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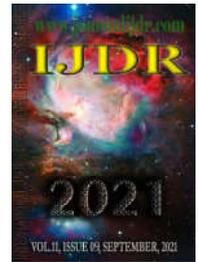
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REVIEW ARTICLE

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MEANINGS OF LIFE BY THE ELDERLY TERMINALLY ILL: AN INTEGRATIVE REVIEW

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ABSTRACT

Objective: To identify the existing knowledge about the meanings attributed to life by the elderly at the end of life. Method: Integrative literature review based on searches on the PubMed, Age Line, and the Virtual Library on Health (Bireme-VLH) databases, with a sample composed of at least 50% of the elderly, with progressive and life-threatening diseases refractory to treatment. **Results:** The study selected a total of 596 articles. After duplicates exclusion, selection by title, abstract, and complete reading, the study selected seven articles from 2001 to 2017, most of which were qualitative. The data analysis allowed us to identify two themes: sources of meaning and strategies to find meaning. The main sources of meaning were: significant relationships with the family, with oneself, with God, or with health professionals; the goodness/utility, valuing the good and the feeling of usefulness; spirituality/transcendence, in connection with God, nature, or higher energy; powerful, personal experiences, such as the contact with the internal strength and the ability to enjoy moments of pleasure and beauty. As strategies to find meaning, the study cites: religion and its belief systems; leaving a material or intangible legacy; internal dialogue; a sense of belonging. **Conclusion:** None of the studies included result from Latin American research, evidencing a lack of this theme in the studies in Brazil and its neighbor countries. Most of the articles describe oncological patients, indicating the need for research with non-oncological patients terminally ill. The findings aim to facilitate personalized attention to this patient profile, in particular by promoting attention to non-physical symptoms.

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INTRODUCTION

Aging, accompanied by feelings of realization and appreciation of the life lived, without sticking to rancor and regrets, allows the integration of the ego and wisdom as the proper quality to the old age (Erikson, 1998). The opposite is called hopelessness, felt like a time that ends, the loss of the meaning of life and of the hope of changing or improving it (Kovács, 2009). According to Erick Erikson, it is a task of this eighth phase of life, the point of view on death (Erikson, 1998). Although the end of life can come at any age, it is in old age that finitude itself tends to emerge most forcefully to consciousness: the encounter with non-being and emptiness (Py, Pacheco, & Oliveira, 2009). Objectively speaking, long-lived people have experienced more normative losses and, probably, more non-normative losses, requiring them to elaborate various mourning. In addition, old people witness the death of the peers, who act as a reference facilitating the reflection on the end itself (Kovács, 2009). Death is also part of the life cycle and is preceded — except for sudden and unexpected deaths — by a terminal decline: the impairment in cognitive and functional abilities, especially perceived in the elderly or with a chronic and life-threatening disease (Papalia & Feldman, 2013). In this context, to preserve the quality of life and the functionality as much as possible,

there is palliative care, defined by the World Health Organization (WHO) (World Health Organization, 2016) as:

“an approach that improves the quality of life of patients (adults and children) and their families facing problems associated with life-threatening diseases. It prevents and alleviates suffering through early identification, correct assessment, and treatment of pain and other issues. Palliative care is the prevention and relief of suffering of any nature — physical, psychological, social or spiritual — experienced by adults and children living with life-limiting health problems”. (p. 5)

