

# Palliative care, spirituality and narrative bioethics in a Specialized Health Care Unit

Camilo Manchola<sup>1</sup>, Elisa Brazão<sup>2</sup>, Anelise Pulschen<sup>3</sup>, Marcos Santos<sup>4</sup>

## Abstract

Through narrative bioethics, this article presents the results of a study of the narratives of six people directly involved in the routine of the palliative care unit at the Hospital de Apoio de Brasília, with the aim of contributing to the study of the complex problems faced by palliative care in daily practice. Focusing on the relationship between spirituality and bioethics, interviews with professionals, patients and families were conducted, seeking answers to the question of the meaning of life and its relationship to suffering. It was concluded that narrative bioethics applied to palliative care can provide important input to clarify issues related to the understanding of the spiritual realm by providing analytical frameworks that take into account human beings which express, feel, say and make sense of what is said.

**Keywords:** Bioethics. Palliative care. Spirituality.

## Resumo

### Cuidados paliativos, espiritualidade e bioética narrativa em unidade de saúde especializada

Por meio da bioética narrativa, este artigo apresenta os resultados de estudo de narrativas de seis pessoas diretamente envolvidas na rotina da Unidade de Cuidados Paliativos do Hospital de Apoio de Brasília. O objetivo foi contribuir para a investigação dos complexos problemas enfrentados pelos cuidados paliativos na prática profissional diária, com foco na relação entre espiritualidade e bioética. Foram realizadas entrevistas com profissionais, pacientes e familiares, buscando respostas à questão do sentido da vida e sua relação com o sofrimento. Conclui-se que a bioética narrativa aplicada aos cuidados paliativos pode oferecer importantes subsídios para elucidar as questões ligadas à compreensão da esfera espiritual, ao prover marcos analíticos voltados para o ser humano, que expressa, sente, diz e cria sentido no que é dito.

**Palavras-chave:** Bioética. Cuidados paliativos. Espiritualidade.

## Resumen

### Cuidados paliativos, espiritualidad y bioética narrativa en una unidad de salud especializada

Por medio de la bioética narrativa, el presente artículo presenta los resultados del estudio de las narrativas de seis personas directamente involucradas en la rutina de la unidad de cuidados paliativos del Hospital de Apoyo de Brasília, con el objetivo de contribuir al estudio de los complejos problemas enfrentados por los cuidados paliativos en la práctica profesional diaria. Enfocándose en la relación entre espiritualidad y bioética, se realizaron entrevistas con profesionales, pacientes y familiares, buscando respuestas a la cuestión del sentido de la vida y su relación con el sufrimiento. Se concluye que la bioética narrativa aplicada a los cuidados paliativos puede proporcionar importantes aportes para aclarar cuestiones relacionadas con la comprensión de la esfera espiritual, al proveer marcos analíticos que toman en cuenta al ser humano que expresa, siente, dice y crea sentido en lo que es dicho.

**Palabras-clave:** Bioética. Cuidados paliativos. Espiritualidad.

Aprovação CEP Secretaria de Saúde do Distrito Federal CAAE 35295414.0.0000.5553

1. **Doutorando** camilomanchola@gmail.com 2. **Especialista** brazaoelisa@gmail.com 3. **Especialista** anelise2602@gmail.com 4. **Doutorando** marcosrxt@gmail.com – Universidade de Brasília, Brasília/DF, Brasil.

## Correspondência

Camilo Manchola – Campus Universitário Darcy Ribeiro. Faculdade de Ciências da Saúde. Programa de Pós-Graduação em Bioética, CEP 70910-900. Brasília/DF, Brasil.

Declararam não haver conflitos de interesse.

Even today, in the academic and professional world, there is a degree of ignorance and denial regarding the complex nature of spirituality and its role in people's lives. A practical example can be found in health care, in which the frequent differentiation and separation between the material and the transcendental results in the dichotomy of humanity.

In fact, the widespread ignorance regarding the importance of spirituality in the formation and activities of human beings in the spheres of health, education, politics and citizenship has produced a reductionist approach, jettisoned its own nature, and is, therefore, inappropriate for addressing its complexity.

However, parallel to this scenario, there are some lines of thoughts in the academic and professional circles that contemplate, since their creation, the physical, social, emotional and spiritual spheres as relatively tangible dimensions of each individual, having as an objective the care of human beings and respect for their integrity. Among these, two lines of thoughts stand out, bioethics, in the academic circle, and palliative care, in the practical field.

This study aims to discuss the elements that narrative bioethics provides for the analysis of issues relevant to palliative care, in particular those related to spirituality as the meaning of life. For this purpose, the study took advantage of conducting semi-structured interviews with six people who are involved in the routine of a palliative care unit.

For sharing multi-inter-disciplinary nature, concrete and complex, Latin American bioethics and palliative care were the inspiration for this study. This is evident in palliative care, which focuses on improving the quality of life of patients diagnosed with life threatening disease as well as in providing assistance to their families<sup>1</sup>. This concept is made all the clearer by addressing not only the definition but also the palliative actions, which range from therapeutic measures of controlling physical and psychological discomforts to social and spiritual support. Thus, this view takes into account the complexity of the care of pain and suffering, with "eyes" looking at the "person" and not at the "disease." In addition, palliative care addresses the connection between spirituality and the meaning of life, concepts that transcend the Cartesian and biomedical training current prevailing in academia.

