



Pain and social processes for hospice cancer patients: An integrative review



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ABSTRACT

Purpose: Hospice cancer patients experience poorly-controlled pain in spite of widely-disseminated evidence-based guidelines for use by hospice care practitioners. Pain management occurs in the context of the interdisciplinary team, centered on a caring triad in the home: the person with pain, their caregiver, and their nurse. This review: 1) Summarizes what is known about differing ways that members of the hospice caring triad (patients, caregivers, and nurses) interpret and respond to cancer pain, in order to develop a cancer pain social processes theoretical framework, 2) Identifies gaps in understanding of hospice cancer pain social processes, and 3) Identifies framework concepts for research-based clinical practice with potential to improve pain outcomes.

Methods: Our integrative review of the literature resulted in the identification and synthesis of 21 unique studies of cancer pain social processes, which were categorized according to a social processes framework and hospice caring triad member roles, using a social processes concepts matrix.

Results: Pain meanings, goals, and related responses vary for persons with pain, caregivers, and nurses. Studies have explored individual social processes concepts or triad member roles. Studies identify the need for pain meaning to be included in hospice pain management plans.

Conclusions: To our knowledge, no single study has generated a framework for hospice cancer pain social processes addressing and incorporating the roles of all three caring triad members. Therefore, comprehensive hospice cancer pain clinical evaluation and interventions plans may be missing key elements of pain management, especially for persons with ongoing poorly controlled pain.

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1. Introduction

Relief of suffering, especially physical pain, is a primary function of hospice care (National Hospice and Palliative Care Organization, 2015). Rates of pain in patients with metastatic and advanced cancer are as high as 64%, with one third of patients reporting moderate to severe pain (van den Beuken-van Everdingen et al., 2007). The problem of poorly controlled pain persists despite the publication of guidelines for the treatment of cancer pain, and pain in adults and older people (American Pain Society, 2011; Herr et al., 2010; RNAO, 2013). While hospice and palliative care programs strive to stay at the forefront of pain control, hospice nurses' clinical practice and use of these evidence-based guidelines varies widely (Coyle, 2004; Herr et al., 2010).

Hospice care usually takes place in the dynamic setting of people's homes, where a constellation of factors affect outcomes of cancer pain management (Lau et al., 2010). However, barriers to and facilitators of excellent cancer pain control in the context of home hospice care have yet to be fully described and integrated into theory to guide nursing practice, especially social processes. Social processes is a complex framework involving cognitive awareness, reflection, behavior, and interactions with others. The purpose of this integrative review is to identify and describe factors impacting management of cancer pain in the home hospice setting, using a social processes framework to organize and interpret current research. We chose a social processes framework as a theoretical lens to guide this review because the experience and meaning of pain for the person with hospice care, and how the family caregiver and nurse relate to and interpret this experience, is not well understood. The following questions guide the literature review and synthesis: 1) What is the experience of pain for the person with cancer, 2) What is the experience of the family caregiver in regards to the person's pain, 3) What is the experience of

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the hospice nurse in regards to the person's pain, and 4) Which social processes related to hospice cancer pain have been identified?

Symbolic interactionism is at the root of social processes, explaining how people create meaning as a result of thoughts, behaviors, and communications (Charmaz, 2010). The social processes framework we have adopted from the National Institute of Mental Health (NIMH) (2012) for the purpose of this review, involves a complex combination of cognitive awareness, reflection, behavior, and interactions with others. How social processes may be impacting pain experience is an area relevant for clinical practice when pain from cancer is poorly controlled. By categorizing and summarizing pain social processes studied so far, we point out considerations for clinicians to address and gaps in understanding of poorly controlled pain.

2. Methods

Integrative review methods were used according to published best practices (Whittemore and Knafl, 2005). Author one searched Cumulative Index of Nursing and Allied Health Literature (CINAHL) and PubMed for peer-reviewed journal articles using the following search terms singly and combined: cancer pain, pain, meaning, goals, control, processes, hospice, palliative care, patient experience of pain, end-of-life suffering, end-of-life pain, cancer pain relief, hospice nurse, and hospice caregiver. To identify studies of pain meaning and experience, the search also included methodological keywords, such as qualitative research and grounded theory. Early searching located only a few studies about all three concepts guiding this review (cancer, pain, and social processes). Because of this, after journal article titles and abstracts had been read, the authors agreed to include two studies about persons with pain from end-stage cancer receiving treatment in both the home and outpatient settings in other countries. The data reported contributed to the pain social processes lens, and it is likely that these same two samples would have been receiving hospice care if in the United States. Studies that focused solely on children, pain meaning not related to cancer, and studies not published in English were excluded. No publication date limits were set. Author one identified 46 articles after eliminating duplicates and including articles identified by hand searching of bibliographies. After reading the studies completely, another 25 studies did not fit the criteria because they focused on chronic non-cancer pain, laboratory studies inducing pain in healthy volunteers, or cancer patients who were not receiving hospice care (Fig. 1 illustrates this process). A total of 21 articles, including one from a text book, were included in the final review. Based on nursing theory, the authors agreed to categorize studies under the broad headings of pain control and pain meaning, and the subcategories of social roles within the hospice triad—person with pain, caregiver, and hospice nurse.

