Human Suffering: An Integrative Literature Review

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Abstract

Introduction: Suffering is a universal multifaceted phenomenon hard to define and often connected to pain. Suffering is not a homogeneous concept. Instead, suffering is a diffused term that includes innumerable ways of dealing with depression, pain, loss, and adversity. Suffering is described as a response or behavior recognized by introspection or observation of the behavior of the person and his/her environment.

Objective: The purpose of this article is to describe the role of the advanced nurse practitioners when dealing with the construct of suffering and to present a review of literature related to the human suffering experience.

Methods: The CINAHL Complete, PubMed, One Search, MEDLINE, PsychInfo, ProQuest Dissertation and Theses Global databases were search using the keywords suffering, experiences, meanings and perceptions of suffering. Search limits included peer-reviewed articles published in the English language from 1980 to 2016.

Results: A total of nine qualitative and five quantitative studies were reviewed. Three major themes were identified: the dimensions of suffering (physical, psychological, social, existential and ethical), enduring suffering and measuring human suffering, and perceiving another's suffering by using reliable and valid instruments.

Conclusion: It is pivotal for the health care system to recognize the role that the nurse practitioners play in promoting effective patients' care and support. Alleviating or reducing human suffering remains a core objective of modern medicine. Therefore, it is vital for the advanced nurse practitioners to acknowledge that the best way to determine whether a patient is suffering is to ask them individually and openly.

Keywords: suffering, suffering and experiences, suffering and meanings, perceptions of suffering.

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Introduction

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Suffering is a universal multifaceted phenomenon that is hard to define; it is not a homogenous concept. Instead, it is a word that describes the innumerable ways that people deal with depression, pain, loss, and adversity. Suffering is related to understanding the intactness of human beings and as such, has been acknowledged in the nursing literature through the exploration of human's experiences. Nursing as a profession must acknowledge human suffering as a significant concept essential to the well-being of every patient (Kahn & Steeves, 1986).

Suffering has been defined in various ways. It has been called "extreme anguish" (Gregory & English, 1994, p. 18), "soul pain" (Coulehan, 2012, p. 227), and even "being less than whole" (Currow & Hegarty, 2006, p. 134). Suffering is defined as the state of severe distress associated with events that threaten the intactness of the person. Suffering occurs when an impending destruction of the person is perceived; and, it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner. Suffering may include pain but is not limited to it, and the relief of suffering is an obligation to medicine. However, its transcendent dimension-the spirit of human life—has been ignored by modern medicine (Cassell, 1982).

Suffering is also defined as the state or experience of one that suffers. The prevalence of encounters with suffering in nursing is emphasized by recognizing that the Latin roots of the word "suffer"

"patient" are strikingly similar, both meaning "to bear." Etymologically speaking, to be a "patient," then, means, "to suffer" (Rodgers & Cowles, 1997, p. 1048). Furthermore, suffering is defined as an individualized, subjective, and complex experience that involves the assignment of an intensely negative meaning to an event or a perceived threat (Rodgers & Cowles, 1997). On the other hand, human suffering was described as a significant phenomenon and universal mystery of human existence. Suffering arises with personal choosings and unfolding meanings that can only be offered by the person(s) living the experience (Milton, 2013).

Suffering is often described as unspeakable, as opposed to what can be spoken; it is what remains concealed, impossible to reveal. It also remains in darkness, eluding illumination; and, it is dread, beyond what is tangible even if hurtful. Suffering is loss, present or anticipated, and loss is another instance of nothing, an absence. Suffering resists definition because it is the reality of what is not (Frank, 2001).

In the book by Viktor E. Frankl, Man's Search for Meaning, suffering, as described experiences in the concentration camps, confirms belief that that meaning is found in any situation, even in great suffering (1992). The experience of suffering itself sets up the opportunity to discover the meaning. Life has a meaning up to the last moment of one's life when people accept the challenge to suffer bravely (Frankl, 1992). Additionally, finding the meaning and value in one's experience could be beneficial, though challenging and painful developmental experience.

Suffering is a feeling to be endured, understood, and interrogated as to its cause as this may provide an insight into the human condition. Suffering may not always destroy human dignity, and may, sometimes, enhance it—for example, when one can suffer in the place of, or for the good of others. (Fitzpatrick, et al., 2016).

