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Bioethics and palliative care: an integrative review

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Abstract

Humanization in healthcare is a process of recovering respect for life, individuality and professional differences with a view to building a solidified environment in healthcare institutions. This process requires the implementation of an interdisciplinary and reflective system of principles and values that govern professional health practice, and it is essential that these professionals seek knowledge about the principles of bioethics to provide care safely, ethically and responsibly. From this assumption, this integrative review aims to highlight the importance of multidisciplinary assistance in palliative care and ways of improving this humanization. The final sample consisted of eight articles highlighting the importance of humanization, a prerequisite for caring for the human person. The conclusion is that health professionals in any area of care must be aware of the principles governing bioethics and, above all, put them into practice.

Keywords: Bioethics. Palliative care. Humanization of assistance.

Resumo

Bioética e cuidados paliativos: revisão integrativa

A humanização em saúde é um processo de resgate do respeito à vida, à individualidade e às diferenças profissionais com vista à construção de um ambiente solidificado nas instituições de saúde. Esse processo requer a implementação de um sistema interdisciplinar e reflexivo dos princípios e valores que regem a prática profissional em saúde, sendo essencial que esses profissionais busquem conhecimento sobre os princípios da bioética para prestação de cuidados com segurança, ética e responsabilidade. Partindo desse pressuposto, esta revisão integrativa tem como objetivo destacar a importância da assistência multidisciplinar nos cuidados paliativos e formas de melhorar essa humanização. A amostra final foi composta por oito artigos que destacam a importância da humanização, pré-requisito para exercer o cuidado à pessoa humana. Conclui-se que o profissional de saúde em qualquer âmbito do cuidado deve carregar o conhecimento sobre os princípios que regem a bioética e, principalmente, colocá-los em prática.

Palavras-chave: Bioética. Cuidados paliativos. Humanização da assistência.

Resumen

Bioética y cuidados paliativos: revisión integradora

La humanización en salud es un proceso de rescate del respeto a la vida, a la individualidad y a las diferencias profesionales para construir un entorno sólido en las instituciones sanitarias. Este proceso requiere la implementación de un sistema interdisciplinario y reflexivo de los principios y valores que regulan la práctica profesional en salud, y es fundamental que estos profesionales busquen conocer los principios de la bioética para brindar cuidados con seguridad, ética y responsabilidad. A partir de este supuesto, esta revisión integradora tiene como objetivo destacar la importancia de la atención multidisciplinaria en los cuidados paliativos y las formas de mejorar esta humanización. La muestra final consistió en ocho artículos que muestran la importancia de la humanización, un requisito previo para el cuidado de la persona humana. Se concluye que los profesionales sanitarios de cualquier ámbito asistencial deben conocer los principios que regulan la bioética y, principalmente, ponerlos en práctica.

Palabras clave: Bioética. Cuidados paliativos. Humanización de la atención.

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The process of humanization of health care seeks to recover respect for life by considering individuality, professional differences and the need to build a solid environment in health care institutions that legitimizes the human aspect of all professionals involved in care. This process requires the implementation of an interdisciplinary system reflecting the principles and values that govern the practice of different health care professionals [1].

Palliative medicine, today, is understood as a medical specialty aimed at providing quality of life to patients with serious diseases, without expectation of cure, using techniques that increase comfort without interfering with survival. The World Health Organization (WHO) defines palliative care as the total and active care provided to the patient whose disease no longer responds to curative treatments and when the control of pain and other psychological, social and spiritual symptoms becomes a priority [2]. The objective of palliative care is to improve the quality of life of patients and comfort their families with a humanized conduct, based on epidemiological and scientific principles, through the management of treatment, information, health education and the provision of care [3,4].

In the hospital setting, if on the one hand the consequences of death become more evident, on the other hand the advancement of medical technology leads to improved therapeutic prospects in various clinical situations [5]. However, this progress affords the possibility of prolonging life at any cost, often implying unnecessary treatments [6,7]. Palliative care professionals need an academic training that prepares them to provide care in the best manner, since no science or specialty alone covers the complexity of human existence. Therefore, it is essential to have a multidisciplinary team—composed of physicians, nurses, psychologists, nutritionists, social workers, speech therapists, pharmacists, physiotherapists, as well as spiritual and religious counselors—to deal with all dimensions and ways of providing care, seeking to reduce suffering and pain, which results in better quality of life for patients and comfort for their families. Multidisciplinary team members need to be specially attentive as to how communication is conducted and consider that patients—with the exception of those who are not able to discuss their treatment—and/or family members are entitled to receive all relevant information about the clinical situation, otherwise they cannot satisfactorily participate in decision-making about the best therapeutic plan and reorganize their lives [9].