The recent development of important literature that links bioethics, spirituality and palliative care, which is particularly concerned with the

promotion of epistemological frameworks aimed at the understanding of palliative care, demonstrates this relationship. However, this literature has not caught a glimpse of the potential relevance of the narrative dimension for the understanding and improvement of day-to-day palliative care. In this specific case, we will study the narratives of six people directly involved in the routine of the Palliative Care Unit of the Hospital de Apoio de Brasília (Brasília Support Hospital).

It is expected, thereby, to stimulate the construction of practical post-positivist humanized, complex and transdisciplinary knowledge, which is necessary and relevant to the topic under discussion. Considering the issues that concern palliative care – the meaning of life, suffering, death, etcetera – methodological assumptions regarding qualitative epistemology will be used, since they emphasize the narrative and the history of those involved in the practice of palliative care.

This paper is organized into six key sections: the first presents the theoretical framework that links palliative care, spirituality and bioethics; the second discusses narrative bioethics; the third explains the methodological framework used; the fourth collates the obtained results; the fifth provides a critical analysis of these results, and the final section suggests overcoming the Cartesian dichotomy to achieve the construction of a perspective that considers human beings as a whole, dealing inclusively with their spiritual yearnings.

## Theoretical framework

### *Palliative care*

*Suffering is only intolerable when nobody cares*<sup>2</sup>.

Speaking of the origin of healthcare and the relief of physical and spiritual suffering is to talk of human history, where pain and suffering are inherent conditions of human nature<sup>3</sup>. Historically, the term hospice is confused with "palliative care". Hospices were hostels in Europe at the beginning of the Christian era that housed and cared for pilgrims and travellers<sup>4</sup>.

The term "palliative" derives from the Latin *pallium*, whose meaning is "blanket", "cape" or "covering". It was used to denote the cloaks offered to the pilgrims when they left the hospices. The purpose of this clothing was to protect them from the weather during their journeys. Currently, the term

“palliative” conveys, not only the idea of shelter and protection, but also incorporates the appreciation of care for human beings based on a holistic approach.

Two women occupy a prominent place in creating the philosophy of what is called palliative care and the modern Hospice Movement, which refers to the care of the terminally ill. The first is Cicely Saunders. Born in London in 1918, she graduated in nursing, social administration and medicine, dedicated her life and career to the care of the terminally ill, and founded the St Christopher’s Hospice in 1967, which would become the world center of excellence in palliative care teaching, research and assistance. Sanders also developed the concept of *total pain*, which translates the idea that caring for the person will only be effective if their physical, mental, social and spiritual dimensions are valued, thus rescuing the integrity of humanity and the complexity of dealing with pain and suffering.

Saunders work began the Hospice Movement and the so called pursuit of “good death.” Without treatments and practices considered futile or stubborn, good death presupposes the search for a peaceful end of life, close to family, marked by respect for the patients’ wishes, in a space where they can make their farewells. For patients this means, therefore, to be cared for with attention, living their last days as fully as possible and with maximum comfort, to finally die with dignity.

In the same period, Elisabeth Kübler-Ross, a Swiss psychiatrist naturalized in the United States, took care of people with advanced illness and facing impending death. In 1969 she released her first book, “On death and dying”. As a result of her research and studies, the Western medical and scientific community began to discuss issues related to Thanatology – the study of death – and the psychological states of the dying, which were identified by Kubler-Ross as denial, anger, bargaining, depression and acceptance<sup>5</sup>.

In 1982, the World Health Organization (WHO), through its Cancer Committee, formed a working group with the aim of proposing policies for hospice and pain relief care for cancer patients. The term “palliative care” in use in Canada, has been adopted by WHO to replace the term *hospice*, which is difficult to translate in certain languages. Later, in 1987, the UK was the first country to recognize palliative medicine as a medical specialty<sup>6</sup>.

In the early 2000s, the agency published new documents recognizing the importance of palliative care as a strategic health policy. Thus, palliative care,

once restricted to the oncological sphere, was extended to other areas such as paediatrics, geriatrics, HIV/AIDS and chronic diseases<sup>6</sup>.

In 2002, WHO published its current definition of palliative care, as follows: *Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*<sup>7</sup>. The same document defined nine guiding principles in the areas of expertise of the multidisciplinary palliative care team:

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards death as a normal process.
- Intends neither to hasten or postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as active as possible until death.
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- Will enhance quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other treatments that are intended to prolong life, such as chemotherapy and radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications<sup>7</sup>.

In Brazil, the practice of palliative care is very recent. The first scattered records regarding health services of this nature arose in the 1980s but the Brazilian Association of Palliative Care was only established in 1997 and the National Academy of Palliative Care in 2005. The first book on palliative care published in Brazil was published 2004<sup>8</sup>.

It was only from 2000 that the country would see a significant development of practice and studies regarding palliative care, as shown by the recent academic publications available<sup>9-11</sup>, as well as by the federal regulations set by the Brazilian Ministry of Health, such as the Política Nacional de Atenção

Oncológica – Portaria 2439/2005 (National Oncological Care Policy – Ordinance 2439/2005), which provides, in section II of Article 1, the organization of a care line that encompasses all levels of health care<sup>12</sup>.

Another important initiative of the Ministry of Health is the issue of Portaria 140/2014 (Ordinance 140/2014)<sup>13</sup>, which deals with the empowerment of the oncological network, regulating the mandatory provision of oncological palliative care services, properly structured and referenced by the Centros de Alta Complexidade em Oncologia (CACON – High Complexity Oncology Centres) and the Unidades de Alta Complexidade em Oncologia (UNACON – High Complexity Oncology Units).

