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An exploratory review of research on cancer pain and information-related needs: What (little) we know

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Introduction. Although much has been reported on cancer information needs, the literature is scant on cancer pain information-related needs. This might be prohibiting understanding of complex experiences of pain and fulfilment of information needs. An exploratory review of research on cancer pain and information-related needs is used to make suggestions for future research. The review reports on research themes, research designs and research gaps.

Method. Key Library and Information Science, Healthcare and inter-disciplinary databases were searched for articles reporting on cancer pain and information-related needs. It is an exploratory review.

Analysis: Thematic analysis identified the following themes: people affected/studied, and the type, stage and care/treatment of cancer as well as care location. It also addressed the research designs including research approaches, research methods, means of data collection and sample sizes.

Results: Research on cancer pain and information-related needs are limited, scattered in terms of cancer type, stage, care/treatment and care location, and the research designs are often too compartmentalised and simplistic to fully appreciate the complexities of cancer pain and the difficulties in contextualising, recognising, expressing, acting-on / fulfilling, and re-assessing pain information-related needs.

Conclusion: Suggestions are offered for further research embracing the commitment for palliative care of cancer pain and ensuring quality of life, enhanced research designs, the need to address the issue of differing terminologies on a broader extent between disciplines and in a narrower context, between patients and healthcare practitioners, and to explore means to address the complexity of cancer pain and cancer pain information-related needs.

Introduction

As a life-threatening disease, cancer often qualifies for palliative care, which extends from the day of diagnosis to end-of-life and which strives to improve patients' quality of life ([Pastrana et al., 2008](#); World Health Organization). A diagnosis with cancer affects all facets of life. Apart from coping with a life-threatening disease and existential uncertainties, patients may face changes in bodily image, poorer quality of

life, fear and uncertainty, loss of hope, social isolation, and highly unpleasant physical symptoms such as pain, nausea, constipation, sexual dysfunction, and other issues of sexual well-being ([Kaur et al., 2014](#); [McClland, Holland and Griggs, 2015](#)). They may need to take decisions in participating in clinical trials ([Casarett et al., 2001](#)) and pain treatment and control ([Taylor, Ferrell, Grant and Cheyney, 1993](#)). Often they are responsible for the self-management of pain ([Koller et al., 2012](#); [Lovell, et al., 2014](#)).

Pain is the most common symptom reported for cancer ([Coleman et al., 2005](#); [Galloway et al., 1993](#)). It can manifest as physical, emotional, and/or spiritual pain ([Thorney and Bruera, 2011](#); [Mako, Galek and Poppito, 2006](#)). Furthermore,

[t]he chronic pain of cancer is quite unlike the acute pain of trauma or the resolving pain of the postoperative period. These pains are easily understood, and even borne, when recovery is expected in a short time. ([Saunders, Baines and Dunlop, 1995, p.12](#)).

‘[T]he increasing functional decline, psychosocial burden, lack of co-ordination of care, and information needs burden patients’ ([Bausewein, 2013](#)) and ‘[p]ain, lack of energy, inability to meet the needs of the family, fear that the condition will get worse and loss of body image – added a lot to [lack of] quality of life’ ([Kaur et al., 2014](#)). Experiences of cancer pain are complex and diverse ([Alexopoulos et al., 2011](#)). There are different types of cancer pain including chronic cancer pain ([Villars, Dodd, West, Koettters, Paul, Schumacher, Tripathy, Koo and Miaskowski, 2007](#)), neuropathic pain ([Lema, Foley and Hausheer, 2010](#); [Stute, Soukup, Menzel, Sabatowski and Grond, 2003](#)) and nociceptive cancer pain ([Kenner, 1994](#)). Cancer pain management is often very complex ([Zernikow et al., 2009](#)). It is marked by fears for addiction, even in the terminal phase ([Vlok, 2007](#)), as well as cognitive challenges in reporting the location and intensity of pain, the frequency of pain and distinguishing between different types of cancer pain and other pain such as surgery-related pain, pain due to treatment, for example, pain from mouth sores resulting from heavy-dosage chemotherapy (mucositis) ([Martinez, Pereira, Chacim, Mesquita, Sousa, Martins, Azevedo and Mariz, 2014](#)), headaches, and even bedsores.

There are many influencing factors such as illness and treatment beliefs ([Glattacker, Heyduck and Meffert, 2012](#)), and diversity in what people want to know (‘*What I really needed was the truth*’) ([Grieve, Adams and McCabe, 2016](#)).