All people diagnosed with life-threatening diseases should receive palliative care concomitant to curative treatment (Ricardo Tavares Carvalho, 2018). However, some diseases are refractory to treatments and evolve into terminality (Nicodemo & Torres, 2018). Except for the possibility of organ transplantation, in the terminal phase, it is no longer possible to carry out disease-modifying therapies with a curative purpose. It is, therefore, a progressive, incurable, and life-threatening disease (Ricardo Tavares Carvalho, 2018; Nicodemo & Torres, 2018). In addition to the control of physical symptoms, the study aims to identify and take care of emotional, social, and spiritual suffering (World Health Organization, 2016). In this context,

spirituality is at the same time universal and personal, and it is the search of each person for a meaning of life and the way it relates to the transcendent (Peres, Arantes, Lessa, & Caous, 2007; Puchalski, King, & Ferrell, 2018; Roze des Ordon, Sinuff, Stelfox, Kondejewski, & Sinclair, 2018; Steinhauer et al., 2017). The latter is an experience beyond sensations that provides meaning to existence (Balducci, 2018). It involves connecting with something greater than oneself regardless if it is meaningful people, values, causes, or life itself (Breitbart & Poppito, 2014). It means finding meaning in life, which can be reached in any circumstances, even in the most suffered ones - this is the great thesis of Viktor Frankl, psychiatrist founder of logotherapy. It is the theoretical School of psychology, of the existential aspect, which understands the will as a primary motivation in the human being. The meaning is found in the world through self-transcendence, seeking it outside oneself (Frankl, 2016). When faced with the reality of terminal illness, the attitude that the patient assumes towards suffering and imminent death is the essentially important. According to Frankl (2016), when one cannot change a situation - such as an incurable disease - , "we are challenged to change ourselves" (p. 137). In a certain way, suffering is eased when it is joined to a meaning, for example, of sacrifice (Frankl, 2016). After all, the awareness of one's death brings with it the awareness of one's life, leading to this existential reflection. It is the spiritual, existential dimension, through which - and only from it - it is possible to accept and desire life despite its suffering.

Empirically, studies have investigated the importance of finding meaning in life in the context of terminality in old age. When Harrop and collaborators (2017) conducted qualitative research with ten patients with advanced lung cancer, they identified the sense of meaning in life as one of the three principal coping resources. Haug and collaborators (2016), also in qualitative research, with twenty-one participants, related the ability to find meaning with the restoration and development of resilience in people with incurable cancer to maintain realistic and life-oriented goals. In quantitative terms, psychiatrist William Breitbart has published the development and results of Meaning-Centered Psychotherapy (MCP). It is an intervention designed, initially, to promote and maintain the sense of meaning, peace, and purpose of life in patients with advanced cancer, and later adapted to patients with terminality criteria (Breitbart et al., 2010, 2015; Rosenfeld, Cham, Pessin, & Breitbart, 2018; Rosenfeld et al., 2017; Sutkeviciūtė, Stančiukaitė, & Bulotienė, 2017). Thus, the objective of this literature review is to explore the existing knowledge about the meanings found for life by the elderly facing the diagnosis of a terminal illness. Since the importance of living a meaningful life until the end is clear, the question is: What are the meanings attributed to life by the elderly at the end of life?

METHOD

The study chose an integrative review for featuring the inclusion of experimental and non-experimental research and combining theoretical and empirical studies of the literature on a given phenomenon (Whittemore & Knaf, 2005). The method followed was proposed by Whittemore & Knaf (2005), who described the data collection and analysis procedure in detail to preserve scientific rigor. The Manual of systematic Integrative Bibliographic Review was used as a complement to organize the review (Moreira, 2014) as well as a summary of how to do an integrative review (Souza, Silva, & Carvalho, 2010). These authors propose five steps for an integrative literature review, in summary: i) identification of the problem; ii) literature; (iii) data evaluation; iv) data analysis; v) presentation. The research question to be answered by the review was defined as: What are the meanings attributed to life by the elderly at the end of life? Thus, the participants of interest are defined as the elderly (that is, people aged 60 years or over, according to Brazilian legislation) (Brasil, 2003) with a terminal-stage disease, understood as a disease with no possibility of cure, progressive, refractory, and threatening of life (Nicodemo & Torres, 2018). Many studies of this nature are carried out under the approach of palliative care, which, although not

