HEALTH CARE WORKER BELIEFS ABOUT PAIN IN OLDER PATIENTS WITH CANCER AND DELIRIUM

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Abstract

Objectives: Health care workers (HCWs) rely on their judgments of pain to inform treatment decisions in older patients with cancer and delirium. Pain judgments may be influenced by HCWs' beliefs about pain. The objectives were to explore HCWs' beliefs about pain in older patients with cancer, and compare beliefs among nurses and physicians. **Methods:** A subsample of 16 HCWs was created from a larger study. Each physician was matched to one nurse on years of clinical experience (+/- 1 year). Thematic analysis of individual interviews was employed using cognitive mapping to identify themes and patterns across HCWs, and within and between nurses and physicians. **Results:** Nurses' and physicians' beliefs about opioid use were inconsistent, but believed opioids play an important role in the relationship of pain and delirium. Nurses' and physicians' provided inconsistent beliefs about the priority of pain management during delirium. HCWs believed difficulty with self-reporting pain was greater in older than younger patients, and doubted the reliability of older patients' reports. HCWs described pain assessment as challenging due to difficulties in distinguishing symptoms of pain and delirium. **Conclusions:** Knowledge gaps about pain in older people with cancer and delirium are common among HCWs. These findings may inform the development of education interventions.

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Introduction

In the final stages of cancer, up to 80% of older people experience moderate to severe pain (Cataldo et al., 2013; Kirkova, Rybicki, Walsh, & Aktas, 2012; Stuver et al., 2012; Walsh, Donnelly, & Rybicki, 2000; Yates et al., 2002), and many of these patients also develop delirium (Bruera, 1992; Cobb et al., 2000; Lawlor & Bush, 2015). Unfortunately, there is little research into cancer pain and delirium, and health care workers (HCWs) continue to face many challenges in providing adequate pain management to these patients (Bush & Bruera, 2009; Mah et al., 2016). During delirium, patient self-report of pain may not be possible or may be unreliable, and there is no standardized pain assessment tool for HCWs to use with these older patients. As a result HCWs often rely on their own judgments of pain to guide treatment decisions and evaluations. Pain judgments may be influenced by a range of HCW factors such as age, gender, clinical experience, and beliefs about pain (Prkachin, Solomon, & Ross, 2007; Tait, Chibnall, & Kalauokalani, 2009). Given our rapidly aging population (Statistics Canada, 2015), it is critical that we begin to engage in research to better understand how HCWs judge pain in older people with delirium. The aim of the research was to explore HCWs' beliefs about pain in older people with advanced cancer and delirium, while taking into consideration the role of clinical experience (i.e., years and discipline). A mixed-methods design using semi-structured interviews was employed to collect data from a sample of HCWs with experience in pain assessment in geriatrics, oncology, or palliative care. Mind-mapping, an innovative approach to qualitative data analysis, was used to identify major themes, relationships, and contradictions both across HCWs and between nurses and physicians.

Cancer Pain and Aging

Pain is a common and feared symptom of advanced and terminal cancer in older people (Bruera & Kim, 2003; Cleeland, 1998). It is a multidimensional phenomenon comprised of neurobiological, psychological and social components (Bruera & Kim, 2003; Gagliese & Melzack, 1997; Turk & Melzack, 2011). Cancer pain may be associated with the disease and/or the treatment. Its prevalence and intensity increase as the diseases progresses (van den Beuken-van Everdingen et al., 2007). During the advanced stages, 30 to 90% of patients report pain (Di Maio et al., 2004; Kirkova et al., 2012; McMillan, 1996; Morris et al., 1986; Stuver et al., 2012; van den Beuken-van Everdingen et al., 2007; Williamson & Schulz, 1995; Wilson et al., 2009; Yates et al., 2002).

Age-related patterns in pain prevalence with advanced cancer are unclear, with studies reporting increases (Kurtz, Given, Given, & Kurtz, 1994), decreases (Kirkova et al., 2012; Morris et al., 1986; Stuver et al., 2012; Walsh et al., 2000), and no change with age (Cataldo et al., 2013; Yates et al., 2002). Most patients with advanced cancer report moderate to severe pain intensity (e.g., 5 or greater on a scale of 0-no pain to 10-worst pain imaginable; Caraceni & Portenoy, 1999; Cataldo et al., 2013; Kirkova et al., 2012; Yates et al., 2002). Studies of age-related patterns of pain intensity have also been inconsistent, with decreases (Castel et al., 2007; Cheung, Le, Gagliese, & Zimmermann, 2011; Di Maio et al., 2004; Jordhøy et al., 2001; Stuver et al., 2012; Wilson et al., 2009) or no change with age reported (Gagliese et al., 2009; Gauthier et al., 2014; Green & Hart-Johnson, 2010; McMillan, 1996; Viganó, Bruera, & Suarez-Almazor, 1998; Williamson & Schulz, 1995; Yates et al., 2002). Lack of research, inconsistent data, and methodological differences across studies make it difficult to draw conclusions about age-related patterns in cancer pain (Gauthier, Ghandeharian, & Gagliese, 2017).

Unfortunately, it has been consistently reported that older cancer patients are more likely than younger patients to receive inadequate pain management (Caltagirone, Spoletini, Gianni, & Spalletta, 2010; Gauthier et al., 2014; Mercadante et al., 2015). Undertreatment of pain in older patients may be associated with a myriad of factors such as co-morbidities, frailty, polypharmacy, tissue or nerve damage, reluctance to report pain, attitudes towards analgesics, low levels of pain literacy, and misconceptions about pain and aging (Closs, Chatwin, & Bennett, 2009; Gagliese, 2009; Gagliese et al., 2012; Gagliese & Melzack, 1997; Potter, Wiseman, Dunn, & Boyle, 2003; Ward et al., 1993; Yates et al., 2002). Previous studies have also identified associations between HCWs' treatment choices and patient age (Ferrell, Eberts, McCaffery, & Grant, 1991; Green, Wheeler, & LaPorte, 2003). For instance, HCWs may have negative attitudes, misconceptions or knowledge gaps about pain and analgesic use in older people (Closs, 1996; Gagliese, 2009; Gagliese et al., 2012). Finally, lack of validated pain assessment protocols for older people with cancer may contribute to inadequate pain management (Gagliese & Melzack, 1997; Gauthier & Gagliese, 2011; Gauthier et al., 2017). If inadequately treated, cancer pain can have profound negative impacts on the patients' and their families' quality of life (Gauthier et al., 2017; Sutton, Porter, & Keefe, 2002)

Cancer Pain and Delirium

Older patients with advanced cancer are at high risk for developing delirium, an acute organic brain disorder marked by an abrupt disturbance of consciousness, attention, perception, and awareness (Cobb et al., 2000; Lawlor & Bush, 2015). At the time of hospitalization, delirium is present in up to 44% of advanced cancer patients, and increases to up to 80% as death approaches (Bond, Neelon, & Belyea, 2006; Breitbart & Alici, 2012; Bush et al., 2014; Centeno, Sanz, & Bruera, 2004; Gagliese, Rodin, Chan, Stevens, & Zimmermann, 2016; Lawlor &

Bruera, 2002; Mah et al., 2016). There are three subtypes of delirium: hypoactive, which is characterized by confusion and sedation; hyperactive, which presents with hallucinations, delusions, agitation, and disorientation; and a mixed presentation with characteristics of both the hypoactive and hyperactive subtypes (Bond et al., 2006; W Breitbart & Strout, 2000; S. Bush et al., 2014; M. Leonard, Agar, Mason, & Lawlor, 2008) Hypoactive delirium is the most common subtype, followed by hyperactive and mixed (William Breitbart & Alici, 2008; K. Mah et al., 2016; Spiller & Keen, 2006).

Critically, the presence of delirium creates significant challenges to the assessment and management of pain and other symptoms in older advanced cancer patients (Bush & Bruera, 2009). According to HCWs, pain during delirium is a very common experience for older patients with cancer (Gagnon, Allard, Mâsse, & Deserres, 2000). In a recent retrospective chart review study, pain was present in over 60% of older palliative care inpatients with delirium and its prevalence did not differ by delirium subtype (Gagliese et al., 2016; Mah et al., 2016). HCWs' judgments of pain intensity may differ by delirium subtype; more intense pain is attributed to patients with agitation than those without agitation (Bruera, 1992). Few studies have investigated HCWs' behavioural observations of pain in older patients with cancer. In a recent study, HCWs routinely used behaviours (e.g., moaning, facial expression) to assess pain in older patients with cancer and delirium who were unable to self-report pain (Gagliese et al., 2016). However, 40% of these HCWs recorded only general impressions of pain (e.g., 'no obvious signs of pain' or 'looks comfortable') rather than specific pain behaviours (Gagliese et al., 2016). Unfortunately, the overlap between behavioural symptoms of delirium and pain (e.g., agitation) may lead to both undertreatment of pain and increases in prescribing opioids, which in turn can contribute to neurotoxicity and exacerbate delirium (Bruera & Kim, 2003; Bush & Bruera, 2009). HCWs have

reported similar difficulties due to behavioural symptom overlap in older patients with dementia (Fox et al., 2004; Gilmore-Bykovskyi & Bowers, 2013; Kaasalainen et al., 2007).

Challenges in pain assessment may result in inadequate pain control in older patients with advanced cancer and delirium (Mah et al., 2016). In one study, HCWs judged that patients with delirium had good pain control on a much smaller proportion of days (< 25% of days) than those without delirium (Mah et al., 2016). Unresolved cancer pain during delirium is associated with profound negative consequences in physical, psychological, and social functioning for both the patient and their family (Bruera et al., 2009; Caltagirone et al., 2010). For instance, patients may experience impairments in communication, extreme exhaustion or fatigue, distress (i.e., agitation, anxiety, fear, and frustration), disturbances in mood (i.e., depression, helplessness, and anger) and changes in personality (Breitbart & Alici, 2008; Breitbart, Gibson, & Tremblay, 2002; Bruera et al., 2009; Lawlor & Bush, 2015; Li, Xiao, Yang, & Zhao, 2017; McPherson, Hadjistavropoulos, Lobchuk, & Kilgour, 2013; Sela, Bruera, Conner-Spady, Cumming, & Walker, 2002; Zaza & Baine, 2002). Family members report difficulty coping with these symptoms, emotional distress, feelings of helplessness, and being burdened with providing proxy-reports for patient care (Breitbart et al., 2002; Bruera et al., 2009; McPherson et al., 2013; Morita et al., 2007; Namba et al., 2007; Toye, Matthews, Hill, & Maher, 2014). Moreover, the patients' families may have misconceptions about the cause of delirium (i.e., effects of opioids) that creates challenges for HCWs in providing adequate pain relief (Breitbart et al., 2002; Cohen, Pace, Kaur, & Bruera, 2009; Lawlor & Bush, 2015; Namba et al., 2007; Toye et al., 2014).

A Framework for HCWs' Pain Judgments in People with Delirium

A standardized tool to assess pain in older cancer patients who develop delirium is not available. Without a validated scale, HCWs face significant barriers to providing adequate pain management, including the difficult task of judging pain in these patients. Critically, these pain judgments inform HCWs' treatment decisions and subsequent evaluations of their patients. Pain judgement may be influenced by various HCW factors, including clinical experience and beliefs about pain. These HCW factors have been incorporated into an adapted framework for HCWs' pain judgments of patients with delirium (see Figure 1).

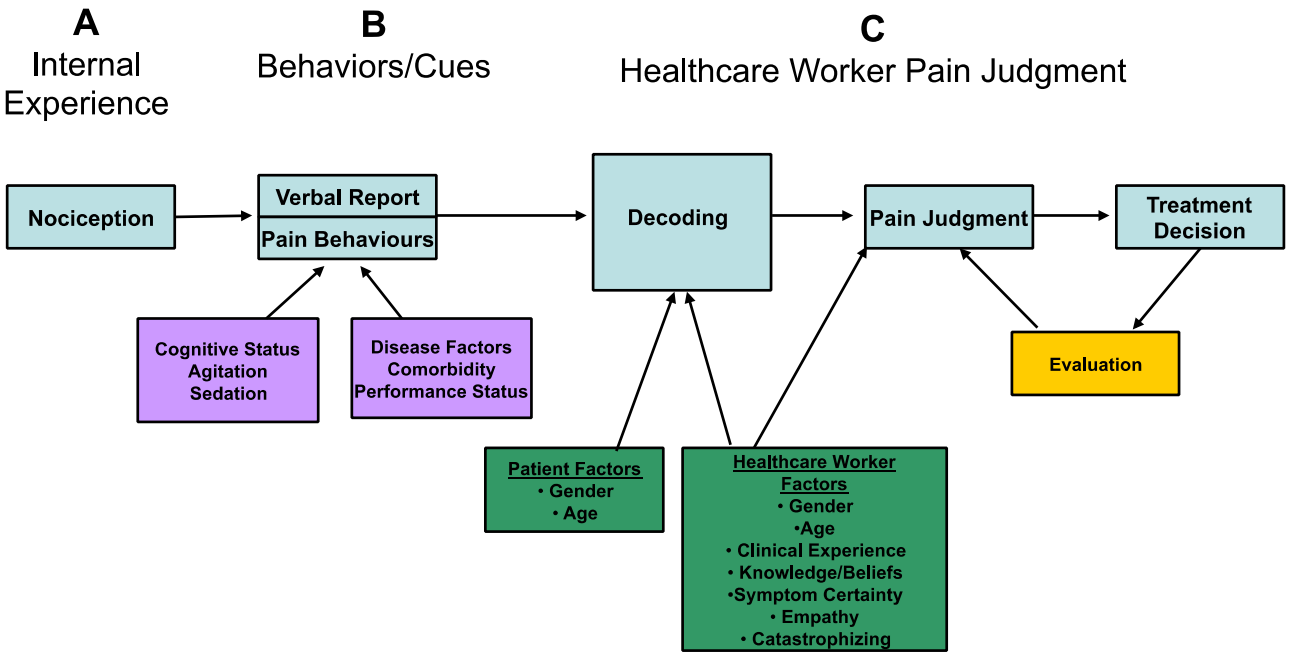

Figure 1. A-B-C model of observer pain judgments for the detection of pain in older cancer patients with delirium (Adapted by L. Gagliese from Prkachin & Craig, 1994; Prkachin et al., 2007)

