Feature Article

Unbearable Suffering: A Concept Analysis

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To understand and analyze the concept of "unbearable suffering" using a concept analysis method and to propose a new nursing diagnosis, the Walker and Avant method of concept analysis was used. Following the concept analysis method in 8 steps, a literature search was carried out in the MEDLINE, Dialnet, WOS, and PsycINFO databases between 2016 and 2020. Articles of theoretical or empirical nature, written in English, with the abstract available were included. As a result, 11 articles (4 theoretical and 7 empirical) were included. In addition, 2 cases were developed. The proposed new diagnosis, "unbearable suffering," refers to the situation of an individual who, because of a variety of factors, regardless of the cause, feels that he/she is unable to bear the suffering he/she is experiencing. The diagnosis is proposed for inclusion in "Domain 9: Coping/Stress Tolerance" and "Class 2: Coping Responses" of the North American Nursing Diagnosis Association taxonomy. Recognition of a nursing diagnosis for unbearable suffering could be key in identifying this type of suffering and facilitating interventions to reduce or mitigate it. Nurses play a fundamental role in situations of high levels of end-of-life suffering.

KEY WORDS
concept analysis, euthanasia, nursing, nursing diagnosis, suffering, unbearable

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For some years now, the question of euthanasia has been the subject of debate in Spain and in other countries. As well as a social issue concerning health professionals, the matter also gives rise to discussion within political, legal, and ethical spheres.[1] A number of countries in the European Union and several states in the United States have legalized euthanasia.[2] In Europe, the Netherlands was the first country to legalize euthanasia and assisted suicide in 2002, followed by Belgium, which was also a pioneer in legalizing child euthanasia with no age limit.[3] Luxembourg followed Belgium in 2009, and Switzerland legalized assisted suicide for non-Swiss residents.[4] Spain is now seeking to join the list of countries where euthanasia is legal.[5]

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The Bill for the Organic Law on the Regulation of Euthanasia in Spain, brought before the Spanish Parliament on December 17, 2020, upholds "the right of every eligible person to request and receive the necessary assistance in dying following due process and observing the necessary guarantees" (all quotes from Spanish sources have been translated by the authors).[6] A new individual right, euthanasia, is thus introduced into the Spanish legal framework.[7] The law states that the etymology of the word *euthanasia* is "good death," from the Greek *eu*, meaning "well or good," and *thanatos*, meaning "death."[8] The term *euthanasia* is defined as "the deliberate act of bringing a person's life to an end on their own express will, with the aim of avoiding suffering."[9] However, a number of authors and professional scientific societies have also attempted to define the term.[10] For Casanova, euthanasia is "the deprivation of life from another person carried out on humanitarian grounds at the request of the person concerned, who is terminally and incurably ill or has a disability that is

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irreversible in the current state of medical science and who wishes to put an end to their own suffering, including situations in which they cannot express their will or their will cannot be taken into consideration for whatever reason.".[7] Similarly, the Spanish Society of Palliative Care defines euthanasia as "a conduct (an action or omission) intentionally aimed at ending the life of a person who is seriously, irreversibly ill for compassionate reasons in a medical setting."[11] In all these definitions, euthanasia may be applied in the context of suffering caused by an incurable disease or condition that the person experiences as unacceptable and that cannot be alleviated by other means.[8] Studies show that there is no unanimity of opinion among professionals or common criteria between professionals and patients for establishing when suffering is or is not unbearable.[12] There is also no consensus among patients themselves as to what constitutes unbearable suffering.[13] The concept of unbearable suffering is always linked to personal experience[14] and is currently prominent in clinical practice as one of the keys to decision making and potential requests for euthanasia from patients.[15] However, despite its importance health field in this and other situations of illness and/or disability, the concept is not clearly defined.[9]

AIMS

In view of the above, this study aims to clarify the concept of "unbearable suffering" using a rigorous concept analysis method and to propose a new nursing diagnosis of the North American Nursing Diagnosis Association (NANDA) that could be developed further.