Patients with no expectation of cure are in a moment of fragility, with psychosocial, spiritual and physical limitations. At this difficult time, there are several palliative conducts that, carried out by a team that knows how to listen and give support, can provide patients and family members with pain relief, decreased discomfort and the possibility of facing the end of life. A good team should recognize, whenever possible, the patient's active place, autonomy and choices and not allow the anticipation of death due to abandonment and isolation; therefore, it is essential that professionals working in the intensive care unit (ICU) seek knowledge about the principles of bioethics to support actions and decisions about the end of a patient's life, in order to identify and provide care with safety, ethics, and responsibility [5,8].

Method

This is an integrative literature review, a methodological approach that provides the synthesis of published studies in order to recognize the current state of the art, enabling general conclusions and identification of gaps in a particular issue [10]. The integrative review was built according to the six classic steps, namely: identification of the theme and selection of the research hypothesis or question; establishment of the inclusion and exclusion criteria for the studies found in the literature search strategy; definitions of the information to be extracted from the selected studies/categorization of the studies; evaluation of the included studies; interpretation of the results; and presentation of the knowledge review/synthesis [11]. The integrative review adopted the following guiding questions: what is the importance of multidisciplinarity in palliative care? How to improve the humanization of palliative care?

The databases used for the selection of articles were: Latin American and Caribbean Health Sciences Literature (LILACS), Virtual Health Library (VHL) and Online Medical Literature Analysis and Retrieval System (MEDLINE). We used the following descriptors: "bioethics," "palliative care," "humanization of care," "palliative care" and "health professionals." For each database, the most appropriate search strategy was applied. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) protocol was adopted for the writing and organization of the review[11].

We adopted the following study eligibility criteria: complete scientific articles available in the database, published in the last ten years, in Portuguese, English and Spanish. The exclusion criteria were: scientific articles that did not address the theme of the objective of the review, duplicates, books, dissertations and theses. All selected articles were read in detail, and, for the purpose of analysis and synthesis, a specific instrument was prepared that consisted of: article title, authors, publication data, objectives, methodology characteristics, results and conclusions.

Results and discussion

The search in the VHL, LILACS and MEDLINE databases retrieved 319 articles in accordance with the methodology used; most were published in international journals—predominantly in North America—and confirmed different types of studies (Figure 1).