HCWs' Beliefs about Pain

Health care workers' cognitions about pain, such as beliefs, knowledge, and attitudes, are behavioural dispositions that may influence their clinical practice (Bergman, 1998; Bernardi, Catania, Lambert, Tridello, & Luzzani, 2007; Edwards et al., 2001; Godin et al., 2008; Majid et al., 2011; Nash, Edwards, & Nebauer, 1993). Although knowledge, beliefs, and attitudes about pain are distinct but related concepts they are often used interchangeably in the literature and will herein be referred to as 'beliefs'. Specifically, HCWs' knowledge about pain in older people informs their beliefs about pain in these patients. Beliefs can be influenced by evidence-based, social (e.g., cultural systems), and affective factors (e.g., emotions) (Bergman, 1998; Fishbein & Ajzen, 1975)). Subjective evaluations of beliefs may be positive or negative (i.e., attitudes), and in turn can impact how new or existing information is processed and understood (Bergman, 1998; Glynn, Voinov, Shapiro, & White, 2017). Unfortunately, HCWs consistently exhibit gaps in knowledge about cancer pain (Ger, Ho, & Wang, 2000; Kasasbeh, McCabe, & Payne, 2016; Omran, Qadire, Ali, Fouad, & Hayek, 2014; Von Roenn, Cleeland, Gonin, Hatfield, & Pandya, 1993; Yildirim, Cicek, & Uyar, 2008), pain during palliative care (Bernardi, Catania, & Tridello, 2007; Gardiner et al., 2012), and pain in older people with or without cognitive impairment (Closs, 1996; Fry, Chenoweth, & Arendts, 2016; Gagliese et al., 2012; Martin, Williams, Hadjistavropoulos, Hadjistavropoulos, & MacLean, 2001; Monroe, Carter, Feldt, Tolley, & Cowan, 2012; Sloman, Ahern, Wright, & Brown, 2001; Yu & Petrini, 2007; Zwakhalen, Hamers, Peijnenburg, & Berger, 2007). Therefore HCWs' beliefs about pain in those patient populations may be more heavily influenced by social and affective biases rather than evidence-based information (Courtney, Tong, & Walsh, 2000; Prkachin et al., 2007). The present study

was interested in examining HCWs' beliefs about pain in older patients with cancer and delirium.

There are two common approaches for studying HCWs' beliefs about pain. The first uses quantitative measures (i.e., scales or questionnaires). A number of measures have been developed to assess HCWs' beliefs about non-malignant pain (Bishop, Thomas, & Foster, 2007; Gunnarsdottir, Donovan, Serlin, Voge, & Ward, 2002; Houben, Gijsen, Peterson, de Jong, & Vlaeyen, 2005; Ward et al., 1993; Watt-Watson, 1987; Watt-Watson, Stevens, Garfinkel, Streiner, & Gallop, 2001) and cancer-related pain (Cleeland, Cleeland, Dar, & Rinehardt, 1986; Ferrell, Mcguire, & Donovan, 1993; Ferrell & Mccaffery, 2014; Kasasbeh et al., 2016; Tafas, Patiraki, McDonald, & Lemonidou, 2002; Weissman & Dahl, 1990) but fewer to assess beliefs about pain in older people (Fetherstonhaugh, Lewis, McAuliffe, & Bauer, 2016; Sloman et al., 2001; Zwakhalen et al., 2007). Across these studies, HCWs report inconsistent and contradictory beliefs about older people with (Zwakhalen et al., 2007) or without (Closs, 1996; Gagliese et al., 2012; Katsma & Souza, 2000; Rantala, Kankkunen, Kivst, & Hartikainen, 2014; Sloman et al., 2001; Yu & Petrini, 2007) dementia. These may include beliefs about pain experience (e.g., older people feel pain less intensely, older patients with dementia experience less pain than cognitively intact patients), pain assessment (e.g., patients with dementia can or cannot provide reliable self-reports of pain), pain management (e.g., pain in older people cannot be managed, analgesics are more effective in treating pain for younger compared to older patients, administering pain medication should be postponed as long as possible because patients with dementia should receive as little pain medication as possible), and the relationship between pain and aging (e.g., pain is a normal part of getting older) (Gagliese, 2009; Gagliese et al., 2012; Sloman, Ahern, Wright, & Brown, 2001; Zwakhalen, Hamers, Peijnenburg, & Berger, 2007). No

validated tools are available to measure HCWs' beliefs about pain in older people with cancer and delirium.

The second approach uses qualitative interviews to examine professional and informal caregivers' beliefs about pain. Previous research has investigated nurses' and physicians' beliefs about older patients with and without dementia within long-term care (Barry, Parsons, Peter Passmore, & Hughes, 2012; De Witt Jansen et al., 2017; Fox, Solomon, Raina, Jadad, & Jadad, 2004; Gilmore-Bykovskyi & Bowers, 2013; Gropelli & Sharer, 2013; Kaasalainen et al., 2007; Karlsson, Sidenvall, Bergh, & Ernsth-Bravell, 2013; Kovach, Griffie, Muchka, Noonan, & Weissman, 2000; Martin et al., 2005) and acute hospital settings (Brorson, Plymoth, Örmon, & Bolmsjö, 2014; Coker et al., 2010; Fry et al., 2016; Gorawara-Bhat, Wong, Dale, & Hogan, 2016; Jones, Sim, & Hughes, 2017). Common themes that emerge from these studies include beliefs about pain assessment (e.g., uncertainty about self-report, difficulty distinguishing between pain and other symptoms of dementia, behavioural observations of pain), pain management (e.g., reluctance to prescribe opioids, risk of adverse events, effectiveness of analgesics, use of non-pharmacological treatments), collaboration with other HCWs or caregivers (e.g., family), impact of pain on patient quality of life, and barriers to providing adequate pain management (e.g., HCWs' misconceptions or knowledge gaps, reluctance to prescribe opioids, need for standardized assessment tools, lack of specialized pain education). There has been no qualitative research into HCW beliefs about pain in older patients with cancer and delirium.

Clinical experience. Previous studies that investigate the relationship between HCWs' clinical experience (e.g., years of practice, speciality, pain education, discipline) and beliefs about cancer pain (Bauwens, Distelmans, Storme, & Kaufman, 2001; Bernardi, Catania, &

Tridello, 2007; Brown, Bowman, & Eason, 1999; Chang et al., 2005; Cleeland et al., 1986; Eftekhar et al., 2007; Fife, Irick, & Painter, 1993; Furstenberg et al., 1998; Ger et al., 2000; Layman Young, Horton, & Davidhizar, 2006; McCaffery & Ferrell, 1995; O'Brien, Dalton, Konsler, & Carlson, 1996; Omran et al., 2014; Ponte & Johnson-Tribino, 2005; Rushton, Eggett, & Sutherland, 2003; Steindal, Bredal, Ranhoff, Sorbye, & Lerdal, 2015; Visentin, Trentin, de Marco, & Zanolin, 2001; Von Roenn et al., 1993; Wells et al., 2001; Wilson, 2007; Yanjun et al., 2010; Yildirim et al., 2008; Zanolin et al., 2007; Zhang et al., 2015) and pain in older people with or without dementia (Barry et al., 2012; Furjanic, Cooney, & McCarthy, 2016; Katsma & Souza, 2000; Ponte & Johnson-Tribino, 2005; Sloman et al., 2001; Yu & Petrini, 2007; Zwakhalen et al., 2007) present mixed findings.

Years of clinical experience. Several studies report an association between years of clinical experience and HCWs' beliefs about pain (Barry et al., 2012; Bauwens et al., 2001; Chang et al., 2005; Ger et al., 2000; Katsma & Souza, 2000; Sloman et al., 2001; Wilson, 2007; Yildirim et al., 2008; Yu & Petrini, 2007; Zhang et al., 2015). For example, HCWs with greater clinical experience in oncology (Yu & Petrini, 2007; Zhang et al., 2015) and geriatrics (Furjanic et al., 2016; Sloman et al., 2001) demonstrate fewer misconceptions about pain in older people. A similar proportion of studies, however, do not report an association between years of clinical experience and pain beliefs (Bernardi, Catania, Lambert, et al., 2007; Brown et al., 1999; Furjanic et al., 2016; Lebovits et al., 1997; Omran et al., 2014; Ponte & Johnson-Tribino, 2005; B. Wilson, 2007; Yanjun et al., 2010; Yildirim et al., 2008; Zwakhalen et al., 2007).

Speciality. Additionally, previous studies report an association between HCW speciality (e.g., surgical, anaesthesiology, oncology, geriatrics, palliative or hospice) and beliefs about pain (Hollen, Hollen, & Stolte; Lebovits et al., 1997; Nuseir, Kassab, & Almomani, 2016; Rushton et

al., 2003; Visentin et al., 2001; Von Roenn et al., 1993; Wilson, 2007; Yu & Petrini, 2007; Zanolin et al., 2007; Zwakhalen et al., 2007). In most studies, HCWs who work within oncology, palliative care or hospice, or geriatrics have fewer knowledge gaps than HCWs who work in surgical or family medicine. Other aspects of clinical experience such as clinical setting (e.g., hospital, nursing home, hospice) (Bauwens et al., 2001;Ferrell & Mccaffery, 2014; Hollen et al.; Ponte & Johnson-Tribino, 2005), and specialized training or education in pain management (Barry et al., 2012; Bernardi, Catania, & Tridello, 2007; Fetherstonhaugh et al., 2016) may be associated with HCWs' beliefs about cancer pain and pain in older people.

Clinical discipline. Few studies examine discipline-specific differences in beliefs about malignant and non-malignant pain (Jho et al., 2014; Lebovits et al., 1997; McCaffery & Ferrell, 1995; Nuseir et al., 2016; Visentin et al., 2001; Wells et al., 2001; Xue, Schulman-Green, Czaplinski, Harris, & McCorkle, 2007; Zanolin et al., 2007). Findings from these quantitative studies suggest that physicians demonstrate fewer misconceptions (i.e., better knowledge scores) about cancer pain than nurses (Furstenberg et al., 1998; Lebovits et al., 1997; Visentin et al., 2001; Wells et al., 2001). Other studies report that the distribution of responses (i.e., beliefs) differ between nurses and physicians (Fife et al., 1993; Wells et al., 2001; Zanolin et al., 2007). Most of these studies, however, do not control for other HCW clinical experience factors (e.g., years of experience). Differences may reflect years of clinical experience rather than discipline-specific factors (Furstenburg et al., 1998). None of these studies compare nurses' and physicians' beliefs about pain in older people with and without cognitive impairment.

Few qualitative studies explore both nurses' and physicians' beliefs about pain in older people within the same study (Fox et al., 2004; Kaasalainen et al., 2007). In two qualitative studies, nurses and physicians working in long-term care facilities were interviewed to identify

their beliefs about pain management in older patients with and without cognitive impairment (Fox et al., 2004; Kaasalainen et al., 2007). Common themes among nurses and physicians across studies included beliefs about pain assessment (e.g., difficulty identifying pain, uncertainty about pain assessment), and pain management (e.g., reluctance to prescribe opioids, individualized pain treatment, issues related to trust and communication between nurses and physicians). One study, however, did not employ standardized data collection methods across HCW discipline, and therefore was unable to systematically compare beliefs by discipline (i.e., nurse vs. physician). Specifically, nurses' data were gathered through focus groups whereas physicians' data were collected using one-on-one interviews. In both studies (Fox et al., 2004; Kaasalainen et al., 2007) there were a disproportionate number of nurses to physicians, such that 80% of the samples were nurses. Further, the potential influence of clinical experience on discipline was not explored in these studies.

The present study was designed to systematically compare beliefs about pain in older people with cancer and delirium among nurses and physicians, while controlling for years of clinical experience. This was done using a 1:1 system for matching nurses and physicians on +1/-1 years of clinical experience.

The Use of Mind-Maps in Health Research

Mind-mapping is a qualitative data analysis approach that uses visual representations to explore ideas (e.g., beliefs) as they occur naturally (Burgess-Allen & Owen-Smith, 2010; Eppler, 2006; Qazi, 2010). Mind-maps can be used for reduction of data, data familiarization, generation of ideas, development of codes, content and/or thematic analysis, and presenting findings. Moreover, researchers can complete their own mind-map to explore their knowledge, beliefs, or

ideas about a specific topic. By identifying these thoughts, we can be reflexive about how our own beliefs may influence the research, and try to minimize potential biases (Eppler, 2006).

Mind-maps use a radially-oriented diagram to represent a single key concept (Figure 2, A) with ideas or words emerging from this central concept. Mind-maps share some similarities with the hierarchical structure of codes and categories derived from traditional qualitative methods, in that main branches (Figure 2, B) represent major ideas/categories, and secondary branches (Figure 2, C) are sub-categories or lower-level codes that help to illustrate examples and context (Burgess-Allen & Owen-Smith, 2010; Eppler, 2006). Connections across and within categories can also be made more easily and readily using linking lines and words (Figure 2, D). Critically, multiple maps can be integrated into a single 'meta-map' that illustrates common major themes, including contradictions, evident across research participants (Burgess-Allen & Owen-Smith, 2010).