THE STUDY/REVIEW

Design

The concept of unbearable suffering will be analyzed using the Walker and Avant method,[16] which consists of the following steps:

1. Choosing a concept: The topic or area of interest should be indicated. This concept should generally be linked to a professional setting, as well as being confusing and/or crucial for the development of clinical practice.
2. Setting the objectives of the concept analysis: This involves stating the purpose of the concept analysis to be performed, whether this is to develop new nursing diagnoses, clarify imprecise concepts used in professional practice, refine a term that seems to have multiple meanings, align the definition of a concept with its practical application, and so forth.
3. Identifying all uses of the concept in the literature: A literature search is carried out, encompassing implicit and explicit uses of the concept. In addition to uses existing in the scientific literature, it is also advisable to include colloquial and cultural uses.
4. Identifying essential attributes: This is a fundamental step in analyzing the concept, whereby words or sentences that appear repeatedly in the literature are identified to reveal the essence of the concept. These attributes are characteristics that are expressed in the concept, acting as elements for differential diagnosis, that is, helping to discriminate between what is an expression of the concept and what is not.[17]
5. Developing a model case featuring the essential attributes of the concept: A health care–based example of the use of the concept should be developed, including its essential attributes. The case should be as representative as possible.
6. Developing a contrary case: This is used to help identify the essential attributes of the concept.
7. Identifying antecedents and consequences of the concept: Incidents or events occurring before the phenomenon (which is necessary for it to occur) and after the phenomenon (arising or resulting from the phenomenon) are surveyed.
8. Defining empirical referents for the essential attributes: Empirical referents are categories or classes of observable phenomena that, when present, demonstrate the occurrence of the concept making it possible to define it. In many instances, attributes are identical to empirical referents. When concepts are abstract (eg, self-esteem, sadness), their empirical indicators are not directly observable and depend on indirect measures.[18]

Data Sources

Following the concept analysis method in 8 steps, a literature search was carried out in the MEDLINE, Dialnet, WOS, and PsycINFO databases. The following search terms were used: "unbearable suffering" AND "euthanasia" and "unbearable suffering" AND "concept analysis" for records published in the previous 5 years (2016-2020), resulting in a total of 148 records. Their abstracts were assessed for eligibility. The following were included: articles of theoretical or empirical nature, written in English, with the abstract available. The following were excluded: anonymous articles, reviews of or comments on articles and/or books, opinion pieces, and editorials. Articles that were irrelevant to the topic, duplicates, and studies addressing unbearable suffering in scenarios other than the desire to bring forward death or requests for euthanasia were also excluded.

Two researchers read and analyzed the 148 abstracts independently. As a result, 11 articles (4 theoretical and 7 empirical) defining the concept of "unbearable suffering" in the context of requests for euthanasia were finally included. A search of manuals, books, and dictionaries was also carried out.

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RESULTS

Choosing a Concept and Objectives of the Concept Analysis

In addition, nursing professionals have a moral obligation to take a comprehensive approach to patients and, consequently, to use all available resources to provide humane care taking into account all aspects of the individual.[13] Nurses have multiple diagnoses at their disposal to help them elucidate what is wrong with a patient and propose a personalized care plan suitable for each situation.[19] However, comprehensive care in the face of "unbearable suffering" is not yet fully developed.[9] As a result, this phenomenon must be addressed from a nursing perspective in terms of its conceptualization, identification, diagnosis, and care through evidence-based interventions.[20] A proper understanding of what constitutes unbearable suffering is absolutely necessary for nurses, because this conceptualization serves as a guide for supporting patients in this terrible situation.[21] Greater clarity regarding the concept could also help clinicians to manage requests for voluntary physician-assisted suicide, which may occur in this situation of profound vulnerability.[12]