Purpose

The purpose of this paper is to describe the role of the advanced nurse practitioners when dealing with the construct of suffering and to present a review of literature related to the human suffering experience. Research in this area is imperative to understand the physical distress felt by the sufferers, and link the gap between the sufferer and the APN. An APN is defined as a 'registered nurse that has the expert knowledge required, the ability to make complex decisions and clinical competence for an expanded work description, whose character is formed by the context and/or the country where he/ she has the right to work'

Methods

Data Sources and Search Criteria

The integrative review of qualitative and quantitative studies was undertaken using the following databases: CINAHL Complete (1980-2016); PubMed (1980-2016); One Search (1980-2016); MEDLINE (1990-2016); PsychInfo; and, ProQuest Dissertation and Theses Global (2000-2016). Broad search terms were used: "suffering", "experiences", "meanings", and "perceptions of suffering". In order to widen the categories, the Boolean operator "OR" and "AND" were utilized separately and in combination with the keywords. Studies of human suffering related to health care and

end-of-life with terminal progressive and incurable cancer were included in this review.

Search Outcome

The overall research yielded 490 potentially relevant articles from peer-reviewed publications from which 382 were duplicated among all different databases. Bibliographies, discussion papers, editorials and inaccessible/unpublished dissertations were subsequently excluded. Abstracts from 108 publications were reviewed and 94 publications were excluded based on exclusion criteria. The remaining 14 articles were included and reviewed in depth. These publications included nine qualitative studies including one dissertation and five quantitative studies (Figure A1, Appendix A). Phenomenology and ethnographic researches comprised the qualitative studies. Nine selected qualitative studies (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Berglund, Westin, Svanstrom, & Sundler, 2012; Ellis, et al. 2015; Nilmanat, et al. 2010; Pilkington & Kilpatrick, 2008; Baumann, Lee, & Im, 2013; Devik, Enmarker, Wiik, & Hellzèn, 2013; Baumann, 2016; and, Braband, 2009) are summarized and illustrated in Table B1 (Appendix B). Five quantitative studies (Baines & Norlander, 2000; Adunsky, Aminoff, Arad, & Bercovitch, 2008; Schulz et al. 2010; Abraham, Kutner, and Beaty, 2006; Ruijs et al. 2009) were selected to explore human experiences of suffering through instruments and evaluation scales as illustrated in Table B2 (Appendix B). Information was collected from research conducted in the United States (5x); Sweden (2x); Finland (1x); Canada (1x), Israel (1x); UK (1x), Thailand (1x); Korea (1x); Netherlands (1x); and Norway (1x).

Quality Appraisal

An appropriate appraisal checklist was used for each qualitative and quantitative research. **Quantitative** studies assessed using Bowling's (2009) checklist, provides comprehensive evaluation criteria to assess the quality of studies (Table A1 & Table A2, Appendix A). The qualitative studies were assessed using the Pearson (2004) Qualitative Assessment and Review Instrument (QARI) critical appraisal instrument. The QARI utilized 10 dichotomous criteria (Table A3 & Table A4, Appendix A).

To understand the complexity of the concept of suffering, the author searched for the meaning of the experiences of suffering described by the participants through storytelling, interviews, testimonies and dialogue in the qualitative studies.

Results

Overall testimonies of participants generated the meanings of suffering and were grouped in main themes. Three major themes were revealed and identified through this integrative review: the dimensions of suffering, enduring suffering and measuring human suffering and perceiving another's suffering. The dimensions of suffering include physical, psychological, social, existential and ethical.

1) Dimensions of Suffering

Physical suffering. One of the most burdensome causes of physical suffering is pain. Suffering is experienced when a physical symptom like pain is overlooked or not alleviated. Excessive pains are so invalidating and can provoke psychological symptoms such as anxiety, depression, and dependencies on their families (Braband,