limited to terminal illnesses, act with greater emphasis on these cases (Ricardo Tavares Carvalho, 2018). Three essential elements constitute the theme of this research: the elderly, the terminality of life, and meaning. In consultation with the Virtual Health Library (Centro Latino-Americano e do Caribe de Informação em Ciências da Saúde, 2018) and the U.S. National Library of Medicine (U.S. National Library of Medicine, 2018a), the research identified five descriptors to represent the elements "elderly" and "terminality of life," each with its correspondence in Portuguese, English, and Spanish: "palliative care" (cuidados paliativos/cuidados paliativos), "hospice care" (cuidados paliativos na terminalidade da vida/cuidados paliativos al final de la vida), "attitude to death" (actitud frente a la muerte/actitud frente a la muerte), "elderly" (idoso/anciano), "80 year old man and over" (idoso de 80 años o más/anciano de 80 o más años). However, there is no suitable descriptor for the sense of meaning, so it was added as a keyword: "meaning" (sentido/sentido). The searches were done in English and with the Boolean operators "AND" and "OR" and established the following search phrase: ("palliative care" OR "hospice care" OR "attitude to death") AND ("aged" OR "aged, 80 and over") AND "meaning." First, before the survey itself, the study searched for systematic, integrative, and meta-analysis reviews to verify the existence of a review similar to the proposal. In the first half of 2019, searches were carried out with combinations of the descriptors and keywords described above. It did not find similar research on the Prospero databases (National Institute for Health Research, 2018), Cochrane Library (Cochrane Library, 2018), and PubMed Clinical Queries (U.S. National Library of Medicine, 2018b).

The study searched the databases PubMed and AgeLine, and the Virtual Library on Health (Bireme-VLH). It considered articles published until December 2019. The inclusion criteria were: article in a scientific journal; the sample comprised of the elderly, or for a minimum of 50% of the older people, the subject approach was the disease in the advanced and/or out of a possible cure, and life-threatening; the theme on the sense of spirituality, as long as the focus was on the aspect of the search for meaning in life, languages; Portuguese, English, or Spanish languages, and access to the full text, either free or via a Virtual Private Network (VPN) linked to the authors' research institution. Initially, the survey evaluated the articles found by the title, which should contain at least two of the three central elements of the review and not refer to a topic contrary to the research. The second selection was applied by reading the abstract and verifying whether the study answered the research question. Finally, in the positive cases, researchers read the full texts for the definitive selection of the included articles. The search was carried out in parallel and independently by two researchers to verify the objectivity of the research and its scientific rigor. These authors discussed the differences in detail until achieve a consensus on the final inclusion or exclusion of the articles. Given the articles contemplated, the most cited and relevant sources of meaning were listed and classified using the thematic analysis method, which made it possible to analyze, interpret and group similar data.

RESULTS

The study searched the databases and raised a total of 596 articles, including seven in the review. The selection is presented in detail in Figure 1, with a diagram elaborated as proposed by Moher and collaborators (2015). The seven studies that the survey found are from 2001 to 2017, written in the English language, and most are qualitative, employing open or semi-structured interviews for data collection, although the methodological references are distinct. The search identified only two articles of quantitative character (Martin Johannes Fegg et al., 2010; Tomás-Sábado et al., 2015), which used the instrument Schedule for Meaning in Life Evaluation (SMiLE), aiming to evaluate individually the meaning of life through three questions (Martin J Fegg, Kramer, Sibylle, & Borasio, 2008). Three searches did not present as the principal objective the exploration of the meaning of life, but it emerges in the investigation of very close contents, such as values of life and spirituality, so that it was possible to identify sources of meaning (Block, 2001; Ebenau, van Gorp, &