Identifying All Uses of the Concept in the Literature

Definition

In Spanish, which is the language in which the concept in question is being developed as part of the legalization of euthanasia, the term *sufrimiento insoportable* (unbearable suffering) consists of 2 different words: a noun, *sufrimiento* (suffering), and a qualifying adjective of quantity, *insoportable* (unbearable). According to the Dictionary of the Spanish Language (DLE) by the Royal Spanish Academy, one of the meanings of the word *sufrimiento* is "affliction, pain, sorrow" ("padecimiento, dolor, pena"), whereas *insoportable* means "that which cannot be borne" ("que no se puede soportar"). The verb *soportar* has 2 meanings according to the DLE: "to bear or carry a load or weight" ("sostener o llevar sobre sí una carga o peso") and "to tolerate or bear with patience" ("tolerar o llevar con paciencia"). Therefore, according to the DLE's definitions, *sufrimiento insoportable* refers to "affliction, pain, or sorrow that cannot be borne, tolerated, or carried with patience" ("padecimiento, dolor o pena que no se puede sostener o tolerar o llevar con paciencia").[22]

Pain/Suffering

On the basis of this definition, the term *sufrimiento* in this dictionary encompasses the concept of pain and even that of sorrow. However, in the scientific literature, there is widespread discussion as to the difference between pain and suffering[13] and a number of authors stress that the two are not synonymous.[23] Pain and suffering have become differentiated to the extent that pain, whether physical or nonphysical, is said to be a universally unsettling concept and can lead to suffering, but pain and suffering can exist independently of one another.[13] In any case, it is clear that suffering permeates all aspects of human existence.[24] It could be argued that it is the body that experiences pain but it is the human being who suffers it.[20] Cassell[25] is one of the most prominent authors in the study of suffering. In his observations, he describes the importance of differentiating between suffering and physical distress.[26] In 1992, Cassell[25,26] defined suffering as "the state of severe distress associated with events that threaten the intactness of the person." Suffering may therefore be described as a complex, negative cognitive and affective state, characterized by

1. the feeling experienced by the person whose integrity is threatened,
2. the feeling of powerlessness to deal with that threat, and
3. deficits in personal and psychosocial resources that would enable the person to deal with that threat.[27]

With regard to suffering in end-of-life contexts, the World Health Organization uses the following definition of palliative care: "Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[28] This definition also emphasizes the need to address pain, physical symptoms, and problems linked to other aspects of the individual. This means that reducing suffering through palliative care requires the person to be addressed as a whole. The causes of suffering can therefore be classified as physical, psychological, social, cultural, or spiritual.

Degrees of Suffering

The concept of "unbearable suffering" is central to the legislation underpinning the granting of requests for euthanasia, but it remains underdeveloped especially in relation to psychiatric patients[8] and the older adults. In clinical practice, the identification of suffering makes it possible to provide support and relief to patients who need it, but suffering cannot be treated unless it is recognized and diagnosed.[20] On the other hand, to be able to speak of unbearable suffering, it seems necessary to know how to measure the "amount" of suffering, because suffering can vary in intensity and duration depending on the situation, the sufferer, and their biography.[29] Differentiating between what is and what is not unbearable suffering is a complex but

unavoidable task. This cannot be reduced to a division between secular and religious views, and although there is widespread agreement that there is a need to implement scales to assess suffering,[8] it most likely will not be resolved by improving the psychometric properties of scales to assess suffering.[14] The unbearable aspect remains a matter for the patient and will always have a subjective and personal character. In fact, the adjective "unbearable" is a personal and subjective matter[30] that is inextricably linked to personal experiences, perceived threats, and the seriousness of the situation as perceived by the individual based on their beliefs and values. What is unbearable for one person may not be unbearable for another.[31]

Determinants of Unbearable Suffering

Research suggests that the most important determinants of unbearable suffering are physical and existential ones.[20] The control of physical symptoms is relatively straightforward using a palliative approach to health care. However, existential issues such as hopelessness emerge as very important determinants, as do social and economic factors such as loneliness and risk for low socioeconomic status, which can make the experience of suffering unbearable.[31]

