

Bioethical issues in publications about palliative care of the elderly: critical analysis

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Abstract

The present study aimed to identify existing studies of bioethics and palliative care among the elderly, and describes cases encountered with a publication date between 2002 and 2013. Publications in the PubMed, Cochrane, Embase, Lilacs, SciELO and Ibecs databases were identified using the keywords “bioethics” AND “palliative care” AND “aged”. Following methodological selection, 16 articles were identified. There were few studies relating to bioethics and palliative care, confirming a lack of literature in this area. Therefore additional studies are required to increase understanding of this theme and the ethical knowledge of health professionals.

Keywords: Bioethics. Palliative care. Aged.

Resumo

Aspectos bioéticos nas publicações sobre cuidados paliativos em idosos: análise crítica

A presente investigação objetivou identificar as publicações existentes sobre bioética e cuidados paliativos em idosos no período entre 2002 e 2013, descrevendo os casos encontrados. Para isso, foram investigadas as bases de dados PubMed, Cochrane, Embase, Lilacs, SciELO e Ibecs, buscando publicações com as palavras-chave “*bioethics*” AND “*palliative care*” AND “*aged*”. Foram encontrados 16 artigos que realmente tratavam de bioética e cuidados paliativos em idosos. Pode-se verificar que são poucos os estudos relacionando bioética e cuidados paliativos, comprovado pela escassa literatura sobre o tema. Assim, o levantamento indica a necessidade de outros trabalhos destinados a aprofundar a temática e aprimorar o conhecimento eticamente correto dos profissionais da saúde.

Palavras-chave: Bioética. Cuidados paliativos. Idoso.

Resumen

Aspectos bioéticos en las publicaciones sobre los cuidados paliativos en las personas mayores: análisis crítico

La investigación tuvo como objetivo identificar las publicaciones existentes sobre bioética y los cuidados paliativos en las personas mayores que describen los casos encontrados en el período 2002-2013. Con este fin, las bases de datos PubMed, Cochrane, Embase, Lilacs, SciELO y Ibecs fueron investigadas, en busca de publicaciones con las palabras-clave “*bioethics*” AND “*palliative care*” AND “*aged*”. Se encontraron 16 artículos que realmente analizaban la bioética y cuidados paliativos en personas mayores. Se puede comprobar que hay pocos estudios relacionados con la bioética en los cuidados paliativos, lo que se comprueba por la escasa literatura sobre el tema. La conclusión es que se necesitan más estudios para profundizar aún más el tema y, por lo tanto, el conocimiento éticamente correcto de los profesionales de la salud.

Palabras-clave: Bioética. Cuidados paliativos. Ancianos.

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Declaram não haver conflito de interesse.

Palliative care is deemed as actions aimed at patients with advanced-stage diseases, who are under physical or psychic distress, or both ¹. The concept is corroborated by Hottis and Parizeau ², who emphasize the importance of patient's comfort. This care will be aimed at the preservation of human dignity, and no longer bodily integrity, acting on pain relief, and not on the disease cause. The World Health Organization (WHO) states that palliative care is aimed at relieving undesirable symptoms due to an illness or treatment carried out by a multidisciplinary team, to improve the quality of life of both patients and their families. Thus, the distress can be mitigated preventively, treating not only pain, but also physical, social, psychological and spiritual symptoms ³.

According to the "Manual de cuidados paliativos" (Palliative care manual), organized by the *Academia Nacional de Cuidados Paliativos* (ANCP - National Association of Palliative Care), its fundamental principles are: promotion of pain relief and other disease symptoms; reaffirmation of life and death as natural processes; integration of psychological, social and spiritual care with clinical care; natural occurrence of death, not postponing or speeding it; support to family members to cope with the disease; support to patients to live actively until death; multidisciplinary approach for the clinical and psychosocial needs of patients and families, including counseling and support in case of mourning ⁴.

The *Universal Declaration on Bioethics and Human Rights* ⁵, although it does not specifically highlight the issue of palliative care, it is emphatic in acknowledging the concern that science should have, in order to improve the quality of life of people, seeking to promote wellness of individuals, families, groups, communities and humanity in general. Palliative care can be the form in which health professionals experience such concern, confirming the cited universal declaration ⁵. In fact, respect and care for the research subject are already stressed in the proposal of Beauchamp and Childress in their study "Principles of biomedical ethics" ⁶. To understand the public concern with the social control of research involving human beings, it is necessary to remember that this bioethical reflection was proposed based on the US socio-cultural context of the 1970s.