In 2006, the Conselho Federal de Medicina (CFM – Brazilian Federal Council of Medicine), by establishing criteria for the practice of orthothanasia through Resolution 1805<sup>14</sup>, highlighted the importance of palliative care in the terminal phase of critical and incurable diseases (...) *doctors are allowed to limit or suspend procedures and treatments that prolong the life of patients, assuring them the necessary care to alleviate the symptoms that lead to suffering, from the perspective of comprehensive care, respecting the will of patients or their legal representative.*

In 2009, CFM included palliative care as a fundamental principle in the Código de Ética Médica (CEM - Code of Medical Ethics)<sup>15</sup>. Subsequently, on the 1<sup>st</sup> August 2011<sup>16</sup>, palliative medicine was regulated as a practice area, allowing the creation of residency programs in palliative medicine in Brazil. The following year, CFM adopted Resolution 1995/2012<sup>17</sup>, which provides for a *living will*, ensuring the patient the opportunity to state in advance the care and treatment they want to receive when they are unable to express themselves.

Palliative care came to rescue, in health care, the holistic perspective of humanity, taking into account patients' physical, mental, social and spiritual dimensions. Palliative care takes care of the "person" rather than the "illness" through a multi-inter-trans-disciplinary approach. This approach, apart from caring for people in pain, suffering and near death, aims at reinterpreting life and values, as well as the perception of the meaning and purpose of life. Kübler-Ross makes the comparison that, *people are like stained-glass windows: they sparkle and shine when the sun is out; but when the darkness sets in, their true beauty is revealed only if there is a light from within*<sup>18</sup>.

### Palliative care and spirituality

Gerald May describes spirituality as *awareness of relationships with all creation, an appreciation of presence and purpose that includes a sense of meaning*<sup>19</sup>, or purpose, which is understood by Frankl as the purpose or reason for one's existence<sup>20</sup>. In other words, it is the search for meaning in what one does and the conviction that each individual has a purpose. Note that, in this study, the concept of spirituality is related to the meaning or significance that life takes for people who deal with palliative care. Therefore, the study does not consider other aspects of spirituality, such as a belief or religion.

Assuming that human beings bring with them several dimensions – physical, psychological, family, financial, socio-cultural, existential, spiritual and transcendental<sup>21</sup> – the belief in an extracorporeal dimension and its survival after death give individuals the ability to enjoy life despite the severity of their illness. This belief provides a sense of peace and strength to face even the most acute physical pain.

Spirituality is the bridge between the existential and transcendental, it is what brings meaning to one's life. It is all that represents the relationship between each individual and what they consider sacred, and it manifests itself in various ways, through religious practices, or otherwise. This relationship, made by the individuals themselves, comes from the need to bring meaning to their existence and to maintain hope in the face of an illness that threatens life. Statements of gratitude, love and forgiveness epitomise, in general, spirituality and the search for peace at the end of life<sup>21</sup>.

Observing the social habits currently shared by the so-called Western world, the relentless pursuit of happiness as a "mandatory attribute" becomes clear. However, the meaning of this happiness for a person diagnosed with advanced cancer, for example, is questionable. Can a person in the face of pain and imminent death "be happy"?

Discussing happiness in a scenario of full health, abundant material wealth and longevity is, of course, simple. However, if basic human necessities are removed, then the meaning of happiness diminishes. The awareness and the feeling of existential brevity lead human beings to question life itself and create the need to give some meaning to the time they have left and to all that is around them: people, goods and/or experiences. In short, the question of spirituality is part of the essence of palliative approach: At the end of "*saying yes to life in spite of everything*" (...) *presupposes that potentially life has a meaning in any circumstances*<sup>22</sup>.



This ability of human beings to rise again in the face of the greatest adversity demonstrates some of their best potential, namely, to *turning suffering into a human achievement and accomplishment; deriving from guilt the opportunity to change oneself for the better; and deriving from life's transitoriness an incentive to take responsible action*<sup>22</sup>. It is in this way that human beings find the strength to face suffering in the success of their quest for meaning, since to find it also brings comfort and tranquillity.

### Spirituality and bioethics

When reviewing scientific literature with the descriptors "bioethics" and "spirituality" in the databases of BVS/Bireme and PubMed, it was possible to find more than 800 documents dealing with spirituality and bioethics. However, when the search was restricted to the existence of these terms in the title, only ten articles were identified, which shows little interest of researchers in the subject. It is also notable that all these texts address the issue from a biomedical and biotechnological perspective. In the case of bioethics, there has been a religious bias, except for one text, which defends the necessary distinction between religion and spirituality<sup>23</sup>.

Many of the articles evaluate the relationship between spirituality and bioethics, and one of them ventures to propose the acceptance of spirituality in the doctor-patient relationship and the doctor's involvement with the beliefs of their patients, as the only way to contribute to better clinical decision making<sup>24</sup>. In response to the article, other authors see this relationship as conflictual, problematic and difficult. Despite some differing views<sup>25,26</sup>, spirituality, focused on the virtues, is considered a subarea of humanities that is essential in medical training<sup>27</sup> because it determines the proper development of science in general and medicine in particular<sup>28</sup>. In this same context, Alves and Selli give it the status of cultural rights, including it among the human rights<sup>29</sup>.