Identifying Essential Attributes

After combining the various definitions and types of suffering, the essential characteristics of the concept of "unbearable suffering" are as follows:

- Experiencing a situation brought about by physical, psychological, social, spiritual, and/or moral causes that threatens the person's integrity and triggers a negative, emotional, subjective response in the person experiencing it.
- Experiencing a degree of distress regarded by the person as unbearable, impossible to tolerate with patience, and impossible to bear in the present and in the future, which is associated with events threatening the person's integrity.
- Wishing for death as the most acceptable alternative or even the only available option.

This concept proposal seeks to integrate the various tools for assessing suffering available in the nursing literature, including the nursing diagnoses described in the NANDA taxonomy[32]:

- Previous diagnosis of "Spiritual distress" (00066). A state of suffering related to the impaired ability to experience meaning in life through connections with self, others, the world, or a superior being.
- Previous diagnosis of "Moral distress" (00175). Response to the inability to carry out one's chosen ethical or moral decision and/or action.
- Previous diagnosis of "Hopelessness" (00124). Subjective state in which an individual sees limited or no alternatives or personal choices available and is unable to mobilize energy on own behalf.
- Previous diagnosis of "Risk for compromised human dignity" (00174). Susceptible for perceived loss of respect and honor, which may compromise health.

The presence of any of these diagnoses in a patient's clinical record should alert health care professionals to the possible relevance of the proposed diagnosis, "unbearable suffering."

Developing a Model Case Featuring the Essential Attributes of the Concept

This was a case of a 52-year-old male patient, single, living alone in Huelva, Spain. Several months ago, he was given a diagnosis of chronic obstructive pulmonary disease (COPD). He came to the emergency department on several occasions with an increase in his usual dyspnea, which had progressed from dyspnea at rest to dyspnea on minimal exertion. In addition, the patient has edema in both lower limbs and increased cough and expectoration. Despite outpatient treatment with antibiotics for bronchitis or pneumonia, there was no improvement. He was therefore admitted to the pulmonology ward with a diagnosis of exacerbated COPD, with 15% lung activity. After several days on the ward, with imminent progression of his disease and no improvement, the decision was made to transfer him to the intensive care unit.

The situation on the ward was as follows: the patient has no known allergies. He has high blood pressure, smoked 2 packs of cigarettes a day for 20 years, and is a former alcoholic. He reports dyspnea on exertion, orthopnea, and being unable to lie down in bed due to suffocation despite home oxygen therapy. The patient sleeps in a sitting position and is unable to exert himself in any way. He has no problems using the toilet but does have problems getting to the toilet because of constant dyspnea. Before the COPD exacerbation, he reported that he was independent, although he needed some help with activities of daily living. Now, he does not even want to move for fear of being unable to breathe, and he does not rest properly during the day or at night.

The patient's brother reports that he has no problems at all in voicing his emotions: "He's been telling me for several weeks now that I have to find myself a partner and that he doesn't have much time left. We're having a terrible time and I can't bear to think that one day he'll be gone." The last news the patient received was that he had been rejected from the waiting list for a lung transplant, leaving him more depressed than ever. The suffering on his face is plain to see. The patient says: "I feel that my life has no meaning and I don't want to live another minute suffocating like this. The suffocation is unbearable. I'm afraid even when it's hygiene time, when they restrain me, because I have a terrible time. I get short of breath, I

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suffocate, I can't stand this ordeal any longer. And what's the point of intubating me? There's no way out. The only thing I want is to die, to rest. I just feel sorry for my brother, but that way he too can rest and rebuild his life."

In this case, the patient has a negative emotional response to his suffering: he is fearful that his personal integrity will be threatened in the future, and as a result, he experiences unbearable suffering.