2009; Berglund et al., 2012; Baumann, et al., 2013; Ellis, et al., 2014; Nilmanat, et al., 2010; & Pilkington & Kilpatrick, 2008). In a study conducted in hospital settings, revealed that findings conflicting relationships might arise when patients are not listened to about the severity of their pains (Arman et al. 2004; Berglund et al. 2012). In one case study, a man tried to solve his problem of chronic pain on his own without support and understanding from health professionals by drinking alcohol (Berglund et al. 2012). In a study with terminal advanced cancer patients, a participant revealed his desire for a hastened death when experiencing excruciating pain and cited "I wanted to grab a knife and stab myself and cut it (pain/cancer) out. I felt angry ... why I am sufferingso?" (Nilmanat, et al., 2010, p. 397). Furthermore, the feeling of hopelessness can frequently result in suffering and desired for hastened death (Ellis et al. 2015; Nilmanat et al. 2010; Braband, 2009; & Baumann et al., 2013). Wanting to die was triggered by uncontrollable pain and distress symptoms and intensified by the overwhelming feeling of worthlessness and a sense of being a burden to others. However, participants expressed their will to live when alleviated from pain (Nilmanat et al. 2010). Nurse practitioners (NPs) in all fields care for people with serious or potentially life-threatening illness.

With the stated aim of palliative care to prevent and relieve suffering, NPs have an opportunity to offer primary palliative care in all practice settings (Wheeler, 2016).

Psychological suffering. Suffering also encompasses psychological desirable and undesirable relationships with others.

Testimonies of participants in various studies evoked psychological suffering wherein participants expressed immense form of isolation from the family, community and the society (Arman et al. 2004; Berglund et al. 2012, Braband, 2009; Nilmanat et al., 2013; Devik et al. 2013; Baumann et al. 2013; Baumann, 2016). Ineffective professional care and support focused on a lack of professionalism, and a failure to recognize and address needs or offer adequate information to empower those who suffered. Patients who suffered in their whole existence often are not offered care as whole human beings. The participants also reported painful testimonies describing and unbearable patients suffering related to ineffective and neglected care from health professionals. They experienced their health to become fragmented and focused on illness diagnoses, neglecting their experiences of human suffering (Arman et al., 2004; Berglund et al, 2012; & Braband, 2009). Advanced nurse practitioners offered holistic care to meet the needs of patients who are suffering. The inner framework, qualified responsible APNs, create safety, trustfulness, and continuity for patients (Nieminen, Mannevaara, Fagerström, 2010).

Another example of psychological suffering is losing one's autonomy as a consequence of debilitating incurable illness/cancer, relegating patients to be dependent on families' support. One qualitative study described a participant's wife's emotional entrapment and suffering as being afraid to be disabled, unable to walk, become paralyzed and be a burden to her husband. Another participant, a mother, felt guilt and loss of dignity when she has to wake

up his 17-year-old son to massage her legs to alleviate her pain (Nilmanat et al., 2010). However, participants' evaluations of their experiences related to care and support affirmed that families tended to offer more reliable support than professionally based care (Braband, 2009).

Becoming depressed as a consequence of suffering is sometimes overlooked and neglected as a result of losing one's good health, excessive pain, and following a traumatic experience in life (Braband, 2009; Arman et al. 2004, & Berglund et al., 2012). Patients might also suffer in silence as described in this example: "I wanted to ask some question, then he (the doctor) looked at me, and said; here it is me who asks questions." (Berglund et al. 2012, p. 4). A study searching for meaning of being old, living on one's own and suffering from incurable cancer showed that patients wait and ask few questions and prefer not to complain to avoid humiliation from health professionals (Devik, et al., 2013). It is the responsibility of advanced nurse practitioners to promote openness and approachable attitude to enhance a relationship devoid of fears shame. Patients feel neglected embarrassed when not answered listened to by the health professionals. The NP must be culturally competent -- able to listen openly and sensitively to the patients' cultural stories and empathize with the cultural influences of the patient's experience of health and disease (Hagedorn &Quinn, 2004).

One of the quantitative studies reviewed tried to elucidate determinants other than physical distress as a component of suffering to understand the nature of suffering (Abraham et al., 2006). Participants in this study who reported experiencing more suffering also reported worse psychological well-being and worse quality of life than those who are suffering less. In this study, distress has been defined as the combination of pain and anxiety. Participants' reporting lack of distress resulting from physical symptoms like pain did not necessarily indicate a lack of suffering because of physical symptoms or lack of overall suffering. However, factors other than physical symptom distress, such as diagnosis, age, and quality of life (QOL) appear to affect the perception of suffering.

