



A Dimensional Analysis of the Concept of Suffering in People With Dementia at End of Life

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Alzheimer disease is 1 of 5 leading causes of death in persons older than 65 years. The term *suffering* is used in all disciplines and a variety of contexts with no clear universal definition. Identifying dimensions and qualities (dimensional analysis) of the concept of suffering will assist in better understanding the concept and being able to apply it to science and practice. The objectives of this article were to analyze and identify dimensions of the concept of suffering for individuals at end of life who have dementia and to establish relationships between the dimensions. The method of dimensional analysis of Caron and Bower and the symbolic interaction theory guided the analysis. Fourteen research studies were selected from databases including CINAHL, PubMed, Ovid/Medline, Academic Search Premier, and PsycInfo between 2000 and 2012. Key search terms included *suffering*, *dementia*, and *end of life* combined. Four dimensions (pain, holistic, discomfort, and despair) and 2 subdimensions (communication and symptoms) were identified in the analysis. Different perspectives were found in the literature, but each one varied in its approach to the concept of suffering. The concept of suffering is complex and multifaceted and encompasses several dimensions. Understanding the dimensions of suffering provides insight into the individual with dementia as a person and not the disease. The analysis reveals that these dimensions are not well explored in the literature and establishes the importance of further research in this area.

KEY WORDS

Alzheimer, dementia, dimensional analysis, end of life, existential suffering, nurses, spiritual suffering, suffering

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In 2010, there were nearly 1.8 million deaths of persons 65 years or older. The 5 leading causes of death in those persons were heart disease, cancer, chronic lower respiratory diseases, stroke, and Alzheimer disease.¹ All of these disorders can be, and usually are, chronic and debilitating, leading the individual to “suffer” with his/her affliction. Many of these chronically ill individuals have an impaired quality of life because of their decline in function, cognitively and physically, making suffering difficult to define in the dying.

Dementia is a progressive, sometimes unpredictable, disease.² It occurs most often in persons 60 years or older and Alzheimer disease is the most prevalent type.³ There are 3 stages of dementia: early stage, middle stage, and late stage. The early stage begins with mild cognitive impairment, and as symptoms worsen, the individual has difficulty caring for himself/herself (middle stage).³ Late-stage dementia (LSD) is noted as the stage in which the individual no longer recognizes family members, becomes chair or bed bound, is unable to communicate, has bowel or bladder incontinence (or both), and most often has swallowing difficulties.³

Unlike persons with cancer who are often considered “terminal,” lay people frequently do not realize that people with LSD actually are terminal.⁴ Although people with LSD are eligible for the hospice benefit under Medicare, hospice care and palliative care are frequently withheld until the individual is near death,⁵ but palliative care should be initiated at diagnosis to help prevent suffering and provide better comfort. Unless culturally or religiously dissuaded, care that is focused on relieving symptoms and providing comfort should be the goal of end-of-life care rather than prolongation of life at whatever cost.⁶

This article will address the following questions: What are the dimensions of the concept of suffering? How will knowing the relationships between the dimensions and qualities of the concept “suffering” ensure widespread acceptance, understanding, and applicability in research and practice of suffering in individuals with dementia at end of life (EOL)? The aims of this article were to analyze and identify dimensions in the concept of suffering for individuals at EOL who have dementia and to establish relationships between the dimensions.

Application to Nursing Knowledge and Clinical Applications

Nurses must deal with suffering of patients on a daily basis, sometimes suffering with them through invasive procedures they know are unnecessary or with conflicts with their own spiritual and cultural beliefs. Assessment of physical suffering, such as pain or discomfort, is fairly easy to assess; however, spiritual, emotional, or psychological suffering is not so easily determined, especially in individuals with dementia who have no purposive language. Instruments have been developed and used to assess suffering in individuals with dementia and have been shown to be reliable indicators of suffering.⁷⁻¹¹ Nurses often provide care that helps patients recapture control over their lives and deal with life's distresses; although this is not always possible in individuals with dementia, nurses can "...accompany patients on their journey..."^{12(p110)}