Given the awareness of abuse towards humans from paradigmatic research cases (hepatitis virus inoculation in mentally retarded children in New York; the Tuskegee case involving African-Americans with

syphilis in Alabama, whose research lasted for 40 years even with the discovery of penicillin, among others), the US government established in 1974, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research ⁷.

The commission published in 1979 the famous Belmont Report ⁷, with the purpose of minimizing ethical conflicts arising from biomedical sciences research. This document highlights three fundamental principles, becoming, according to Pessini and Barchifontaine ⁸, the classic principlist statement: respect for people, which took into account the respect for the autonomy of the individual and the care for those who had their autonomy reduced; beneficence, which emphasized the concern to not cause damage, maximizing benefits and reducing risks; and justice, which aimed to treat everyone equally.

From this report, Beauchamp and Childress extended this concern with humans taking part in clinical and welfare studies. Based on the normative ethics of British ethicist David Ross ⁹, which addresses *prima facie* duties, that guide the pursuit of solutions for moral dilemmas, considering the point of view of the people involved in the process, the authors made a reflection on ethical principles that should be taken into account in the biomedical field: respect for autonomy, beneficence, non-maleficence and justice. The principle of respect for autonomy advocates self-determination of the individual and their ability to decide what, in their view, would be the best for themselves ¹⁰. The principle of beneficence seeks the good of human beings and requires positive actions, because it implies using knowledge and technical skills to minimize risks and maximize benefits to the patient ¹¹. The principle of non-maleficence is based on the Hippocratic tradition – *it creates the habit of two things: help or, at least, not cause damages* – and is applicable to all people. The principle of social justice is associated with equitable distribution of benefits in medicine or health in general ¹⁰. These basic principles, considered as non-absolute and ranked according to the situation, became relevant and influenced bioethics in such a way, that even today this subject has a strong principlist foundation.

To assess the quality of death in several countries throughout the world ¹³, the Lien Foundation, from Singapore, ordered a study. British magazine *The Economist* ¹⁴ published in 2010, the results and conclusions of this study, as well as the ranking of countries with the best quality of death. A total of 40 countries were assessed, according to the es-

established criteria. The study analyzed quantitative indicators, such as life expectancy and GDP spent with health, in addition to qualitative criteria, based on the individual evaluation of each country, such as public awareness on services and treatment available to people in end of life and access to medication and palliative care.

The United Kingdom was considered the best place to die because of the advanced actions in palliative care, according to research of the British Broadcasting Corporation (BBC)¹³. Historically, this country has been addressing palliative care seriously, objectively and with the necessary scientificity and humanism, due to the pioneering attitude of Dr. Cecily Saunders, an English nurse, social worker and physician who introduced the modern Hospice Movement when she founded in 1967, St. Christopher's Hospice, with the purpose of providing care to ill people and developing studies in the field¹⁵. Only in 1982, the WHO would create a group to define policies aimed at pain relief and hospice care¹⁶.

Brazil, according to the same BBC research, was assigned as the third worst country to die because of the poor quality of end-of-life care¹⁴. This result shows the lack of investment, by our governmental bodies, in studies that depict improvements and practical actions in the health field, mainly in end-of-life care. It also allows inferring that there are flaws in the training of professionals that deal with terminally ill patients.

It is known that between the 16th and 18th centuries, the topic of death was addressed differently from how it is today: regarding death, it was common to show an interest from a scientific point of view to aesthetic, even erotic attraction, which viewed a decomposing body as a state of beauty¹⁷. Contemporarily, however, "death" is taboo, denied by both patient and family, and usually, a neglected theme even by health professionals. Hence, death revolves the imaginary, but it is difficult to be expressed, understood and experienced; and, when it is inevitable, it is relocated to hospitals, particularly to intensive care units (ICU). Ariès¹⁷ draws attention to the problem, which emerged with the passage from domesticated death in the Middle Age to the negated and locked-up death at ICUs. Awareness to the need for humanized care arises then, as an answer to this exclusion of the terminally ill patient: Advocating the importance of welcoming the patient, providing their comfort and of their family,

respecting their values and beliefs, which need to be considered and accepted¹⁸.

