying modifies the personal view of death; intensifies about the respect of it, raises awareness of human vulnerability and transmits feelings of mutual benefit (patient / family and nurse). For nurses in the study monitoring is based on a relationship of affection, which assumes a connection between two people, like touch, time, and the act of listening, looking and intentional dialogue.

I feel stressful and difficult situations, very desperate but what prevails is always the certainty that we minimize the loneliness, and the relationship with the patient, the willingness to be with the patient is the bridge to achieve full comfort. (E2)

Monitoring is more than being with him. It is intensively living with him and his family so that loneliness and despair decrease

significantly. (E11)

I've been through cases where I was fully involved, and as death advances the first feeling is that maybe I was involved more than I should. When a person dies it is easy to feel that life is an absolute, noble and very volatile value. (E12)

Providing care is essential to all people, regardless of their clinical condition, but the emotional connection between the triad nurse / patient / family is most frequently observed with respect to patients with no chance of cure.¹⁶ Nurses share a daily variety of feelings surrounding suffering, since the terminal illness affects people with successive losses, jeopardizing their balance. Such losses arise primarily from the disease itself (symptoms, hospitalizations, treatments, relapse or absence of a cure), and there is also loss of social role (rupture with the professional, social and family environment), leading to a loss of identity and references, experienced as decadence and lived with a great anguish. Emotional reactions to serious illness are complex to handle, so the nurse needs to learn how to build a relationship in their practice of caring in the context of intense emotions.¹⁷

The complex daily work with patients in deep suffering, implies that the nurse controls emotions, express feelings of enthusiasm, care and confidence, ability for hard work, tenacity and persistence, analytical reasoning, communication and relational ability, self-organization, self-confidence, self-control, self-efficiency, curiosity, pleasure in learning, understanding of emotions and feelings, ability for decision-making, sharing and cooperation.¹⁸

Ability to provide comfort care for patients at the end of life means the challenge to mainly manage positive emotions, and emotional involvement assumes a mutual meaning positively influencing all those involved in cases of comfort. However, through the speech is known the concern of nurses over the involvement, because they consider it dangerously projective, with the emergence of feelings of anxiety, sadness and anger, if the nurse cannot enhance the experience of comforting the person with no chance of cure as a way of boosting self-knowledge.

Monitoring the person in the last stage of life is often a way of knowing yourself better, to discover my personal values. (E4)

Providing comfort to someone who is sick and with short time of life is very rewarding, but if it is not a process with knowledge, it is

difficult to manage because we many times see ourselves in the person we are taking care. (E18)

Responsibility is one of the essential ethical notions and it is correlative to freedom, since we are responsible for the actions that are voluntarily chosen. The responsibility is constitutive of the act, rather than consecutive to the act, which concludes that we are responsible for the act while choosing it and performing it and not merely the result of its consequences.² The responsibility is reported as something inherent to the nurse who comforts and the person with no chance of cure. These findings emphasize the concern of nurses over the boundary line between their personal and professional responsibility, the rights of patients at the end of life, and the values involved in the professional relationship established between them.

Comforting the patient at the end of life is an act of professional responsibility, but I also think it's personal. I can always choose whether or not to provide care which aim to promote the comfort of those who 'are about to die'. (E9)

We are responsible for the decision of being with those who live the last stage of life. Someone who knows that death is about to come, triggers on us the responsibility to provide care to promote their comfort at all levels. (E19)

♦ Category 2: Conflicting points

In addition to technical skills, emerged from the analysis of the speeches, the personal characteristics of nurses as essential factor for providing comfort to patients with no chance of cure, with particular emphasis on respect, sensitivity, accuracy and humbleness compared with the focus of comfort. The models of care and the attention to detail space and environment are key factors for the humanization of terminal life.¹⁹

It is common to find environments poorly humanized during the process of death / dying, where the technical care is almost perfect. However, it is assumed as a lack of feelings, leading the nurse to go beyond technical knowledge in order to achieve human essence.²⁰

The physical environment and the organization of care provided to the person without the possibility of cure was valued by the nurses in the study as an axis that conflicts with the comfort of the person. The possibility of dying in family is highlighted as a reality little explored by people / families, but recognized as a unique and solemn moment, which requires the presence of

humanist values such as respect, dignity and spirituality, and family support so that the person can die at home, surrounded by important people and significant objects.

Very often patients tell us they would like to die close to loved ones. They say they miss things, the family environment of silence and sometimes they complain about things here. (E5)

Sometimes they even complain whether there are flowers or not, with the light, etc.. We cannot ignore the patient when he knows he has a short time of life, they value all the details, things that we must value in order to comfort the patient. (E6)

Many patients expressed their willingness to die at home but are afraid to ask the family. The fear comes because they know that there is not family support, but it would be very important to make the access to die at home possible. (E10)

My experience tells me that being aware of surroundings is essential for patients to feel really comfortable. At this stage of life they value things that for us, sometimes, are considered irrelevant and unimportant. But day by day the patient shows us exactly the opposite. (E11)

The family of the patient with no chance of cure plays an important role in the support to face the various crises of life, emotional ruptures, conflicts, demands as well as stating, protecting and setting standards for monitoring, values and beliefs.