International Relevance of Concept

To date, there is no standard definition of suffering or a consensus as to what constitutes suffering. Suffering is used interchangeably with pain, distress, stress, anxiety, and a myriad of other terms, symptoms, and conditions. Studies have shown that people with dementia (PWD) suffer⁸⁻¹¹; however, are the perceptions of suffering accurate, especially from a caregivers' viewpoint? A review of the literature noted a lack of consistency in the manner that suffering is defined.¹³ Given recent discussions regarding end-of-life issues and palliative care with the chronically ill, it is imperative that suffering be defined to ensure that individuals with terminal or chronic conditions maintain quality of life during their illness.

BACKGROUND

The term *suffering* is used in all disciplines and a variety of contexts. The medical model tends to look at suffering from conditions or symptoms and treatments, which is the paradigm followed by nursing for many years. Cassell¹⁴ pointed out that there has always been a distinction in medicine that separates mind and body. Cassell notes that physicians do not think of suffering abstractly; rather, they tend to provide treatment for a diagnosis in which suffering is associated. Cassell and Rich¹⁵ noted, however, "There is no such thing as a pain or nausea, vomiting, or dyspnea that solely occurs in the body without having an impact on the conscious person..."^(p436) Suffering is unique to each individual, and only the individual can put into context his/her suffering.¹⁶⁻¹⁸ From a nursing perspective, Ferrell and Coyle¹² developed principles of suffering, which define suffering in a different context. Their principles of suffering include the whole person, and again, only the individual can explain what he or she is feeling; it "...represents a deeply personal state."^(p16) This suggests a movement to a more holistic approach by both disciplines.^{12,14}

Real, everyday situations can have an effect on one's state of suffering.¹⁸ A child's perspective on suffering refocuses from the physical to the psychological realms.¹⁸ A catastrophe, such as an act of terrorism or severe flooding, has been shown to produce a large amount of suffering, not only physically but psychologically as well,^{19,20} creating feelings of helplessness and worthlessness. Spiritually, some have suggested that suffering brings people closer to their God and provides meaning to their lives,²¹ whereas others view spirituality as influencing the process of suffering.²² Existential suffering and spiritual suffering are often classified as the same in the literature.¹⁴

Depictions of suffering have also been illustrated in art, religion, and the sciences. Art has been used to depict suffering over the ages. "The Sick Child," painted by Edvard Munch in 1896, is 1 example.²³ The painting shows a young girl (his late sister Sophie, who died of tuberculosis) propped in a chair; an older woman (his aunt Karen) with her head bowed on the arm of the chair holds the girl's left hand.

Suffering is an essential component in Christianity. While one is suffering, God reveals his love, and suffering is replaced with "salvation and cure."^{24(p234)} The Buddhists have 4 noble truths regarding suffering: (1) suffering is part of life, (2) suffering is caused by egocentric yearning, (3) suffering can be stopped, and (4) when suffering ends, true happiness will be revealed.^{24,25}

Philosophers and social scientists have termed positive and negative effects as *pleasure* and *suffering*, respectively. Max Horkheimer negatively viewed happiness as freedom from suffering, although he believed that shared suffering could improve society, that the oppressed person's feelings of compassion as well as one's own suffering could work together to effect this change.²⁶

In a study using a phenomenological, hermeneutic approach, Pilkington and Kilpatrick²⁷ identified suffering as "unbounded desolation emerging with resolute acquiescence with benevolent affiliations"^(p232) as viewed through the lived experiences of the study participants. Although their study added much to the concept of suffering, the concept continues to be nebulous when viewed from these authors' perspective. Carnevale²⁸ argues in his conceptual analysis that suffering is an emotion, which can include physical symptoms such as pain. He also notes that suffering can comprise "expressive behaviors"^{28(p176)} that are either voluntary, such as calling out, or involuntary, such as moaning.²⁸ He posits that suffering is a subjective emotion; it cannot be objectively assessed as it is only lived by the person who is suffering.