Social suffering. Another dimension of suffering is social. Friends and their actions were highly valued. Unconditional love from families and friends was often viewed as a gift to sustain those who suffered. However, ineffective care and support from family and friends revealed the impact of tested relationships, insensitive communication, and the fear of rejection from loved ones and friends. A qualitative study of older adults living in a home revealed one of the participants greatest source of suffering; i.e., her children's not wanting to have anything to do with her and her husband, and cutting off all communication, without any explanation (Bauman, 2016). The term "benevolent affiliations" were used to accentuate the value that participants placed on significant connections with other persons, things, and ideas, which, for them, were a source of help, comfort, faith, hope, and courage, so that they felt lucky, thankful, fortunate, and blessed to have them (Pilkington & Kilpatrick, 2008, p. 234). For a participant, sensing a loved one's emotional pain toward her suffering represented the ultimate loss

procuring guilt and hopelessness (Ellis et al., 2015). Patients believed that health care teams were more effective in providing care after the implementation of a nurse practitioner. Patients and their families valued ANPs human approach, trust, respect, being open to discussion, listening to patient and family concerns as the most important processes in providing care (Kilpatrick, Jabbour & Fortin, 2016).

Existential suffering. In this dimension, the patient can feel powerless when hindered to participate or to take responsibility for one's health decision. Participants expressed lack of freedom to decide and participate in their patient-oriented care (Arman et al. 2004; Berglund et al. 2012). Consequently, this could increase feeling of insecurity, forcing the patients to carry on an undignified fight for themselves provoking existential suffering (Arman et al, 2004). In the qualitative study by Pilkington & Kilpatrick (2008) with elderly residing in long term homes, a participant talked of his frustration of abandoning his freedom to be independent and autonomous to accomplish his every day activities, e.g., driving his car (Baumann, 2016). Uncontrollable pain and distress symptoms when not alleviated can also provoke an overwhelming feeling of worthlessness and a sense of being a burden to others resulting to a desire for a hastened death. One of the roles of advanced nurse practitioners is to encourage patients to participate in the decision-making and to facilitate the reacquisition of their autonomy and independence. ANPs team roles include improved communication, involvement in decisionmaking, cohesion, care coordination, problem-solving, and a focus on the needs of patients and families. *Ethical suffering.* The ethical dimension of suffering includes the loss of dignity. Nearly all of the participants in the literature review mentioned their loss of dignity when suffering (Arman, et al., 2004; Berglund, et al., 2012; Ellis, et al., 2015; Braband, 2009; Baumann, et al., 2013; Nilmanat, et al., 2010; Nordman, et al., 2008; & Devik, et al., 2013). An example was the story of two men with Hansen's disease and cancer and the woman with advanced cancer who were obliged to live in a prison-like shelter in Korea; their stories showed how people with Hansen's disease in Korea suffer a unique form of betrayal and shame because of the fear and ignorance of people around them (Baumann, et al., 2013). This form of human treatment violates dignity, which is the humanbecoming ethical phenomenon. The participants also talked about their spirituality in their suffering. One of them felt betrayed by God when she was diagnosed with cancer (Baumann, et al., 2013). On the other hand, some participants experienced transformation through suffering and evolved coping skills such as gaining more spiritual perception to life, self, and suffering (Ellis et al., 2015). Individuals and groups are regarded as adaptive systems whose behavior is a response to environmental

stimuli (Roy, 2009). Roy identified three types of environmental stimuli: focal, contextual, and residual, which are constantly changing forces affecting individuals and groups (Roy, 2009). Environmental stimuli are directly related to coping processes and to the mode of adaptation. The coping processes mediate the indirect relation between the environmental stimuli and the modes of adaptation (Roy, 2014). Individuals use coping processes to interact with

environmental stressors to maintain adaption in the four adaptive modes: physiological mode, the self-concept mode, the adaptive role function in society, and the interdependence adaptive mode (Alkrisat & Dee, 2014; Roy, 2009). The advanced nurse practitioner promotes positive patient outcomes and effective adaptation by guiding patients to make individual choices enhancing their wellbeing.