By reviewing the literature on spirituality and health care, two articles conclude that the health crisis is a clear response to the lack of doctors concerned about the spirituality of patients<sup>30</sup>, therefore supporting its reinterpretation and legitimacy in the clinical context<sup>31</sup>. Muldoon and King<sup>32</sup> address spirituality based on its connection with bioethics, as well as on its difference with respect to religion. The authors begin by defining the topic: *Spirituality is understood here in its wide but increasingly frequent usage as the experiential integration of one's life in terms of one's ultima values and meaning. It is in the light of this understanding and orientation*

*of their lives that persons decide, act, and respond to life-situations. And then conclude: the spirituality of a person's spirituality, so defined, influences his or her morality in general and response to health care issues in particular. For this reason, it is of interest to some health-care workers and bioethicists. In fact, references to spirituality do occur periodically in health-care practice, where it is differentiated both from religion and from medical treatment*<sup>33</sup>.

### The narrative bioethics

*Humankind is a literary genus and a narrative species. Human life consists of history or biography. This is the etymological bios of bioethics, which refers to the good life or to wellbeing (from the ancient Greek biota). As García Márquez said, life is not what one lived, but what one remembers and how one remembers it in order to recount it*<sup>34</sup>.

Although the neologism "bioethics" was created by the German biologist Fritz Jahr in 1927<sup>35</sup>, bioethics only begin to be widely developed as a scientific field from the 1970s, with the publication of the article "Bioethics, the science of survival," by the North American scientist Van Rensselaer Potter<sup>36</sup>. A new discipline emerged that, according to the author, would contribute to the future of humankind, given its ability to build a bridge between the two major areas of knowledge: science and the humanities. Even today, bioethics has travelled different paths, some closer, others less close to the original proposal by Potter. Thus, it can be said that there are more inclusive bioethics, post-positivist, that are therefore closer to Potter's theory than others, which are considered more rationalist and positivist. Amongst the latter, which included Principlist bioethics or biomedics<sup>37</sup>, and, among the first, Latin American bioethics, which is also called anti-hegemonic.

Intensely politicized, Latin American bioethics<sup>38</sup> advocates overcame the isolation between the two major areas and, at the same time, questioned the neutral character of scientific interpretation, proposing instead a complex, multi-disciplinary and concrete analysis of reality. Thus, anti-hegemonic bioethics postulates *the collective construction of a thought and the creation of a practical bioethics that takes into account the specifics and peculiarities of social, cultural, and historical context*<sup>39</sup>, and *a theory of knowledge that is a spiritual reproduction of reality*<sup>40</sup>.

Within the context of Latin American bioethics, lies narrative bioethics (BEN)<sup>41</sup>, which was the first attempt to substantiate bioethics in the region. It emerged in Argentina in 1993<sup>42</sup>, with José Alberto Mainetti<sup>43</sup>, a disciple of Paul Ricoeur, as a product of the dialogue between narrative medicine, ethical hermeneutic and deliberative ethics. In its origin, BEN is eminently Ricoeurian and, therefore, Aristotelian. For Aristotle, discussions are, par excellence, the method used by practical rational thinking and is therefore ideal for an ethical practice such as bioethics. Currently, the Ricoeurian groundwork has been complemented by references to Ortega y Gasset (*reason is a narrative*<sup>44</sup>), Hanna Arendt, Alasdair Mac Intyre, Martha Nussbaum, Wilhelm Schaap, Clifford Geertz and Jerome Bruner.

The bioethics narrative makes use of resources from narrative analysis, which cover storytelling, imagination, interpretation and contextualization, referring to the casuistry, hermeneutical and literary dimensions – the latter is perceived as a *restorer of literature, as well as a teacher would be in relation to moral knowledge*<sup>34</sup>. Thus, BEN becomes a new theoretical, epistemological and methodological theory for a field in search of human consciousness, through a humanitarian approach towards the individual and their circumstances<sup>44</sup>. It also comes from the appreciation of *the role of imagination in ethics and in moral reasoning, unlike the rationalist tradition of moral absolutism, which prevents the incorruptible subjectivity of human understanding*<sup>34</sup>.

Epistemologically, narrative bioethics proposes a new paradigm to the world of knowledge, a paradigm of narrative, which differs from the others because its rationality is not classical or positivist, but a narrative-descriptive-argumentative-hermeneutic-deliberative. In addition, BEB advocates a method of knowledge resulting from inductive analysis, wherein the unique, concrete and situational are contextualized, once they respond to the *complexity of the moral world*<sup>45</sup>.

Given what has been expounded, narrative bioethics requires the development of linguistic, interpretive, critical, reflective, communicative capabilities and negotiation skills. Moreover, it fills the gaps of positivism, by providing a human sense to bioethics and to human life in general, taking advantage of an approach that moves away from Manichaeism, reductionism and belief in absolute and definitive truths. In the words of Ricoeur, cited by Domingo Moratalla and Feito Grande, *the narration can be a laboratory of moral judgment*<sup>44</sup>.

## Methodological references

This study was conducted at the Cancer Care Unit of the Brasília Support Hospital (Hospital de Apoio de Brasília – HAB), which belongs to the Federal District public health network. The hospital has five ambulatory specialties: acupuncture; neonatal screening; medical clinic; physical and rehabilitation medicine and palliative care.