The patient's suffering is subjective and personal. It is not limited to physical symptoms such as fear of feeling pain at some point in his disease or his dyspnea; the patient is also concerned with moral questions, such as seeing his brother suffer. He often questions the meaning of his life and his identity, giving rise to a constant state of anxiety, fear, and insomnia. He fails to perceive sufficient meaning in his life, and it is safe to say that his case displays the defining characteristics of unbearable suffering.

Developing a Contrary Case

This was a case of a 65-year-old male patient given a diagnosis of lung cancer with bone metastases 7 months ago. He has received chemotherapy, but the disease has progressed. He has been admitted to the palliative care unit because of his gradually deteriorating general condition, with uncontrolled pain, dyspnea, nausea, and vomiting.

At the unit, he is reassured that his pain, vomiting, and dyspnea will be controlled. He will be accompanied by his relatives, and everyone will try to make him as comfortable as possible. His wife tells us that he has been very calm since he was admitted: "We're aware that his time will soon come. We're in God's hands now. We must have faith."

The patient reports that, although his pain is not completely relieved, he feels that God has decided that he will soon be reunited with him: "This is His will, and I don't mind suffering a little because suffering leads us to God, and God is love. Besides, I'm happy because I'm surrounded by my family."

In this case, although the patient is terminally ill and his pain is not controlled, he does not feel that his integrity as an individual is threatened. Moreover, there is no negative emotional response from the patient. His beliefs, in this case his Christian faith, provide him with sufficient support so that his intense physical symptoms do not turn into unbearable suffering. As a result, his symptoms do not arouse a desire to voluntarily end his own life and request euthanasia as a therapeutic option.

Identifying Antecedents and Consequences of the Concept

The most frequent antecedents of the concept of unbearable suffering in the scientific literature relate to the following:

- Presence of poorly controlled physical symptoms, such as pain, nausea and/or vomiting, shortness of breath, and so forth.[15]
- Pointless suffering, loss of dignity, and unacceptable weakness and quality of life.[5]
- Hopelessness.[8]
- Watching loved ones suffer; not wanting to be a burden to them.[33]
- The desire for death and request for euthanasia are triggered by unbearable suffering.[34] It is very important to be clear that unbearable suffering can be caused by any of these antecedents individually, by the sum of some of the antecedents, or by all of them and that, at the same time, unbearable suffering is influenced by essentially personal elements, as well as by cultural and social factors.[35]

Defining Empirical Referents for the Essential Attributes

Suffering is subjective in nature, so attributes can only be identified if and when the sufferer mentions them or by observing behaviors consistent with the presence of suffering. Given the complexity of the concept, there are currently no instruments available to assess it, and it is particularly difficult to assess it in people who have experienced intellectual disability throughout their lives.[36] Because of the absence of tools for diagnosing suffering as unbearable, we believe it is necessary to develop and incorporate a new diagnosis into nursing taxonomies. For instance, this diagnostic proposal (Figure 1) could be considered for inclusion in "Domain 9: Coping/Stress Tolerance" and "Class 2: Coping Responses" of the NANDA taxonomy.[32]

Diagnosis: Unbearable suffering.

Definition: A situation in which an individual, because of a variety of factors, feels unable to bear the suffering they are experiencing, whatever the cause.

Related factors:

- Uncontrolled physical symptoms causing a high level of suffering.
- Perceived loss of meaning in life.
- Perceived pointless suffering and/or unacceptable quality of life.
- Feeling of being a burden to their loved ones or belief that the situation the patient is experiencing causes suffering and/or places a great burden on their loved ones.
- Preexisting nursing diagnoses: 00066, 00175, 00124, and 00174.

Defining characteristics:

- Expressing the presence of very intense suffering.
- Repeatedly expressing an inability to cope with their suffering for any longer.
- Expressing a desire to cease living.