2) Enduring Suffering

Two phenomenological studies revealed the idea of choosing an attitude toward moving on with suffering (Pilkington & Kilpatrick, 2008) and demonstrate a strong will and hope for survival (Devil, et al., 2013). Every participant's description contained the idea that one must get through suffering and that one gets used to, or accepts it; and yet, his or her descriptions did not suggest passivity or defeat. The concept of enduring explained that a comparison could be drawn between the resolute acquiescence, which was transposed to persistent enduring (Morse, 2001; Pilkington & Kilpatrick, 2008). Enduring occurs as a response to a threat to the integrity of self that enables the person to go through the motions of doing (Morse, 2001). However, suffering posited to be a paradoxical, all-at-once connecting-separating with unbounded desolation and benevolent affiliations (Pilkington & Kilpatrick, 2008).

3) Measuring Suffering and Perceiving Another's Suffering

A study by Ruijs et al. (2009) aimed at developing and testing a quantitative instrument to measure the nature and intensity of unbearable suffering in 64

end-stage cancer patients; researchers developed the State of Suffering - Five (SOS-V) instrument which measures five domains: medical signs and symptoms, loss of function, personal aspects, aspects of the environment, and nature and prognosis of the disease. In the study, suffering is defined as unbearable, a subjective experience of suffering that is so serious and uncontrollable that it overwhelmed one's bearing capacity. When tested among the end-stage cancer patients, the Cronbach's alphas of the subscales were in majority above 0.7. The sum scores of (sub) scales were correlated strongly to overall measure on suffering. The internal consistency of the total SOS-V was substantial with Cronbachs alpha' of 0.90 for presence of aspects of suffering and 0.93 for unbearability of aspects of suffering (Ruijs et al., 2009). Researchers concluded that the SOS-V makes it possible to identify and study unbearable suffering in a quantitative and patient-oriented way; however, a limitation of this study is that it was not feasible to study test-retest reliability because it might have limited the willingness of end of life participants to participate in the study due to the need to retest within a week's time.

Another study conducted by Schulz et al. (2010) assessed the experience and perception of physical, psychological, and existential suffering in older individuals between caregivers and care recipients. Scales were administered to three populations of older adults and /or their family caregivers. Participants consisted of individuals with Alzheimer's disease (AD) and their family caregivers (N= 105 dyads), married couples in which one partner had osteoarthritis (N= 53 dyads), and African

American and Hispanic caregivers of care recipients with AD (N= 121). Care recipients rated their own suffering, whereas caregivers provided ratings of perceived suffering of their respective care recipients. Three instruments were developed to assess the three domains of suffering: physical, psychological and existential suffering. The physical symptom scale consists of nine items (e.g., pain, nausea, shortness of breath dry mouth, lack of appetite, etc.). Psychological symptoms are measured with 15 items (e.g., confident, afraid, irritable, depressed, cheerful, hopeless, abandoned, etc.) using the same response options employed with the physical symptoms scale, yielding scores from 0 (no psychological suffering) to 45 (high psychological suffering). Existential suffering is measured with nine statements (e.g., "I feel peaceful", "My life has been a failure", "I feel a sense of purpose in my life", "Life is not worth living anymore", etc.). Both the psychological and the existential suffering scales demonstrated very good internal consistency. The Cronbach's alphas for both scales were .83 or higher for all samples. These results suggest moderate to good stability of the suffering measures over a period of 3-6 weeks.. Data analysis shows that caregivers overestimate the magnitude of suffering of their care recipient. Caregivers report the perceived suffering of the care recipient to be almost twice as high as care recipient self-reports. One of the limitations of this research is that it is difficult to interpret the absolute levels of suffering reported by caregivers and care recipients included in this study because there are no normative data available on suffering in these samples (Schulz, et al., 2010).

There is a scant knowledge on the relationship between patients' perception of pain and their perception of physical, spiritual, and personal or family suffering. A study by Baines & Norlander (2000) examined the relationship between terminally ill hospice patients' rating of suffering in three categories: physical, spiritual, and personal or family suffering. They used the Suffering Assessment Tool developed over a four-month period by hospice professional staff, including nurses, social workers, chaplains, and physicians. The tool was based on the pain assessment principle that pain is what a patient reports it to be. A convenience sample of 92 patients were asked to rate their worst pain within the last 24 hours and to rate their suffering at the time of the interview. All items were rated on a 0-10 Numeric Intensity Scale. Pain scores and suffering scores were divided into four categories: no pain or no suffering (0), mild pain or mild suffering (1-3), moderate pain or moderate suffering (4-6), and severe pain or severe suffering (7-10). When suffering was analyzed for patients reporting no pain versus any pain, there were statistically significant differences noted in spiritual suffering and suffering due to fear of the future categories. Physical suffering ranged from 2.7 to 5.57. Spiritual suffering ranged from 0.65 to 1.92.