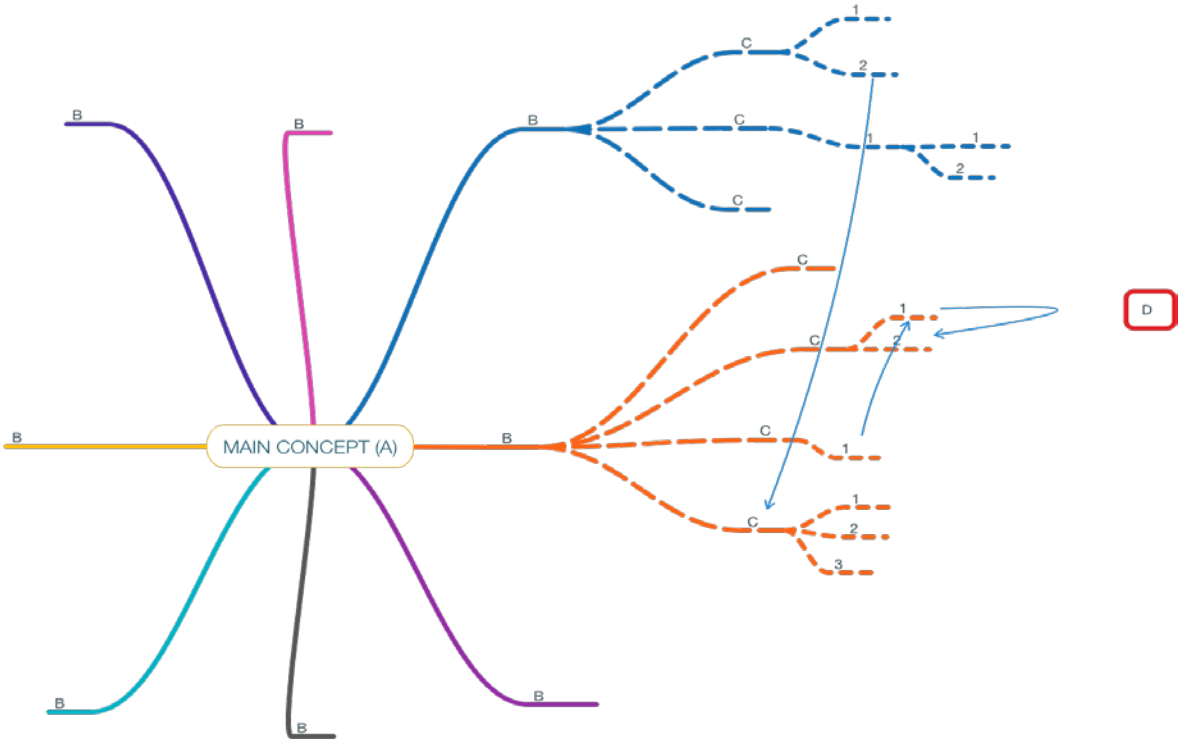

Figure 2. Mind-Map Template

The use of mind-maps is a well-established technique within education for note taking, brainstorming, and problem solving (Spencer, Anderson, & Ellis, 2013). In health care, mind-maps have been used in nursing education, care planning, and needs assessment and evaluation (Eppler, 2006; Spencer et al., 2013). Although not yet extensively used in health research, mind-maps have been used to explore topics within aging (e.g., anticipatory falling, anxiety in dementia) (Qazi, 2010; Shaw, Connelly, & McWilliam, 2015) and public health (Burgess-Allen & Owen-Smith, 2010) in both caregiver and patient populations.

Other mapping techniques include cognitive and concept maps that have been used in health-related research within caregiver and patient populations to examine various topics within pain (Van Hulle Vincent, 2007), cancer (Semple, 2010), and health care setting culture (Wilson, McCormack, & Ives, 2005). Although the term mind-map has been used interchangeably, and shares some overlap with these other techniques, it is a distinct approach. Mind-maps have a flexible design that accommodates exploratory approaches and are not restricted by the rules and guidelines of concept and cognitive mapping (Burgess-Allen & Owen-Smith, 2010; Eppler, 2006). Specifically, these other mapping techniques include hierarchical, linear, top-down, and causal-linking approaches that focus on and make connections between, multiple key concepts within one map, rather than focus on beliefs that begin from a single central concept or idea (Eppler, 2006; Wheeldon, 2010), such as pain in older patients with cancer and delirium.

In the present study, we explored cognitive representations of aging, cancer, and delirium, which are each complex, multi-determined phenomena. Beliefs about these interrelated concepts were not expected to be linear or hierarchical, but rather fluid and based on patterns that can occur simultaneously and potentially contradict each other. Therefore, mind-maps were more

suitable than cognitive or concept mapping when exploring a single, novel concept such as older patients with advanced cancer and delirium.

Although mind-maps have been used to explore aging-related topics, they have not been used in the study of pain or cancer. Therefore the current study is the first to use this innovative approach for a novel in-depth exploration of HCWs' beliefs about pain in older patients with cancer, and with or without delirium. This research is critical to advance our understanding of how HCWs assess and manage pain in this vulnerable group at the end-of-life and how nurses' and physicians' beliefs about pain in this group may differ to better target educational initiatives.

Objectives

The objectives of the research were:

1. To identify HCWs' beliefs about pain in older patients with cancer and delirium.
2. To examine beliefs about pain in older patients with cancer and delirium separately by HCW discipline (nurse versus physician).

Methods

Study Design and Setting

A mixed qualitative-quantitative design was used as part of a larger on-going, CIHR-funded research program in delirium and cancer pain. These studies are carried out at The University Health Network (UHN), which is made up of the Toronto General Hospital, Toronto Western Hospital, Toronto Rehabilitation Institute, and Princess Margaret Cancer Center in downtown Toronto, Ontario.

Study Population

HCWs (physicians and nurses) with experience in oncology, geriatrics, palliative care, internal medicine, anaesthesia, or family medicine were recruited. HCWs within these disciplines are primarily responsible for pain assessment, and their inclusion allowed for varying perspectives in the data. Inclusion criteria were age ≥ 18 years, ability to speak and read English well enough to provide informed consent, be interviewed, and complete questionnaires.

The sample size for the larger study consisted of 53 HCWs. For the present study, a matched subsample was created. This subsample was made up of two groups, physicians and nurses, matched on years of experience. Matching was undertaken based on previous research that suggests an association between clinical experience, pain judgments (Chibnall, Tait, & Jovel, 2014; Prkachin et al., 2007; Ruben, van Osch, & Blanch-Hartigan, 2015; Tait et al., 2009; Tait, Chibnall, Miller, & Werner, 2011) and beliefs about pain (Barry et al., 2012; Bauwens et al., 2001; Burns & McIlfatrick, 2015; Cleeland et al., 1986; Eftekhar et al., 2007; Fife et al., 1993; Furjanic et al., 2016; Ger & et al, 2004; Visentin et al., 2001; Von Roenn et al., 1993; Zanolin et al., 2007). Of the 53 HCWs, 8 were physicians. Therefore, each physician was matched to one nurse (+/- 1 year of experience) in a 1:1 matching (8 nurses: 8 physicians). In cases where there were multiple nurses who could be matched with a particular physician, a random number generator was used to select the nurse for the matched pair. All physicians were successfully matched to one nurse with similar experience.

Procedure

Recruitment methods included presentations, electronic postings through email, and posters on site. Contact information for the research team via email or telephone/and or sign-up sheets was provided. Interested HCWs met with a research assistant (RA) individually at a mutually

convenient time. Following consent, participants provided demographic information; professional information about training, position, and experience; and completed a questionnaire package (to be reported separately). HCWs then took part in an individual, one-hour, audio-recorded, semi-structured interview about cancer pain in older patients with or without delirium. Topics covered included professional experiences, knowledge/attitudes, and pain judgments. HCWs were provided with the diagnostic criteria for delirium and delirium subtypes (American Psychiatric Association, 2013) to distinguish delirium from other types of cognitive impairment (e.g., dementia) and to ensure standardization across HCWs. The interview guide was informed by a literature review and through research team discussion. When more detail was needed the RA prompted the HCW. For sample questions and prompts see Appendix A. The present analysis reports on sample characteristics and the qualitative data about HCWs' beliefs about pain in older people with cancer and delirium for the matched subsample.

Participants were provided with monetary compensation for their time. Ethical approval was obtained from the Research Ethics Boards of the University Health Network and York University.

Measures (Appendix B)

Demographic and clinical information collected included age, gender, education, professional discipline (i.e., nurse or physician), specialty, years of professional clinical experience (i.e., total years, pain assessment, palliative or oncology, geriatrics, and cognitively impaired patients), percentage of time caring for younger (<65) and older (≥65) patients, number of advanced cancer patients cared for per month, and specialized training in pain management.

Data Analysis Plan

NVivo 10 and MindNode software 2.0 was used for qualitative analyses. IBM SPSS 23 software was used for quantitative analyses. The sample was described using frequencies for categorical variables (i.e., gender, discipline, speciality, training), and means and standard deviations (range) for continuous variables (i.e., age, years of professional clinical experience). Categorical variables of interest were collapsed to allow for more stable distributions. For each group (nurses versus physicians), the mean and range of experience was calculated and t-tests performed to ensure matching was successful.

Objective 1: Developing Mind Maps

In order to identify HCWs' beliefs about pain in older cancer patients with or without delirium, a thematic analysis using an iterative process of mind-mapping was completed. Interviews were transcribed verbatim by Wordmap, and then checked line-by-line by the RA using the audio-recorded interview. SG and LG first read all the transcripts as a whole in random order. SG then re-read all the transcripts to extract sections of relevant text (i.e., unitizing). Unitizing text helped to reduce and manage the data in order to better and more readily identify meaningful words, phrases, or paragraphs for coding (Campbell, Quincy, Osserman, & Pedersen, 2013). As part of ensuring researcher reflexivity (Finlay, 2002) , SG and LG then each hand-drew a mind-map separately to illustrate their own beliefs and initial impressions of the transcripts.

After SG and LG completed their own maps, SG used a random number generator to select two transcripts (12%) for concurrent mapping by LG and SG. This was done to develop an initial coding scheme and minimize researcher bias. SG then created a first-cycle mind-map by hand for all subsequent transcripts in a random order regardless of HCW discipline. This led to revisions and refinement of the initial coding scheme through a process of open coding and

cross-referencing. After the first-cycle mapping was complete for all HCWs, each transcript/map was reviewed and cross-referenced again in order to further refine the coding scheme (i.e., axial coding). For the second-cycle mapping, MindNode software was used to replicate the maps electronically and make revisions to the maps based on the revised coding scheme.

In order to minimize researcher bias and ensure rigour and reliability, 50% of the transcripts and maps (excluding the 12% mapped concurrently) were randomly selected within each discipline (4 nurses and 4 physicians) for review by LG to ensure coding consistency (Campbell et al., 2013). These versions of the transcripts included the unitized sections of the text, but not the code label (i.e., codes were only present in the mind-map). Discrepancies in unitization or labels were discussed between SG and LG until 100% agreement was reached. After this review, all mind-maps were revised and the coding scheme adjusted (third-cycle mapping). This iterative process of unitizing, coding, discussing discrepancies, and refining codes and code definitions helped to promote inter-rater agreement, minimize bias, and ensure rigour.

All coded/mapped transcripts were then subjected to a formal computer-assisted analysis. First, mind-maps were replicated in Nvivo to enable linking of codes to individual data samples. Words or phrases were then selected in-text and linked to the codes derived from the mind-maps. In-text computer-assisted coding also helped to identify any missed or incorrectly coded material. This process ended with a comprehensive list (i.e., final coding scheme) of beliefs that reflected the within-category hierarchical structure of the maps. Mind-maps were then revised and finalized using this coding scheme (fourth-cycle mapping).

A full sample meta-map was created using all 16 mind-maps to represent common ideas (codes) or patterns across the sample and to enable thematic analysis. First, computer-generated

frequencies helped to identify the most common ideas/codes in the sample. In order to be comprehensive yet conservative and enable interpretation (Burgess-Allen & Owen-Smith, 2010), codes/branches that were mentioned by at least 50% of HCWs for first level (main category) and 30% for second-and lower level branches (sub-categories) were retained for the meta-map.

Repeated concepts or ideas, contradictions, and relationships/connections between ideas were examined until more salient themes and sub-themes emerged. To minimize bias, SG and LG met regularly to discuss emerging themes. Finally, themes, sub-themes, and relationships within-or-between these themes were summarized in-text and participant quotes were used for illustration and context.

Objective 2: Mind-Maps by Discipline

In order to examine the role of HCW discipline (nurses versus physicians) in beliefs, discipline-specific meta-maps were developed separately for nurses and physicians using the same process outlined above. Patterns including similarities and differences in themes, sub-themes, contradictions, and connections were then analyzed within and between groups. To identify similarities and differences between nurses and physicians, discipline-specific meta-maps were merged into a single meta-map that was colour-coded based on discipline. For each category or sub-category, the proportion of responses belonging to either nurses or physicians must have been 68% ≥ to have that code/branch classified into either of the two groups. Codes/branches that did not meet the inclusion criteria were classified as being similar in both groups.

Results

Sample Characteristics

Demographic and clinical information is listed in Table 1. The sample consisted of 16 HCWs (8 nurses, 8 physicians) with 2 to 25 years (Median = 7.7) of total professional clinical experience. There were no significant differences between nurses and physicians in years of clinical experience in total, in pain assessment, with cognitively impaired patients, in geriatrics, and in palliative care or oncology. The majority of the sample was female, with significantly more male physicians and female nurses. There were more nurses than physicians who had undergone specialized training in pain management. Lastly, nurses had significantly more patients that were 65 years of age or older under their care than did physicians, whereas the proportion of younger patients under the care of physicians and nurses did not differ. However, these differences may reflect a non-normal distribution for the physicians.

Qualitative data: Thematic Analysis of Mind-maps

Four meta-maps were developed to illustrate findings in the full sample (Figure 3), nurses only (Figure 4), physicians only (Figure 5), and to compare meta-maps between nurses and physicians (Figure 6). Eight major themes that reflect HCWs' beliefs about older patients with cancer were identified: *pain assessment, pain management, patient variability, education, clinical experience, consensus building, barriers, and general pain.* Specific age-related and delirium-related beliefs were incorporated into the major pain assessment, pain management, and general pain themes.

Pain Assessment in Cognitively Intact Older People

Themes emerging from the full sample. All participants reported beliefs about pain assessment in older patients with cancer (Figure 3). Within this theme, three sub-themes were evident: self-report, pain behaviour, and age-tailored.

Obtaining patients' self-report of pain was mentioned by all participants; however, many HCWs believed that older patients have difficulty with self-reports of pain, and that these reports were unreliable or doubtful. More specifically, HCWs believed that older patients have difficulty describing or rating the intensity of their pain. Some HCWs associated this difficulty with language barriers in older patients with cancer. Pain intensity was most commonly mentioned, whereas other characteristics of pain (e.g., qualities, impact) were mentioned much less frequently and did not meet inclusion criteria for the full-sample meta-map. Most HCWs believed scales should be used to gather information about pain intensity. Common scales that were mentioned included the 0-10 point Numeric Rating Scale (NRS) (Downie 1978; Jensen, 1986; Huskisson 1974), and to a lesser extent, the Faces Pain Scale (FPS) (K. Herr, Mobily, Kohout, & Wagenaar, 1998; Stuppy, 1998) and Verbal Descriptor Scale (VDS)(Ware, Epps, Herr, & Packard, 2006). Some HCWs believed that older patients have difficulty completing NRS scales and that a VDS or FPS should be used instead.