DATA SOURCES

Concept analysis is 1 method of clarifying concepts, by defining them to use them to develop knowledge.²⁹ Dimensional analysis is beneficial to researchers when attempting



to contextualize and understand the various perspectives of a concept. Dimensional analysis explores how a concept is constructed. The dimensions or qualities of the concept are established and relationships formed between the dimensions or qualities.²⁹ These dimensions are used to define or develop the essential meanings associated with a concept. In the analysis, explicit and implicit assumptions of suffering will be identified. The method of dimensional analysis of Caron and Bowers²⁹ guided this analysis, as did the theoretical framework of symbolic interactionism. Because social behavior and actions cannot be realized unless their meaning is revealed, symbolic interactionism has an important role in dimensional analysis.²⁹

Computerized databases were searched, including CINAHL, PubMed, Ovid/Medline, Academic Search Premier, and PsycInfo. Key search terms included *suffering*, *dementia*, and *end of life* singly and then combined. The search criteria used for inclusion and exclusion were very broad in nature because dimensional analysis requires a wide ambit in which to explore the concept. Inclusion criteria were (1) publication between January 2000 and July 2012, (2) English language, and (3) adult participants.

The number of articles found with the term *suffering* alone netted 127 000 publications (Table). When combined with *dementia*, this number dropped significantly to 4541. Performing a search for all 3 key words—*suffering*, *dementia*, and *end of life*—revealed 326 articles. Reading the abstracts, and in some cases, the entire article, revealed that most of the articles did not meet the criteria for inclusion, such as using the term *suffering* in the context of “suffering with...” rather than using *suffering* as a condition. The number of articles was therefore reduced to 43. The references of these 43 articles were reviewed, and as a result, 7 additional articles were identified. Of these 50, only those publications of studies conducted on suffering were selected, thus leaving 14 articles for dimensional analysis.

THEORETICAL FRAMEWORK

A major framework of sociological theory, symbolic interaction theory is based on the hypothesis that humans discover and delineate the meaning associated with the world around them through interactions with others. Behavior is defined by symbols or the meanings related to symbols.³⁰ When humans interact within their environment, their behavior responds to symbols related to those social interactions. Likened to the self-fulfilling prophecy, where predictions come true with the actions of the person, Leming and Dickinson³⁰ explain: “We define situations as real, and they become real in their consequences.”^(p32)

Dimensional analysis is predicated on the theory that concepts are defined within a specific perspective and different meanings are attributed to those meanings based on whose perspective is being represented as well as the context in which it is used.²⁹ Symbolic interactionists believe that the meanings of a given situation emerge over time and are based on situations that have occurred in the past and the present during social interactions.³¹ By examining the concept through dimensional analysis and symbolic interactionism, new meaning and perspectives can be illustrated.

Hopes of individuals induce responses that corroborate what one originally anticipated, resulting in what some would term the *self-fulfilling prophecy*. For example, a person with dementia may have expectations of suffering at EOL. The care providers may have expectations or beliefs that PWD do not suffer at EOL and may be oblivious to the person's suffering. When suffering is not recognized and therefore not alleviated, the individual's fears or responses are confirmed. However, it is difficult for providers to make a connection with PWD when PWD have little to no purposive language; therefore, providers have limited interactions with which to evoke meaning.

TABLE Search Results for Articles Regarding Suffering in Individuals With Dementia

Database	Suffering	Suffering and Dementia	Suffering, Dementia, and End of Life	Reading of Abstracts and Articles
CINAHL	116	156	16	14
PubMed	97 119	1628	38	9
Ovid/Medline	1108	1414	226	13
Academic Search Premier	23 797	885	25	3
PsycInfo	5000	458	21	4
Review of references within selected articles				7
Total included for review, N = 14				

RESULTS

Four dimensions and 2 subdimensions were identified during the analysis (Figure). These dimensions and subdimensions (in parentheses) were pain (communication), holistic (communication), discomfort (symptoms and communication), and despair. Although some of the authors whose manuscripts were included in the analysis considered a certain dimension as suffering, other authors did not, and thus, suffering was inferred from the authors' discourse.