Longevity has been increasing worldwide, and thus, the need to provide quality care and intervention to the elderly, who are ill and often with advanced-stage clinical diseases, has also increased, especially in the case of chronic diseases, such as dementia, cancer, lung disease, heart disease and kidney disease. This context justifies the importance of investigating what has been discussed and performed in terms of palliative care, particularly to the elderly.

This article, therefore, aims at identifying existing publications on bioethics and palliative care to the elderly, describing each of the cases found on researched databases and seeking to recognize, among non-absolute ethical principles that characterize principlism, that which stands out in the described treatment.

Method

This study is a systematic review that sought to identify existing publications in six important databases: Cochrane, Embase, PubMed, Lilacs, SciELO and Ibecs. As inclusion criteria, articles from 2002 to 2013 were researched, related to palliative care, bioethics and the elderly. The studies were identified by means of electronic search on databases, considering any article published between January 1, 2002 and November 2, 2013, in English, Spanish and Portuguese, and articles published in other languages were excluded. The descriptors in the search strategy were: "*palliative care*" AND "*aged*" AND "*bioethics*". Case reports and articles related to presentations in conferences, in addition to monographs, were also disregarded. The studies were read and assessed by the authors, in order to find if they met inclusion criteria.

It is worth highlighting that, although the publications have been researched on databases using the words "*palliative care*" AND "*aged*" AND "*bioethics*", the studies found were not always pertinent to terminally ill aged patients, but to terminally ill patients in general, who require palliative care.

Results

After literature search, a total of 31 studies were identified: 20 at PubMed, 6 at Embase,

3 at Lilacs and 2 at Cochrane. At SciELO and Lilacs databases, no articles were found with the used markers. A total of 15 studies were excluded from these, because they did not emphasize the bioethical aspects in palliative care, due to being published in languages other than those listed in the inclusion criteria, or also due to being duplicated in more than one database. In the final selection, thus, 16 articles remained, which are listed in Table 1, in the end. From this initial survey, a brief summary was systematized from each selected article, highlighting its core theme, as reproduced in the following topics.

Study 1 – Vieira RW, Goldim R. Bioética e cuidados paliativos: tomada de decisão e qualidade de vida (Bioethics and palliative care: decision-making and life quality)¹⁹

In 2012, Vieira and Goldim published a study held with 98 cancer patients, developed throughout one year. The authors evaluated the decision-making process and the quality of life of patients, using the instruments of psychological and moral development, WHOQOL-OLD and WHOQOL-BREF. They demonstrated that patients have the ability to make decisions aimed at their best interests. Regarding life quality, the best results were within the scope of social relations, environment and intimacy, because in the WHOQOL-OLD domains, Social Participation had the lowest mean and Intimacy, the highest mean. Whereas in the application of WHOQOL-BREF, Environment had the best performance. Researchers concluded that patients were pleased with the ability to establish social, personal and intimate relationships, even if hospitalized and that palliative care should be provided in the sense of improving the quality of life, thus, seeking to integrate the patient to the decision-making process.

Study 2 – Schüklenk U, van Delden JJM, Downie J, McLean SAM, Upshur R, Weinstock D. End-of-life decision-making in Canada: The report by the Royal Society of Canada expert panel on end-of-life decision-making²⁰

In 2011, in Canada, the authors published a report on *end-of-life and decision-making*. This study consisted of five topics, which address: a) what is known about end of life and assisted suicide; b) legal analysis of what is allowed in Canada and forms of assisted death; c) ethical approach to assisted death; d) life experiences that decriminalized forms of assisted death; e) recommendations on palliative

care in Canada, as well as to the forms of assisted death addressed in this document.

Study 3 – Peppersack T. Comment on Monod et al.: “Ethical issues in nutrition support of severely disabled elderly persons”²¹

The article makes comments on ethical issues and nutrition support in cases of severely disabled elderly persons. This reflection made, based on article “Ethical issues in nutritional support of severely disabled elderly persons”, by Monod et al²², shows the importance of care to be provided to patients who are not able to express their nutrition needs/wishes - especially those with advanced dementia. Here, the first barrier to be overcome is to acknowledge that dementia cases may be terminal. Hence, it is possible to make an appropriate plan for artificial nutrition, treatment intensity, drug use, in addition to understanding the patient’s needs and desires and help them with advance directives for decision-making (which will not always be possible, due to lack of understanding by the patient). The ethical debate, in such cases, is aimed at the pursuit of wellness in the end of life, *i.e.*, at the principle of beneficence.