> *"It's very difficult for them and sometimes the answers are nonsense... Sometimes you are sure that their pain is zero. "I [the patient] have pain eight out of ten". I don't think this. Actually, they [the patients] don't understand how it [0-10 NRS] works…especially elderly patients… Usually they [patients] don't have enough insight and usually the assessment is not good. That's like children. You cannot assess their*

> *pain. They are in pain but the severity of pain, you cannot assess it. We cannot assess it. "* (Physician, 15 years of clinical experience)

Most HCWs believed that assessment should include observations of patient behaviour for indicators of pain, such as facial and bodily expressions. Some HCWs assessed consistency between patients' self-report and their behaviour and were more likely to believe their observations of behaviour than patients' self-report due to doubts or concerns about older patients' ability to provide a reliable self-report of pain.

> *"You have some people who say that they are in pain, but their face really doesn't show it and it's very unlikely that they actually have pain."* (Physician, 11 years of experience)

> *"If they say 'oh, I have zero pain', but I see them like sort of grimacing or just non-verbal cues…So that's sort of a cue for me to say I need to probe a bit more. "* (Nurse, 11 years of experience)

Finally, beliefs about whether pain assessment should be age-tailored were contradictory with almost the same proportion of HCWs endorsing the need for an age-tailored approach (46%) as did not endorse this (53%).

Age-related beliefs about pain assessment. The majority of participants mentioned beliefs about age-related differences in pain assessment. Most common was the belief that older patients had greater difficulty than younger patients with self-report in general or with the NRS for pain intensity. HCWs also believed that older patients verbalized or complained about pain less often than younger patients, and that when they did verbalize, their reports were less reliable than those of younger patients. The belief that older patients' pain reports were less reliable was

related to the belief that older patients had less insight or fewer descriptors than younger patients for their pain.

> *"Personally [I] think that working with older patients at times can be difficult because it's hard to understand exactly what their needs are…For example, pain, they may not be able to use the pain scale properly depending on their literacy level and everything else as well. Overall, I would say it's [more] difficult working with older patients than it would be with younger patients."* (Nurse, 2 years of clinical experience)

Some participants believed that older patients asked for pain relief less frequently than younger patients and that greater caution was needed when assessing pain in older than younger patients.

> *"In younger patients, you would more leave it to them demanding medication and relief whereas in elderly patients, I would more look into whether I need to give it before he demands it. Like a younger patient would specifically say, "I have pain. Please give me something." An elderly patient may not even say that and I think it's the duty of the physician treating the patient"* (Physician, 11 years of clinical experience)

Themes according to HCW discipline. Nurses and physicians believed that older patients with cancer have difficulty with, and provide unreliable, self-reports of pain. Further, nurses believed that language barriers were a source of difficulty with self-report, and physicians believed older patients with cancer were generally unwilling or reluctant to report pain.

Nurses' and physicians' beliefs about self-report of pain intensity did not differ with the exception that nurses mentioned the FPS could be used for assessment. Physicians mentioned that other pain characteristics in addition to pain intensity, such as pain location and impact or interference with activity and physical functioning, should be assessed. Nurses mentioned that a patient's history with pain medication should be assessed.

Both nurses and physicians believed that patient behaviour should be used for pain assessment. Physicians consistently mentioned behaviour change (e.g., facial, activity, body movement or posture) as indicative of pain. Physicians also mentioned that a physical exam should be part of pain assessment (i.e., palpation), and that an objective tool for pain assessment was needed.

Age-related differences in pain assessment. Nurses and physicians expressed contradictory beliefs about the need for age-tailored pain assessment. Although half of HCWs believed age-tailored assessment was not needed, both nurses and physicians believed that older patients had greater difficulty with self-report than younger patients. Moreover, nurses believed that older patients had greater difficulty than younger patients with using an NRS, but both younger and older patients display similar behaviours related to pain. Physicians believed that compared to younger patients, older patients verbalize and complain about pain less often, provide less reliable pain reports, and have fewer insights or descriptors for their pain. Furthermore, physicians believed there was a need for greater caution with assessment in older compared to younger patients.

Pain Assessment in Older People with Delirium

Themes emerging from the full sample. HCWs generally believed that pain assessment in patients with delirium was very difficult or not possible. Beliefs about the use of self-report in

patients with delirium were contradictory, with similar proportions of HCWs endorsing and not endorsing the use of patient self-report. Reluctance to elicit self-report was related to HCWs' belief that self-report in patients with delirium was unreliable, that patients have difficulty with self-report due to cognitive impairments (i.e., concentration, comprehension), and that they cannot indicate or locate their own pain.

As a result of difficulties using patient self-report, many HCWs described that they relied on behaviour to assess pain in these patients.

> *"I guess, from their behaviour, from their non-verbal behaviour because you can't really trust what they're saying."* (Nurse, 2 years of clinical experience)

Specifically, HCWs believed that aggressive/combative/violent behaviour, facial expression (e.g., grimace, furrowed brow), body posture or movement (e.g., posture, tense or stiff movement), and general changes in behaviour were indicative of pain in older patients with cancer and delirium. However, HCWs expressed that it was difficult to distinguish between behavioural manifestations of pain and other symptoms of delirium. In addition to pain behaviour, some HCWs believed vital signs should be used as part of pain assessment. HCWs believed that analgesic trials were required to determine whether cancer patients with delirium received adequate pain control. Specifically, an analgesic is provided to a patient if pain is suspected (e.g., treatment or procedures, pathological conditions, proxy or family reports of pain), and their behaviours are observed for improvement. If there is no change, HCWs escalate the dose gradually (titrate) or change the analgesic type (rotation) until a therapeutic effect is observed without bothersome side effects or no benefit is determined (Herr et al., 2011). In the

present study, HCWs believed that pain relief was achieved if patients returned to baseline behaviour or were able to sleep.

> *"…Even yourself, if you hurt yourself and you do take a couple Advils, you're not groaning and moaning as much after you've taken something. So I think the patient would just kind of subside and just relax, rest and fall asleep ultimately."* (Nurse, 15 years of clinical experience)

HCWs' beliefs about pain assessment across the delirium subtypes varied. HCWs believed that patients with hyperactive delirium displayed more behaviour indicative of pain compared to patients with hypoactive delirium. Moreover, HCWs expressed contradictory beliefs regarding which subtype was "easier" to assess with similar proportions describing patients with hyperactive delirium as easier to assess and vice versa.

Themes according to HCW discipline. Nurses and physicians believed that pain assessment in patients with delirium was very difficult or not possible. Nurses' and physicians' beliefs about self-report of pain and pain behaviour in older cancer patients with delirium were similar, but physicians also mentioned that a change in behaviour should be used as an indicator of pain intensity. Moreover, both nurses and physicians believed it was very difficult to distinguish behavioural manifestations of pain from other symptoms of delirium; however, some nurses expressed that HCWs' clinical experience informs this pain judgment. Nurses and physicians similarly believed about the use of analgesic trials and behavioural observations to determine a patient's response to pain intervention, but nurses also believed sleep was indicative of pain relief. In addition to patient behaviour, physicians believed vital signs should be used in pain assessment, and that there were differences in pain assessment due to delirium subtype.

Pain Management in Cognitively Intact Older People

Themes emerging from the full sample. Most participants had beliefs about pain management in older patients with cancer. Within this major theme, three sub-themes emerged: pharmacological methods, non-pharmacological methods, and age-related differences.

The most frequently discussed pharmacological intervention was the use of opioids. HCWs' beliefs about opioids for older people with cancer pain were contradictory. Although most HCWs believed opioids should be used for pain management, a few believed opioids should be delayed as long as possible or used as a last resort.

> *"Personally, I try to use less potent drugs first … before going to opioids because they can alter their behaviour. They can become more… they can depress them chemically, emotionally. You will mask the pain. It can mask the pain and not manage it… If it's [non-opioids] not working, then maybe we can try different things."* (Physician, 5 years of clinical experience)

Less than half of HCWs mentioned that opioids were an effective form of pain relief in this group. Reluctance to use opioids was related to the belief that non-opioids should be used instead of opioids and that opioid use is complicated in older patients due to frailty, risk of toxicity, and cognitive impairments.

Some HCWs believed non-pharmacological methods should be used for pain management in older patients with cancer; however, there was a lack of consistency in the treatment options mentioned and none met inclusion criteria for the meta-map.

Age-related differences in pain management. Over half of participants believed there were age-related differences in pain management. HCWs' beliefs about the need for an age-

tailored approach to pain management were contradictory, with a greater proportion of HCWs that believed such tailoring was needed (70%) than not (30%).

An age-tailored approach was related to analgesic use and reluctance to prescribe. HCWs believed analgesics should be used less frequently and at lower doses in older than younger patients, and that there was a greater risk for analgesic-related side effects in older than younger patients. Moreover, participants believed pharmacological treatment was more difficult in older than younger patients; this difficulty was related to HCWs' belief that older patients have lower creatinine clearance and greater comorbidities than younger patients.

> *"…age-based approach, you want to be careful about certain things so creatinine clearances and the age of a certain population you're a bit more cautious about the use of Tylenol dosing, like certain dosing might be tailored to age… If they're greater than 65, for example, for pain, not necessarily just neuropathic pain then they might be starting with 100mg 3 times a day versus a bigger dose."* (Nurse, 3 years of clinical experience)

Some HCWs also believed that older patients worry more than younger patients about the risk of analgesics and that older patients were less willing than younger patients to try these treatments.

> *"I feel that there is a difference. In the 20's, 30's, related to the patients that are older, I feel that patients that are younger are more open to taking medications because they're not as afraid, I would say, in a sense to feel the consequences or the side effects."* (Nurse, 2 years of clinical experience)

Themes according to HCW discipline. Both nurses and physicians believed opioids should be used and that they were an effective form of pain management; however, they expressed contradictory beliefs about opioids. Specifically, physicians believed opioids should be used as a last resort, that opioid use was complicated, and that non-opioid analgesics should be used more frequently for this population. A few nurses and physicians believed older patients worry about the side effects of opioids such as confusion, and therefore are reluctant to use opioids. Furthermore, a few nurses believed that patient controlled analgesia should be used, that anticipatory prescribing was needed, that opioids should be balanced with side effects. Only nurses mentioned that non-pharmacological treatments such as massage or touch therapy, relaxation techniques, guided imagery, exercise or physiotherapy, should be used for pain management.

Age-related beliefs about pain management. Nurses' beliefs about the need for an age-tailored approach to pain management were contradictory, with similar proportions of nurses who believed such tailoring was or was not needed. Whereas physicians consistently mentioned that such tailoring was needed. Nurses' and physicians' attitudes towards the use of opioids in different age groups were similar, but their responses varied. For instance, both nurses and physicians believed pharmacological treatments were more difficult to use in older than in younger patients, but nurses mentioned this difficulty was related to lower creatinine clearance in older than in younger patients, whereas physicians mentioned this difficulty was related to greater comorbidities in older than in younger patients. Moreover, both nurses and physicians believed that older patients should be given lower doses of opioids than younger patients. Physicians believed that there was a greater risk for side effects from opioids in older than younger patients. Finally, both nurses and physicians believed that older patients worried more

than younger patients about the risk of opioid-related adverse events, and that older patients were less willing or open than younger patients to trying pharmacological treatment.

Pain management in Older People with Delirium

Themes emerging from the full sample. All participants reported beliefs about pain management in older patients with cancer and delirium. Most beliefs were about pharmacological treatment, specifically the use of opioids. The majority of participants believed that opioids cause or exacerbate delirium. Despite this, participants still believed opioids should be used to manage pain in older cancer patients with delirium.

> *"I think it's a very grey area, because someone with delirium can very well have severe pain that requires opioid use. Yet, I know that opioid use can also exacerbate any current delirium, or may have even caused it in the first place. It's a very fine balance, and I don't think there's always that perfect answer."* (Nurse, 2.5 years of clinical experience)

> *"I think the pendulum swings back and forth between the predominant feeling being that older patients don't get their pain treated enough just because they are old, so we should give them more opioids and then we start running into seeing more and more opioid-induced delirium or complications and people hold back on it. I think there is really no easy way around, just evaluating our patients frequently and titrating their medications carefully*." (Physician, 10.5 years of clinical experience)

The use of opioids in older patents with delirium was related to HCWs' beliefs about the relationship between pain and delirium, such that pain causes and exacerbates symptoms of delirium.

> "*They're all interrelated* [opioids, pain and delirium], *obviously. I think what we use for our assessment is what was the predisposing condition or circumstances. If they were on the same medication before and was not delirious, then maybe there's something new that's triggering the delirium now. Perhaps its pain that's uncontrollable, or perhaps it's other reasons, metabolic, infectious or otherwise."* (Physician, 3 years of clinical experience)

Although the majority of participants believed pain should be treated during delirium, some HCWs mentioned there was a need to prioritize between pain and delirium management. However, beliefs about treatment priority were contradictory, with a greater proportion of HCWs who believed pain should be treated prior to delirium (67%) than those who believed delirium should be treated first.

> *"In my opinion, I would rather control someone's pain than worry about their delusions as long as they're not in harmful for [to] themselves or others."* (Nurse, 2 years of clinical experience)

> *"The first step we would do is actually treat that delirium because the person is, of course, at risk of falls, and things like that. We would give the antipsychotic first, rather than breakthrough. Then, once we get the person a bit more settled, that's when we try to reassess pain."* (Physician, 3 years of clinical experience)

Themes according to HCW discipline. Nurses' and physicians' beliefs about the use of opioids in older patients with cancer and delirium were similar, but a few physicians reported reluctance to provide opioids. Some nurses believed opioid dosage should depend on pain intensity, and that it should be balanced with side effects. Nurses believed that pain should be managed first with an analgesic trial prior to treating delirium, but physicians' beliefs about treatment priority were mixed. Specifically, there was a similar proportion of physicians who believed pain management should be prioritized over delirium or that symptoms of delirium should be managed first with anti-psychotics or relaxants. Physicians' beliefs that delirium should be treated prior to pain may be related to their beliefs about symptoms of hyperactive delirium (i.e., aggression, violence, distress) and concerns about the safety of patients and HCWs. Finally, a few physicians believed factors such as pain intensity, changes in pain medication, and pathology should be considered in deciding whether pain or delirium should be treated first.