The Palliative Care Unit, where the interviews were held, currently has a multiprofessional and interdisciplinary team of health professionals from different specialties. The unit also features the work of employees in the dining, cooking, cleaning, security, and voluntary cooperation services in numerous activities designed to alleviate the suffering of patients and hospitalized families.

The unit is a benchmark in the public and private system of the Federal District. Despite promoting multiprofessional care for cancer patients without purpose of applying disease modifying treatment, the unit adopts the concrete proposal to humanize the relationship with patients and families.

The turnover of patients in this unit is high, considering the condition in which they are admitted. In the terminal phase, the average stay of patients is one week; hence the great importance given to the quality and completeness of care provided to them and their families.

The study conducted interviews with six people directly involved in the HAB palliative care routine: a doctor, a patient, a patient's family member, a social worker, an employee of a cleaning service and a nursing assistant. Interviewees were indicated by the palliative care team, taking into account their level of knowledge, experience and involvement in the studied context.

The study was approved by the Comitê de Ética em Pesquisa (CEP – Research Ethics Committee) of the Federal District Health Department on 20<sup>th</sup> October 2014, according to the norms established by Resolution 466/2012 of the Conselho Nacional de Saúde (National Health Council). All persons selected were informed, invited to participate, voluntarily, and to sign the free and informed consent forms (ICF). The principle of autonomous participation and the privacy of participants were respected, as were the confidentiality and the secrecy of data.

Given that the research was of a basic nature, took a qualitative approach and had a descriptive purpose, the study was based on the methodological principles of qualitative epistemology<sup>46</sup>, which

emphasizes the role of the researcher and the research participant, and retrieves the value of history as theory<sup>47</sup>.

As research tools, we then used un-validated semi-structured interviews, based on the tools used by Silva in the study related to palliative care<sup>48</sup>, that is, conversational dynamics and completing sentences. According to qualitative epistemology, research tools do not have the objective of reaching truths or specific information, but moments of reflection between researchers and participants.

Therefore, the following guiding questions were developed: “what is the meaning of life?”; “what is suffering?” and “what is the relationship between the meaning of life and suffering?”. Other questions arose naturally during dynamic conversations with the participants, so that other content was added in the development of the research. These questions were posed to initiate the conversation and encourage participant involvement with the object of study of this research.

The completing sentences method refers to a list of deliberately incomplete sentences developed by the researchers for this research. Participants could respond according to what came to mind when reading the statements. The phrases used for this purpose were, among others, “my life project ...”, “death ...”, “when I die ...”, “my greatest fear ...” and “my family ...”.

The analysis of the responses received used a hermeneutic, deliberative and narrative approach, which, according to Domingo Moratalla and Feito Grande<sup>44</sup>, offers valuable resources to enhance the deliberation regarding the key narrative; that is, allows the understanding of the reasons, purposes and contents that are part of the participants’ narratives. Thus, we sought to identify the reasons in the narrative reports (moral arguments based on an argumentative logic model) that valued communication and the construction of meaning based on the narrative model.

## Results

All persons invited to participate in the survey were responsive and answered all leading questions. According to González Rey<sup>46</sup>, in qualitative studies, it is important to involve the subjects participating in the research, so that the information obtained and the theoretical research constructs have scientific legitimacy.

In the question “what is the meaning of life?”, the responses received included “seek spiritual evolution”, “what gives meaning, what makes us grow”, “for me, the meaning of life is love,” “leave an inheritance in feelings “and” help someone”, among others.

When asked about the meaning of suffering, respondents answered in different ways, “suffering is an opportunity for reflection (...) of reviewing the path that you have been following”; “it is what will feed us to reframe life, which will give it a new meaning”; “it is part of this great sense of life”; “it is the lack of love”; “I have been suffering a lot regarding the disease; cancer is a disease that will kill bit by bit, but I’m not afraid of suffering, I deal with it face-to-face, and it is not cancer makes me smaller; I strive so that suffering ends and I mature.”

The third question - “do you think there is a relationship between the meaning of life and suffering?” - received unanimously, affirmative answers. In an attempt to explain and justify the answers, the following constructs were collated, “they are synonyms”; “one is linked to the other”; “they go in parallel”; “the two things go together,” and “nothing is by chance, everything has a meaning.”

However, the interviewed doctor, when putting himself in the place of the terminal patient, stressed that the environment of suffering is quite intense and that this is often reflected in questions from patients such as “what is the meaning of my life?” “what am I doing here?” and “am I at peace with myself?”. Following similar reasoning, the social worker reported that “even if a human being is going through a moment like this, spiritual development should be sought, because people cannot live without this bigger dimension.” It is interesting to highlight the response obtained from the outsourced staff – the cleaning assistant – according to whom “the person suffering can always get an opportunity, everything has a meaning.”

The patient described the meaning of life, despite his intense suffering, as “to leave a legacy for my children, not a material one, but an inheritance of feelings, that is, the meaning of it all.” He added that his biggest fear was “not being able to pass this on to the people who will remain.” During his stay in hospital, the patient interviewed asked “forgiveness” from two friends, because of a particular situation – an attitude that was part of the preservation of his dignity and a comfort during his goodbyes.

In the second round of questions, we used the completing sentences tool, as shown above, and

it was observed how the respondents portrayed death and their dying. Through content analysis, it was found that most reported fears regarding the incomplete questions dealing with suffering, dying and leaving their children. At the end of the interview, they were asked about the family, and the words that they used to define it were “all”, “support base”, “safe haven” and “what brings me comfort,” among other responses.