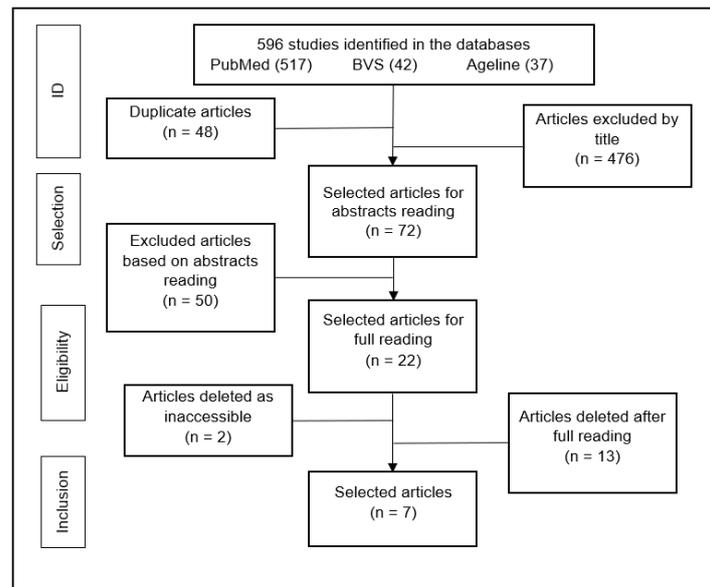
Hasselaar, 2017; Mok, Wong, & Wong, 2010). Five samples were composed of patients with advanced cancer(Block, 2001; Ebenau et al., 2017; Lethborg, Aranda, Bloch, Franz, & Kissane, 2006; Mok et al., 2010; Tomás-Sábado et al., 2015), only one included other terminal diseases (Martin Johannes Fegg et al., 2010), and another did not describe the clinical picture of the patients interviewed(Dwyer, Nordenfelt, & Ternstedt, 2008). Only three studies were conducted exclusively with the elderly(Block, 2001; Dwyer et al., 2008; Ebenau et al., 2017), and the others were included because at least half of the people in the sample were 60 years of age or older(Martin Johannes Fegg et al., 2010; Lethborg et al., 2006; Mok et al., 2010; Tomás-Sábado et al., 2015).Chart 1 summarizes the main information of the articles.

DISCUSSION

The two main themes identified were: “sources of meaning” and “strategies to find meaning.”

Sources of Meaning: The study grouped the most cited and important sources of meaning.

Meaningful relationships: The participants cited family as a source of meaning in four articles, but more broadly, almost all refer to some form of meaningful relationship as a crucial meaning of life.



Source: Prepared by the authors, 2021.

Figure 1. PRISMO diagram of selection of articles — São Paulo, State of Sao Paulo, 2021