Feelings of fear, guilt, depression and anger often arise in the patient's family with no chance of cure, that is why nurses direct their attention to them. In this sense, nurses should be concerned with the quality of life of patients, sparing no efforts to reduce their suffering, but also their family.¹⁶

The nurses in the study mentioned the family as a factor influencing the provision of comfort in the context of the end of life, not only for the importance of their presence and the fear that arises in them for being exposed to the patient's family, but also for the tenuous availability showed by them in comfort care. The break, despair and suffering of the family were situations identified by nurses in the study. However, they stressed that family involvement is essential for comfort care.

When providing comfort care to the patient thinking only about him, I feel sometimes that I leave behind a very important part - the family. (E3)

The family does not always

help. Sometimes it's much more difficult to help the family than the patient. We spend less time with them and maybe that's why they do not know us well, but it is difficult to get them involved in care, in the conversations. (E9)

The experience shows me that investing in the patient and their family gives us better improvements. Often the family is who challenges us the most, even though they are suspicious and confronting at first, but then they become partners regarding care. (E15)

The training and experience allow nurses to understand and respect each other, based on a framework which seeks to abstain from judgments of value related to the person to whom we provides care.²¹ Job satisfaction can be achieved through security grounded and based on knowledge, leading professionals to feel confident in their actions, by being able to correctly identify the needs of patients. Hence the importance and need for professional to improve specific knowledge and skills in order to be able to safely and efficiently take care of patients with no chance of cure and their família.¹⁶

In the training of nurses the development of skills and abilities related to signs and symptoms of disease processes are put first. The recovery and health promotion are also given importance, leaving the process of death and dying as a secondary grief of family members.²²

The statements of the nurses of the study showed a strong need for investment in their training. Show that regardless of the level of graduation it is crucial potentiate the development of skills acquired in real situations of comfort care to people with no chance of cure.

I feel that the training I had gave no approach for this. Almost everything has been learned from experience and with older colleagues. I feel that there is a lack of training, of discussion of this subject. Even though there is some approach it is still not enough. (E2)

I see big difference between me and younger colleagues. They had training, even that only a little, on palliative care. There are new issues and the hospital should invest more in training. (E5)

I received training on palliative care and it was a major point in life. Without such training we would certainly make a lot of mistakes while providing comfort care with the overall vision that I have today ... or at least try to provide! (E18)

The complex daily work with patients in deep suffering, implies that the nurse controls

emotions, expressing feelings of enthusiasm, care and confidence, ability for hard work, tenacity and persistence, analytical reasoning, communication and relational ability, self-organization, self-confidence, self-control, self-efficiency, curiosity, pleasure in learning, understanding of emotions and feelings, ability for decision-making, sharing and cooperation.¹⁸

Being a nurse is a commitment to life and it is necessary to be able to deal with its preservation, with training based on cure. When the nurses in their daily lives deal with death in general, they tend to get away from it.²³

Death as a limit helps us to grow, but death experienced as a limit, is also pain, loss of function of the body, of affection. Beliefs in part support socialization and direct the rituals of death as a way of dealing with terror.²⁴

Finally this analytical category is possible to highlight the difficulty in dealing with death, presents itself as an increased constraint to provide comfort care. The process of facing death by the nurse, the patient and the family connects with culture, beliefs and fears that the process of death and dying inspires the provision of care. The nursing experience with death situations can positively enhance the availability and competence to provide comfort care in the last stage of life.

The person who is about to die serves as a mirror for me, and this is not always easy to manage. Many questions are raised for the patients as well. I think it helps to believe in something superior, but it all depends on what the patient and family believe. (E7)

The patients in their last stage of life, show me how finite I am, and confront me with my own death. (E14)

Dealing with beliefs about death is difficult. I confess I'm a different person because I work with these patients. Every day I appreciate the fact of life, and I like being with people I love. Undoubtedly, every day. (E20)

CONCLUSION

According to the data analyzed in this study means that the objective was achieved, because it revealed the nurses' understanding regarding the meaning of comforting the person with no chance of cure. By means of the categories identified, it was realized that nurses are aware of the importance of comfort at the end of life, they are able to identify factors that enhance positively and negatively comfort care, but also state that

the interpersonal relationship between the triad nurse / person end of life / family is fundamental to providing quality comfort care.

We emphasize the need to work the issue of terminal, ensuring the acquisition and development of skills in the area in order to promote comfort to the patient and their family, regardless the fact the nurses shall take care of themselves. We can see the strategic need to enhance training at different levels of the Nursing School on the subject Palliative Care. Noteworthy was the lack of reflection on the personal meaning of the body, emphasizing human dignity, and death not only as a natural process but essentially as a demanding step to several levels for professionals, patients and family members and as being influenced by many factors.

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Submission: 2012/07/17

Accepted: 2013/05/08

Publishing: 2013/02/01

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