Study 4 – García-Solier R, Sánchez-Araña Moreno T, Rueda-Villar T, Ruiz-Doblado S. Psychological and psychiatric assistance in palliative care (IV): Ten years of a consultation-liaison program²³

The authors conducted a study on *psychiatric and psychological assistance*, for ten years. In this study, a total of 73 terminally ill patients were monitored, most of them with cancer. An analysis of the interference of drugs, psychotherapy, family influence and support team was conducted regarding the most common psychological disorders of these patients. The terminally ill patients were not fully aware of their diagnosis, thereby the bioethical support team had an important role in these cases. The researchers concluded that paternalist attitudes by family members and physicians should be changed, and what it required to improve psychosocial assistance.

Study 5 – Song J, Wall MM, Ratner ER, Bartels DM, Ulvestad N, Gelberg L. Engaging homeless persons in end of life preparations²⁴

This study describes an engaging research conducted with 59 homeless people and their end of life preparation. The study assisted them to prepare their *advance directives of volition*. The process demonstrated that homeless people will only define

an advance directive when there is opportunity for that. Such population showed a great interest in end of life care. This simple planning act (advance directive) presented itself as a guarantee of autonomy and dignity to these people.

Study 6 – Merlo DF, Beccaro M, Costantini M, Italian Survey of the Dying of Cancer Study Group. An unconventional cancer treatment lacking clinical efficacy remains available to Italian cancer patients²⁵

A study performed by independent researchers, in conjunction with an Italian research center, published the study results whose objective was to investigate experiences related to end of life care in patients with terminal cancer. Caregivers of 2,000 patients were identified, because these people were the ones who spent most time with terminally ill patients in their last three months, and a questionnaire on multitherapy was applied. It was found that 95% of patients with terminal cancer were the subject of multitherapy. The unconventional treatment seemed to be popular among Italians with terminal cancer. It was concluded that it is necessary to identify the ethical implications by means of routine monitoring of these treatments.

Study 7 – Pang MC, Volicer L, Chung PM, Chung YM, Leung WK, White P. Comparing the ethical challenges of forgoing tube feeding in American and Hong Kong patients with advanced dementia²⁶

It is a study held with US and Hong Kong patients with advanced dementia, focusing on the ethical challenges of tube feeding. Decision-making standards were evaluated on the refusal of tube feeding and their ethical dilemmas, by comparison of a study performed in Boston with another study performed in Hong Kong. As there is a culture aimed at the preservation of life in this city, all patients who died were receiving some sort of feeding; in exceptional cases and upon family request, tube feeding was removed.

The authors reached the following conclusions on the studied subjects in Boston: great importance given to temporal diagnoses about death; growing concern of physicians in doing what is best for the patient, not just prolonging their life; search for more relational approach in the final days of life of the patient, providing a pleasant environment without discomfort. Whereas in Hong Kong, despite the culture of life preservation, some patients and family members were against tube feeding, and employees reported that they would

not opt for this type of feeding if they were in the patient's place.

Study 8 – Watkins LT, Sacajiu G, Karasz A. The role of the bioethicist in family meetings about end of life care²⁷

This observational study sought to find how bioethicists supported decision-making during family meetings about end of life care. To reach a pragmatic objective, bioethicists intervened in decision-making at decisive moments, with based opinions. They also acted as mediators in the pursuit of consensus between family and medical staff. In addition to the role of consultants and mediators, it was identified that bioethicists started to have a persuasive "function".

Study 9 – Lam PT, Chan KS, Tse CY, Leung MW. Retrospective analysis of antibiotic use and survival in advanced cancer patients with infections²⁸

The authors conducted this study in order to find the standard use of antibiotics in palliative care unit. Thus, it was sought to identify possible factors that could affect results after the infection. The study was performed by reviewing medical records and identification of patients who had infections, compared to the antibiotic they used. At the hospital selected for the study, there were 20 beds in the palliative care unit, from a total of 1,300 beds, serving a population of approximately 569,400 people in the region. Almost all patients with advanced cancer, who were hospitalized there, died at the hospital.