Suffering related to loss of enjoyment of life ranged from 3.52 to 5.36. Suffering related to concern for loved ones ranged from 3.34 to 5.42. Suffering related to unfinished business ranged from 0.98 to 1.77. Suffering related to fear of the future ranged from 0.75 to 2.66. Although there is support in this study that unrelieved severe pain causes unnecessary suffering,

these findings raise questions about the intrinsic link between pain and suffering. Patients reported suffering even though they were not having pain or conversely reported minimal suffering even though they were experiencing severe pain. This supports the view that patients can experience pain without suffering and suffering without pain and could indicate that patients make a distinction between physical pain and physical suffering. The lowest mean suffering scores were in the area of unfinished business; an explanation of the low scores in this category could be that patients are well aware of their terminal status at the time of a hospice referral and are already attending to their affairs. The highest mean scores were seen in the concern for loved ones category. The literature defining suffering recognizes a very strong family and social component in which patients consistently identify concern for family as a source of distress (Baines & Norlander, 2000).

Suffering is the most feared symptom for patients with advanced cancer. One of the main aims of palliative care is to relieve suffering. Unfortunately, measuring suffering among this population may be difficult and should involve standardized symptom assessment. A study conducted to evaluate suffering of endof-life cancer patients during their final hospicestayandtheirpossibleinterrelations with survival (Adunsky et al., 2008). Researchers used the recently developed Mini-Suffering state Examination (MSSE) as a tool to permit better assessment and control of suffering in end-of-life care. The MSSE consists of 10 items relating to the patients characteristics as well as the perception of his or her condition by the medical staff and the patient's family. This tool has the potential of monitoring and measuring the extent of suffering which may inform medical and nursing approach, prevent negligence and mistreatment, and change treatment protocols and diminish the patient's level of suffering. The tool has been developed and tested among endof-life dementia patients. The reliability of the MSSE questionnaire was evaluated by the Cronbach's alpha test. Patients were evaluated by the MSE during the first week of admission to the hospice and once weekly, until death. A total of 152 patients (84 females, 68 males) were included in this study. Cronbach's alpha for the MSSE tool was 0.78 as compared with 0.735 and 0.718 in the original MSSE reliability study. Overall, most patients died with a surprisingly low MSSE score, these differences being statistically significant (P < .001). The MSSE, in contrast with various clinical instruments, is designed to measure suffering rather than quality of life or satisfaction with care at end of life (Adunsky et al., 2008).

Discussion

This integrative review allowed the author to capture the meaning of suffering through experiences told, narrated, and described by the participants. Overall, testimonies of participants generated the meanings of suffering and were grouped into emergent themes. Three major themes were revealed and identified through this integrative review: the dimensions of suffering, enduring suffering and measuring human suffering, and perceiving another's suffering. The dimensions of suffering include physical, psychological, social, existential and ethical.

The three major themes portray the constructs of human suffering and broaden the reader's existing knowledge related to human suffering. In this era where advanced medicine seeks to alleviate the most burdensome pains and relieved unbearable suffering, this paper may provide comparable situations and experiences which may help ease and/or lessen the burden of one's suffering. Participants in this review talked about their suffering related to health care and their unbearable end-of-life suffering. Testimonies were narrated and captured to describe the importance of the care and support these participants have received from their families, friends, and health professionals; however, evidence also showed ineffective care and support from them.

Patients felt mistreated and not respected when health professionals ignored them. In these situations, they lost their dignity and autonomy and their vulnerability increased. Health professionals oftentimes think they know best, thus hindering patients' autonomy to participate in care decision-making. Health professionals are often described as uncaring because of lack of competence and skill to recognize suffering in patients and families. This review also revealed how loss of normal functioning becomes a threat to dignity and independence for some patients, which results in perceptions of being a burden on family members and caregivers, and subsequently decreases personal value and may bring about a sense of total hopelessness and powerlessness in some patients. Advanced nurse practitioners are expert in dealing relationship with patients and their families. They encouraged and promote patients' dignity by encouraging them to participate in the decision-making and be independent in their choice of lives.