Title, Year, Countries	Nature of the study	Objective	Sample	Data analysis	Level of evidence	Main results concerning the meaning of life
Psychological considerations, growth and transcendence at the end of life: the art of possible (Block, 2001). United States	Experience Report	Share experience, theories and guidance on psychological and psychiatric issues concerning people at the end of life	A 77-year-old with pancreatic cancer with metastases in the liver and lungs	Experience Report	Level 5: evidence from case or experience reports	Relationship with family; being part of a larger whole, legacy
Life values of elderly people suffering from incurable cancer: a literature review (Ebenau, van Gurp, & Hasselaar, 2017). Netherlands	Literature review	Identify and describe the most important values in the life of elderly people with incurable cancer	30 empirical articles on life values in older adults over 65 with incurable cancer	Structured in four steps according to Thomas & Harden (2008)	Level 4: evidence from descriptive (non-experimental) or qualitative studies	Spirituality and religion; material or immaterial legacy
Three nursing home residents speak about meaning at the end of life (Dwyer, Nordenfelt, & Ternstedt, 2008). Sweden	Qualitative research	Understand how three elderly women create meaning in everyday life in a nursing home	Three elderly women aged 93 and 95 in nursing homes with unspecified health conditions that compromise functionality and threaten life	According to the principles of hermeneutics of Odman (1992)	Level 4: evidence from descriptive (non-experimental) or qualitative studies	Relationship with the family; feeling of being valued and important to others; desire to contribute to the quality of life of others (social engagement)
The meaning of spirituality and spiritual care among the Hong Kong Chinese terminally ill (Mok, Wong, & Wong, 2010). China	Qualitative research	Explore the phenomenon of spirituality and spiritual care in Chinese patients in terminality	15 palliative care ward patients with different types of incurable cancer, between 53 and 89 years (mean 62.9 years)	Phenomenological interpretation not specified	Level 4: evidence from descriptive (non-experimental) or qualitative studies	Receiving and providing love in human relationships and connections; faith in God or a greater power; being a good person
Meaning in life in palliative care patients (Fegg et al., 2010). Germany	Cross-sectional quantitative research	Investigate meanings of life in patients in palliative care and compare them to those of the German population	100 patients in palliative care between 20 and over 70 years (59% elderly) with different diagnoses of cancer and amyotrophic lateral sclerosis	Statistical analysis	Level 4: evidence from descriptive (non-experimental) or qualitative studies	Family, spouse, health and spirituality
What gives meaning in life to patients with advanced cancer? A comparison between Spanish, German, and Swiss patients (Tomás-Sábado et al., 2015). Spain	Cross-sectional quantitative research	Identify the aspects that give meaning to life in a sample of Spanish patients with advanced cancer in palliative care	101 patients aged 33 to 84 years (mean 61.7 years) with advanced and incurable cancer receiving palliative care	Statistical analysis	Level 4: evidence from descriptive (non-experimental) or qualitative studies	Family, spirituality, spouse and altruism / social commitment
The role of meaning in advanced cancer—integrating the constructs of assumptive world, sense of coherence and meaning-based coping (Lethborg, Aranda, Bloch, Franz, & Kissane, 2006). Australia	Qualitative	Explore how people with advanced cancer experience and apply sense; verify this experience as part of a presumed world structure, sense of coherence, and sense-based coping.	10 patients aged between 36 and 78 years (mean 58 years, 50% elderly) with different types of advanced cancer and estimated survival of 6 to 12 months	Qualitative analysis based on three steps according to Patton (1990)	Level 4: evidence from descriptive (non-experimental) or qualitative studies	Relationships, internal forces, personal meaning, significant moments of beauty, peace and intimacy with loved ones, human connection and union with nature

Source: Prepared by the authors, 2021.

Chart 1. Characteristics of the selected studies — São Paulo, State of São Paulo, 2021

The various expressions found with this meaning were: family, feeling of being valued and important to others, receiving and providing love in relationships, human connections, spouse, relationships, friends, peace, and intimacy with loved ones. The study found that family and significant relationships are, therefore, one of the most mentioned and possibly most expected sources of meaning in these patients. It is worth questioning whether advanced age can lead to a greater appreciation of relationships due to the feeling of having generated a family, which in turn developed other families through children and grandchildren. Understood even more broadly, meaning, even if based on faith in God, concerns a relationship, for example, to a deity, relying on God's presence until death and beyond death (Mok et al., 2010). The importance of this source of meaning can be based on the feeling of being accompanied, especially when the end of life is approaching. Concerning the general population, patients in this context valued spouses and friends more, according to the research of Fegg and collaborators (2010). A patient included the doctor responsible for their care in their significant relationships, demonstrating the relevance that health professionals can exercise as resources in dealing with finitude and as part of the meaning of patients' lives (Block, 2001).

Kindness/utility: Several articles identified the feeling of doing good and being useful as a source of meaning, cited as a desire to contribute to the quality of life of others, be a good person, consider altruism and social commitment, material or immaterial legacy (Dwyer et al., 2008; Ebenau et al., 2017; Mok et al., 2010; Tomás-Sábado et al., 2015). Although indirectly, it is also about the appreciation of human relationships.