> *"Of course you have to cure for the pain first… technically you start treating for both things but again, you have to assess what degree of the pain the patient is suffering from. If that degree is like less severe, and it also depends like if there is any underlying pathology like, so, depending, maybe that pathology causes both things, delirium and pain. So it depends on the cause of the pain, because everything is inter-related, so that pain could be part of that delirium."* (Physician, 2 years of clinical experience)

Patient Variability in Older People with or without Delirium

Themes emerging from the full sample. All participants believed that the experience of pain in older patients with and without delirium varied across patients due to individual differences in culture, personality, beliefs or expectations, and cancer characteristics.

> *"You know there are some patients who you can tell that they're in pain and yet they don't want to admit that they're in pain, and other cultures where any little pain is catastrophic."*(Nurse, 10 years of clinical experience)

Pain Education about Older People with or without Delirium

Themes emerging from the full sample. Most participants reported beliefs about 'pain education'. Specifically, HCWs believed that education about pain in older patients with cancer was needed for HCWs and, to a lesser extent, for patients and their families.

> *"Education is at the heart of everything, for patients, for staff and for family."* (Nurse, 24 years of clinical experience)

Specifically, HCWs believed these educational initiatives should address opioid misconceptions (e.g., likelihood of addiction, relationship with delirium), as misconceptions may contribute to reluctance towards opioid use among HCWs, patients and families.

> *"Certainly in older patients there is that belief that they don't want to get hooked on the medication. Usually, if you explain to them that as long as you are using it for pain and nothing else, that it's not addictive, I find most of them are able to get their head around that and take it." (Physician, 10.5 years of clinical experience)*

Impact of Clinical Experience on Pain Assessment

Themes emerging from the full sample. The majority of HCWs believed that greater clinical experience makes HCWs better at, and more confident or comfortable with, pain assessment. For instance some HCWs believed greater experience improved HCWS' observational judgments of pain behaviour or cues and HCWs' use of pain scales.

> *"…it's very difficult to get information from them [the patients] so you depend on your experience and your judgment. You don't depend on the patient. This is very challenging. You're treating a patient based on your experience, not on his feeling. We don't know what he is feeling. We depend on our experience. The only way you can do is clinical experience. So people who lacks experiences, junior staff, of course, it will be difficult for them because they will not be able to assess it."* (Physician, 15 years of clinical experience).

Consensus Building

Themes emerging from the full sample. Most participants believed in the importance of consensus building, such that HCWs should collaborate with a patient's family and other HCWs (e.g., nurses or physicians, pain specialists) to inform their decisions about pain assessment and management.

> *"I find that I need to work with my team and also involve the family to tell us more about the patient… I always sort of collaborate with my colleagues and say, 'hey, this is what my session was, do you mind just sort of seeing what your thoughts are?"* (Nurse, 11 years of clinical experience)

> *"I think we're lucky on the palliative care unit that we have a clinical nurse specialist who helped to support the nurses if they have difficulty doing pain assessment or communicating with the family."* (Physician, 3 years of clinical experience)

Both nurses and physicians believed family and HCWs were helpful in pain assessment and management as they can provide comfort to the patient, as well as provide information about patients' baseline or 'normal' behaviour and pain history.

> *"I think it's really about finding a balance and then communicating with your co-workers, whoever's working with you, taking over for you, what works for this patient, what doesn't. I find family presence is usually beneficial to have them around, comforting."* (Nurse, 5 years of clinical experience)

Barriers in Pain Management in Older People with or without delirium

Themes emerging from the full sample. The majority of participants reported beliefs about barriers to pain assessment and management in older patients with cancer. About half of HCWs believed family members of patients interfere with HCW treatment decisions due to their concerns about pain medication use and lack of pain knowledge.

> *"They [the family] interrupt a lot and things and either you have to take out time and explain what you're doing and all that, so if they don't understand then they keep nagging... and asking and all that. Sometimes they're too fussy and they just don't know, or maybe they don't have patience."*(Physician, 2 years of clinical experience)

Participants also believed that other HCWs could be a barrier to providing patients with adequate pain management, partially due to their reluctance to give opioids to older patients with cancer.

> *"You may have very different opinions within that group [HCWs] of what should be done for the patient that it can lead to difficulty in getting a treatment plan carried out… I come see them [the patients] the next morning; they're clearly in pain, haven't gotten any breakthrough medication and just [because] the nurse overnight felt that well, the patient was either too elderly or too confused and didn't want to make the confusion worse ".* (Physician, 10.5 years of clinical experience)

Themes according to HCW discipline. Both nurses and physicians believed that families and other HCWs could be a barrier; however only nurses mentioned that family members were concerned about pain medication and that other HCWs were reluctant to give opioids and thus provide inadequate treatment.

General Pain

Beliefs that did not fall under the major themes were included within 'general pain'.

Themes emerging from the full sample. Some HCWs mentioned that chronic pain was highly prevalent in older patients with cancer. A few HCWs also mentioned that pain in this group was multidimensional comprising biological or physical, psychological, and social factors.

Age-related differences in pain experience. The majority of HCWs reported beliefs about the experience of pain in different age groups. Most commonly, HCWs believed that older patients were more willing to tolerate pain than younger patients. Beliefs about pain intensity were contradictory, with similar proportions of nurses and physicians believing that older patients experience either lower or the same pain intensity as younger patients.

> *"I think that everyone can experience pain equally, no matter their age. I think maybe the way they communicate their pain or express their experience with pain can vary with age and also, just their general life experience, personality, their cultural experience… I attribute differences more so to individual differences, personalities."* (Nurse, 2.5 years of clinical experience)

Lastly, some participants believed that older patients were better able than younger patients to accept and adjust to or cope with pain.

> *"You see some people [older cancer patients] have had a lot of pain in their life, whether it's psychological or whether it's physical. Now this pain adding onto it, either they're [older patients] used to having pain so they know how to deal with it and they have their coping mechanisms already in place, whereas the younger population wouldn't necessarily have that... Very older quite often, they're quite quiet and whatever happens they have them and they give up and just let me die with their pain."* (Nurse, 10 years of clinical experience)

Themes according to HCW discipline. Both nurses and physicians mentioned high pain prevalence and biopsychosocial pain or total pain. Nurses and physicians expressed similar beliefs beliefs about age-related differences in pain intensity, tolerance, adaptation, and acceptance. Physicians also believed that the impact of pain on physical functioning was greater in older than in younger patients because older patients had greater comorbidities and lower physiological reserves than younger patients.

Table 1

Sample Characteristics (N=16)

	Total sample (N=16)	Nurses (N=8)	Physicians (N=8)
Variable	N % or Mean ± SD	N % or Mean ±	N% or Mean ±
Age (in years)	37.06 ± 9.79	37.25 ± 11.89	36.25 ± 7.9
Gender			
Female	10 (62.5)	7 (87.5)	3 (37.5)*
Male	6 (37.5)	1 (12.5)	5 (62.5)*
Clinical experience total (years)	9.2 ± 7.41	9.18 ± 7.85	9.31 ± 7.48
Pain assessment	8.59 ± 6.29	9.18 ± 7.85	8 ± 4.74
Cognitively impaired	5.59 ± 5.10	5.43 ± 4.88	5.75 ± 5.65
Palliative care or Oncology	5.68 ± 4.76	5.43 ± 4.7	5.93 ± 5.14
Geriatrics	6.34 ± 5	6.56 ± 5.01	6.12 ± 5.33
Percentage of patients			
Older (65+)	65.62 ± 18.06	75 ± 11.64	56.25 ± 19.03*
Number of advanced cancer patients	29.38 (median=	18.78 ± 13.06	32.5 ± 38.52
(per month)	17.75) ± 29.38		
Specialized training in pain management			
Yes	6 (37.5)	6	1*
No	10 (62.5)	2	7*

Notes: Paired-samples t-tests for continuous variables, ** $p<0.05$, ** $p< 0.01$*; Fisher's exact test for categorical variables, **adjusted residual >2.0 or < -2.0, $p<0.05$*