## Discussion

Pain, suffering, spirituality and the meaning of life are essential components to all the stakeholders involved in a palliative care unit. The care given to patients is not synonymous with religiosity or a lack of scientific or medical rigor, but rather a holistic approach to life and the values of those who are part of this unit<sup>32</sup>. In this sense, spirituality should be seen as a kind of palliative care to be incorporated and offered in health services, since it is an essential part of the processes of illness, recovery, healing and death faced daily by patients.

The answers of the respondents clearly show the importance of palliative care, as they show that the situation in which they experienced daily challenges caused them to rethink themselves, reflect on the meaning of life and find purpose for what they have been facing. Thus, it was observed that spirituality belongs to the routine of all participants, which reinforces the argument that it should be taken into account in the provision of palliative care, whether of patients in the terminally ill phase of life, in particular, or of all those suffering from an illness, in general. From this recognition of the patients themselves regarding the importance of considering the spiritual dimension in health care, must start with the creation of strategies to include this dimension in health care.

Following this reasoning, bioethics considers it equally important to provide pain relief using the technological means available and to offer spiritual support to those admitted to palliative care units. Thus, it is essential to pay attention to what patients, families, nurses, doctors, volunteers and staff feel and think about spirituality and the meaning of life. And bioethics is a fundamental part of that context, given its capacity, as few disciplines in the medical field, to identify the problems arising from the absence of a complex and all-encompassing view of reality, and to count on sufficient experience and resources to defend the inclusion of this integrated perspective in health services.

It is understood, then, that addressing this need is the role of bioethics, although based on the assumption that this approach is facilitated by direct contact and proximity with each other. Thus, the adopted epistemological framework has proved relevant to the objectives of this research. This was the instrument that all participants used to express their needs, thoughts and feelings. The role of bioethics is therefore clearly as an inducer of reflection regarding the importance of thinking about spirituality as an essential type of palliative care. This is a tool that allows one to defend and legitimate, epistemologically and methodologically, the need to include other dimensions of humanity in the process of disease, death and healing.

It is desirable and necessary to listen and give voice to those in palliative care units, through a bioethics focused on storytelling. In this sense, the “narrative bioethics” of palliative care is an approach that offers the possibility of promoting discussions usually disregarded in academic and biomedical circles. Thus BEN should be seen as a technique of data collection and comprehension of the intersubjectivity of survey participants, especially in the case of terminally ill patients; but it should be seen as a moral reasoning technique designed to assist both healthcare professionals as well as patients and families in difficult circumstances related to the end of life.

Understanding the individual as belonging to a context and as having a history, taking care of all their dimensions in a practical and concrete way, positively influences the reality of people living in such complex situations as the terminal stages of life.

*A narrative emphasis in ethics also maintains that ethical decisions occur within the framework of interacting life-stories, each of which embodies a certain core vision and set of values. In each instance it is the life stories of people, their lived narratives, that provide a common thread. The telling of these stories and the discernment of the lived spirituality they contain may assist persons in the process of achieving understanding, making decisions, and finding purpose in the experience of illness, injury, or disability<sup>33</sup>.*

Thus, given the specific characteristics that the work of a palliative care unit presents, bioethics should not be understood only as a framework for analysis and reflection of the situations experienced in this context. Rather, it is an instrument of action that prioritizes the narrative role and highlights the need and efforts of people to make sense of



*their lives in the face of illness, injury, or impending death*<sup>33</sup>, as developed in this study.

Allowing family members, patients, professionals and employees to voice their opinions strengthened even further the understanding that bioethics, due to its ability to create a bridge between science and the humanities, contributes to the future of the human species, without losing the evolution of the history of each individual narrative. Moreover, it became clear that narrative bioethics, as a technique, offers huge advantages to those who deal with situations as delicate and complex as those that the end of life implies.

In the context described above, the limitations of the role of bioethics in the study, analysis and practice of palliative care are revealed. This reality can be remedied by an approach based on narrative analysis, as adopted here, and also by the adoption of research development proposals as in qualitative epistemology. It is clear that narrative bioethics not only legitimizes the incorporation of the spiritual realm in the context of health care, but also offers us tools for this integration to occur.

### Final considerations

A bioethical and narrative approach has much to offer in the analysis of situations that occur in the context of palliative care. Such an approach,

which makes use of hermeneutical and deliberative methodologies, provides major contributions to the understanding of the spiritual dimension of human beings, when analysing the “why”, “what for” and “how”, present in the narratives of human beings who are faced with ultimate questions, such as death, finitude, suffering, pain and transcorporeal dimensions.

Therefore, narrative bioethics can provide important information to these questions, whether by providing analytical frameworks that are able to take into consideration human beings, who express themselves, feel and create a sense of what is said, or by revealing, in the narratives of people who deal with suffering and the end of life, the reasons, purpose and content that, supposedly, can enrich the practice and the day to day of palliative care as an academic discipline in the making.

In summary, the approach of palliative care from the narrative bioethics gives rise to three fundamental events necessary for such care. The first, concerning the definition of spirituality as a kind of palliative care to be incorporated and offered in health services. The second, concerning the role of bioethics as an inducer of reflection regarding the importance of such care. And the third, and last, regarding the relevance of narrative bioethics as a data collection technique and an understanding of the inter-subjectivity of research participants, especially in the case of terminally ill patients.