Figure 1. Articles included and excluded according to eligibility criteria

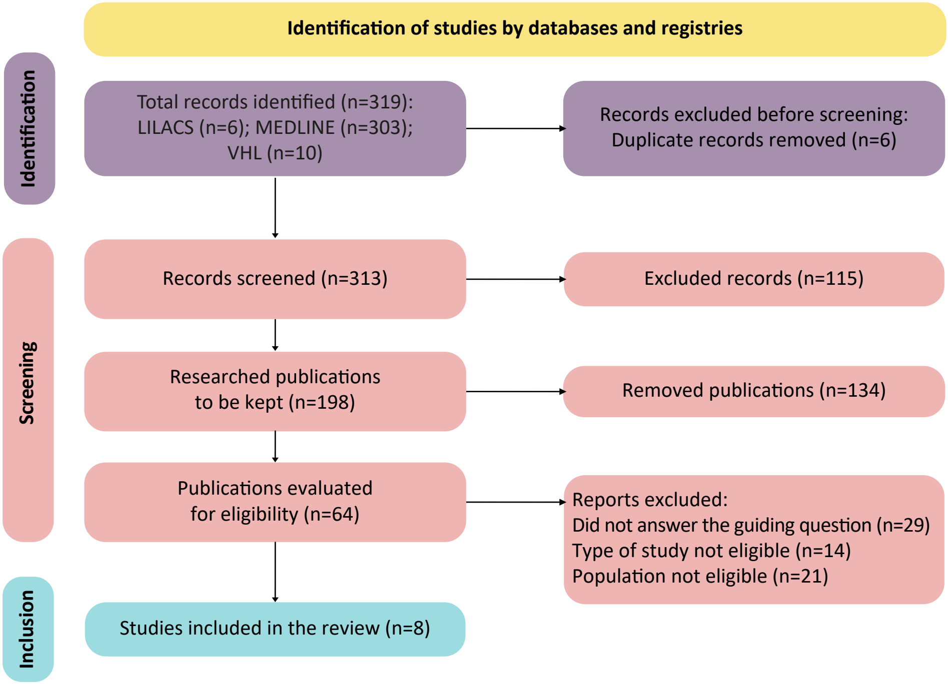

Chart 1. General characterization of the empirical analysis material

Author; year	Type of study and research location	Objective of the study	Main results	Conclusion
Claessens P, Menten J, Schotsmans P, Broeckaert B, Palsed Consortium. 2011[12]	Prospective, longitudinal and descriptive study; Northern Belgium	Describe the characteristics of patients sedated due to refractory symptoms in palliative care units	The authors conceptualize palliative sedation as "slow euthanasia" or hidden euthanasia.	It is concluded that palliative sedation respects the patient's clinical condition.
Ferrand E, Dreyfus JF, Chastrusse M, Ellien F, Lemaire F, Fischler M. 2012[13]	Multicenter research; France	Evaluate the evolution of requests to hasten death expressed to different types of palliative care teams	A patient who requests the hastening of death is in a situation of unbearable suffering, which may not be the main concern of these patients.	It is important to provide multidisciplinary care with a broad view of the patient, respecting their will and autonomy.
Vasconcelos MF, da Costa SF, Lopes ME, Abrão FM, Batista PS, Oliveira RC. 2013[14]	Exploratory study, with qualitative approach; João Pessoa/PB	Examine the principles of bioethics	Category 1: respect for autonomy; category 2: valorization of the principles of bioethics in the practice of palliative care for patients with HIV/AIDS	Ethical principles are important in the multidisciplinary setting and mitigate the possible harms of health care.
Aparicio M, Centeno C, Carrasco JM, Barbosa A, Arantzamendi M. 2017[15]	Qualitative exploratory study	Analyze what is most valued by family caregivers	The study shows that some family caregivers highly value their experience with the home palliative care team.	It is essential to consider the importance of the relationship between the health care professional and the patient/family caregiver.
Cicero-Oneto CE, Mata-Valderrama G, Valdez-Martínez E. 2018[16]	Multicenter retrospective descriptive study; Mexico City	Evaluate adolescents aged 14 to 18 years with cancer	The hospital was the place with the highest number of deaths for several reasons.	It is urgently necessary to implement palliative care services to improve the quality of life of terminally ill patients, without excluding curative care.
Midtbust MH, Alnes RE, Gjengedal E, Lykkeslet E. 2018[17]	Phenomenological research approach based on the philosophy of Husserl; Norway	Clarify the experiences of health care professionals in providing palliative care to people with severe dementia in nursing homes	Health care professionals need to know the patient well to recognize their limitations in palliative care.	Cooperation between family, patient and health care professionals becomes fundamental in palliative care so the patient has quality care.

continues...

Chart 1. Continuation

Author; year	Type of study and research location	Objective of the study	Main results	Conclusion
Panfilis L, Di Leo S, Peruselli C, Ghirotto L, Tanzi S. 2019[18]	Qualitative study with thematic analysis; Northern Italy	Understand how health care professionals interpret and treat ethical issues in palliative care	Five themes related to morality were identified.	For health care professionals, the recognition of moral principles, the confrontation of ethical dilemmas and the valorization of dialogue and communication are fundamental in the relationship of care.
De Panfilis L, Tanzi S, Perin M, Turola E, Artioli G. 2020[19]	Mixed evaluation method study; Italy	Evaluate, quantitatively and qualitatively, the impact of ethical skills in terms of competencies and performance	The triangulation of the data led, in most cases, to confirmatory and new results.	The participants found the innovative structure of the training relevant, especially with regard to the integration of the theoretical-interactive and practical parts.

Regarding the year of publication of the articles, the period of greatest emphasis with regard to the guiding question of this study was between 2017 and 2019, as shown in Table 1.