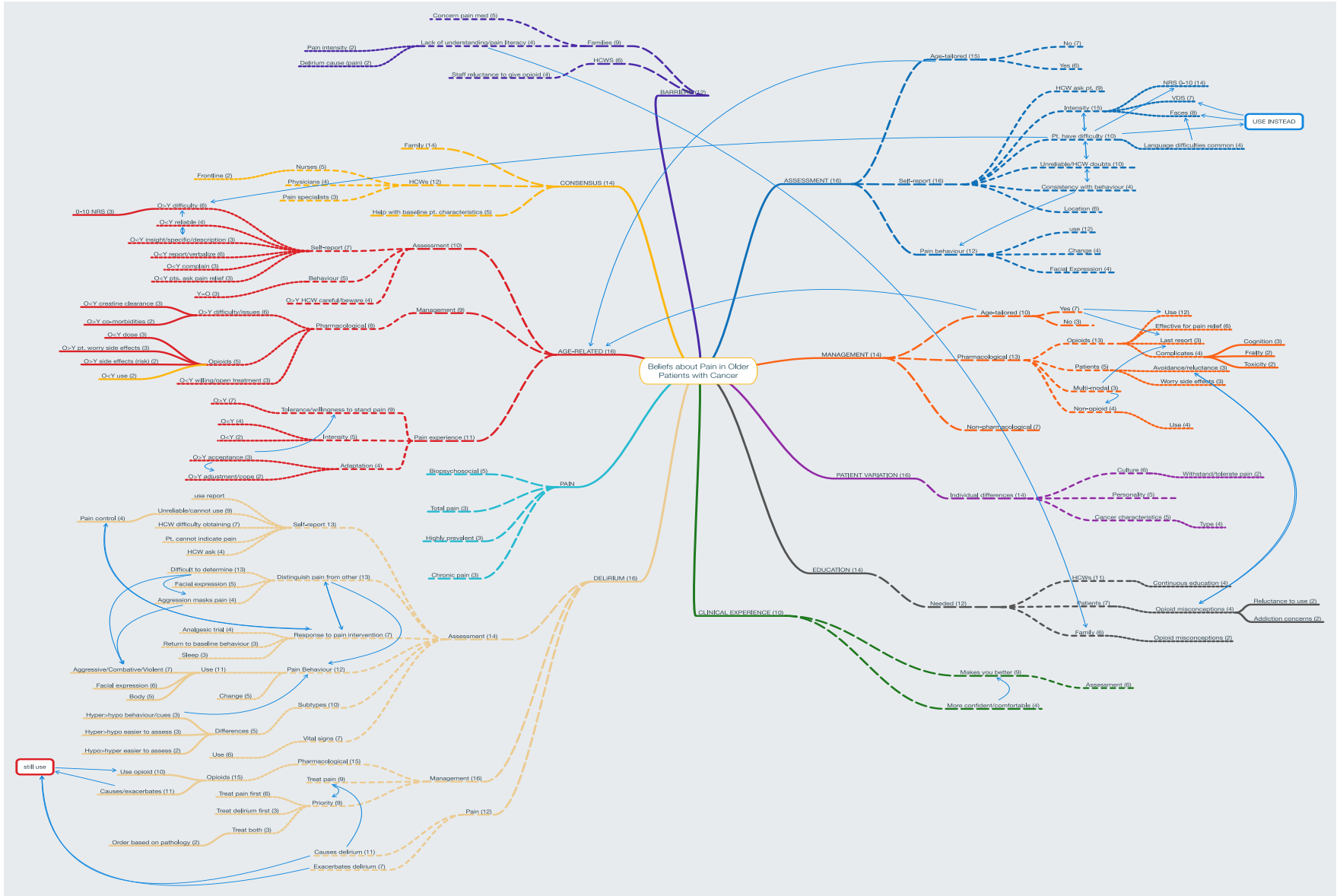

Figure 3. Full Sample Meta-Map

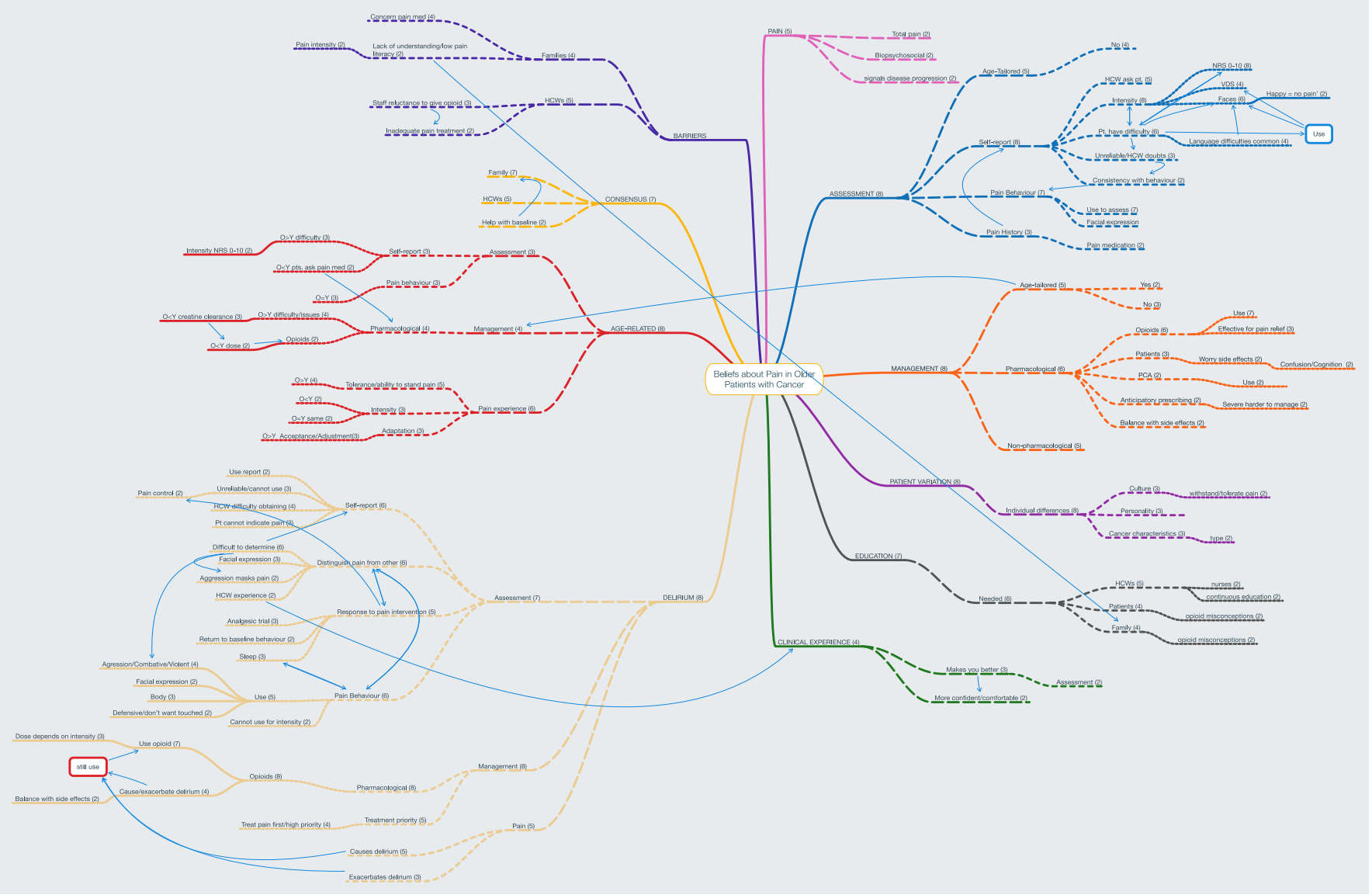

Figure 4. Nurses Meta-Map

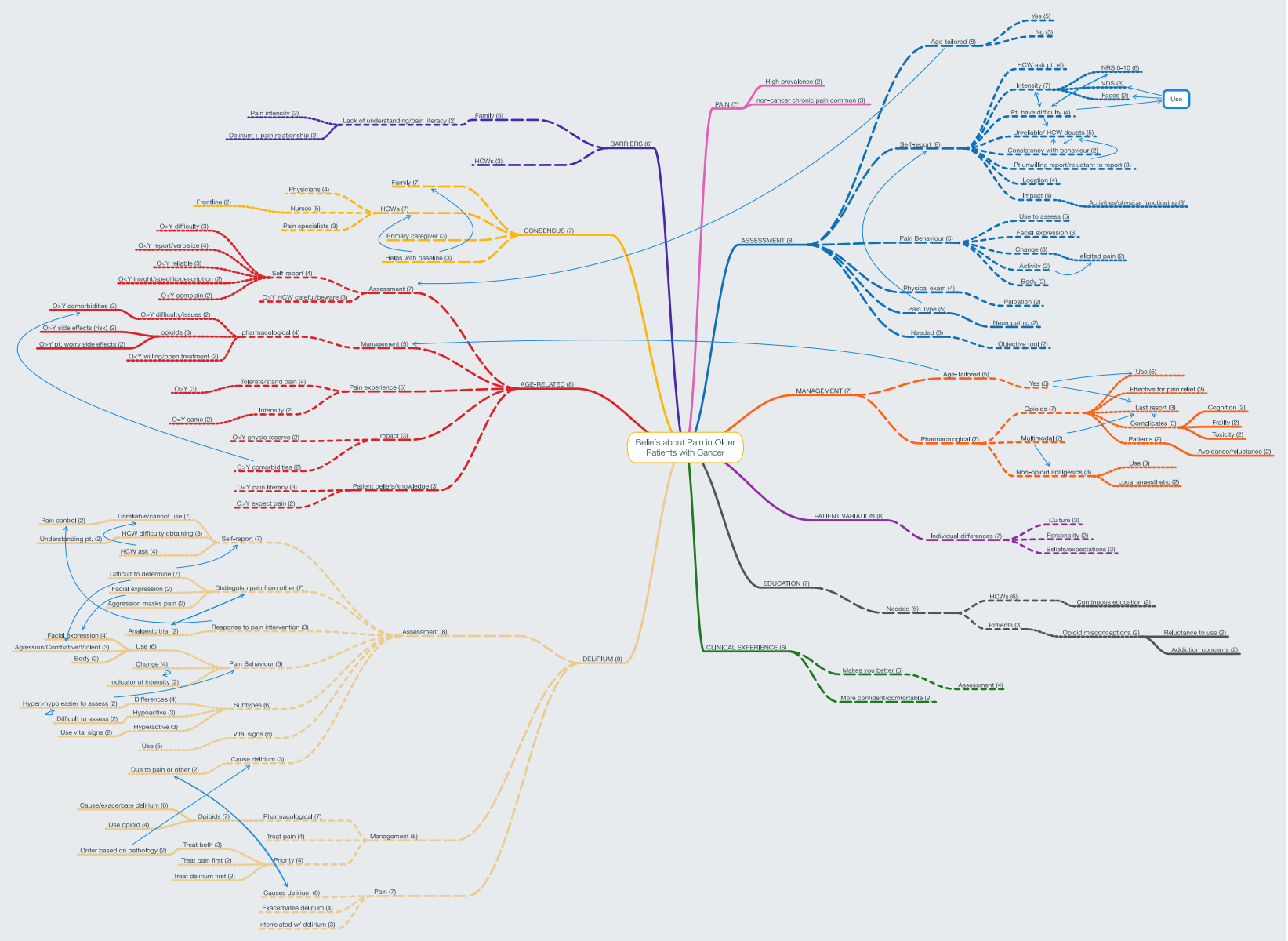

Figure 5. Physicians Meta-Map

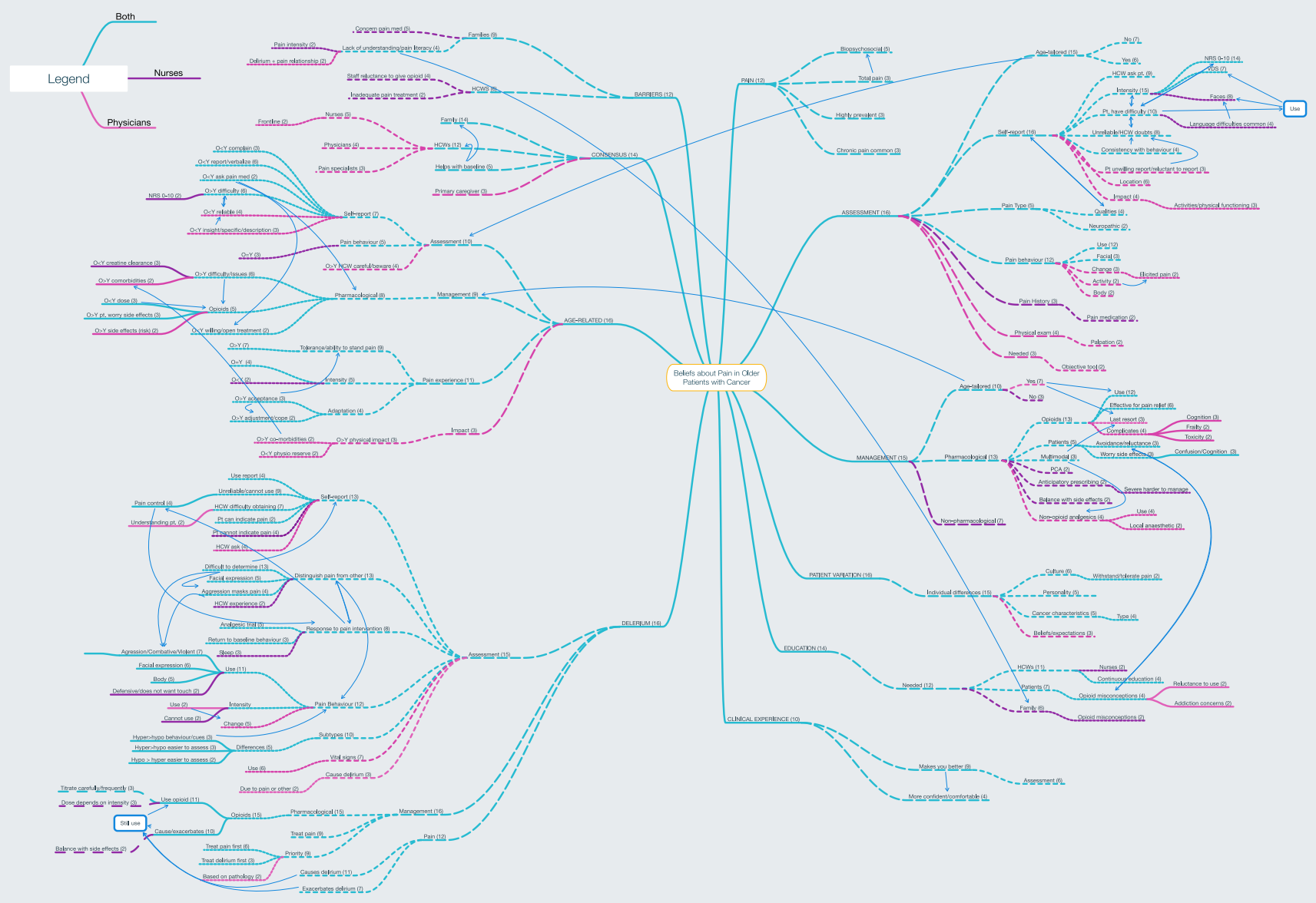

Figure 6. Nurses and Physicians Comparison Meta-Map

Discussion

Novel findings from the present study provide insights regarding the assessment and management of pain in older people with cancer. HCWs' beliefs suggest that knowledge gaps and misconceptions about pain in this group are highly prevalent and that education for nurses and physicians is urgently needed. Our study highlights inconsistent and contradictory beliefs across and within HCW discipline. Nurses' and physicians' beliefs about the appropriateness of opioid use were inconsistent, and some HCWs believed that other nurses' and physicians' misconceptions and gaps in knowledge about opioids were associated with a reluctance to use opioids in older patients. Importantly, most HCWs believed opioids play an important role in the interrelated relationship of pain and delirium, believed older patients have difficulty with self-reporting pain and thus doubted the reliability of these reports, and experienced frustration with the assessment and management of pain due to difficulties in distinguishing symptoms of pain and delirium. Collectively, these findings highlight factors that may be implicated in the consistent undertreatment of pain in older patients with cancer (Deandrea, Montanari, & Apolone, 2008). The multifaceted and complex nature of cancer pain, aging, and delirium require methods of data analysis that can accommodate an in-depth exploration of HCW cognitions about these interrelated concepts. The present study used mind-maps as an innovative approach to efficiently organize information and analyze data with a non-hierarchical structure, and to identify relationships, contradictions, and inconsistencies within and across HCWs.

In the present study, HCWs consistently described feeling uncertain about the presence of pain in older patients with cancer and delirium. This uncertainty was primarily due to HCWs' difficulties distinguishing between symptoms of pain and delirium due to behavioural symptom

overlap. For example, some HCWs believed that anxiety and aggression were indicative of both pain and hyperactive delirium. To help differentiate between symptoms of pain and delirium, HCWs believed an analgesic trial should be used and subsequent behaviour observed for any changes. Specifically, HCWs described provision of an initial dose and followed by observation of patient behaviour for a return to 'baseline' or 'normal' behaviour and reduced sleep disturbances. Nurses and physicians also believed analgesic trials can be used to assess the effectiveness of pain interventions. Although most HCWs believed pain management should be prioritized over delirium, a few physicians believed analgesics should be delayed following further investigation into the cause of delirium (e.g., pathology) and in patients with hyperactive delirium sedatives should be provided prior to analgesics to ease pain assessment and ensure the safety of the patients and HCWs. Our findings are concerning as they suggest HCWs may routinely discount signs of pain due to delirium or vice versa (Hadjistavropoulos, Voyer, Sharpe, Verreault, & Aubin, 2008), thus leading to the underestimation or overestimation of pain (Bruera, 1992).

To our knowledge no other studies report on HCW beliefs' about difficulty distinguishing between behavioural symptom overlap in older patients with cancer and delirium. The present findings are consistent with reports from HCWs regarding difficulty in distinguishing between symptoms of pain and dementia in older patients with and without superimposed delirium (Gilmore-Bykovskyi & Bowers, 2013; Kaasalainen et al., 2007; Karlsson et al., 2013; Martin et al., 2005). Comorbid delirium and dementia is common with advancing age and complicates differential diagnoses and treatment decisions related to pain (Bush et al., 2014; Hadjistavropoulos et al., 2008; Lawlor & Bush, 2015; Leonard et al., 2014). Behavioural indicators (e.g., hallucinations, delusions, sleep disturbances, withdrawal) of pain in older

patients with dementia and delirium can also overlap (Bruera et al., 2009; Bush et al., 2014; Bush & Bruera, 2009). HCWs in the present study did not mention pain assessment within the context of dementia superimposed with delirium. Future research should investigate HCWs' beliefs about the impact of dementia in differential diagnoses of pain in older patients with cancer and delirium.

HCWs in previous studies also believed analgesic trials should be used as a diagnostic tool to identify pain in older patients with dementia (Gilmore-Bykovskyi & Bowers, 2013; Kaasalainen et al., 2007). Clinical recommendations state that older critically-ill patients who are non-verbal or cognitively impaired and show signs of distress should be assumed to be in pain (Herr et al., 2011). Therefore, an analgesic trial should be used as both a therapeutic and diagnostic tool prior to using other type of sedatives (Herr et al., 2011; Oldham & Pisani, 2015). Specifically, HCWs should begin with low doses of an analgesic that are 25-50% of adult doses and titrate by increases of 25 to 50%, using stronger analgesics if there is no change in behaviours and pain is still suspected (Herr et al., 2011). Critically, the preferential evidence for sedative use in this population is weak and sedation may mask or obscure signs of pain (Herr et al., 2011; Oldham & Pisani, 2015). Considering these clinical recommendations, it is concerning that some HCWs believed pain treatment should be delayed until after treatment of delirium. Future research should further elucidate HCWs' beliefs about analgesic trials and treatment priority in older patients with cancer.

Despite HCWs' difficulty in distinguishing behavioural signs of pain and delirium, nurses and physicians in the present study believed behavioural observations should be the primary source of pain assessment in older patients with cancer and delirium. For instance, HCWs believed behaviours such as guarding or withdrawing, moaning or crying, facial expressions

were indicative of pain. Critically, however, HCWs did not describe the use of tools to aid in identifying presence or change in behaviours, at baseline or in response to pain interventions. Some HCWs believed 'objective' or observational tools to assess pain behaviour in older patients with cancer were urgently needed. HCWs' beliefs about pain behaviours in the present study are consistent with HCWs' beliefs about pain behaviour in older patients with dementia (Brorson et al., 2014; Gilmore-Bykovskyi & Bowers, 2013; Kaasalainen et al., 2007; Karlsson et al., 2013; Kovach et al., 2000; Martin et al., 2005; Mentes, Teer, & Cadogan, 2004), and in older post-operative patients with delirium (Decker, 2009; Feldt & Oh, 2000). In a recent chart-review study, HCWs documented similar behaviours in older patients with cancer and delirium, but almost half of the HCWs recorded only general impressions of pain behaviour (i.e., no obvious signs of pain) (Gagliese et al., 2016).