People with advanced cancer who were hospitalized from January to July 2002 were included in the study. The medical records of the patients were analyzed from their hospitalization to their death. The surviving patients were excluded from the study. A total of 105 patients were selected, and 18 of them were excluded, due to meeting the exclusion criteria. Of the 87 included patients, 19.55% had not infection, whereas 80.45% had at least one infection, totaling 120 infection cases. The average length of stay (LOS) at the hospital until their death was 63 days. In 97.5% of cases, antibiotics were used as treatment.

The researchers concluded that the existence of infection cases is common in people with advanced cancer. Regarding palliative care, dyspnea was identified as one of the symptoms associated with the worst prognosis for infection, whereas the

use of antibiotics was associated with the best prognosis. In addition, they highlighted that bioethical principles are more easily achieved when antibiotics are used as life-support treatment.

Study 10 – Kaldjian LC, Weir RF, Duffy TP. A clinician's approach to clinical ethical reasoning²⁹

The authors conducted a study focused on what the physician should have for *clinical-ethical reasoning*. It is an approach of how physicians should act to solve ethical conflicts, based on clinical thinking. Therefore, the article emphasizes that clinical reasoning should be incorporated to bioethical principles (beneficence, non-maleficence, respect for autonomy, justice). The authors also aimed, in ethical pluralism, at a way to diversify the stated values, trying to lead physicians to a more comprehensive reasoning on ethics. The first step is to identify the ethical issue clearly. Then, it is necessary to gather and organize data (medical facts, assistance targets, patient's objectives and preferences and context). With this assessment, physicians should ask themselves on the possibility of an existing essentially ethical conflict in question. At this point, the professional should find if they need more information and even if a dialogue is necessary. Following these steps, the physician can determine the best course of action, based on reference ethical values (bioethical principles, rights, consequences, similar cases, professional guidance, ethical integrity of the medical doctor). This course of action, while incorporating clinical reasoning, would be, according to the authors, a way to promote, in medical practice, a bioethical approach that supports their clinical decisions.

Study 11 – Olson E, Cristian A. The role of rehabilitation medicine and palliative care in the treatment of patients with end-stage disease³⁰

This study focused on the use of rehabilitation medicine in palliative care. With rehabilitation, it is sought to recover functionality and independence by means of exercises. For terminally ill patients, rest breaks are necessary between exercises, because this type of patient can not be subjected to major efforts; in addition, breaks between exercise sessions should be more prolonged. The most recurring symptoms in terminally ill patients, according to the authors, are fatigue, weakness, pain, dyspnea and delirium.

Patients can be treated by multidisciplinary teams, with the administration of painkillers and rehabilitation sessions. The article in question also addressed ethical issues from the planning point of

view to face such diseases. The issues addressed were resuscitation, advance directives of volition, decision-making, resource allocation and medical futility.

According to the authors, proper definitions and goals should follow the patient's volition, according to the ethical principle of respect for autonomy. Regarding informed consent, the issues related to decision making, which may be variable with the progression of the disease and use of medication that restricts understanding. They conclude that it is necessary to promote more educational activities for the health team, aiming to raise their awareness on the benefits of palliative care and rehabilitation medicine.

Study 12 – Barbero Gutiérrez J, Garrido Elustondo S, De Miguel Sánchez C, Vicente Sánchez F, Macé Gutiérrez I, Fernández García C. Effectiveness of a training course in bioethics and of the introduction of a checklist to detect ethical problems in a home care support team³¹

This study showed the importance of the *training course in bioethics* in the solution of ethical problems related to homecare to terminally ill patients. A checklist was also presented that helps identifying ethical problems, in order to improve the study performed by the homecare team. Having taken part in the course and used the checklist, professionals who did not belong to the bioethics field, could detect a higher number of ethical problems in the treatment of patients with terminal illnesses.

Study 13 – Csikai EL. Social workers' participation in the resolution of ethical dilemmas in hospice care³²

The author conducted a study on the participation of social workers in the resolution of ethical dilemmas in palliative care at hospices that did not have direct access to ethics committees. The objective was to find common ethical issues, the resolution method and participation of workers in a "kind of ethics committee" created by the institution that did not have formal ethics committees. The sample that integrated the study consisted of 110 social workers engaged in ethical dilemmas on a daily basis. The most commonly discussed issues referred to the patient's condition, family engagement and denial of the terminal illness by family members. The most complex cases were taken to a multidisciplinary team. The other two forms of conflict resolution most cited in the study were discussions with the clinical director and information

conversations with the medical staff. Of the respondents, 54% reported that it would be important the presence of an ethics committee at their institution. Discussion cases on euthanasia, assisted suicide and suicide assisted by relatives were mentioned. Social workers found that training in bioethics should be continuous, including the disclosure of laws, medical advances and bioethicists' thinking. The author concludes that it is important to promote education in ethical issues on end of life care for all health professionals.

