

Journal of Qualitative Research in Health Sciences



Original Article





Concept Analysis of Suffering in Parents of Children with Cancer

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Abstract

Background: The concept of suffering is fundamental when dealing with life-threatening diseases like cancer, affecting both patients and their families. However, this concept has not been thoroughly examined in nursing culture. Therefore, this study aimed to analyze the concept of suffering among parents of children with cancer.

Methods: Walker and Avant's eight-step method was used to analyze this concept. The literature review was conducted using Google Scholar, Ovid, Medline, and CINAHL databases from 2000 to 2022 focusing on suffering, conceptual analysis of suffering, and cancer and suffering as keywords.

Results: Initially, 138 articles were obtained. After reviewing the articles and eliminating the irrelevant ones, 47 articles were deemed pertinent for further analysis. Among these, 10 articles directly related to the topic of suffering in families due to cancer were chosen as the basis for concept analysis.

Conclusion: The analysis of the concept of suffering in parents of children with cancer involved choosing the concept, defining the purpose of analysis, identifying all potential uses of the concept, describing its attributes, presenting a model case, determining borderline, related, contrary, and unrelated cases, identifying antecedents and consequences (preliminaries and delays), and detailing empirical referents.

Keywords: Suffering, Cancer, Parents, Concept analysis

Citation: Azarbarzin M, Sadeghi N, Alavi A, Ghaljaei F. Concept analysis of suffering in parents of children with cancer. *J Qual Res Health Sci.* 2024;13(3):157–163. doi:10.34172/jqr.2024.23

Received: August 20, 2023, Accepted: June 27, 2024, ePublished: September 23, 2024

Introduction

Cancer is the second leading cause of death in children following accidents. Despite the relatively low prevalence of this disease, approximately 16 000 children under the age of 15 die each year from cancer. The threatening nature of childhood cancer and the aggressive treatments of this disease induce acute stress among family members. The family's demands to cope with severe physical symptoms such as pain and the fear of treatment failure are notably high (1).

In many ways, the families' reaction to the diagnosis of terminal illness is similar to the response of families to the chronic illness of their child. With advancements in medical treatment for many life-threatening diseases like cancer, these conditions are now classified as chronic disorders. However, there are significant differences in adapting to a disease like cancer compared to chronic diseases. While many children with cancer may survive for

a short period after diagnosis, those with chronic diseases such as diabetes can live a normal life (2).

The results of the study by Heath et al showed that 89% of parents of children with cancer reported significant suffering due to symptoms such as weakness, pain, and shortness of breath in their children. From the point of view of doctors, the primary objective of interventions for these children is to provide treatment and address treatment-related toxicity, while quality of life, growth, and development are typically considered secondary goals. Changing this perspective for doctors, especially when there is little hope for treatment, is a challenging task and unfortunately, 25% of these children do not survive (3).

When a child and their family are faced with a prolonged and potentially life-threatening illness, professionals make a concerted effort to deliver optimal care by addressing the psychological, religious, and emotional needs of the child and their family throughout the period of illness and



at the end of life (4).

The shock of learning about cancer and the distressing outcomes of the disease inflict indescribable suffering on patients and their families. The waiting and grieving lead to psychological issues for the families of patients with cancer. Therefore, it is necessary to provide nursing interventions to help the family adapt to the inevitable prognosis of grief and impending death (5).

Suffering is an inseparable part of human experience and an important aspect of nursing and care for patients. The concept of suffering is fundamental when dealing with life-threatening diseases like cancer, affecting both patients and their families. Nonetheless, this concept has not been thoroughly investigated in nursing culture. Accordingly, this study aimed to analyze the concept of suffering among parents of children with cancer.