Clinical recommendations for the assessment of pain in older critically ill patients who are non-verbal or with cognitive impairment include the use of established pain behaviour tools or scales (Herr et al., 2011). However, there is no standardized tool for HCWs to assess pain in older cognitively impaired patients with cancer. Therefore it is not surprising that HCWs in the present study do not describe pain behaviour assessment tools. A recent systematic meta-review of behavioural pain assessment identified 28 separate tools for pain assessment in older patients with cognitive impairment due to dementia, and determined there was insufficient evidence for the reliability, validity, and clinical utility for these scales (Lichtner et al., 2014). Moreover, little research has examined pain behaviours in older patients with delirium (Decker & Perry, 2003; Feldt & Oh, 2000). A recent meta-analysis of assessment tools for patients following hip fracture who were cognitively impaired identified the Facial Action Coding System as the most valid tool available to assess pain in these patients (Smith, Hameed, Cross, Sahota, & Fox, 2013), although

it is not possible to use this tool at the bedside. None of these tools help to differentiate between behaviours associated with pain, dementia, and delirium. Critically, none of these tools have been validated for older patients with cancer, and thus future research should aim to develop and validate a standardized tool to assess pain behaviours in older patients with cancer and delirium. Without a validated tool, HCWs must rely on their own impressions of pain behaviour to guide their judgments.

In addition to patient behaviour, HCWs in the present study expressed beliefs about self-report in older patients with cancer. Nurses and physicians consistently believed that older cancer patients with and without delirium have difficulty providing self-reports of pain. As such, HCWs had doubts about the reliability of these patients' reports. Concerns about difficulty and reliability were exacerbated for patients with delirium. The majority believed patients with delirium cannot reliably indicate pain and that caution should be used when using these reports in treatment decisions. Critically, HCWs believed that older patients' reports of pain were less reliable than reports of younger patients, and that older patients experience greater difficulty with rating pain intensity than younger patients. For example, HCWs consistently believed that older patients have greater difficulty with the NRS than younger patients with cancer. As such, HCWs believed Verbal Descriptor Scales (VDS) or the Faces Pain Scale (FPS) was a better choice for older patients. HCWs' beliefs about patients' self-report may influence their judgment of pain in older patients with cancer (Prkachin et al., 2007).

Our findings are consistent with studies into adult cancer pain, as nurses' and physicians' beliefs about the reliability of self-report in these patients are mixed, with similar proportions within each study reporting that the patient is or is not the most accurate judge of pain intensity (Bernardi et al., 2007; Brown et al., 1999; Cleeland et al., 1986; Fife et al., 1993; Viscentin et al.,

2001). Additionally, nurses in acute and long-term care settings have reported difficulty with and doubts about self-report among older patients with and without dementia (Barry et al., 2012; Fri et al., 2016; Furjanic et al., 2016; Gilmore-Bykovskyi & Bowers, 2013; Kaasalainen et al., 2007; Karlsson et al., 2013; Kovach et al., 2000; Martin et al., 2005).

Despite previous findings that increasing age may be associated with greater mistakes on Visual Analog Scale [VAS (Gagliese et al., 2005; Peters et al., 2007)] in patients with surgical and chronic pain, the VDS and NRS have consistently been shown to be valid and reliable measures for older patients with cancer (Brunelli et al., 2010; Gauthier et al., 2014) and non-cancer pain (Gagliese et al., 2005; Peters et al., 2007; Taylor et al., 2005; Wood et al., 2010). Moreover, older patients preferred the VDS and NRS above others (i.e., horizontal and vertical VAS) (Gagliese et al., 2005; Herr et al., 2004; Peters et al., 2007). Although there is some preliminary evidence for the reliability and validity of the FPS in older people (Herr, 2011; Herr et al., 1998; Stuppy, 1998), its construct validity has been challenged due to the faces representing constructs other than pain such as negative affect (e.g., sadness, distress), fatigue, or boredom (Gagliese and Gauthier, 2011; Herr et al., 1998). Additionally, age-related visual impairments may interfere with its completion or patient compliance (Gagliese and Gauthier, 2011). Critically, the reliability and validity of the NRS and VDS does not differ in younger and older patients who are cognitively intact for the assessment of post-operative (Gagliese et al., 2005) and cancer-related pain (Gauthier et al., 2014). Expert clinical recommendations for the assessment of pain intensity in older people with cancer include patient self-report using a NRS, or VDS in those with limited numerical literacy (Hadjistavropoulos et al., 2007; Herr et al., 2011).

In the present study, HCWs believed that observations of behaviours should be used to validate patients' reports of pain. As such, HCWs may diminish older patients' self-reports of pain, and rely more heavily on other sources of assessment such as patient behaviour. Previous studies report that HCWs may not accurately document patients' reports of pain if they are not consistent with patient behaviour (Katsma & Souza, 2000; McCaffery and Ferrell, 1997; 2000). For example, in a sample of long-term care nurses only 36% of participants' believed the smiling patient, whereas 56% believed the grimacing patient (Katsma & Souza, 2000). Additionally, 45% and 30% of nurses did not chart the correct pain report for the smiling and grimacing patient, respectively. Rather they recorded their personal opinion of the patients' pain (Katsma & Souza, 2000). As such HCWs may diminish older patients' self-reports of pain, and rely more heavily on other sources of assessment such as patient behaviour.

Our findings suggest that HCWs' beliefs are inconsistent with the empirical evidence that cognitively intact older patients with and without cancer can reliably self-report the presence and intensity of pain using a range of pain scales (Brunelli et al., 2010; Donald et al., 2004; Gagliese, Weizblit, Ellis, & Chan, 2005; Gauthier et al., 2014; Peters, Patijn, & Lamé, 2007; Taylor, Harris, Epps, & Herr, 2005; Wood, Nicholas, Blyth, Asghari, & Gibson, 2010). Taken together, the inconsistency between HCWs' beliefs about self-report and the empirical evidence regarding self-report by older people illustrate an important and fundamental gap in HCW knowledge about pain in older people. This gap should be the focus of future educational efforts as even brief educational interventions have been shown to improve HCWs' knowledge about pain in older people (Gagliese et al 2012).

In the present study, the majority of HCWs believed older patients with delirium cannot reliability report pain intensity. Therefore, HCWs may only elicit reports of pain presence

(yes/no) to guide their judgements of pain in older patients with delirium who can provide verbal reports (Fry et al., 2016; Martin et al., 2005). In a recent chart-review study, HCWs documented patients' self-reports in older cancer patients with delirium, such that 86% of assessments were based on patient self-report (Gagliese et al., 2016). These notations consisted mainly of pain presence (i.e., denies or does not complain of pain) and little information was reported on pain intensity (Gagliese et al., 2016). It was unclear from this study if HCWs explicitly asked patients' about their pain or if they believed these reports and used them to inform treatment decisions.

Nonetheless, there has been debate regarding the reliability of self-report by older patients' with cognitive impairment. Cognitively impaired patients in hospital and long-term care settings have provided reliable and valid self-reports of pain using various pain intensity scales (Chibnall & Tait, 2001; Closs et al., 2004; Pautex et al., 2005; Taylor et al., 2005). However the feasibility (e.g., completion), reliability (e.g., test-retest), and validity (e.g., convergent, construct) of these self-reports diminishes for patients with severe dementia (Chibnall et al., 2001; Closs et al., 2004; Pautex et al., 2005). Little research has investigated the reliability and validity of self-report in patients with delirium. In one study, older patients with post-operative pain related to hip fractures, with delirium and/or dementia were able to reliably report pain presence, and most were able to complete the VDS (Feldt & Oh, 2000). However, both cognitively intact and impaired patients who initially indicated no pain presence later reported intermittent pain (Feldt & Oh, 2000). Due to the transient nature of delirium, clinical guidelines recommend the use of self-reports of pain in patients with delirium if they are able to verbally report pain (Bush & Bruera, 2009; Delgado-Guay & Bruera, 2008b).

Collectively, our findings suggest that HCWs' beliefs about self-report are inconsistent with empirical evidence that cognitively impaired older patients can reliably self-report the presence and intensity of pain (Chibnall & Tait, 2001; Closs et al., 2004; Feldt & Oh, 2000; Pautex et al., 2005; Taylor et al., 2005). However, further research is urgently needed to assess the reliability and validity of older cancer patients' self-report of pain during delirium. Critically, our findings suggest that HCWs approach to pain assessment may contradict clinical guidelines for self-report of pain in older patients with cancer and delirium (Bush & Bruera, 2009; Herr et al., 2011), and therefore this gap should be addressed in future HCW educational interventions.

HCWs' beliefs about age-related differences in the reliability of self-report may be related to HCWs' beliefs that older patients are less likely to report pain. Specifically, physicians believed that older patients with cancer are generally reluctant to report, and both nurses and physicians believed older patients were more willing to tolerate pain and less likely to verbalize pain or complain of pain than younger patients. Previous research suggests that older patients with chronic pain may be more reluctant to express pain than younger patients (Yong, Gibson, Horne, & Helme, 2001; Yong, Bell, Workman, & Gibson, 2003). However, a recent study in patients with cancer that examined attitudes of stoicism (e.g., pain concealment) and cautiousness (e.g., reluctance to report pain) indicated no age-differences in these constructs (Mah et al., 2017). Furthermore, older and younger cancer patients have not demonstrated differences in reluctance to disclose or to minimize pain intensity (Gagliese, 2009; Gauthier et al., 2014). Future research is needed to elucidate HCWs' age-related beliefs about patient willingness to report pain as these beliefs may impact HCWs' judgments of pain.

In the present study, nurses and physicians consistently believed that collaboration with patients' families and other HCWs (nurses, physicians, pain specialists) critically informed pain

assessment. HCWs described that in acute palliative care settings HCWs may not have sufficient time with older patients prior to the onset of delirium, and therefore must rely on families to inform judgments regarding changes in patient behaviour (i.e., change in behaviour from baseline or 'normal' behaviour). Our findings extend previous research into HCWs' beliefs about the role of family and other HCWs in the assessment and management of pain in older patients with dementia (Brorson et al., 2014; Kaasalainen et al., 2007; Karlsson et al., 2013). Clinical recommendations advise that family members or primary caregivers can be used a proxy for pain in situations where older patients may become nonverbal or unable to communicate pain (Herr et al., 2011).

Although HCWs in the present study described family members and other HCWs as facilitators in pain assessment, they also believed that patients' families and other HCWs were sometimes a barrier to pain management. Specifically, nurses and physicians believed families' misconceptions about opioids (e.g., fear of addiction, cognitive impairments, relationship with pain and delirium) interfered with HCWs treatment decisions. Additionally, HCWs consistently described encountering other HCWs with erroneous beliefs about pain management in older patients with cancer. Specifically, nurses in the present study consistently expressed that they encounter physicians with misconceptions about opioids that may result in a reluctance to prescribe opioids, despite recommendations from nurses. As such, most HCWs believed that education about pharmacological pain management in older patients with cancer and delirium was urgently needed for patients' families, the HCW themselves, and other HCW staff.

Contradictory beliefs about family members and other HCWs as being both facilitators and barriers has been previously reported by nurses working in long-term care settings (Fox et al., 2004). Moreover, nurses and physicians have reported similar concerns about other HCWs'

opioid misconceptions and the need for pain management education in older patients with and without dementia (Kovach et al., 2000). Physician reluctance to prescribe opioids in older patients with and without dementia has been reported previously by nurses in long-term (Kaasalainen et al., 2007; Kovach et al., 2000; Martin et al., 2005; Tarzian & Hoffmann, 2005) and acute health care settings (Rantala et al., 2014). Critically, misconceptions about pharmacological treatments may influence HCWs' reluctance to prescribe these opioids in older patients with cancer (Ger et al., 2000), and may negatively impact collaboration across HCWs.

In the present study, nurses and physicians provided contradictory beliefs about the appropriateness of opioid use, such that almost half of the physicians believed opioids should be used as a last resort. Rather, these physicians believed non-opioid analgesics and non-steroidal inflammatory agents should be the primary approach to achieving pain relief in these individuals. On the contrary, nurses consistently believed opioids were appropriate for use in older cancer patients with or without delirium. Clinical guidelines for pain management in older patients with cancer and delirium support the use of opioids for the management of moderate-to-severe pain in older patients (Bush & Bruera, 2009; Bush, Tierney, & Lawlor, 2017; Delgado-Guay & Bruera, 2008; Paice & Ferrell, 2011; Portenoy, 2011; Urban, Cherny, & Catane, 2010). It was unclear in the present study if HCWs' beliefs about opioid use were influenced by patient pain severity. Future research should explore how pain severity may impact HCWs' beliefs about opioid use.

Previous studies report inconsistency across physicians regarding opioid use in older patients with cancer (Cleeland et al., 1986; Ger et al., 2000; Visentin et al., 2001) and older patients with and without dementia in acute care (Kaasalainen et al., 2007). Physicians' beliefs about opioid use may have differed from the nurses as physicians may fear scrutiny over prescribing practices from regulatory boards (Eftekhar et al., 2007; Ponte & Johnson-Tribino,

2005; Zhang et al., 2015). In the present study, it was unclear if physicians were concerned about regulatory procedures. Future research should explore whether fear of scrutiny impacts physicians' beliefs about opioid use in older patients within the context of cancer and delirium. Physicians' reluctance towards opioid use in older patients with cancer may be related to their beliefs about opioid addiction and respiratory depression in patients with cancer (Bauwens et al., 2001; Cleeland et al., 1986; Ger et al., 2000; Wells et al., 2001; Yanjun et al., 2010; Zanolin et al., 2007). Only a few physicians in the present study believed opioid use should be limited to reduce the risk of opioid addiction. Unfortunately, most studies that report on HCW misconceptions about opioid use in older patients are limited to nurses. Therefore it remains unclear if misconceptions about addiction and respiratory depression negatively impact physician beliefs about opioid use in older patients with cancer.