Study 14 – Sykes N, Thorns A. Sedative use in the last week of life and the implications for end-of-life decision making³³

This study aimed at determining the implications of changing sedative doses for terminally ill patients. There are ethical controversies on this procedure because, in some cases, it is seen as anticipated death. A total of 237 cases of patients who died in a palliative care unit were reviewed, noticing the change in sedative dose, compared to patients who were not sedated. The group that was not sedated in the last seven days or 48 hours of life had the lowest survival rate. The increased sedative dose in the last hours of life was not associated with reduced overall survival rate.

Study 15 – Pantilat SZ. End-of-life care for the hospitalized patient³⁴

The author conducted a study reporting end of life care for hospitalized patients. He found the importance of medical intervention for pain relief of terminally ill patients, because the medical staff acts to mitigate the symptoms of these patients, such as pain, nausea, vomiting, depression, among other discomfort. The possibility of the patient to die at home was pointed as an alternative, making the end of life a more humanized process.

Study 16 – Tanneberger S, Malavasi I, Mariano P, Pannuti F, Strocchi E. Planning palliative or terminal care: The dilemma of doctors' prognoses in terminally ill cancer patients³⁵

Understanding what a terminally ill patient is and what palliative care should be provided to them at such stage, is a crucial factor for the physician to know how to correctly plan the palliative care required for each patient. The authors conclude that an assistance network of palliative care is necessary, regardless of life expectancy of the terminally ill patient.

Discussion

As aforementioned, palliative care aims to relieve uncomfortable symptoms in end of life patients, seeking to offer improved life quality to them and their families. The act of caring, therefore, is intrinsically assumed as the pursuit of the other's wellbeing. In this sense, the analyzed literature records the discussion, in Study 9²⁸, on the use or not of antibiotics to fight infections in terminally ill cancer patients. The authors are emphatic while advocating this therapy, highlighting that, although there is no consensus on that, the patient's wellbeing should prevail, demonstrating the advocated principle of beneficence, in spite of respect for the patient's autonomy. In Study 6, whose objective was to investigate the therapies used in terminally ill cancer patients, Merlo²⁵ et al also emphasized the importance of identifying the ethical implications of these interventions by means of routine monitoring of these treatments, to ensure the principle of beneficence.

In Studies 3²¹ and 7²⁶, respectively, strategies related to nutrition are discussed, to improve the quality of life of terminally-ill dementia patients. According to these two studies, tube feeding is aimed at improved wellness and life quality of these patients. The principle of beneficence is also highlighted here, pointed by the authors, which thus corroborate Mainetti³⁶, who draws attention to beneficence as the action of actively granting benefits to others. The authors emphasize the importance of respect for patient's volition (autonomy) when they are in conditions to make decisions, because dementia limits their ability to issue proper judgments. This was also the focus of the research in Study 14³³ on the ethical controversies of using sedatives or not in the last weeks of life.

Throughout the terminally ill patient's treatment, family members also present cases of mood swings, stress and anxiety. According to Soares³⁷, the literature has plenty of evidence that strategies focused on family members, among which improved communication and prevention of conflicts, result in greater satisfaction as to the quality of assistance provided to the ICU patient. Dialogue with family members, aimed at helping them in decision making, was the core theme of Study 8²⁷. Bioethics committees, at large hospitals, attempt to reach this understanding and assist in the pursuit of the most suitable joint decision for the patient's good, because they are the agents who seek to assess ethical dilemmas arising from hospital routine³⁸. Csikai³², in

Study 13, also highlights the importance of the creation of ethical committees in hospices.

Terminally ill elderly patients present functional symptoms and losses, both of cognitive and physical or emotional nature, which reduce their life quality, requiring an ethically correct treatment. These are issues to be considered in clinical practice, as shown in Study 16³⁵, which emphasizes the importance of medical intervention to relieve these symptoms. Mitigated suffering and discomfort is also emphasized in Study 15³⁴. It is found, in both publications, the pursuit of beneficence, regardless of life expectancy, with the purpose of providing benefits regarding comfort and life quality.

