

Article

The Impact of Spiritual-Based Care Interventions on the Quality of Life of Children with Chronic Diseases: a Philosophical Perspective

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Abstract:

Background: Chronic disease is the leading cause of death and disability in children. Various complex stressors faced by children due to illness and a series of treatments can negatively impact children's welfare, which can negatively affect children's quality of life.

Objectives: This literature aims to study the philosophy of spiritual-based care interventions to improve the quality of life of children with chronic diseases viewed from three philosophical perspectives, namely ontology, epistemology, and axiology.

Methods: A literature search was performed on five databases, namely SCOPUS, PubMed, ProQuest, ScienceDirect, and SAGEpub. Population limitations and diagnoses in this literature of children with chronic disease. This research is a quantitative study focusing on publications between 2017-2021.

Results: The philosophy of spiritual care intervention is humanistic, pragmatic, and religious intervention. Humanistic interventions are interventions in which nurses are actively involved in spiritual care. Pragmatic intervention is the activeness of a nurse in assessing the spiritual needs of patients. Meanwhile, religious intervention is an intervention that is directly related to the practice or ritual of a specific belief system. Spiritual care is an essential part of holistic care, which is considered an indicator of improving the quality of care. It will ultimately affect the optimal quality of life of children.

Conclusion: Spiritual-based care interventions are essential to improve the quality of life of children with chronic diseases. Spiritual care given to children with chronic illnesses must consider all aspects such as developmental stage, life experience, and socio-cultural of the child.

Keywords: Nursing; Spiritual care; Quality of life; Chronic disease; Children

1. INTRODUCTION

Chronic diseases are the leading cause of death worldwide, with increasing prevalence in all age groups, genders, and ethnicities (Anderson & Durstine, 2019; Global Burden Report, 2019). As many as 1 in 4 children under 17 years suffer from chronic health problems (van Cleave, 2010). This resulted in about 65% of children aged less than 15 years dying because of chronic conditions (Hardelid et al., 2014). School-age children diagnosed with chronic diseases increased by 30% (van Cleave, 2010).

A chronic disease lasts a long time because it cannot be cured and cannot even be treated with severe symptoms (Compas et al., 2012; Ijoma et al., 2019). From the moment it appears, a person with the chronic disease requires the ability to adapt to deal with various stressors in the long term, dealing with disability and malaise, with varying degrees of severity, which tend to worsen over time (Bonino, 2021). This is supported by other studies that explain that chronic health conditions are associated with high levels of problems in the physical, emotional, developmental, and behavioral aspects that result in a decrease in the quality of life of children with chronic diseases (Bai et al., 2017; Blackman et al., 2011; Nijhof et al., 2018; Toledano-Toledano & Domínguez-Guedea, 2019). In fact, parents of children with chronic diseases perceive their children to have a poorer quality of life (Hall et al., 2019).

Previous research has shown that children with chronic diseases tend to have neurocognitive deficits (Compas et al., 2017), have sleep problems (Hysing et al., 2009), have impaired self-concept (Ferro & Boyle, 2015), and have a low self-image. A negative body is associated with symptoms of depression, social anxiety, low self-esteem, eating disorders, and suboptimal self-care (Pinquart, 2013). With various problems that occur in children with chronic diseases and a series of adverse effects caused by the disease or the treatment process they undergo, it is important to take a new holistic approach, one of which is the provision of spiritual care-based interventions. This literature aims to explain the philosophy of spiritual-based care interventions to improve the quality of life of children with chronic diseases viewed from 3 perspectives, namely ontology, epistemology, and axiology.

2. METHODS

Literature searches were carried out on five databases, namely SCOPUS, PubMed, ProQuest, ScienceDirect, and SAGEPub. Population limitations and diagnoses in this literature of children with chronic disease. This research is quantitative research focusing on publications between 2017-2021.

3. RESULTS AND DISCUSSION

3.1 Philosophy of intervention based on spiritual care from an Ontology perspective

Chronic diseases are the leading cause of death worldwide, increasing prevalence in all age groups, genders, and ethnicities. Most deaths from chronic diseases occur in lower-middle-income countries but are also a significant health problem in developed countries (Anderson & Durstine, 2019). Chronic diseases tend to last a lifetime or almost a lifetime, thus affecting the perception of emotional, economic, social, occupational, and individual well-being (Ijoma et al., 2019). Chronic disease is a medical condition that lasts for three months or more and can worsen over time. Chronic disease can also be defined as a disease that can appear at any time, recur over a long time, and worsen over time. The CDC defines a chronic illness as a condition that lasts one year or more and requires ongoing medical attention or limits daily activities that last one year or more or both (Centers For Disease Control And Prevention, 2021).