Table 1. Distribution of articles according to year of publication

Period (years)	N	%
2020 to 2021	1	12%
2017 to 2019	4	50%
2014 to 2016	0	0%
2011 to 2013	3	38%
Total	8	100%

The quality of life of patients in palliative care is a challenge in terms of health and ethical issues. Human dignity and human rights are bioethical principles that require respect for the well-being of individuals in their entirety. Decision-making in any clinical intervention of interest to the patient's health should only be carried out with prior, free and informed consent of the individual in question and based on adequate information. Based on this assumption, humanization is a prerequisite for exercising care and respect for the human person. This care is related to what the professional will add in their actions and that is essential for our development and fulfillment as human beings[20].

Palliative sedation is conceptualized by authors as slow or hidden euthanasia, which is the administration of sedative drug in doses and combinations necessary to alleviate pain and consciousness and which is performed in exceptional cases, that is, in which refractory suffering is evident and in which the patient is close to the end of life. This study states that it is the proportionality of the sedative dose and the patient's suffering that determines whether it is slow euthanasia or palliative sedation.

This slow euthanasia method is decriminalized in Belgium, which may explain the low palliative sedation in the study. Ethical issues concerning palliative sedation are still scarce, although there is much information. When patients receive palliative sedation, data on decision, duration, and type of palliative sedation received are collected. The decision to make a patient unconscious is a delicate one and it is not solely the responsibility of the physician who takes care of that patient, but of the entire multidisciplinary team, the patient and their family, although the principle of patient autonomy must be taken into account. There are exceptional acute cases (massive hemorrhage, acute terminal dyspnea) in which patients receive palliative sedation almost instantly, but these cases were not found in the study [11].

The problem for a patient to express the request to hasten death, the challenge of dealing with the difficulty, the feeling of loss of dignity, and the lack of realistic treatment alternatives are concerning factors similar to those legally required to request euthanasia in the Netherlands or Belgium. The request to hasten patient death is illegal but common. And, despite the provision of multidisciplinary palliative care, it is not an appropriate solution for everyone. In the Netherlands and Belgium, this type of euthanasia should only be requested if the attending physician is convinced that the patient is in a situation of unbearable suffering [12]. Therefore, multiprofessional health care with a broad view of the patient is important, as well as familiarity with the family and respect for the patient's will and autonomy, in order to preserve their mental health, which is very important when considering the quality of life of end-of-life patients.

For a more humanized care, it is essential to follow the principle of beneficence, which aims to protect the patient from possible damage during the hospitalization period. In addition, priority should be given to the principle of autonomy, which values dialogue between the family, the patient and the health care team. The process of discussing the therapeutic plan should involve all participants in order to promote transparency and collaboration, which contributes to the best progress of the treatment. In turn, the principle of justice emphasizes the equitable and respectful care for human dignity, which is of major importance in the context where the patient is without cure and hospitalized [13]. The author also notes that the nurses' posture is supported by the Code of Ethics of Nursing Professionals, which recommends the promotion of human health in its entirety, according to the principles of ethics and bioethics [13].

There is no one better than the patient's family to know their preferences, how they like their food, the organization of their belongings, their daily activities. Similarly, no one is more qualified than the physician or caregiver to know how the specific care of each patient should be carried out. Thus, the mutual exchange of knowledge and expertise between family members and health care professionals, with the patient as the agent of their own choices, is essential for the practice of palliative care [14].

The medical record is a fundamental document for recording the actions performed by the medical team, and these pieces of information were omitted in the study, since in almost all records it was difficult to find the specifications of the palliative treatment initiated and the moment when the cancer was no longer curable. Mexico's health care system regulates that hospitals will provide palliative care to terminally ill patients from the moment the terminal stage of the disease is diagnosed and the patient has been informed of existing care options. Changes in these regulations for palliative care at all stages of the disease are ethically considered [15]. Thus, in December 2014, an agreement was issued by the Ministry of Health establishing that the provision of palliative care should cover both terminally ill patients and those in need of pain relief and suffering from some life-limiting symptomatic disease and that, in addition, pain relief treatments do not exclude curative care [21].