Pain (Communication)

Questions have been raised whether PWD have pain, especially in LSD, when individuals are unable to purposefully communicate their needs. Two articles were identified relating *pain* to suffering as a dimension. Husebo and colleagues³² found that patients with severe dementia did not experience less pain intensity than did those with mild, moderate, or no dementia. In fact, those with severe dementia on opioids were assessed as having greater pain intensity than patients with no dementia. Their findings suggest that suffering is complex, including undertreatment of pain. Nourhashemi et al³³ conducted a study for a 2-year period that showed that patients who may have been suffering were not given pain medications. Pain was assessed and documented by the patients' caregivers or care provider with "an 8-item behavioral scale to rate the intensity of pain in non-verbally communicating patients. The scale is divided into two parts (before and during nursing care) and scored from 0-4."^{33(p458)} Of 112 subjects in the study, 32% of patients with advanced dementia with a pain score of 7 or greater received no analgesics. The authors' findings suggest that adequate treatment of pain may relieve suffering and possibly decrease or prevent behavioral issues. The observation scales used in both of these studies were documented by caregivers of the patients, leading to possible variations in observed behaviors. Nourhashemi et al³³ also noted that patients with varying types of dementia may exhibit different facial or behavioral expressions and may not receive the same treatment as other individuals with dementia. Both of these studies suggest that pain in individuals with dementia

may go untreated because of this lack of ability to purposefully communicate.

Holistic (Communication)

Suffering encompasses more than just physical disorders; it also involves individuals' perceptions and beliefs and interactions with others. Therefore, suffering should be evaluated not from 1 single aspect but the perspective of the entire being^{7-11,34}; thus, suffering is holistic. Schulz, McGinnis, et al⁹ noted that suffering was moderate to high in the emotional and existential aspects of suffering, such as sadness, depression, hopelessness, worthlessness, and feelings of being a burden. Because their study showed a correlation between caregiver depression and patient suffering, results suggest that goals should be aimed at eliminating suffering, which will "require monitoring of patient affect, physical symptoms, and their spiritual/existential concerns..."^{9(p175)} Whereas Schulz, McGinnis, and colleagues⁹ conducted their study with a validated instrument (Revised Memory and Behavior Problems Checklist), Schulz, Monin, et al¹⁰ developed an instrument to measure suffering from 3 domains: physical, psychological, and existential suffering. These authors felt that suffering is more than just physical attributes that the patient may have and that suffering results from processing information from all domains.¹⁰ Three different groups were used in their study: individuals with Alzheimer disease, patients with osteoarthritis and their spouses, and caregivers of individuals with Alzheimer disease.¹⁰ The first sample, individuals with Alzheimer, were able to self-report their suffering, according to the authors.¹⁰ The authors' results showed that caregivers overestimated the degree of suffering of patients who self-reported.¹⁰ Although the authors' instrument can be used for self-reporting, individuals with LSD are unable to purposefully communicate their needs, and therefore, the instrument would be used based on observation; observation and caregivers' perceptions are subjective.

Aminoff et al⁷ also developed an instrument to measure suffering in LSD patients and used it to assess patients in a memory clinic. This instrument was also used to study the level of suffering during the final hospital stay of patients with dementia⁸ and again in a study to evaluate the relationship between the level of suffering and survival rates of patients with LSD dementia.³⁴ As with Schulz, McGinnis, et al,⁹ who felt that continuous monitoring is needed for the elimination of suffering, Aminoff and colleagues⁷ felt that their instrument will be beneficial in providing continuous monitoring and control of suffering. However, the authors' beliefs that suffering should encompass the domains of physical, psychological, and spiritual suffering are not evidenced in their 10-item instrument, which embraces only the physical domain and is based on observation with 8 of the items; the last 2 items are based on subjective opinions from medical staff and caregivers.