Chronic disease also can become a dangerous condition if not treated properly. Globally, it is estimated that chronic health conditions affect 10% to 30% of children. In America, about 50% of its citizens have one chronic disease, 26% have two or more, and 13% have a disability, this population includes adolescents (Bauer et al., 2014). Studies have found that many people aged 17 and under have one or more chronic health conditions related to bodily functions and daily activities. This prevalence has increased to around 43% (Compas et al., 2012). High depressive symptoms were found among students with chronic health conditions who reported that their illness or disability affected their activities (18%) or their ability to socialize (40%). This was significantly higher than among students without chronic health conditions (10%) (Denny et al., 2014).

Past research has revealed the adverse effects of chronic disease on patients' physical, psychological, socio-economic, and behavioral functions and their caregivers or families (Bai et al., 2017; Nijhof et al., 2018; Toledano-Toledano & Domínguez-Guedea, 2019). Indirectly, this can impact a lower quality of life (Bai et al., 2017). Chronic illness causes millions of children and adolescents to experience significant stress related to emotional and behavioral problems and interferes with adherence to medication regimens (Compas et al., 2012). Stress conditions affect the nervous system, immune system, and endocrine (Fuenmayor & de Fernandez, 2021; Müller, 2020). A child who has early life stress that comes from hospitalization stress and chronic illness will tend to experience disturbances in cognitive and affective stress regulation and adrenal and endocrine changes (White et al., 2021).

3.2 Philosophy of spiritual care based interventions from an Epistemological perspective

Children with chronic disease may have activity limitations, recurrent pain or discomfort, impaired growth and development, and frequent hospitalizations. This condition can have an impact on the child and his family. The impact on children can be seen in their psychosocial development, involvement with peers, and achievements in school. The psychosocial status of parents, activities and economic status of the family, and the role of the family in society will also be significantly affected by chronic illnesses suffered by children. Based on this, a nurse must be able to provide holistic nursing care to improve the quality of care. Spiritual care is an essential part of holistic care, which is considered an indicator of improving the quality of care (Ghorbani et al., 2021).

The nursing literature defines spirituality as 'the most human experience of seeking to transcend oneself and find meaning and purpose through relationships with other people, nature, and/or God, which may or may not involve religious structures or traditions' (C. M. Puchalski et al., 2019). The definition derived from the global consensus states that spirituality is a dynamic and intrinsic aspect of humanity. People seek ultimate meaning, purpose, and transcendence, and experience connection with self, family, other people, community, society, nature, and significance or holy. Spirituality is expressed through beliefs, values, traditions, and practices' (C. Puchalski et al., 2009). Based on a systematic review by Robert et al. (2019), spirituality is faith, meaning, religion, a sense of divinity or higher power, vitality and gratitude, spirituality, existential health, and hope.

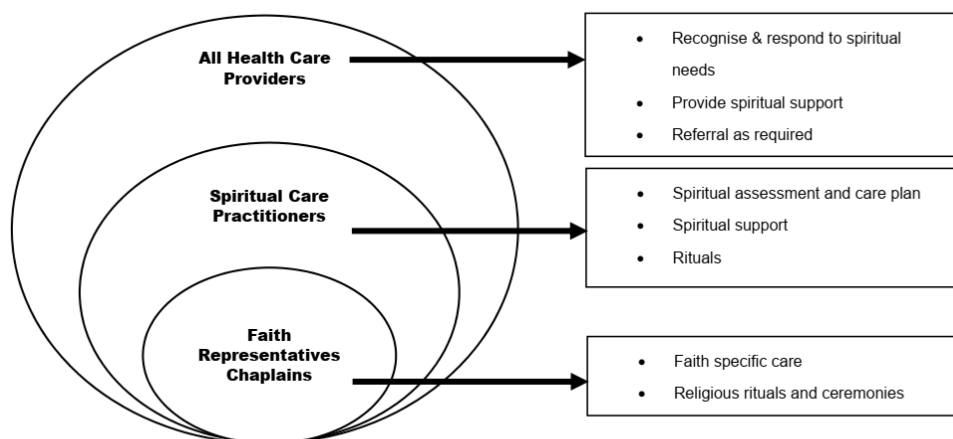


Figure 1. Model of Spiritual Care.