The notion of “total pain” developed by Saunders in the 1960s, recognizes the emotional factor – in addition to social and spiritual factor – as an aspect involved in pain and other physical symptoms. It is possible to observe that, according to the psychological disposition of the patient, the limitations imposed by organically determined symptoms can be increased in certain cases and mitigated in others⁴. Such concern was the focus of Study 4²³, which indicates that psychosocial assistance addressed to terminally ill patients in hospitals should be optimized and communication, feedback between patient and physician, improved. Hence, it is crucial that therapeutic listening should be improved, in order to help the patient understand, recognize and transform the pain, to face the illness and death. It would be a more comprehensive way of applying the principle of beneficence in tune with the idea of “total pain” that includes biopsychosocial aspects.

In the same end of life context, health professionals that work with palliative care are confronted with the process of dying, with pain and mourning, and are often not prepared to deal with such phenomenon, which leads them to think about their own finiteness. In Study 16³⁵, the proper understanding of what is palliative care given to a terminally ill patient, is considered the primary point of the treatment, so that, regardless of life expectancy, improved assistance is given to the patient. Thus, Barbero Gutiérrez et al proposed, in Study 12³¹, the creation of a training course in bioethics to help health professionals face ethical dilemmas involving palliative care in a better way.

The medicine student’s humanization is essential in their training process, because society requires sensitive physicians, who see the patient as someone with their own beliefs and values that need to be respected³⁹. According to Kovács⁴⁰, it is necessary that health professionals learn about

human death and suffering. Therefore, the author proposes a challenge to healthcare universities and schools: that they include in the training of such professionals, the development of values such as compassion, sensitiveness, devotion and ethics, in order to better deal with terminally ill patients⁴⁰. Confirming this line of thought, Kaldjian Weir and Duffy conducted Study 10²⁹, which addresses moral reasoning as a starting point of the medical doctor in their attempt to assist in the resolution of ethical conflicts. Also, within this context, Olson and Cristian addressed, in Study 11³⁰, ethical issues involving rehabilitation medicine and planning of how to face the terminal illness. As it can be found, all these solutions converge to the understanding and the pursuit of wellness of the human being who is ill and in the end of life.

Decision-making, often addressed in the selected articles, is an interconnected matter to end of life care. This theme is related to the principle of respect for autonomy, highlighted in Study 2²⁰. Allowing the patient itself to choose what should be done in relation to their treatment means recognizing, in a patent manner, their right to make decisions according to the life and action plan, based on their axiological scale, aspirations and particular beliefs. Study 1¹⁹ also corroborates such idea. This decision-making as to palliative care should be, whenever possible, respected; however, it is necessary to see if the person is able for such act. In this sense, advance directives of volition allow the person to previously state the actions to be taken when they are not longer capable of manifesting themselves⁴¹; this planning was addressed in Study 5²⁴.

Another moment in which the principle of respect for autonomy presents itself refers to communication to patient about their disease and prognosis, which is addressed in Study 12³¹. Even if family members do not agree with this communication, it is the physician’s duty to do so if questioned by the patient. The benefits that each treatment may bring, which are covered by palliative care, should be taken into account to prevent the patient from being subjected to futile and unnecessary treatments.

Pessini and Bertachini⁴² also highlight the importance of addressing the ethics of care regarding palliative care. While focusing on the context of bioethics, it is not enough to approach principlism, because it is in ethics of care and virtues that the vulnerability of human beings stands out. In this sense, the ethics of care not only addresses deci-

sions that should be made, but also the quality of relations, such as continuity, openness and trust.

Final considerations

Issues related to death, terminally ill patients, palliative care and limited support treatment to patients with incurable and terminal illnesses are also worth of in-depth discussion. For years, the theme of palliative care was neglected, and the intention of this study was to show what was published on the subject between 2002 and 2013, and that still represents very little against the theme's relevance.

By analyzing the articles classified by the principlist view, the growing concern of researchers with the patient's opinion and consent is frequently identified, and such concern is often extended to families. Such attitude of respect for the other's will characterizes the principle of respect for autonomy. Such autonomy refers to the dignity of human beings, from the ideas of Kant⁴³ and his deontological ethics and John Stuart Mill⁴⁴, one of the utmost representatives of British utilitarianism. This principle can be identified then, in some of the studied texts, being notably explained in ones and subtly suggested in others.