Methods

The concept of suffering in parents of children with cancer was analyzed using Walker and Avant's eight-step method, which is a modified form of Wilson's method. These eight steps are:

- 1. Choosing a concept
- 2. Determining the purpose of analysis
- 3. Identifying all uses of the concept
- 4. Defining descriptive characteristics
- 5. Presenting a model case
- 6. Determining borderline, related, contrary, and unrelated cases
- 7. Identifying antecedents and consequences (preliminaries and delays)
- 8. Detailing empirical referents (6).

A literature review was conducted to examine the studies in this field using Google Scholar, Ovid, Medline, and CINAHL databases from 2000 to 2022 focusing on suffering, conceptual analysis of suffering, and cancer and suffering as keywords. A total of 138 initial articles were obtained. After reviewing the articles and removing the irrelevant ones, 47 articles were selected. Among these, 10 articles directly related to the topic of suffering in families of a child with cancer were chosen as the basis for concept analysis.

Result and Discussion Walker and Avant's eight-step method

Choosing the concept

Definition and meanings of the concept of suffering: In the Oxford Dictionary, the word "suffering" is defined as physical or mental pain, sadness, mourning, punishment, and the pain of loss. According to the Dehkhoda Dictionary, "suffering" means to bother, be hurt, endure hardship, cause harm to others, be sick in affliction, and feel oppressed. Moreover, "sufferer" is defined as the one who suffers and endures oppression, faces annoying events and sufferings in life, endures the harassment of

others, and bears the burden of others' hardships (7). In the Moein Dictionary, suffering means harassment, torment, torture, and revulsion (8). It is a feeling of displeasure, unhappiness, and disgust associated with injury or the threat of injury in a person (9).

Suffering in the field of psychology encompasses physical bothering, spiritual distress, pain, and grief resulting from severe diseases that alter an individual's past and their relationship with others. In essence, suffering in psychology refers to pain, grief, and turmoil that result in a family's inability to resolve issues leading to changes in one's life and relations with others (5).

Suffering also includes the significance of disease symptoms for patients and their families influencing the intensity of stress experienced as well as the treatment decisions. It is a distinctive experience that goes beyond physical, mental, and spiritual symptoms, involving the individual as a whole with memory, intelligence, and insight (10).

Furthermore, suffering in families of patients with cancer is defined as the inability to accept reality, denial of reality, a state of indifference (numbness), conflict between spiritual feelings and reality, and fear of loneliness and an uncertain future (11).

Suffering is a complex concept that encompasses loss and is associated with sadness and bereavement, but its nature is broader. Suffering may involve physical pain, but it transcends mere physical discomfort and entails the fear of loss and the perceived loss of coherence, independence, and genuine humanity. This in turn affects physical, mental, and spiritual health and ultimately causes a sense of losing control over one's entire life.

Suffering is the perception of serious threat or harm to oneself. It becomes evident when there is a disparity between what individuals expect from themselves and what they actually do. According to Cassel, suffering is triggered by the perception of imminent harm to oneself or certain aspects of one's being (12). Stilwell et al. defined suffering as a perceived disruption of self-coherence, which undermines the psychological structure and represents a subjective concept of identity (13). Suffering is a state of intense stress related to events that threaten a person's health and integrity. It is also defined as a wound that never heals and remains a constant source of distress in everyday life (14).

Suffering manifests with symptoms such as feeling meaningless and worthless, being a burden on others, dependency, inability to self-care, death anxiety, fear, panic, the desire for control over death, loneliness, and lack of social and economic support (15).

Determining the purpose of analysis

Suffering has different meanings across various disciplines and definitions, and understanding each meaning requires special attention. In the nursing profession, a significant number of patients experience suffering, particularly parents of a child with cancer. Thus, by paying attention to these experiences, the quality of care and nursing practice can be improved which would ultimately lead to increased patient satisfaction. Therefore, the authors decided to examine this concept in Iranian nursing culture to clarify its significance in this context and consequently, improve providing nursing care for these people.

