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The Meaning of Hope for Women Diagnosed With Terminal Illness: A Literature Review

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Abstract

Humans navigate health, illness, and the journey of life as it unfolds, with death being the eventual and unavoidable outcome. Death is a certainty, an inherent unknown in life, and women and their families deal with this inevitable topic in a variety of ways. Some focus on grief, pain, and all that will be lost while others focus on peace and hope. None of us know how we will handle the prospect of death until we are going through it ourselves or with a loved one. "Those who are dying and those who care about them often have valuable gifts to offer one another" (Callanan & Kelley, 1992, p. 13).

Nurses have the privilege to comfort and care for humans upon entry into the world, departure from the world, and all along the trajectory of life's joyous and arduous pathways. Provision 1 of the ANA Code of Ethics says the nurse shall practice with compassion and respect for the inherent dignity, uniqueness, and worth of every person (ANA, 2015). This includes caring for the living as well as the dying, with the utmost respect and sensitivity.

There is (for some) a sense of fear associated with loss of control during significant illness and impending death. Dr. Rick Holm, a Brookings, SD family practice physician who is also known as "The Prairie Doc", and was recently diagnosed with pancreatic cancer, says that "fear of death can be overcome with connectedness and spirit" (Holm, 2017). Through stories, song, blogs, a weekly television broadcast, and countless experiences with patient care during the final stages of life, Dr. Holm encourages others to reach out to one another for spiritual connectedness, guidance, and warm embrace literally and figuratively, and to "listen with hope for life" (Holm, 2017).

Planning for end of life is challenging for patients, their loved ones, and for healthcare professionals as well. "Coping with terminal illness is more than hard work- it's all consuming and creeps into every corner of your life" (Callanan & Kelley, 1992, p. 2). While it is important to guide and support patients and families, health situations must be approached in a transparent and realistic manner. However, that does not mean that all hope is lost, or that hope is experienced by all in the same way. The authors of "Final Gifts" liken coping with terminal illness to a stone thrown into a pond, with multiple ripples reaching out and affecting everyone around the dying person (Callanan & Kelley, 1992, p. 2).

Healthcare advances and increased longevity (despite complex diagnoses) have changed trajectories for many patients, however end of life remains a perplexing time (NINR, n.d.). Furthermore, a diagnosis of terminal illness is devastating physically, mentally, spiritually, and emotionally for women and their families. The National Institute of Nursing Research (NINR) supports the research endeavors of nurse scientists striving to improve comfort and reduce symptoms of advancing illness for patients and to guide them through end of life processes (n.d.).

End-of-life and palliative care science develops strategies to prevent, reduce, or comfort the symptoms of advanced illness. It includes management of pain and other symptoms and emotional, social, spiritual and informed decision-making support. Interventions address supportive, palliative, and hospice needs across a continuum of services in coordination with individuals, families and their health care teams (NINR, 2017).

According to the World Health Organization, women live an average of four years longer than men, and the average life expectancy was more than 80 years of age in 46 countries (WHO, 2013). In the United

States the top three leading causes of female death in all races and age groups combined were: (a) heart disease, (b) cancer, and (c) chronic lower respiratory disease. Heart disease remains the leader in mortality at 22.3%, followed by cancer at 21.6%, and finally chronic lower respiratory disease at 6% (CDC, 2017).

Life culminates in death. Does (or how does) hope impact life expectancy? What impacts health outcomes and ability to persevere? Do women handle end of life differently? What are the factors that help to improve quality of life, or give hope to those women where the situation might seem hopeless? According to the literature, hope is an important coping mechanism for people experiencing stressful situations (Broadhurst, 2016; Devik et al., 2013; Tae et al., 2012). Dufault and Martoccio (1985), defined hope as “a multidimensional dynamic life force characterized by confidence in the face of uncertainty. Hopeful people expect to achieve a personally significant future good”. Hope constitutes (a) a delicately balanced approach to painful life experiences, (b) a sense of interconnectedness with others, (c) a reliance on one’s spiritual nature, and (d) the ability to maintain a rational or mindful approach to these life experiences (Farran et al., 1995).