*Work carried out was based on research developed in the XVI Specialization Course in Bioethics at the University of Brasilia (UNB).*

### References

1. Santos FS. Tanatologia: a ciência da educação para a vida. In: Santos FS, organizador. Cuidados paliativos: discutindo a vida, a morte e o morrer. São Paulo: Atheneu; 2009. p. 1-29.
2. Saunders C. Hospice and palliative care: an interdisciplinary approach. London: Edward Arnold; 1991. p. 116.
3. Santos FS. Abordando a espiritualidade na prática clínica. In: Santos FS, organizador. Op. cit. p. 373-85.
4. Caponeiro R, Cavalcante de Melo AG. Cuidados paliativos: abordagem contínua e integral. In: Santos FS, organizador. Op. cit. p. 257-67.
5. Kübler-Ross E. Sobre a morte e o morrer. 7ª ed. São Paulo: Martins Fontes; 1996.
6. Maciel, MGS. Definições e princípios. In: Oliveira RA, coordenador. Cuidado paliativo. São Paulo: Crempes; 2008 [acesso 8 fev 2016]. Disponível: <http://www.paliativo.org.br/dl.php?bid=15>
7. World Health Organization. National cancer control programmes: policies and managerial guidelines. 2nd ed. Geneva: WHO; 2002 [acesso 8 fev 2016]. p. 84. Disponível: <http://bit.ly/1UbsrZq>
8. Pessini L, Bertachini L, organizadores. Humanização e cuidados paliativos. São Paulo: Edunisc/Loyola; 2004.
9. Almeida AS, Barlem ELD, Tomaszewski-Barlem JG, Lunardi VL. Produção científica da enfermagem sobre morte/morrer em unidades de terapia intensiva. Enferm Foco. [Internet]. 2013 [acesso 8 fev 2016];4(3-4):170-83. Disponível: <http://bit.ly/1P8iYu6>