Identifying all uses of the concept

Suffering is usually associated with intense mental states such as sadness, longing, fear, heartbreak, despair, and numerous other emotional states. Suffering is not synonymous with pain although it is often closely related to it (16).

Pain is often mistaken for disability and suffering. The concepts of pain and suffering are intertwined, sometimes causing confusion in conversations between patients and doctors. This confusion arises because pain is often perceived as having the same meaning as suffering (13). Some individuals find it challenging to differentiate between suffering and pain, as they believe there is no suffering without pain (17). However, pain can exist without causing suffering (16). Thus, it is crucial to differentiate suffering and pain to effectively address pain-related issues (17).

The standard definition of pain is the presence of an unpleasant sensation and an emotional experience associated with potential or acute tissue damage, often described in terms of injury. From another perspective, pain represents a threat or harm to a person's biological integrity. Suffering is a broader state with more dimensions compared to pain and has many potential causes, of which pain is only one. It is important to note that not all instances of pain cause suffering and not all forms of suffering manifest as pain.

The term suffering refers to enduring something unpleasant and uncomfortable, experiencing loss or damage, or facing a disability. According to Cassel, suffering is the consequence of being at imminent risk of destroying a person as a whole or partially, which involves damage to one's integrity (13). Suffering can be associated with any aspect of an individual (16).

Distress is one of the terms related to suffering which can be found in various articles. It conveys a sense of similarity to suffering (18). Distress is characterized as grief. In psychology, distress is delineated into six stages including apathy, longing, protest, confusion, depression, and improvement. In Kubler-Ross's model, distress is described through five stages including denial, anger, friendship, depression, and acceptance. Thus, distress has similar components to suffering, encompassing not only the aforementioned characteristics but also involving a series of psychological transformations. In other words, distress mirrors suffering; while suffering represents one of

the mentioned aspects, distress predicts it as a process (5).

Suffering is associated with both physical and emotional manifestations such as crying, pain, mental sadness, guilt, and withdrawal (18). The distress that may have been created as a result of suffering can be alleviated, but it cannot be entirely avoided or prevented. Sometimes, we need to attribute the suffering experienced by people around us and their exposure to distress to God, thereby finding comfort and satisfaction. We do more because we believe that God is aware of our distress (19). The literature indicates distress is one of the terms similar to suffering, but it is not synonymous with suffering itself.

Bereavement is also one of the terms similar to suffering, but it should be noted that suffering is a more complicated concept that is related to bereavement and grief and it is of a broader nature (13). Bereavement is a subset of life events and has both components of loss and restoration of life that must be balanced. Research has shown that individuals who had lost a spouse, experienced positive adjustments, were able to discuss their grief, and did not have distress during the interviews. Pre-bereavement care is effective in preparing people to confront the challenges faced during bereavement. Mourning is caused by pain, loss, end-of-life illnesses, or mental illnesses. There is a similarity between suffering and mourning in terms of causes, but mourning can be prevented and reduced. There is a possibility of adaptation in mourning and it may not be accompanied by distress, but suffering is accompanied by distress (20).

Defining descriptive characteristics

According to Walker and Avant, descriptive characteristics are special attributes that appear continuously with the concept and help to differentiate it from the related concepts (21). Accordingly, the characteristics of the concept of suffering are described as follows:

Suffering is a complex, subjective, and individual experience primarily caused by being in a situation of threat or perceived threat that carries a strong negative meaning (13). According to Cassel, suffering is experienced by the whole person, not just by his body, and it causes the person to see his special resources threatened by challenges in the realm of wholeness as a social and psychological complexity (16,17). Cassel describes suffering as a state in which intense mental concern is created for a person as a result of an event that threatens a person's health (14). The uniqueness of suffering is also highlighted in the statement, "Different people suffer in different ways" (22). According to Arthur Kleinman (1988), suffering is the experience of intrapersonal distress, caused by a tragic or significant event in one's daily life (23). Stilwell et al. argued individuality in suffering is derived from various authors' perspectives. They believed the experience of suffering varies from one person to another and depends on the understanding and interpretation of the