Spirituality/transcendence: Belief and the contact with the mystery of the transcendent, such as Death, God, or an inconceivable force, can present religion as the main way. Thus, this source of meaning was found in four articles (Ebenau et al., 2017; Martin Johannes Fegg et al., 2010; Mok et al., 2010; Tomás-Sábado et al., 2015). However, to understand transcendence as broader than religious systems, other studies were included. The union with nature (Lethborg et al., 2006) and belief in an unspecified higher force (Mok et al., 2010) are examples. In particular, a sense based on transcendence from an agnostic point of view is cited, namely, arising from the feeling of being part of a greater whole, the universe, composed of cycles of generation and destruction; the feeling of connection with something greater than oneself, to which one is united even after individual death through the molecules in the soil, as reported by Block (2001). Patients in palliative care at the end of life were more likely than the general population to find meaning in spirituality, nature, and animals (Martin Johannes Fegg et al., 2010). Belief and trust in God, in heaven or nature, as a source of the meaning of life, promoted strength to remain actively involved in life (Mok et al., 2010) and, more generally, meaning-based coping tends to make patients more engaged in making the most of their remaining time (Lethborg et al., 2006).

Meaningful personal experiences: Subjective resources and experiences were identified as a source of meaning mainly in the research of Lethborg and collaborators (2006), cited as "deep understanding of internal forces and sense of personal meaning" (p. 34), which involves reflection on oneself generating security and self-confidence. These authors also bring as a personal experience the cherished moments of beauty, in the sense of enjoying every pleasure in life, however simple it may be, as well as the moments of tranquility and peace (Lethborg et al., 2006).

Strategies to find meaning: Some articles explored how people find meaning in life, as well as what the meanings are. Thus, they were identified as strategies to find meaning: religion and its belief systems; leaving a material or immaterial legacy; internal dialogue; a sense of belonging (Dwyer et al., 2008; Ebenau et al., 2017; Mok et al., 2010). Religion can act as a means of contact with the transcendent, regardless of the religious strand. The legacy as meaning was associated with optimism and hope, which in turn are a source of strength and resilience to deal with the loss of identity and

imminent death, according to a literature review by Ebenau and collaborators (2017). Dwyer and collaborators (2008) mainly explored the internal dialogue, understood as a resource for finding meaning more than as a meaning itself; it involves thoughts and memories and the ability to reflect existentially on one's own life. Analogous to the presence of significant relationships as a source of meaning, the lack of meaning was associated with the absence of a sense of belonging and the high level of dependence (Dwyer et al., 2008).

CONCLUSION

From the analysis of the studies, two major themes related to the meaning of life attributed to the elderly terminally ill emerged. The first was identified as "sources of meaning," more specifically: meaningful relationships; kindness/utility; spirituality/transcendence; meaningful personal experiences. The second was categorized as "strategies to find meaning," contemplating factors linked to religion and its beliefs, leaving a legacy, internal dialogue, and sense of belonging. The fact that no article is the result of Latin American research demonstrates the absence of this theme in the studies of Brazil and its neighbor countries, highlighting the contribution of this literature review and the importance of new studies in this line. Notably, the religiosity experienced in Latin America is quite different from that experienced in the countries of origin of the articles studied, which emphasizes the need for more work contemplating the region. Most of the articles analyzed involve samples only with cancer patients, and only one cites this fact as a limitation of the research. Studies prove that the highest cause of death is currently heart disease, so the research does not represent such a health scenario well. However, the justification for this lies in the fact that the development of palliative care and end-of-life care was linked to oncology, so only more recent research has paid attention to non-oncological end-of-life frames. Palliative care has recently been incorporated into other diseases, such as organ failure or neurodegenerative diseases, although today they are the majority in a general hospital with the care of teams specialized in palliative care. The study found many surveys of a quantitative nature in the process of selecting the articles. However, most investigated the association of the presence of meaning in life with other constructs and were not interested in knowing what the meanings were. The identification of the meanings of life in the profile of these people allows health professionals to plan care with a focus on what makes sense to the patient, beyond the physical symptoms, enabling person-centered care, since these professionals are also part of their relationships and interact with the elderly in their process of finding the meaning of life. It includes assistance that is more consistent with the multidimensional conception of end-of-life suffering.

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