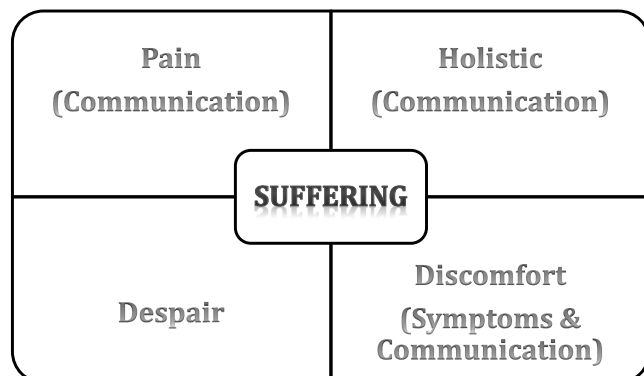


FIGURE. Dimensional analysis of suffering in individuals with dementia model.



Discomfort (Symptoms and Communication)

Discomfort is generally associated with a lack of comfort or making someone feel bad. Although pain can be discomfort, *discomfort* as a dimension of suffering (distinct from pain) was identified in 5 studies.³⁵⁻³⁹ Indeed, in the study conducted by van der Steen, Ooms, et al,³⁸ 1 of the research questions addressed was “Is suffering (discomfort) due to pneumonia recognizable in demented nursing home patients and is this different in differing treated patients?”^(p1682) The studies identified for this dimension showed an association between symptoms, such as dyspnea, fever, drowsiness, fear, anxiety, agitation, aspiration, and pressure ulcers, and discomfort.³⁵⁻³⁹

The study of van der Steen, Ooms, et al³⁸ revealed that suffering is more severe right before death from pneumonia than from other causes because of the discomfort associated with pneumonia symptoms. They also concluded that those patients not treated with antibiotics had more discomfort than did those treated with antibiotics. Whereas Givens et al³⁶ found that antibiotics were not associated with improved comfort in nursing home patients, van der Steen, Pasman, et al³⁹ did find a correlation between the use of antibiotics and decreased discomfort and felt that pneumonia was a cause of increased suffering. The authors’ study also revealed that discomfort with pneumonia was higher than in patients with issues with intake of food and fluids.³⁹

In their Italian study, Guilio et al³⁵ focused on the last month of life for severely demented older adults. Results of this retrospective study revealed that 124 of 141 patients were noted to be in discomfort because of severe symptoms. Physical restraints, causing discomfort, were used in 58% of the patients and 29 of the patients were artificially fed through a tube. The authors also noted that 88% of the patients studied had experienced severe physical symptoms such as dyspnea, fever, bedsores, and emesis during the month before death.³⁵ In studies conducted by Givens et al³⁶ and Mitchell et al,³⁷ symptoms were also the focus. In the course of 18 months, their studies revealed that 55% of nursing home residents died.^{36,37} Of those, 46% had dyspnea, 39% had stage II or greater pressure ulcers, 54% had agitation, and 41% aspirated. Among the residents who died, the percentage of residents who had those symptoms increased as EOL drew nearer. The authors found that health care proxies felt that the main goal of care should be comfort but noted that “physical suffering was common among residents.”^{37(p6)}

Most of these studies³⁶⁻³⁹ used instruments that relied on observation or evaluation and proxy reporting by care providers because of the individuals’ inability to purposefully communicate their needs. Guilio et al³⁵ used chart reviews but focused on physical symptoms, treatments, and life-sustaining procedures to gather their data. None of the authors examined how important communication was in

addressing discomfort of symptoms at EOL in dementia patients, but all felt that alleviating symptoms is essential at EOL.