individual. Besides, the subjective nature of suffering is associated with its individuality and is a prominent aspect of this concept in various literatures. Since suffering is not easily observed and measured, it presents a distinct and abstract problem, making it a particularly intricate issue (13). Hall also believed suffering is a complex concept that includes loss and is related to distress and bereavement, but it has a broader nature (12). Whitman pointed out that suffering is an inherent part of life till one reaches ultimate purity (24). Until reaching this stage, suffering is always present throughout life. Adaptation to suffering or fear of suffering in the end stages of life is the natural part of every individual's life cycle (25).

Suffering has physical, cognitive, emotional, social, and spiritual components, which add to the complexity of the concept (13). It may include physical pain, but it is more than that. Suffering encompasses a loss that affects a person's physical, psychological, social, and spiritual health, ultimately leading to a loss of control over one's life (12).

Suffering is influenced by a person's cultural background, personal beliefs, roles, and social interactions (14). Stilwell et al. also believed to understand someone's suffering, we must consider that patients are social, psychological, and dynamic beings (13). According to Cassel's definition, one's identity, personal history, and the social and cultural contexts of human existence affect the meaning of suffering (26). Kraus and Batsida investigated the impact of religion on suffering and health by studying people of Mexican origin living in America and concluded that the religious background of people has a significant impact on dealing with cases of illness and suffering. They also mentioned that the words pain and suffering are deeply embedded in many aspects of Mexican American life, including religion (27).

People look at suffering from different perspectives. Some individuals perceive suffering as a process of losing humanity and everything associated with humanness and human dignity (13). According to Hall, suffering involves the threat of loss or the perceived loss of individual integrity, autonomy, and humanness (12). Suffering is considered a threat or harm to one's integrity. It includes a separation between what individuals expect from themselves and what they are (13). Suffering is associated with loss of control, which causes insecurity. Those experiencing suffering often feel helpless and trapped and cannot escape from this cycle (16).

Suffering is an inevitable part of life, and from another point of view, being human means suffering. People belonging to any cultural or social group, have suffered at least once in their life and have tried to adapt to this suffering. To do so, they try to understand and explain suffering, overcome it, and give it meaning (22). Suffering in humans starts from birth and stays with them until death. Human life in general is full of suffering and there

is suffering everywhere and at all stages of human life (23).

Suffering is a specific aspect of nursing and the healthcare system. In fact, it is a general aspect of human life and has been the focus of many writings by philosophers, scholars, and healthcare professionals (13). Nurses who care for people with suffering are valuable voices in explaining the lived experiences of the individuals who are in this situation (16).

People can understand the suffering of others and react to it. Reacting to the suffering of others is part of being involved in the process of sympathy, and sympathy is a process that leads to multiple cognitive and emotional reactions (23).

Suffering is often accompanied by asking the question 'why'. Suffering people often search for meaning and answers to the unknowns associated with suffering (16). Whitman argued most suffering people ask 'why me?', and they often feel that these conditions are not fair. If a Hindu asks 'why me?' or feels that this situation is unfair, the answer will be that his current situation is the result of his previous actions (24).

Presenting a sample model

Kowsar, a 4-year-old girl, was admitted to the pediatric ward and diagnosed with Wilms' tumor, which metastasized to the liver. The nurse reported the following after taking the history: "The mother says when I took Kowsar to the doctor due to pain on the left side of her abdomen, I suspected she might have kidney stones. However, when the doctor explained the results of the test to me and my husband, I could not believe it, and I prayed to God hoping the test results were incorrect and not related to my daughter. Every day, I see my daughter growing weaker before my eyes and there is nothing I can do. I feel that a piece of me is slowly separating from me; I am no longer able to look at my daughter. Her hair is falling out, her color is turning yellow. If I show you my daughter's photo, you will not believe that the girl lying on the bed is my daughter. Each time they want to prepare her for chemotherapy, I feel short of breath and nauseous. I hate that others feel sorry for me, and that is why I do not want to talk to anyone; no one knows what happened to me and her father. I'm so scared, about what will happen; whether my daughter will respond to chemotherapy or not; I cannot bear to be hurt so much. I hate to live without my daughter and I wish to die every day. I wish I was sick instead of her; I wish they would give me chemotherapy drugs. All life has become meaningless and worthless for me and her father. I want to know why they say God is just, what kind of justice is this? After all, for what sin does this little girl have to suffer so much in her life? I do not believe in anything anymore".