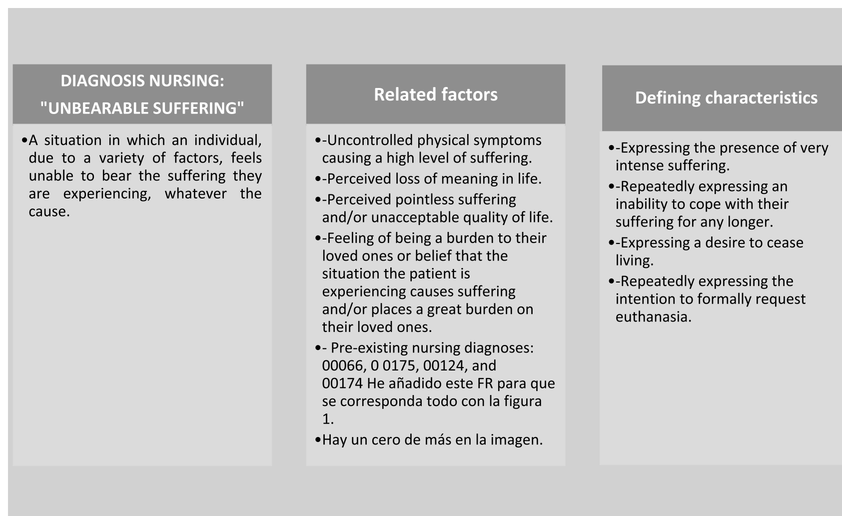

FIGURE 1. Nursing diagnosis: "unbearable suffering." Source: the authors.

- Repeatedly expressing the intention to formally request euthanasia.

DISCUSSION

Because of their training and comprehensive approach to care, nursing professionals are aware of the holistic nature of individuals.[24] They establish direct contact and build empathic, trusting relationships with the patients under their care at times of great suffering.[37] These relationships make them ideally suited to understand and assess the level of intensity of patients' suffering[9,16] and play a key role when patients are seeking assistance in dying with dignity by requesting euthanasia.[29] A number of studies have illustrated nursing teams' views on the wide range of desperate circumstances leading to requests for euthanasia.[9,20] The vast majority of nurses are in favor of accepting requests for euthanasia in different care settings.[14] However, they also raise concerns about their decision-making competence over the patient and the presence or absence of unbearable suffering.[20] The truth is that, whether in countries where euthanasia is legalized or where it is not, the nurse can be the key to identifying situations of unbearable suffering[34] of sick people.

To do so, they need to develop their own tools, such as nursing diagnoses.[35] Without a diagnosis to identify the unbearable suffering experienced by these individuals, it is difficult for nurses to make informed decisions.[20] A concept is practically nonexistent if it is not named, so it is important to develop a new diagnosis for inclusion in the nursing literature on suffering, which covers the gradual nature of unbearability.[13]

In this situation, nurses will have to make a previous differential diagnosis,[38] because the elements that determine it are mainly pain or poorly controlled symptoms,[34] as well as other situations of existential origin such as hopelessness, loss of meaning in life,[3] and feeling like a burden to their loved ones.[3]

In the event that any of these situations have not been previously addressed, every therapeutic effort should be made to address this issue, hoping that in this way the person can move to a more tolerable gradient of suffering. In this regard, the development of this diagnosis, like others,[12] may require assessment scales that integrate qualitative and quantitative questions and a grid of indicators that helps nurses to assess the situation in depth and breadth.