The central concepts of nurses' spiritual care interventions in palliative care are humanistic, pragmatic, and religious interventions. Humanistic interventions are interventions in which nurses are actively involved in spiritual care and demonstrate that they can demonstrate their professional presence to the dying person. They are also closely involved in communication and listening and allow the person to express their spiritual needs. Practical interventions involve referrals to pastoral care and caregivers and other health practitioners with experiences in spiritual care. They are active in assessing the person's spiritual needs and caring for them whenever possible. That is, their intervention is mainly related to referral and facilitation. At the same time, religious intervention is directly related to the practice or ritual of a specific belief system or pastoral service or the involvement of a religious person, for example, a priest or cleric (Ronaldson et al., 2017). Meanwhile, Ghorbani et al. (2021) suggested eight categories of spiritual care-based interventions in the nursing field, including:

1) Exploration of spiritual perspective

Exploration of the patient's spiritual perspective includes 1) diagnosing signs of spiritual distress through observation, interviews, and the use of instruments to assess spiritual distress; 2) assessment of the patient's source of strength and hope through interviews to build a deeper relationship with the patient, identify the patient's spiritual and religious beliefs, to identify the patient's source of strength and hope, and to assess the patient's spiritual suffering, and 3) diagnosing spiritual needs through

listening to stories the patient in a compassionate manner to establish a relationship with him or her in a clinical setting; identify spiritual problems and design a spiritual treatment plan.

2) Presence of healing

The nurse's unique presence as a complete physical, psychological, and spiritual presence through caring presence and altruism

3) Self-therapeutic use

Establishing a therapeutic relationship, actively listening to the patient about the story being told, being non-judgmental, and the nurse's unconditional acceptance of the patient in nursing situations

4) Intuitive sense

Feeling one's presence, emotional identification with the patient, understanding the patient's condition, recognizing opportunities for spiritual conversation with the patient

5) Patient-centered

It considers the uniqueness and special situation of the patient to provide appropriate spiritual care. In addition, respect the patient's values and beliefs.

6) Meaning-centered therapeutic intervention

Meaning-centered therapeutic interventions can be carried out by: encouraging patients to develop relationships with others, such as friends and family; transferring healing and positive energy to the patient by touching him, establishing eye contact with him, treating him kindly, making him feel confident, understanding him, and using supportive words; facilitating patient access to religious resources and facilities; facilitating the use of complementary interventions such as relaxation, yoga, therapeutic touch, aromatherapy, and others; and encourage patients to join support groups and participate in special celebrations such as birthday parties.

7) Creation of a spiritually nurturing environment

Maintain ethical aspects of care, respect patient's spiritual/religious/cultural values , and try to create a safe therapeutic environment

8) Documentation and evaluation of spiritual care.

Document spiritual interventions and outcomes in nursing records. In addition, it encourages patients to express their spiritual state after treatment, discuss results with patients and record them according to an appropriate pattern.

Spiritual care as a process involves several organically related phases: (1) identification of spiritual needs and resources, (2) understanding the patient's specific needs, (3) development of an individual spiritual care plan involving health care/spiritual care professionals relevant, (4) provision of spiritual care, and (5) evaluating the spiritual care provided (Nissen et al., 2021). Spiritual-based interventions can be given in several forms, namely religious and non-religious interventions. Religious interventions include treating patients' religious beliefs without prejudice, allowing them to connect with God and express their values and beliefs, helping them practice their religion, and referring them to clerics and religious leaders. Non-religious interventions include the presence of nurses for patients and their families, making direct eye contact when communicating with patients, sympathizing with patients and their families, listening attentively to patients and their families, and having love and enthusiasm for patients (Zehtab & Adib Hajbaghery, 2014).