The principle of beneficence also arises from the analysis, because both health professionals and the authors of the articles seemed to favor the

mitigation of pain and discomfort of terminally ill patients upon the use of palliative care and techniques. It is worth highlighting that the analysis did not detect any search for the patient's cure. The reports emphasize the struggle of professionals for maximized well-being of those who have no prospects of prolonged life, resorting to the use of skills and technical expertise, which can identify the influence of utilitarian calculation, appropriate to this principle.

However, if the position of Mainetti³⁶ is accepted, that the principle of non-maleficence (refraining from doing evil) does not mean doing nothing, but which may imply a moral obligation to assist others through positive actions, which includes palliative care, it is also possible to identify it in some moments, showing why some authors integrate the principle of beneficence to the principle of non-maleficence. The professionals who are dedicated to palliative care, and who believe that this care is a way to alleviate the suffering of those who are terminally ill, seek the good of human beings, but often do not use all the technology available to continue a futile treatment. Hence, this fact makes it possible to affirm that the principle of beneficence, identified in the analyses, covers the principle of non-maleficence, which is applied to all and deemed a fundamental principle of Hippocratic action. Such symbiosis of the two principles requires an in-depth study in the context of principlism, regarding the field of palliative care.

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Participation of the authors

Anelise Crippa and Claudia Adriana Facco Lufiego participated in the design, systematic review, data analysis and article writing. Anamaria Gonçalves dos Santos Feijó participated in the data analysis, article writing and final review. Geraldo Attilio De Carli and Irenio Gomes participated in the topic concept and guidance.



ANNEX

Table 1. List of selected articles per author, year and title

Author	Year	Title
Vieira RW, Goldim R	2012	Bioética e cuidados paliativos: tomada de decisão e qualidade de vida (Bioethics and palliative care: decision-making and life quality)
Schüklenk U, van Delden JJM, Downie J, McLean SAM, Upshur R, Weinstock D	2011	End-of-life decision-making in Canada: The report by the Royal Society of Canada expert panel on end-of-life decision-making
Pepersack T	2011	Comment on Monod et al.: "Ethical issues in nutrition support of severely disabled elderly persons"
García-Solier R, Sánchez-Araña Moreno T, Rueda-Villar T, Ruiz-Doblado S	2008	Psychological and psychiatric assistance in palliative care (IV): Ten years of a consultation-liaison program
Song J, Wall MM, Ratner ER, Bartels DM, Ulvestad N, Gelberg L	2008	Engaging homeless persons in end of life preparations
Merlo DF, Beccaro M, Costantini M, Italian Survey of the Dying of Cancer Study Group	2008	An unconventional cancer treatment lacking clinical efficacy remains available to Italian cancer patients
Pang MC, Volicer L, Chung PM, Chung YM, Leung WK, White P	2007	Comparing the ethical challenges of forgoing tube feeding in American and Hong Kong patients with advanced dementia
Watkins LT, Sacajiu G, Karasz A	2007	The role of the bioethicist in family meetings about end of life care
Lam PT, Chan KS, Tse CY, Leung MW	2005	Retrospective analysis of antibiotic use and survival in advanced cancer patients with infections
Kaldjian LC, Weir RF, Duffy TP	2005	A clinician's approach to clinical ethical reasoning
Olson E, Cristian A	2005	The role of rehabilitation medicine and palliative care in the treatment of patients with end-stage disease
Barbero Gutiérrez J, Garrido Elustondo S, De Miguel Sánchez C, Vicente Sánchez F, Macé Gutiérrez I, Fernández García C	2004	Effectiveness of a training course in bioethics and of the introduction of a checklist to detect ethical problems in a home care support team
Csikai EL	2004	Social workers' participation in the resolution of ethical dilemmas in hospice care
Sykes N, Thorns A	2003	Sedative use in the last week of life and the implications for end-of-life decision making
Pantilat SZ	2002	End-of-life care for the hospitalized patient
Tanneberger S, Malavasi I, Mariano P, Pannuti F, Strocchi E	2002	Planning palliative or terminal care: The dilemma of doctors' prognoses in terminally ill cancer patients