3. Results

Most of the literature reviewed was about the cancer pain management experiences of clinicians, particularly studies about controlling pain. Some articles presented the perspectives of persons with pain from cancer, and people supporting them. These studies tended to explore the value of having support, or the personal effects of being a caregiver for a person with cancer pain. We present our findings under the major categories of cancer pain meaning and cancer pain control, discussed from the perspectives of each: person with pain, caregiver, and hospice nurse. Then, we further explore the literature within the social processes context.

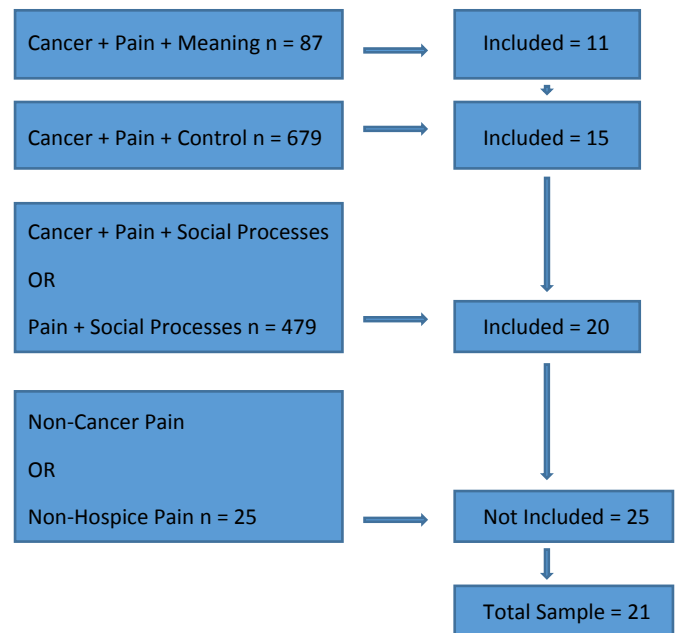


Fig. 1. Literature search process. All terms above were searched in Cumulative Index of Nursing and Allied Health Literature (CINAHL) and PubMed.

3.1. Cancer pain meaning

3.1.1. Role of pain meaning

Munhall (2012) identified nursing as a human science differentiated from natural sciences by its focus on meaning. Effective nursing assessment and management interventions for pain therefore should be rooted in the meaning of pain. One element of meaning is the situated context, which is comprised of an individual's unique circumstances, how the person interprets those, and how they are integrated into a social construct unique to that person's self. Meaning is critical for understanding how and when change may occur (Munhall, 2012). The lived experience of cancer will necessarily vary for each person. Therefore how that individual interprets and adapts to symptoms such as pain from cancer will also be unique. Because meaning of cancer pain occurs within a social context, it is important to examine not just the meaning of pain for the person with cancer, but how meaning is interpreted by family caregivers and nurses.

3.1.2. Pain meaning for hospice patients with cancer

Pain has been identified as a challenge for hospice patients with cancer. Barkwell (1991) conducted a mixed methods study examining correlations between patient-identified pain meaning, coping strategies, depression levels and pain levels based on Melzak and Wall's gate control theory, Lipowski's meanings of illness, and Lazarus' psychology of coping framework. Two groups of 50 patients with terminal cancer diagnoses either receiving home care or hospice care were asked to rank their pain meaning within preset categories. Challenge was the most relatable meaning of pain (36%), with punishment ranked second most relatable (23%), and enemy third (20%). There were significant correlations between assigned meaning of pain as a challenge, coping strategy, and depression levels. Individuals in both groups who considered their pain to be a challenge were more likely to have higher coping scores and lower pain levels than those who labelled their pain as punishment or an enemy (Barkwell, 1991).

Two studies using phenomenology to explore cancer pain

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