Determining borderline, related, contrary, and unrelated cases <u>Borderline case</u>

Ali is a 9-year-old child suffering from mouth ulcers following Hodgkin's disease and several sessions of chemotherapy. His mother said, "When I see the wounds in my child's mouth, I get very annoyed, I don't like to eat because I feel that my mouth burns when I eat. Today, when my child asked me for a sandwich and I bought it for him, he could not eat it due to the burning of his oral wounds and tears were flowing from his eyes. I am in a lot of pain with him, but I am sure that his wounds will heal soon. God will surely see me and my son and will not leave me alone".

Related case

Sarah is a 4-year-old child currently hospitalized due to leukemia. She also stayed in the hospital for a bone marrow transplant for some time. Her father has been away from his workplace for some time and is anxious and worried about losing his job and not being able to pay the costs of treatment. Her mother said, "I also have a 2-year-old son who is being cared for by his grandmother. I miss him very much, but what can we do? Our whole life is messed up. Leukemia is a bad pain. When I think I might lose my daughter, I cannot eat or sleep out of sadness. I do not want to talk to anyone; I want to be with my daughter more; I cry most of the time. The people around us love us so much that we do not feel alone, but even with their help, we cannot escape the situation. The world is very worthless, and only God should help us".

Contrary case

Muhaddeseh is an 8-year-old girl who is hospitalized due to leukemia. She has undergone chemotherapy several times and has developed alopecia. Her mother talks to the nurses regularly and is looking for a solution. She said, "my child's hair is falling out little by little. Do you remember how thick and beautiful her hair was? What do you think I can do? What kind of wig do you think I should buy? Which model? What foods should I give my child to gain weight? I have a strong belief in the power of God and I know my child will be fine. Her doctor also told me that her hair will grow back. I really hope she gets better".

Unrelated case

Hassan is a 12-year-old boy who suffers from advanced bone cancer. His mother, who is in the ward with him, has not accepted this issue at all and strongly denies his illness. Despite the explanation of the doctor and nurses, she believes her child is growing and the pain in his bones is due to his growing age and the doctor has made a mistake in his diagnosis.

Identifying antecedents and consequences (preliminaries and delays)

Antecedents of suffering

Suffering is a complicated concept, with one of its prerequisites being loss. This loss is so significant that it can affect the individuals' spiritual, physical, and psychological well-being, ultimately influencing their sense of control over their own life. Suffering includes the perceived risk of losing or the actual loss of one's integrity, independence, and identity (12). Individuals experiencing suffering may feel as though they are undergoing a process of losing their humanity, and suffering is provoked in situations where there is a profound sense of loss or the threat of loss, particularly when the threat or loss pertains to one's personality or identity (13).

Another antecedent of suffering is major life events, which can lead to profound life challenges. Kleinman defined suffering as a mental experience that occurs as a result of significant life events as well as routine daily life experiences. Suffering occurs due to critical threats to one's existence, health and well-being, intimate relationships, personal values, and performance capabilities (23). Wijsbek defined suffering as a condition related to threatening events (28).