All professionals report that knowing the patient well in the provision of palliative care is paramount, especially for those who suffer from dementia. The cooperation of family members is also a key factor in the provision of palliative care, as they are the ones who are most aware of the patient's desires and emotions, which are partially limited and difficult to understand for professionals. The objective of family agreement with palliative care in the final phase of the patient's life is to promote mainly physical and psychological well-being [16].

The health care professionals (nine physicians and seven nurses) who worked in care had only participated in a 4-hour training on palliative care through the hospital unit specialized in this field, in which it was possible to observe the importance of knowledge about moral principles, the facing of ethical dilemmas and the importance of communication in the relationship of care. The professionals themselves recognized the relevance of the issue and reported their current difficulty in approaching patients under care. It is important to know that care implies clarification on the issue, to finally adopt in practice the humanization of care with patients under palliative care[17].

The satisfactory results found through semi-structured interviews identified three broad themes: 1) applying ethical reflections in clinical practice; 2) recognizing ethical issues; and 3) being aware of ethical thinking: individual comparisons and comparisons shared among the team. This study addresses a more in-depth and specialized training regarding the integration of theoretical and practical parts, reinforcing the importance of knowledge and subsequent training in the practice of care provided to patients[18].

Final considerations

The findings of the integrative review show that it is essential that health care professionals in any field of care be aware of the principles that govern bioethics and, especially, adopt them in practice. Based on the analysis of the studies, it was observed that previously patients were passive agents, that is, they did not have their statements taken into account and only were subject to the action, which was decided by the medical team, by their family or by the one who proved more intellectually and psychologically capable in the face of the patient’s situation.

Over the years, the comparison between humanized care, which values the individual in their entirety, and care focused only on the professional technique showed the lack of a comprehensive approach to bioethics and care focused only on the professional technique. It can be observed that bioethics was not fully present and that people did not receive individualized care that respected their psychosocial conditions.

Therefore, this paradigm shift, by incorporating the holistic view of the human being, is of fundamental importance for a care that respects the dignity, choices and suffering of the patient and, consequently, promotes a more ethical, responsible and humanized care.

References

1. Oliveira FT, Flávio DA, Marengo MO, Silva RHA. Bioética e humanização na fase final da vida: visão de médicos. Rev. bioét. (Impr.) [Internet]. 2011 [acesso 22 ago 2024];19(1):247-58. Disponível: https://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/553
2. Palliative care. World Health Organization [Internet]. 2002 [acesso 22 ago 2024]. Disponível: https://www.who.int/cancer/palliative/definition/en/
3. Wittmann-Vieira R, Goldim JR. Bioética e cuidados paliativos: tomada de decisões e qualidade de vida. Acta Paul Enferm [Internet]. 2012 [acesso 22 ago 2024];25(3):334-9. DOI: 10.1590/S0103-21002012000300003
4. Palmeira HM, Scorsolini-Comin F, Peres RS. Cuidados paliativos no Brasil: revisão integrativa da literatura científica. Aletheia [Internet]. 2011[acesso 22 ago 2024];35-36:179-89. Disponível: https://tinyurl.com/2t35wrh8
5. Pegoraro MMO, Paganini MC. Cuidados paliativos e limitação de suporte de vida em terapia intensiva. Rev. bioét. (Impr.) [Internet]. 2019 [acesso 22 ago 2024];27(4):699-710. DOI: 10.1590/1983-80422019274353
6. Machado KDG, Leo Pessini L, Hossne WS. A formação em cuidados paliativos da equipe que atua em unidade de terapia intensiva: um olhar da bioética. Bioethikos [Internet]. 2007 [acesso 22 ago 2024];1(1):34-42. Disponível: https://saocamilo-sp.br/assets/artigo/bioethikos/54/A_cuidados_paliativos.pdf
7. Oliveira TCB, Maranhão TLG, Barroso ML. Equipe multiprofissional de cuidados paliativos da oncologia pediátrica: uma revisão sistemática. Rev Psic [Internet]. 2017 [acesso 22 ago 2024];11(35). DOI: 10.14295v11i35.754