10. Santana JCB, Pessini L, Sá AC. Desejos dos pacientes em situação de terminalidade: uma reflexão bioética. *Rev Enfermagem Revista*. [Internet]. 2015 maio-jun [acesso 8 fev 2016];18(1):28-50. Disponível: <http://200.229.32.55/index.php/enfermagemrevista/article/view/9367>
11. Pessini L, Barchifontaine C, Bertachini L, organizadores. *Bioética, cuidado e humanização*. São Paulo: Loyola/Centro Universitário São Camilo; 2014.
12. Brasil. Ministério da Saúde. Portaria nº 2.439, de 9 de dezembro de 2005. Institui a Política Nacional de Atenção Oncológica: Promoção, Prevenção, Diagnóstico, Tratamento, Reabilitação e Cuidados Paliativos, a ser implantada em todas as unidades federadas, respeitadas as competências das três esferas de gestão. [Internet]. 2005 [acesso 15 dez 2014]. Disponível: <https://www.nescon.medicina.ufmg.br/biblioteca/imagem/2206.pdf>
13. Brasil. Ministério da Saúde. Portaria nº 140, de 27 de fevereiro de 2014. Redefine os critérios e parâmetros para organização, planejamento, monitoramento, controle e avaliação dos estabelecimentos de saúde habilitados na atenção especializada em oncologia e define as condições estruturais, de funcionamento e de recursos humanos para a habilitação destes estabelecimentos no âmbito do Sistema Único de Saúde (SUS). [Internet]. 2014 [acesso 15 dez 2014]. Disponível: [http://bvsms.saude.gov.br/bvs/saudelegis/sas/2014/prt0140\\_27\\_02\\_2014.html](http://bvsms.saude.gov.br/bvs/saudelegis/sas/2014/prt0140_27_02_2014.html)
14. Conselho Federal de Medicina. Resolução nº 1.805, de 9 de novembro de 2006. Na fase terminal de enfermidades graves e incuráveis é permitido ao médico limitar ou suspender procedimentos e tratamentos que prolonguem a vida do doente, garantindo-lhe os cuidados necessários para aliviar os sintomas que levam ao sofrimento, na perspectiva de uma assistência integral, respeitada a vontade do paciente ou de seu representante legal. (Publicada no Diário Oficial da União. Brasília, p. 169, 28 nov 2006. Seção 1). [Internet]. 2006 [acesso 15 dez 2014]. Disponível: [http://www.portalm medico.org.br/resolucoes/cfm/2006/1805\\_2006.htm](http://www.portalm medico.org.br/resolucoes/cfm/2006/1805_2006.htm)
15. Conselho Federal de Medicina. Resolução nº 1.931, de 17 de setembro de 2009. Aprova o Código de Ética Médica. Diário Oficial da União. Brasília, p. 90, 24 set 2009. Seção 1. [Internet]. 2009 [acesso 15 de dez 2014]. Disponível: [http://www.portalm medico.org.br/resolucoes/CFM/2009/1931\\_2009.pdf](http://www.portalm medico.org.br/resolucoes/CFM/2009/1931_2009.pdf)
16. Conselho Federal de Medicina. Resolução nº 1.973, de 1º de agosto de 2011. Dispõe sobre a nova redação do Anexo II da Resolução CFM nº 1.845/08, que celebra o convênio de reconhecimento de especialidades médicas firmado entre o Conselho Federal de Medicina (CFM), a Associação Médica Brasileira (AMB) e a Comissão Nacional de Residência Médica (CNRM). (Publicada no Diário Oficial da União. Brasília, p. 144-7, 1º ago 2011. Seção 1).
17. Conselho Federal de Medicina. Resolução nº 1.995, de 9 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes. (Publicada no Diário Oficial da União. Brasília, p. 269-70, 31 ago 2012. Seção 1). [Internet]. 2012 [acesso 15 de dez 2014]. Disponível: [http://www.portalm medico.org.br/resolucoes/CFM/2012/1995\\_2012.pdf](http://www.portalm medico.org.br/resolucoes/CFM/2012/1995_2012.pdf)
18. Kübler-Ross E. Op. cit. p. 52.
19. May G. *Care of mind/care of spirit*. San Francisco: Harper and Row; 1982. p. 7. tradução livre.
20. Frankl VE. *Em busca de sentido*. 34ª ed. São Leopoldo/Petrópolis: Sinodal/Vozes; 2013.
21. Saporetti LA. Espiritualidade em cuidados paliativos. In: Santos FS, organizador. Op. cit. p. 269-81.
22. Frankl VE. Op. cit. p. 25.
23. Sprague S. What part of spirituality don't you understand? *Am J Bioeth*. 2007;7(7):28-9.
24. Kuczewski M. Talking about spirituality in the clinical setting: can being professional require being personal? *Am J Bioeth*. 2007;7(7):4-11.
25. Cochrane T. Religious delusions and the limits of spirituality in decision-making. *Am J Bioeth*. 2007;7(7):14-5.
26. Goldberg D, Brody D. Spirituality: respect but don't reveal. *Am J Bioeth*. 2007;7(7):21-2.
27. Sliester C, Wasson K, Ramondetta L. From technician to professional: integrating spirituality into medical practice. *American Journal of Bioethics*. 2007;7(7):26-7.
28. Eisen A. The challenge of spirituality in the clinic: symptom of a larger syndrome. *Am J Bioeth*. 2007;7(7):12-3.
29. Alves JS, Selli L. Cuidado espiritual ao paciente terminal: uma abordagem a partir da bioética. *Rev Bras Bioética*. 2007;3(1):65-85.
30. Long T. Review of 'The rebirth of the clinic: an introduction to spirituality' and 'A balm for Gilead: meditations on spirituality' by David P. Sulmasy. *Am J Bioeth*. 2010;10(4):87-9.
31. Klink A. Review of Daniel P. Sulmasy, 'The Rebirth of the Clinic: An Introduction to Spirituality in Healthcare'. *Am J Bioeth*. 2008;8(7):54-5.
32. Muldoon M, King N. Spirituality, health care, and bioethics. *J Relig Health*. 1995;34(4):329-50.
33. Muldoon M, King N. Op. cit. p. 330. tradução livre.
34. Mainetti JA. Bioética narrativa [verbetes]. In: Tealdi JC, director. *Diccionario latinoamericano de bioética*. Bogotá: Red Bioética Unesco/Universidad Nacional de Colombia; 2008. p. 167.
35. Pessini L. As origens da bioética: do credo bioético de Potter ao imperativo bioético de Fritz Jahr. *Rev. bioét. (Impr.)*. 2013;21(1):9-19.
36. Potter V. Bioethics, the science of survival. *Persp Biol Med*. 1970;14:127-53.
37. Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 7ª ed. New York: Oxford University Press; 2013.
38. Garrafa V, Osório L. Epistemología de la bioética: enfoque latino-americano. *Revista Colombiana de Bioética*. 2009;4(1):73-92.

39. Garrafa V, Kottow M, Saada A, organizadores. Bases conceituais da bioética: enfoque latino-americano. São Paulo: Gaia/Unesco; 2006. p. 34.
40. Sotolongo PL. O tema da complexidade no contexto da bioética. In: Garrafa V, Kottow M, Saada A, organizadores. Op. cit. p. 93-113.
41. Manchola-Castillo C. Por una bioética distinta: narrativa y latinoamericana. Revista Redbioética/UNESCO. 2014 jul-dez;2(10):70-80.
42. Mainetti JA. Bioética ficta. La Plata: Quirón; 1993.
43. Mainetti JA, Pérez, ML. Los discursos de la bioética en América Latina. In: Pessini L, Barchifontaine CP, Lolas F, coordinadores. Perspectivas de la bioética en Iberoamérica. Santiago de Chile: OPS; 2007.
44. Domingo Moratalla T, Feito Grande L. Bioética narrativa. Madrid: Escolar y Mayo; 2013. p. 58.
45. Gracia D. El comentario de Diego Gracia. Revista Bioética Complutense. 2014 mar;17:6-8. p. 7.
46. González Rey FL. Pesquisa qualitativa e subjetividade: os processos de construção da informação. São Paulo: Thomson Learning; 2005.
47. González Rey FL. Sujeito e subjetividade: uma aproximação histórico-cultural. São Paulo: Pioneira Thomson Learning, 2003.
48. Silva G. Os sentidos subjetivos de adolescentes com câncer [dissertação]. Campinas: Pontifícia Universidade Católica de Campinas; 2008.

#### Participation of the authors

The authors participated equally in all stages of the article's production. Anelise Pulschen, Camilo Manchola and Elisa Brazão, participated as trainee students, Marcos Santos, participated as a professor advisor.

Recebido: 28. 4.2015

Revisado: 1.10.2015

Aprovado: 16.12.2015