Importantly, our findings suggest that most HCWs believed pharmacological pain management should be approached similarly in older patients with and without delirium. Specifically, HCWs in the present study believed the relationship between pain and delirium is complex and interrelated. HCWs described how both opioids and unrelieved pain can cause or exacerbate delirium, and that there is a need to balance opioid use against the risk of delirium. These findings are inconsistent with several studies that examine HCWs' beliefs about non-malignant pain in older patients with dementia (Barry et al., 2012; Furjanic et al., 2016; Kaasalainen et al., 2007; Kovach et al., 2000; Sloman et al., 2001; Yu & Petrini, 2007). In these studies the majority of HCWs reported reluctance to use opioids in patients with cognitive impairment. Mixed findings between the present and previous studies may reflect HCWs' beliefs about these cognitive disorders and its relationship with pain and opioids, and beliefs about patients' ability to self-report. Specifically, dementia is a progressive neurodegenerative disorder

whereas delirium is an acute transient disorder that may be reversible in the terminal phases of cancer (Centeno et al., 2004; Winell & Roth, 2005). Future research should systematically explore differences in HCWs' beliefs about opioid use in older patients with dementia versus older patients with delirium. Unfortunately, the overlap of dementia and delirium is not uncommon in older patients with cancer (Mukaetova-Ladinska, Teodorczuk, Khoo, & Cerejeira, 2017). Future research should elucidate how this complex overlap influences beliefs about opioid use in older patients cancer. Collectively, our findings suggest that HCWs' beliefs about the appropriateness of opioid use in older patients with cancer is consistent with empirical evidence that opioids can be safely used for cancer pain in older patients with (Bush & Bruera, 2009; Bush et al., 2014) or without delirium (Mercadante & Arcuri, 2007; Urban, Cherny, & Catane, 2010). Our findings also suggest that HCWs' understanding of the impact of pain on the development and exacerbation of delirium play an important role in their treatment decisions (Morrison et al., 2003).

It was unclear in the present study if HCWs believed lower doses should be consistently provided to older cancer patients with delirium than those without. Disparities in opioid provision between cognitively intact and impaired older patients have been previously reported (Reynolds et al., 2008). Moreover, a recent chart-review study among HCWs who provide pain management to older cancer patients with delirium reported that the proportion of days that patients were judged to have good pain control was significantly higher in cognitive intact patients than those with delirium (Mah et al., 2016). Future research is needed to systematically explore differences in opioid provision to older patients with and without delirium to elucidate differences in prescribing practices.

HCWs in the present study believed analgesic provision should be approached differently in older and younger patients. This need for an age-tailored approach was related to HCWs' beliefs that provision of opioids was more complex and thus difficult in older than younger patients with cancer. For instance, HCWs believed that age-related changes in physiological functioning (e.g., reduced creatinine clearance, polypharmacy, frailty) and cognitive impairment might increase the risk for opioid-related adverse events (e.g., organ failure and delirium). As such, HCWs in the present study believed older patients should receive lower doses than younger patients, and that greater caution is needed with opioid use in older than younger patients. It has been reported older patients may require lower doses than younger patients to achieve similar levels of analgesia for chronic and post-operative pain (Buntin-Mushock, Phillip, Moriyama, & Palmer, 2005; Gagliese et al., 2005). Our findings suggest that HCWs' age-related beliefs about opioid use are consistent with the empirical evidence that opioid provision should be approached with more caution in older than in younger patients with cancer due to physiological changes associated with advancing age (Mercadante & Arcuri, 2007). However, HCWs' beliefs also highlight potential disparities in opioid provision among younger and older patients with cancer. Previous findings report that older patients with cancer at end-of-life receive significantly fewer opioid prescriptions than younger patients (Gauthier et al., 2014; Higginson & Gao, 2012), and that opioid provision in older patients is delayed significantly longer than in younger patients (Ziegler et al., 2016). These age-related differences in opioid provision may contribute to the consistent undertreatment of pain in older patients with cancer. Further research is needed to compare opioid provision (e.g., frequency, dosage) in younger and older patients with cancer.

In the present study, only a few HCWs mentioned the need for multi-modal approaches to pharmacological pain management. Nurses believed that non-pharmacological approaches can

be effective for pain relief, however there was no consistency across the types of treatment mentioned. On the contrary, none of the physicians in the present study mentioned the need for non-pharmacological pain management. Clinical guidelines recommend the use of opioids in conjunction with non-pharmacological methods for effective pain management in older patients with cancer (Delgado-Guay & Bruera, 2008a, 2008b; Urban et al., 2010). It has been reported previously that nurses are significantly more likely than physicians to believe that non-pharmacological methods are effective for pain relief (Wells et al., 2001). Further research is needed to explore HCWs' beliefs about multi-modal pain management in older patients with cancer.

Inconsistent beliefs about pain management (i.e., opioid use, non-pharmacological management) between nurses and physicians in the present study may be related to differences in HCW speciality and education or training. Specifically, HCWs with greater experience in oncology or palliative care and geriatrics report fewer knowledge gaps or less erroneous beliefs about pain management than HCWs from other specialities (e.g., surgical) (Eftekhar et al., 2007; Furjanic et al., 2016; Ger et al., 2001; Sloman et al., 2001). Nurses and physicians in the present study did not differ in their years of clinical experience in oncology, palliative care, or geriatrics. Due to the limited sample size of physicians, it was not possible to match nurses and physicians on HCW speciality in addition to their years of overall clinical experience. The proportion of nurses who had received specialized training or education in pain management was significantly higher than the physicians. Specialized education programs in pain may be associated with beliefs about pain, as HCWs with specialized training report fewer knowledge gaps about pharmacological pain management in older cognitively impaired or intact patients and adult

cancer patients (Barry et al., 2012; Bernardi, Catania, Lambert, et al., 2007; Fetherstonhaugh et al., 2016; Yanjun et al., 2010; Zhang et al., 2015).

Nurses and physicians consistently believed there was a need for education about pain in older patients with cancer and delirium. Numerous studies report that education interventions increase HCWs' knowledge and appropriate beliefs about pain in older patients and in patients with cancer within nursing home, hospital, and palliative care settings (Borglin, Gustafsson, & Kron, 2000; Gagliese et al., 2012; Ger & et al, 2004; Howell, Butler, Vincent, Watt-Watson, & Stearns, 2000; Jones et al., 2004; Long, 2013; Treece et al., 2006; Wells et al., 2001). Future research is needed, however, to determine if these positive changes in beliefs are sustained over time, as findings are mixed (Ger & et al, 2004; Howell et al., 2000; Wells et al., 2001). Moreover, the positive impact of pain education on beliefs may also differ between nurses and physicians (Wells et al., 2001). As most studies are conducted among nurses, future research is needed to elucidate the influence of specialized pain education on physicians' beliefs about pain management in older patients with cancer.

Educational interventions among nurses' and physicians' include multi-modal learning opportunities covering topics related to pain assessment (i.e., use of patient self-report, pain scales, behavioural cues, proxy report), pain management (i.e., opioids use, non-pharmacological methods, multi-modal therapy, analgesic appropriateness for type and intensity of pain) that can span over several weeks to months (Borglin et al., 2000; Ger et al., 2004; Howell et al, 2000; Jones et al., 2004; Treeze et al., 2006). Methods of delivery may include training videos, lectures or seminars (e.g., grand rounds), interactive learning in small groups, case-study discussions, print-material (e.g., brochures, textbooks), standardized pain assessment materials (pocket pain rating scale cards, standardized procedure for obtaining reports of pain, pain behaviour cues) and

institutional feedback including family, patient, and nursing staff satisfaction with care (Borglin et al., 2000; Gagliest et al., 2012; Ger et al., 2004; Howell et al., 2000; Jones et al., 2004; Treece et al., 2006). Future research should evaluate the effectiveness of education interventions on sustained HCW behaviour change in clinical practice and its' impact on patient pain outcomes (Borglin et al., 2000).

Limitations, Strengths, and Future Directions

The present study has several limitations that should be considered. Firstly, our sample size was small and therefore more research is needed among HCWs in similar settings. However, previous qualitative research into HCWs' beliefs about pain in older people with and without dementia include comparable sample sizes that range from 7 to 80 participants. Additionally, the sample size of the present study was determined based on the number of physicians included in the study, as we were interested in comparing beliefs' between nurses and physicians. Difficulties recruiting physicians in health care studies have been previously reported (Asch, Connor, Hamilton, & Fox, 2000). Comparisons were made possible by matching nurses and physicians on clinical experience using a 1:1 matching. Most previous studies that have investigated HCWs' beliefs about pain in similar patient groups were comprised of only nurses. Therefore the present study contributes novel insights regarding physicians' beliefs about pain in older people. Moreover, to our knowledge this is the first study to compare nurses and physicians' beliefs about pain in older people using qualitative data, while taking years of HCW clinical experience into account.

Secondly, all HCWs were recruited from a network of comprehensive, urban hospitals. Therefore the findings cannot be generalized to HCWs working outside of urban or hospital settings. Future research is needed to extend the current findings to HCWs who work in rural and

community settings (e.g., outpatient clinics, long-term care settings). However, most previous studies that explore HCWs' beliefs about pain in older people have used samples of HCWs in long-term care settings within the community or hospitals. As such, the current study uses a novel population and extends previous findings by addressing pain beliefs within the context of palliative or critical care.

Within qualitative research the issue of trustworthiness or rigour is of importance. The present study took several steps to ensure rigour, and thus the 'validity' of the current findings. For example, semi-structured interview guides were used as a means to standardize study procedure and data collection. Additionally, transcript checking was completed my multiple reviewers to ensure data accuracy, and an iterative approach was used while coding the data as multiple reviewers were used to develop and revise coding schemes as needed. Critically, the researcher practiced reflexivity throughout the study using personal mind-maps and journal entries to increase transparency regarding initial impressions of the transcript, previous knowledge or preconceptions about cancer pain in older people, and rationale for coding choices.

To our knowledge this was the first study to use mind-maps to explore HCWs' beliefs about pain in older people, in people with cancer, and delirium. Although the use of mind-maps within research is in its infancy, its use as a tool within HCW education is more well-established (Spencer et al., 2013). Additionally, the use of other mapping techniques within research (i.e., concept mapping) has suggested advantages of using visual mapping approaches to analyze qualitative data over more traditional coding and data analytic methods (Eppler, 2006). Accordingly, the use of mind-maps in the present study enabled the researcher to more clearly illustrate contradictions across HCWs and between nurses and physicians. Moreover, connections between beliefs could be easily identified and compared across HCWs more readily.

The mind-maps were also useful as it allowed for a more rapid approach to become familiar with the data and to develop an initial coding scheme. After completing multiple mind-maps for each participant as part of the iterative data analysis procedure, a more traditional analysis was completed by checking and highlighting phrases or words in transcripts using computer-assisted methods. Any information missed could then be easily incorporated into the mind map under the relevant categories. Future research should incorporate mind-maps into their design to determine its feasibility and usefulness in clinical health research. Moreover, HCW educational programs aimed to increase knowledge about pain in older people with cancer could use mind maps as both an educational and awareness tool, in addition to being used as data.

Conclusions

Aging, cancer and delirium are multiply determined, and interrelated concepts marked by heterogeneity within and between individuals. This interaction can impact on every aspect of the disease experience and may contribute to the poorer outcomes documented in older than younger patients throughout the trajectory of the disease (Gauthier et al., 2017). Cancer in older people, therefore, requires consideration of the overlap and interaction of these phenomena. Although HCWs in the present study reported on these complexities and described pain as an individualized experience (e.g., personality, culture, disease characteristics, and beliefs), inconsistent and erroneous beliefs were common. HCWs' beliefs may result in inaccurate pain judgments and the undertreatment of pain in older individuals. Our study extends previous findings that knowledge gaps about pain in older patients are common among nurses and physicians. Future research should develop educational interventions for HCWs, and evaluate the impact of these programs on sustained belief change and treatment decisions.

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Appendix A

HCW Interview Sample Questions

Knowledge/Attitudes

1. Tell me about your experiences working with older cancer patients.
2. What is your impression of the pain experienced by older cancer patients?
3. Describe your usual approach to pain assessment for older people.
    a. How does this differ from your approach with younger people?
4. How does the experience of cancer pain change with age?
5. How should pain management protocols be tailored to patients of different ages?
6. Tell me about your experiences working with older cancer patients who are cognitively impaired?
7. What is your impression of the pain experienced by older cancer patients during delirium?
8. How does pain differ in older cancer patients with hyperactive, hypoactive or mixed delirium?
9. What is your impression of the relationship between opioids, pain and delirium in older cancer patients? (Probe any concerns expressed about opioid use)
10. How should cancer pain be managed in older patients with delirium?
11. What barriers/obstacles/challenges have you encountered when assessing or managing pain in older cancer patients with delirium? (Probe for patient, family, HCW and system based barriers)

Generation of Pain Cues,

1. How do you recognize pain (behavioral and clinical cues) in patients with each subtype of delirium?
    a. which of these cues are the most important?
    b. which of these cues are the most common?
2. Are there different cues for mild, moderate and severe pain?
    a. How can you tell them apart?
3. How do you differentiate pain from other symptoms or sources of discomfort such as agitation? (probe any symptoms or sources of discomfort mentioned)
4. How confident do you feel about your ability to detect pain in older people with hyperactive/hypoactive/mixed delirium (0-10 NRS)
5. How can you tell if older patients with delirium (hyperactive/hypoactive/mixed) have adequate pain control?

Notes: Prompts such as “Can you tell me more?” may be used to clarify responses and elicit further detail. If a HCW is having difficulty answering general questions, ask them to describe patients (without violating confidentiality) that they cared for who fit the question

Appendix B

Delirium Study (ST1-DECS-HCW)

Time: _____ HCW #:_____

Date: ___/____/_____ HCW Initials:_____

Please provide the following demographic and professional information.

1. Age: _____

2. Gender: _____

3. Discipline: Physician / RN

4. Specialty: _____

5. Sub-Specialty: _____

6. Institution of Study: _____

7. Number of years in practice / Year of Graduation: _____/_____

8. Number of years working in your Specialty: _____

9. Years of experience in pain assessment: _____

10. Years of experience in Palliative care / Oncology: _____

11. Years of experience working with geriatrics: _____

12. Years of experience working with cognitively impaired patients: _____

13. Number of advanced cancer patients you care for per month: _____

14. Percentage of patient in your care: Older (≥ 65 years)_____%
Younger_____%

15. Specialized Training in Pain management: _____

16. Date training received: _____