8. Almeida F, Munhoz CJM, Oliveira JC. Bioética e sua interface com a unidade de terapia intensiva: uma revisão integrativa. Braz J Dev [Internet]. 2021 [acesso 22 ago 2024];7(4):34928-36. DOI: 10.34117/bjdv7n4-110
9. Passos El Horr VM, Araújo AJ, Cunha T. Ética budista como referencial para a bioética: revisão integrativa da literatura. RIB [Internet]. 2021 [acesso 22 ago 2024];16:1-6. DOI: 10.14422/ribi16y2021.007
10. Souza MT, Silva MD, Carvalho R. Integrative review: what is it? How to do it? Einstein (São Paulo) [Internet]. 2010 [acesso 02 agos 2024];8(1):102-6. DOI: 10.1590/S1679-45082010RW1134
11. Page MJ, Moher D, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD *et al*. PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. BMJ [Internet]. 2021 [acesso 22 ago 2024];372(29):160. DOI: 10.1136/bmj.n160
12. Claessens P, Menten J, Schotsmans P, Broeckaert B, Palsed Consortium. Palliative sedation, not slow euthanasia: a prospective, longitudinal study of sedation in Flemish palliative care units. J Pain Symptom Manage BMC Palliat Care [Internet]. 2011 [acesso 22 ago 2024];41(1):14-24. DOI: 10.1016/j.jpainsymman.2010.04.019
13. Ferrand E, Dreyfus JF, Chastrusse M, Ellien F, Lemaire F, Fischler M. Evolution of requests to hasten death among patients managed by palliative care teams in France: a multicentre cross-sectional survey (DemandE). Eur J Cancer [Internet]. 2012 [acesso 22 ago 2024];48(3):368-76. DOI: 10.1016/j.ejca.2011.09.020
14. Vasconcelos MF, da Costa SF, Lopes ME, Abrão FM, Batista PS, Oliveira RC. Palliative care for HIV/AIDS patients: bioethical principles adopted by nurses. Cien Saude Colet [Internet]. 2013 [acesso 22 ago 2024];18(9):2559-66. DOI: 10.1590/s1413-81232013000900010
15. Aparicio M, Centeno C, Carrasco JM, Barbosa A, Arantzamendi M. What are families most grateful for after receiving palliative care? Content analysis of written documents received: a chance to improve the quality of care. BMC Palliat Care [Internet]. 2017 [acesso 22 ago 2024];16(1):47. DOI: 10.1186/s12904-017-0229-5
16. Cicero-Oneto CE, Mata-Valderrama G, Valdez-Martínez E. La mortalidad en adolescentes con cáncer: características clínico epidemiológicas de muerte y aspectos éticos emergentes. Gac Med Mex [Internet]. 2018 [acesso 22 ago 2024];154(1):8-15. DOI: 10.24875/GMM.17002698
17. Midtbust MH, Alnes RE, Gjengedal E, Lykkeslet E. A painful experience of limited understanding: healthcare professionals' experiences with palliative care of people with severe dementia in Norwegian nursing homes. BMC Palliat Care [Internet]. 2018 [acesso 22 ago 2024];17(1):1-9. DOI: 10.1186/s12904-018-0282-8
18. Panfilis L, Di Leo S, Peruselli C, Ghirotto L, Tanzi S. I go into crisis when: ethics of care and moral dilemmas in palliative care. BMC Palliat Care [Internet]. 2019 [acesso 22 ago 2024];18(1):70. DOI: 10.1186/s12904-019-0453-2
19. De Panfilis L, Tanzi S, Perin M, Turola E, Artioli G. "Teach for ethics in palliative care": a mixed-method evaluation of a medical ethics training programme. BMC Palliat Care [Internet]. 2020 [acesso 22 ago 2024];19(1):149. DOI: 10.1186/s12904-020-00653-7
20. Brasil. Ministério da Saúde. Resolução nº 41, de 31 de outubro de 2018. Dispõe sobre as diretrizes para a organização dos cuidados paliativos, à luz dos cuidados continuados integrados, no âmbito Sistema Único de Saúde (SUS). Diário Oficial da União [Internet]. Brasília, 23 nov 2018 [acesso 2 dez 2024]. Disponível: https://bit.ly/3uNfq2U
21. Brasil. Ministério da Saúde. Portaria nº 2.439, de 8 de dezembro de 2014. Estabelece a definição e as diretrizes para a implementação de cuidados paliativos no Sistema Único de Saúde (SUS). Diário Oficial da União [Internet]. Brasília, 8 dez 2014 [acesso 2 dez 2024]. Disponível: http://www.inca.gov.br

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