Spiritual care-based interventions are an intervention strategy that cannot be ignored in providing holistic nursing care in pediatric settings, including nursing care for children with chronic diseases. However, several factors must be considered in

implementing spiritual care-based interventions, especially for children and adolescents, namely: 1) observation and listening skills in understanding the patient's spiritual expression; 2) the assessment and planning of spiritual care must consider aspects related to the stage of development, life experience, family context and socio-cultural; 3) nurses can use different approaches and multiple tools to assess spirituality, especially in children and adolescents. It is important to develop specific instruments for assessing spirituality in pediatric patients and their validation in different treatment contexts (Alvarenga et al., 2017). Other studies explain that various factors such as nurses' personal, hospital organizational, and patient-related factors affect the provision of spiritual care (Mascio et al., 2021).

3.3 Philosophy of intervention based on spiritual care from an axiological perspective

Spiritual care in health care research has increased over the last few decades. This shows that spiritual needs increase along with the increase in life-threatening illnesses. Previous research has shown that spiritual care improves the quality of life, but failure to provide spiritual care leads to an increased likelihood of depression and lower health conditions (Nissen et al., 2021).

Little evidence is found in the literature on the effectiveness of spiritual care-based interventions in clinical settings in children. However, several previous studies have explained the effectiveness of spiritual care-based interventions in children, including children with chronic diseases. Spiritual interventions for children and youth, such as active listening; minimizing their separation from those closest to them; enabling the realization of spiritual values and beliefs; offer comfort, safety, and play; and using art and music, have a positive effect on hospitalized children (Alvarenga et al., 2017).

Other studies have also revealed that spiritual care-based interventions aim to provide holistic care that is beneficial for improving the well-being of children and adolescents during illness and hospitalization (Alvarenga et al., 2017). Spirituality is an integral aspect of a child's life and development. Children need spiritual care from health professionals when facing chronic physical conditions (Damsma Bakker et al., 2018). In addition, spiritual care can help pediatric patients to recover early. When pediatric patients fulfill their spiritual needs, they will have a better health conditions. Patients feel motivated and assertive. Spirituality is a positive approach to a better quality of life (Romdzati & Yuliandari, 2021).

Many studies reveal the effect of spirituality on the health status of patients. According to a study, spiritual health will lead patients to a meaningful and purposeful life. Spiritual care positively affects an individual's stress response, spiritual well-being (i.e., the balance between physical, psychosocial, and spiritual aspects of self), sense of integrity and excellence, and interpersonal relationships (Zehtab & Adib Hajbaghery, 2014). Spiritual-based care also significantly ameliorates patients with anxiety disorders and depression (Durmuş & Ekinci, 2022; Salari et al., 2021; Sankhe et al., 2017).

Spirituality-based care programs offered by nurses can positively influence the coping of pediatric patients with chronic diseases such as cancer (Torabi et al., 2018). Religious and spiritual treatments help reduce the intensity of pain caused by the illness and the intervention received. In addition, spiritual care can increase patient satisfaction with pain control experienced (Hindmarch et al., 2022; Keivan et al., 2019). The influence of religiosity/spirituality on therapeutic adherence requires that healthcare professionals acquire sensitivity and competence to address these issues with their patients (Badanta-Romero et al., 2018). Spiritual care is related to providing compassion and empathy during periods of increased stress, distress, and anxiety in care (Roman et al., 2020).

4. CONCLUSION

The philosophy of intervention based on spiritual care from an ontology perspective is that chronic disease is the leading cause of death and disability worldwide that lasts almost a lifetime. If not treated properly, this disease can become a dangerous condition. Chronic disease can adversely affect the patient's physical, psychological, socio-economic function, and behavior, which

will have an impact on a lower quality of life. Spiritual care-based intervention is one form of intervention that can be relied upon in managing patients with chronic diseases. The philosophy of spiritual care-based intervention from an ontology perspective is that a nurse must be able to provide holistic nursing care to improve the quality of care. Spiritual care is an important part of holistic care that is considered an indicator of improving the quality of care. Spiritual care-based interventions are an intervention strategy that cannot be ignored in providing holistic nursing care in pediatric settings, including nursing care for children with chronic diseases. However, several factors must be considered in implementing spiritual care-based interventions, especially for children and adolescents. Meanwhile, the philosophy of spiritual care-based interventions from an axiological perspective is that spiritual care-based interventions can positively affect coping, stress levels, pain levels, interpersonal relationships, and well-being. Ultimately can improve the quality of life of children with chronic diseases.

CONFLICT OF INTEREST: The author(s) declares that there is no conflict of interest.

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