Illness and pain can also serve as the underlying factors contributing to suffering. Suffering is usually caused by physical illness, disability, and bodily deformity. Pain is a common mechanism that leads to suffering (13). Suffering is mainly formed by the individual's experience and interpretation of the disease. It is defined as a wound that does not heal and disrupts a person's daily life (14). Suffering includes physical pain (12) and is triggered by physical or mental pain, resulting from an organismic dysfunction such as illness, disability, or other limitations that disturb the person's existential structure. Patients in the terminal stages of a disease suffer from pain and other distressing discomforts that usually cannot be resolved (29). Suffering can be induced by death or end-of-life illnesses (2).

Religion and ethics are the antecedents completely connected to the concept of suffering. This connection is manifested through the experience of morality in a sense of having done something wrong (e.g., having harmed others) and also compassion for suffering people (23). Suffering in the context of religious issues arises from imbalance in life satisfaction, moral and religious challenges, philosophical questions about life, fear of losing body and soul, the pursuit of a meaningful existence, worries about family, feelings of anxiety, encounters with the unknown, despair, and uncertainty about eternal life (29).

Socioenvironmental issues can also be the underlying causes of suffering. Specific social problems are considered as the antecedents of suffering, such as job loss, homelessness, poverty, and overall low social status (13). Being stigmatized and the resulting emotional damage exacerbate suffering (30).

Personal characteristics can also serve as the background

for suffering. Certain personal characteristics make a person more exposed to suffering, such as alertness, one's understanding of the past and the future, a sense of purpose and meaning in life, as well as cognitive and emotional awareness (13). Suffering can also be influenced by an individual's cultural background, beliefs, roles, and social relations. The experience of suffering emerges from disruptions in daily life and routines, prompting the individuals to reassess their life assumptions and values (14). Loss of wholeness is an indicator of distress, yet the precise reasons for its occurrence and how individuals experience this loss remain unclear (28).

Consequences of suffering

Suffering can lead to various consequences, including panic, intense fear of the unknown, family distress, family dysfunction, physical and mental problems, depression, and anxiety. Suffering and loss are usually interconnected and manifest as loss of peace, tranquility, faith, belief, hope, balance, stability, and social role (31). Suffering causes loss of control and insecurity. In most cases, suffering is accompanied by loss. The loss may encompass losing a relationship, some aspects of oneself, or some physical aspects of the body. It may even only exist in the mind of the person who is suffering, without being noticed as a feeling of failure.

Suffering is usually associated with intense mental states such as sadness, longing, fear, heartbreak, despair, and thousands of other mental states (16). Following suffering, feelings of meaninglessness, worthlessness, and loneliness emerge and the person feels dependent and imposed upon (31,32). Suffering is often accompanied by a sense of detachment from the world. Individuals may experience extreme loneliness and yearn to connect with others while feeling extreme distress about being dependent on others (16). The individual is confronted with a lack of social and economic support (31), and most people who suffer feel helpless and trapped in a situation from which they cannot escape, asking 'why' (16) and wishing to control the time of their death (31,32).

Nevertheless, suffering might lead to the development of human personality and mental state and help a person to differentiate right from wrong and unreal from real.

Detailing empirical referents

There is no specific questionnaire for assessing suffering. While pain or stress can be quantified with special questionnaires or criteria, there is no standard or questionnaire to measure the extent of suffering. Thus, it seems necessary to develop a tool to evaluate suffering, which is recommended for further research.

Conclusion

The concept of suffering in parents of children with cancer was investigated by choosing the concept, determining the purpose of analysis, specifying all the possible uses of the concept, describing its descriptive characteristics, presenting a model for the concept, determining borderline, related, contrary, and unrelated samples, identifying the antecedents and consequences (preliminaries and delays), and detailing empirical referents

Acknowledgments

This study reports the results of a PhD dissertation approved by the Isfahan University of Medical Sciences. We express our gratitude for support from the graduate studies program of the university.

Authors' Contribution

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Competing Interests

The authors declared no competing interests.

Ethical Approval

Not applicable.

Funding

This article has no funding source.

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