Hope is explained by Herth and fellow researchers as a concept with four central attributes: (a) an experiential process, (b) a spiritual or transcendent process, (c) a rational thought process, and (d) a relational process, or the pain, soul, mind, and heart of hope (1995). When interviewing an elderly woman who resided in a subsidized housing unit for senior citizens about hope, the author was asked to return the next day. Upon her return the elderly woman had set the table with her nicest china and made baked goods for the event. Despite having little to no income and very little material resources, the woman made a special effort to make the interview “an occasion”, displaying rational and relational attributes of hope for the interaction to come (Farran et al., 1995).

Women are resilient. Historically, women have been the caretakers in the home, focused on domestic responsibilities, companionship, and childrearing. *Stoic, sponges, soundboard, supportive-* adjectives used to describe matriarchal traits. Women today have multiple life roles: homemaker, career person, mother, daughter, wife, friend, neighbor, nurse, informal caregiver, and nurturer to name a few. Most families are comprised of dual income earners, schedules are hectic, and yet the traditional chores and tasks still need to be accomplished from day to day. What toll do these multiple, multitasking, conflicting responsibilities have on women as they age? Researchers have explored the aspects of hope and inner strength in women, but these concepts are not fully explored in relation to end of life. Hope and inner strength are important to consider as we discuss the finality of life, planning for comfort and care, and what hope means to the dying woman (Broadhurst, 2016; Devik et al., 2013; Kylma et al., 1997; Tae et al., 2012). This is a critical area of research for nursing science because if we can understand what gives women hope, and what positively and negatively impacts hope, we can perhaps provide them with improved care and better quality of life as they traverse their final days.

Research Question which led to the literature review.

What is the meaning of hope for women diagnosed with terminal illness?

Specific aims. To explore: (a) how hope is defined and fostered during illness, (b) what is hope in the face of terminal illness, and (c) how do women experience hope?

Proposed Methodology. Heideggerian interpretive phenomenology, semi-structured interviews, 10-12 participants (purposive and snowball sampling from the cancer care institute and/or hospice).

Significance. There is little available information or research on terminally ill women and hope in the literature. It is not clearly known how hope impacts quality of life or end of life processes in terminally ill women. If nurse scientists can understand what gives terminally ill women hope, we can gain insight from their experiences and optimize quality of life.

Title:

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Abstract Summary:

The concept of hope at the end of life is a personal and complicated phenomenon. Researchers have investigated the concept of hope as it relates to caregivers and nurses. However, the meaning of hope for women at the end of life is underreported and literature shows further study is needed.

Content Outline:

Abstract Summary: The concept of hope at the end of life is a personal and complicated phenomenon. Researchers have investigated the concept of hope as it relates to caregivers and nurses. However, the meaning of hope for women at the end of life is underreported and literature shows further study is needed.

Objectives: This literature review summarizes research relevant to the examination of hope in women in the face of terminal illness.

Methods: Using the search terms hope, terminal illness, and women, CINAHL-EBSCO; (SC) SCOPUS; and (PI) Psych Info databases were searched for the years 2008-2018. Less than 20 articles met the inclusion criteria.

Results: There is little available information or research on hope in the literature. It is not clearly known how hope impacts quality of life or end of life processes in terminally ill women. If nurse scientists can understand what gives terminally ill women hope, we can gain insight from their experiences and optimize quality of life during end-of-life.

Discussion: There are a limited number of studies that address hope in women who are terminally ill; this suggests further research is needed to understand how hope impacts terminally ill women.

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Author Summary: Stephanie Orth is a graduate nursing student with experience in women's health, nursing education, nursing regulation, and as a caregiver for a terminally ill mother. She has a passion for women's health issues and seeks to add to the body of literature on hope and terminally ill women.