Despair

Two studies linked suffering to being unbearable and hopeless.^{11,40} Hopelessness implies despair, especially if one has a terminal illness, as there appears to be no hope. The studies by these authors were conducted in the Netherlands, where advance directives for euthanasia (ADEs) in dementia are legal. These directives, however, have strict criteria for implementation, including “the physician is convinced that the patients suffering is unbearable, and that there is no prospect of improvement.”^{40(p257)} The results of the study by de Boer et al⁴⁰ revealed that more than half of the physician participants (n = 434) felt that it was impossible to know if someone who is cognitively impaired experiences hopeless and unbearable suffering. A little more than one-third of the physicians felt that severe suffering in a patient with advanced dementia was the result of additional illnesses rather than dementia itself; however, 40% of the participants disagreed with this statement. In the study by Rurup et al,¹¹ even though most of the nursing home physicians (n = 410) thought that there was some degree of unbearable and hopeless suffering in the patients with dementia (n = 40), the nursing home did not comply with ADEs. Their survey was divided into unbearable and hopeless suffering, which was rated from “did not” to “to a very high degree.” Nine of the nursing home physicians felt that their patients suffered unbearably to a high or very high degree, whereas 18 were of the opinion that their patients suffered hopelessly to a high or a very high degree.¹¹ These studies revealed that physicians did feel that patients with dementia are suffering, but to what extent remains unclear, potentially leaving the patients in despair.

Perspective

Although there are many studies in the literature on suffering that encompass many illnesses and catastrophes, relatively few studies have been published on the suffering of patients with dementia. Most of the studies in this analysis focused on the patients’ perspective of suffering, usually from observation rather than through communication with the patient.^{7-11,32-33,35-39} It is difficult to assess those who do not use language purposively, such as individuals with LSD. Shulz et al^{9,10} also provided perspectives from caregivers in their studies, assessing the caregivers’ perceptions of their loved ones’ suffering. Providers’ perspectives were studied by de Boer et al⁴⁰ and Rurup et al¹¹ but focused on whether the providers felt that suffering was unbearable and hopeless and their thoughts on euthanasia in PWD. There were no studies found that focused on nursing’s perspective regarding suffering in PWD.

Contextual Elements

Most of the studies selected for this analysis were conducted with nursing home residents^{32,35-39} or in hospital geriatric wards.^{8,33} The 2 studies by Shulz et al^{9,10} were conducted in the community setting and the PWD were assumed to be living at home. Although the same vulnerable population participated in all of the studies, one cannot exclude that the hospital-based participants may have been more acutely ill than those in the nursing home or in the community settings. de Boer et al⁴⁰ and Rurup et al¹¹ conducted studies with physicians who were practicing in the community and within nursing home settings to determine their opinions and use of ADEs in dementia. In the study of Rurup et al,¹¹ nursing home physicians were interviewed more comprehensively than the other physicians were, but only about their most recent case with a resident with dementia who had an advanced directive for euthanasia.

Assumptions

An explicit assumption is that suffering can be measured in PWD. Aminoff et al⁷ and Aminoff and Adunsky^{8,34} used scales that observed PWD's suffering and assessed the opinions of family and health care providers. The study of Shulz, Monin, et al¹⁰ was based on the caregivers' perceptions of the PWD's suffering as noted in the scales developed by the authors.

An implicit assumption identified is that PWD do not suffer. Based upon the observations and assessments of Aminoff et al⁷ and Aminoff and Adunsky,^{8,34} that assumption seems unwarranted. Shulz, Monin, et al¹⁰ developed scales to measure physical, psychological, and existential suffering that were self-administered, with patients rating their own suffering. One group had Alzheimer disease and was deemed capable (by 3-minute interview) of answering the questions on their own, whereas caregivers of another Alzheimer group answered for the individual based on their observations and perceptions of the individual's suffering. In another study, Shulz, McGinnis, et al⁹ had caregivers assess the PWD's emotional and existential suffering using the Revised Memory and Behavior Problems Checklist. These patients had moderate to severe cognitive impairment, and the caregivers, again, completed the instruments based on their perceptions of the PWD's suffering.