Suffering also provokes painful isolation and feelings of worthlessness in patients for having to depend on family members for assistance with daily activities. Guilt and shame accompany the sufferers and increase their fears of being a burden to others much more to their families and friends. Unbearable suffering in the form of excessive pain may induce the desire to hasten death and suicide. Findings revealed that the suffering caused by loneliness, feeling of worthlessness, and the fear of becoming a burden overshadowed the impacts of physical symptoms. Consequently, patients' experiences of suffering need to be affirmed, appreciated, and treated with respect.

Limitations

The main limitation of this integrative review is the heterogeneity of the studies included to portray human suffering as a multifaceted phenomenon. Studies included in this review were primarily selected from different countries and various health care settings. The variability of health care settings described the universality of suffering experiences and implies that human suffering is not limited to one setting or one type of patient. However, similarities among words used to describe suffering may send altered connotations, particularly among international readers. The author focused the majority of her research on the terminally ill, patients with incurable disease, and those in the end of life stage, which limits the generalizability of the review to the entire population.

Conclusion

It is imperative to encourage the advanced nurse practitioners to expand and hone their competencies related to recognizing others' suffering and to offer effective care and support. Emphasis was given to acknowledge all efforts, including alternative therapeutic measures, aimed at diminishing pain and suffering. The hope is to amplify the advanced nurse practitioners' current body of knowledge on the relationship between patients' perception of pain and their perception of physical, psychological, existential and personal or family suffering to help refocus pain management practice and ameliorate approach to care of the dying and end of life patients. Findings from this review have revealed valid and reliable survey instruments which may be used by the advanced nurse practitioners to assess patients' suffering and the perceived suffering of others, which would facilitate the dispensation of patients' oriented care and treatment, thus alleviating their suffering and honoring their dignity.

Further research is needed to test the validity of the advanced nurse practitioners questions used to assess human suffering. Alleviating or reduce human suffering remain a core objective of modern medicine; it is therefore vital for the advanced nurse practitioners to acknowledge that the best way to determine whether a patient is suffering is to ask them individually and openly.

Conflict of interest

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References

- 1. Abraham, A., Kutner, J. S., & Beaty, B. (2006). Suffering at the end of life in the setting of low physical symptom distress. Journal of Palliative Medicine, 9(3), 658-665.
- 2. Alkrisat, M., & Dee, V. (2014). The validation of the coping and adaptation processing scale based on the Roy adaptation model. Journal of Nursing Measurement, 22(3), 368-380
- 3. Arman, M., Rehnsfeldt, A., Lindholm, L., Hamrin, E., & Eriksson, K. (2004). Suffering related to health care: A study of breast cancer patients' experiences. International Journal of Nursing Practice, 10, 248-256.
- 4. Adunsky, A., Aminoff, B. Z., Arad, M., & Bercovitch, M. (2008). Minisuffering state examination: Suffering and survival of end-of-life cancer patients in a Hospice setting.
- 5. American Journal of Hospice &Palliative Medicine, 24, 493-498.
- 6. Baines, B. K., & Norlander, L. (2000). The relationship of pain and suffering in a Hospice population. American Journal of Hospice and Palliative Medicine, 17(5), 319–326.
- 7. Braband, B. (2009). The suffering journey: Lived experiences of persons who have endured life-impacting events. Doctoral dissertation. ProQuest, UMI Number: 3398508.
- 8. Baumann, S. L., Lee, O. J., & Im, S-B. (2013). Stories of suffering with leprosy and cancer in Korea. Nursing Science Quarterly, 26(3), 274-279.
- 9. Baumann, S. L. (2016). The living