"Unbearable suffering" does not necessarily constitute grounds for a request for euthanasia.[8] Euthanasia is requested when the individual considers that his/her life is unsustainable, meaningless, unbearable, and undignified and is convinced that his/her circumstances will not change over time. People's hopelessness and despair in the face of unbearable suffering can lead them to request euthanasia.[37] Their suffering can be lessened and better tolerated through holistic care addressing all aspects of the human being delivered by a multidisciplinary team.[34]

It is also possible that people continue to view their suffering as unbearable despite the best possible comprehensive care. In this case, the individual experiencing "unbearable suffering" requires the support of professionals who are experts in the field of suffering management and compassionate care.[20,30] In addition, individuals desiring and requesting euthanasia must be supported by a comprehensive care plan right up to the end of their lives, including the assessment, approval, and implementation of euthanasia.[6,24]

Future Lines of Research and Implications for Practice

Researchers could use the results of this concept analysis as a framework for future studies to develop a structured

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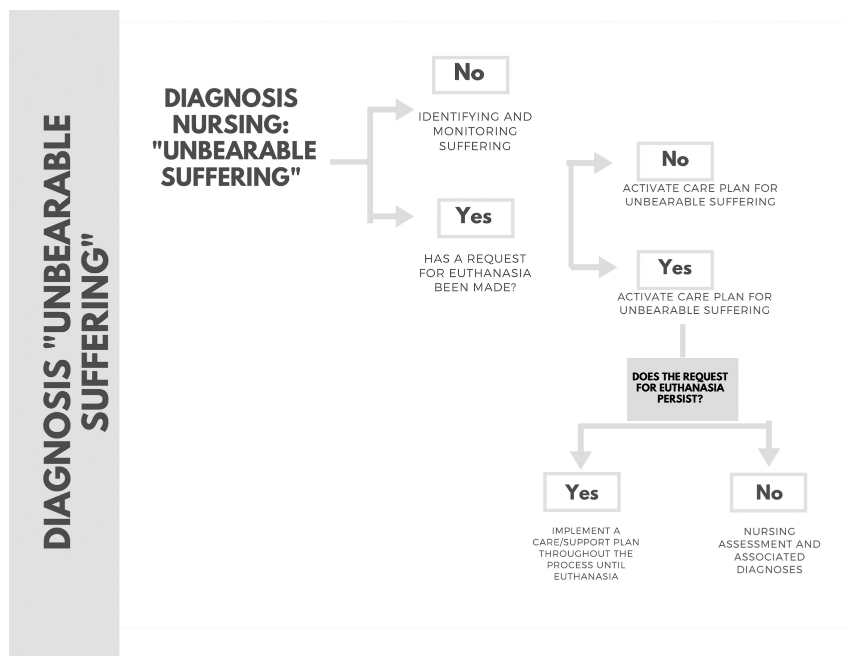

FIGURE 2. The nursing care process for "unbearable suffering."

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diagnostic and assessment tool for unbearable suffering. Identification and validation of the nursing objectives and interventions to be implemented may be the subject of research in the field of clinical practice leading to the development of nursing care processes for individuals in this situation (Figure 2).

Furthermore, most laws regulating euthanasia around the world make little reference to the role of nursing, as they reflect a markedly medico-centric approach. With the development of these professional tools, nurses will be able to play a decisive role in monitoring requests for euthanasia, leading to improvements in the discipline's own level of competence in dealing with highly intense human experiences.

CONCLUSIONS

Experiencing unbearable suffering is an extremely intense situation for an individual, and given its high level of complexity and difficulty, nursing care must be commensurate with this human response. To care for people experiencing unbearable suffering, it is important to delve deeper into the meaning of the concept and design tools specific to the nursing discipline. The proposed diagnosis of "unbearable suffering" and its measurement scale is a theory-based proposal that requires further development and validation in the field of nursing care.

"Unbearable suffering" underpins the criteria for requesting euthanasia in many laws regulating the practice in different countries. The existence of a nursing diagnosis of "unbearable suffering" could facilitate the identification of this type of suffering in advance so that an individual's desire to die and need to request euthanasia can be averted. In any case, this diagnosis has value regardless of whether it generates a request for euthanasia and whether or not it is legalized, because its value lies in the possible therapeutic response expressed in care for people in situations of high level of suffering. If the unbearable suffering persists and leads to a request for euthanasia in a place where its administration is possible, accompanying and caring for patients in the transit to a requested death is a huge challenge for nursing.

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