Another implicit assumption is that providers will alleviate suffering at EOL. However, in the study of de Boer et al,⁴⁰ more than half of the physicians felt that it was impossible to determine whether a person with cognitive impairment is suffering unbearably or hopelessly. Close to one-third of care providers for older adults believed that severe suffering is a direct cause of additional illnesses or complications that are untreatable.⁴⁰

Although observation may be able to partially address suffering in PWD, it addresses only the physical or clinical aspects of suffering. In addition, even though family care-

givers have discussions with PWD before their losing their cognitive awareness, the dimensions of suffering may change during the course of the disease and the caregivers' perceptions may not be accurately portraying the suffering of PWD, especially under the holistic dimension.

DISCUSSION

Although not considered a terminal diagnosis by many, for those who are given a diagnosis of dementia, the realization that they will most likely die of this distressing illness is real. They acquire their thoughts and ideas from interactions with others and the environment and give new meanings to their diagnosis and the suffering they will endure. The meanings for this particular situation, according to symbolic interactionists, developed from the individuals' experiences over the past and during the present²⁹ but are defined by the individual himself/herself.⁴⁰ Although not communicated, the meanings are validated when health care providers fail to understand the meanings defined by the individual, resulting in a self-fulfilling prophecy and suffering by the individual.

This dimensional analysis identified 4 dimensions of the concept of suffering as it relates to EOL in individuals with dementia. The relationships of these dimensions should be considered when evaluating one's suffering in individuals with dementia, especially because individuals with LSD are usually unable to communicate their needs. The data gathered from this analysis reveal that individuals with dementia do suffer in all aspects of their lives, and assessment and evaluation of their suffering need to be consistent and personalized and to encompass all of the identified dimensions.

In addition, 2 subdimensions were discovered that were deemed important. Communication is a significant subdimension that has key implications related to individuals with dementia, especially at EOL, as these individuals are not able to purposefully communicate their needs. Discomfort was identified from authors who used symptoms assessment in their studies, and although not all of the studies focused on suffering, suffering could be inferred from their results.

LIMITATIONS

Although an exhaustive search was carried out for studies that explored suffering in PWD at EOL, it is possible that significant articles have been missed. The search was limited in that there are relatively small numbers of studies conducted on PWD, especially with regard to suffering at EOL. In addition, because this analysis was theoretically based, other researchers may interpret the concept differently and produce different results and conclusions.

Although the results of studies using observations scales were deemed valid by the researchers, the use of observation



scales in measuring suffering is subjective. Carnevale²⁸ acknowledges that suffering is also subjective based on the person's experience and therefore cannot be measured objectively or "validly assessed by another."^(p177)

CONCLUSION

Suffering has not been clearly defined yet in the literature; however, suffering is unique to each individual and needs to be consistently assessed. The issue of suffering affects everyone at EOL, but particularly PWD, because they often are not able to communicate their needs effectively and, most often, not at all. In addition, dementia may not be considered a terminal illness; however, McCarthy et al⁴¹ conducted a retrospective study in which PWD had similar symptoms to cancer patients, but there were differences in that PWD had their symptoms more frequently and for a longer duration than the cancer patients did. Although it is difficult to assess and describe in persons who do not use language purposefully and may have minimal volitional movement, this article assumes that individuals with dementia suffer, even in the last stages of the disease.

Although a specific conceptual definition cannot be agreed upon, health care researchers need to develop an instrument aimed at measuring all dimensions of suffering from a holistic approach so suffering for that individual can be eased or relieved. These dimensions should be aimed at the physical and psychological aspects as well as existential and spiritual domains. Efforts should be made to assess individuals' perceptions of suffering to ensure PWD are treated effectively at EOL.

The concept of suffering is complex and multifaceted and takes on several dimensions. Understanding the dimensions of suffering provides insight into the individual with dementia as a person and not the disease and helps alleviate the suffering of not only the patient but also the family and perhaps the care staff as well. A dimensional analysis of suffering was not found in the literature; therefore, this analysis may represent relatively unfamiliar views. However, the analysis reveals that these dimensions are not well explored in the literature and establishes the importance of further research in this area.

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