- experience of suffering: A Parse method study with older adults. Nursing Science Quarterly, 29(4), 308-315.
- 10. Berglund, M., Westin, L., Svanström, R., & Sundler, A. J. (2012). Suffering caused by care-elderly patients' experiences from hospital settings. International Journal of Qualitative Studies on Health and Well-being, 7, 18688.
- 11. Cassell, E. J. (1982). The nature of suffering and the goals of medicine. The New England Journal of Medicine, 306(11), 639-645
- 12. Chapman, C. R., & Gavrin, J. (1993). Suffering and its relationship to pain. Journal of Palliative Care, 9, 5-13.
- 13. Currow, D., & Hegarty, M. (2006). Suffering–At the bedside of the dying. Journal of Religion, Spirituality & Aging, 18(2–3), 123–136.
- 14. Cutcliffe, J. R., Hummelvoll, J. K., Granerud, A., & Eriksson, B. G. (2015). Mental health nurses responding to suffering in the 21st century occidental world: Accompanying people in their search for meaning. Archives of Psychiatric Nursing, 29, 19-25.
- 15. Coulehan, J. (2012). To suffer with: The poetry of compassion. In J. Malpas & N. Lickiss (Eds.), Perspectives on human suffering (pp. 227-244). Dordrecht, The Netherlands: Springer Science & Business Media.
- Ellis, J., Cobb, M., O'Connor, T., Dunn, L., Irving, G., & Lloyd-Williams, M. (2014). Themeaning of suffering in patients with advanced progressive cancer. Chronic Illness, 11(3), 198-209.
- 17. Devik, S. A., Enmarker, I., Wiik, G. B., & Hellzèn, O. (2013). Meanings of being old, living on one's own and suffering from incurable cancer in rural Norway. European Journal of

- Oncology Nursing, 17, 781-787.
- 18. Frankl, V. (1961). Logotherapy and the challenge of suffering. Review of Existential Psychiatry, 1, 3-7.
- 19. Frankl, E. V. (1992). Man's search for Meaning: An Introduction to Logotherapy. Beacon Press: Boston.
- 20. Frank, A. W. (2001). Can we research suffering? Qualitative Health Research, 11(3), 353-362.
- 21. Fitzpatrick, S. J., Kerridge, I.H., Jordens, C. F. C., Zoloth, L., Tollefsen, C., Tsomo, K. L., &Sarma, D. (2016). Religious perspectives on human suffering: Implications for medicine and bioethics. Journal of Religion Health, 55(1), 159-173.
- 22. Gregory, D., & English, J. (1994). The myth of control: Suffering in palliative care. Journal of Palliative Care, 10(2), 18–23.
- 23. Kahn, D. L. & Steeves, R.H. (1986). The experience of suffering: Conceptual clarification and theoretical definition. Journal of Advanced Nursing, 11, 623-631.
- 24. Kilpatrick, K., Jabbour, M., & Fortin, C. (Processes in healthcare teams that include nurse practitioners: what do patients and families perceive to be effective. Journal of Clinical Nursing. 25, 619-630
- 25. Milton, C. L. (2013). Suffering. Nursing Science Quarterly, 26(3), 226-228.
- 26. Morse, J. M. (2001). Toward a praxis theory of suffering. Advances in Nursing Science, 24(1),47-59.
- 27. Nienimen, A-L., Mannevaara, B., & Fagerström, L. (2011). Advanced practice nurses' scope of practice: a qualitative study of advanced clinical competencies. Scandinavian Journal of Caring Sciences. 25, 661-670.
- 28. Nilmanat, K., Chailungka, P., Phungrassami, T., Promnoi, C.,

- Tulathamkit, K., Noo-urai, P., & Phattaranavig, S. (2010). Living with suffering as voiced by Thai patients with advanced terminal cancer. International Journal of Palliative Care, 16(8), 393-399.
- 29. Pilkington, F. B., & Kilpatrick, D. (2008). The lived experience of suffering: A Parse research method study. Nursing Science Quarterly, 21(3), 228-237.
- 30. Rodgers, B. L., & Cowles, K. V. (1997). A conceptual foundation for human suffering in nursing care. Journal of Advanced Nursing, 25, 1048-1053.
- 31. Roy, C. (2009). The Roy adaptation model (3rd ed.). Upper Saddle River, NJ: Pearson Prentice Hall.
- 32. Ruijs, K. D.M., Onwuteaka-Philipsen, B. D., van der Wal, G., & Kerkhof, A. J.F.M. (2009). Unbearability of suffering at the end of life: the development of a new measuring device, the SOS-V. BMC Palliative Care, 8(16). doi: 10.1186/1472-684X-8-16
- 33. Schulz, R., Monin, J. K., Czaja, S. J., Lingler, J. H., Beach, S.R., Martire, L. M., & Cook, T. B. (2010). Measuring the experience and perception of suffering. The Gerontologist, 50(6), 774-784.
- 34. Wheeler, M.S. (2016). Primary Palliative care for Every Nurse Practitioner. The Journal for Nurse Practitioner, 12, 647-653.