The World Health Organisation’s (WHO) philosophy of palliative care emphasises comprehensive physical and psychosocial patient-centred care and relief of pain and other symptoms. The highest priority in terms of routine care, clinical trials, and quality assurance should be given to pain assessment, pain control and pain management ([Anderson, 2011](#); [Pergolizzi, Gharibo and Ho, 2015](#); WHO). They furthermore stress the importance of information provision in palliative care, which is also echoed by others ([Cappiello et al., 2007](#); [Krakowski et al., 2008](#); [Zucca et al., 2014](#)). This also applies to cancer pain ([Bender et al., 2008](#)). Sometimes disclosure and the provision of information might, however, be influenced by institutional or country-specific regulations and guidelines such as legislation obliging healthcare professionals to disclose information ([Caraceni, 2011](#); [Chrisiaens et al., 2010](#); [Gartwaite, 2005](#); [Orentlicher and Caplan, 2000](#)), and the need to maintain hope or adhere to ethical issues ([Robbins, 1982](#)).

In spite of many initiatives to provide information on cancer pain and pain management ([Krakowski et al., 2008](#); [Kunhardt & Klingenfuss, 2001](#)), ongoing frustrations and barriers are reported regarding cancer pain, information-related needs, and information interactions ([Docherty et al., 2008](#); [Hovind et al., 2013](#); [Johnson and Case, 2012](#); [Kaur et al., 2014](#); [McCaffery, 1992](#); [Schlenz et al., 2011](#)). These include information needs on the causes of pain, mechanisms to access pain, the prevention and treatment of pain ([Krakowski et al., 2008](#)), self-management, pain management at the end of life ([Coleman et al., 2005](#)), rehabilitation ([Kaur et al., 2014](#)), cancer survival or remission ([Chwistek and Ewerth, 2016](#)), and avoiding addiction ([Paice, Toy and Shott, 1998](#)). Existing research and understanding seems to be inadequate in these areas.

The purpose of this paper is to assess the status quo of research on cancer pain and information-related needs in order to identify research gaps, and to offer suggestions for future research. Healthcare information needs can be researched for many different contexts, diseases, treatment and symptoms such as chronic pain ([Stinson, White, Isaac, 2013](#); [Glattacker, Heyduck and Meffert, 2012](#)), low back pain ([Nielsen, Jull & Hodges, 2014](#)) or complex regional pain syndrome ([Grieve, Adams and McCabe, 2016](#)). The authors decided to focus on cancer due to the high numbers of people affected by a cancer diagnoses ([Siegel, Miller and](#)

[Jemal, 2016](#)), and on pain due to its complexity and the limited coverage of cancer pain information-related needs in existing research. As information needs in all contexts, academic, workplace, and everyday life decision-making can be complex ([Cole, 2012](#); [Dorner, Gorman and Calvert, 2015](#)) it is even more so for cancer pain information-related needs – as we will point out in this paper.

Apart from the introduction and clarification of key concepts (information needs, pain, palliative care), the status quo of research on cancer pain and information needs will be reflected based on a thematic analysis of the focus of studies (i.e. dominant themes), and an analysis of research designs and terminological issues.

Research problem and sub-problem

To address the limitations of research on cancer pain and information needs the following problem statement guided this paper:

How can a review of research on pain, and the information needs of cancer patients and their families be used to inform research that can deepen understanding of cancer pain and information-related needs?

In searching for an answer, the following sub-problems were addressed:

- What is revealed by published studies on cancer pain and information needs in terms of foci, purpose, findings and limitations?
- What has been reported on findings regarding information needs in cancer contexts (i.e. a wider interpretation than just pain) that can inform studies on cancer pain and information needs?
- Which limitations can be noted regarding research designs and terminological issues?
- How can future research address the research gaps?

Brief background on cancer, pain management, palliative care, and information provision

As noted in the introduction, cancer pain differs from other types of pain in terms of intensity, duration, co-occurrence of other types of pain, treatment, and also in terms of how it is associated with maintaining hope ([Anghelescu et al., 2010](#); [Fayers et al., 2011](#)). Acknowledging pain is often associated with fear for what the pain might mean, admitting advanced stages of cancer, and perceptions that pain must be tolerated ([Vlok, 2007](#)).

Cancer patients face a dual problem: not only do they need to assess and describe their pain so that it can be treated and managed by healthcare professionals, they are expected to be able to distinguish between different types of pain such as chronic and acute pain ([Hovind, et al., 2013](#); [McDonald, 2009](#)). ‘*They [however receive] no explanations for and little help with chronic pain*’ ([Hovind et al., 2013](#)). Their pain cannot be seen ([Vlok, 2007](#)). Often cancer patients are expected to self-manage their pain, for example, when in home care ([Nikoletti et al., 2008](#)), and to participate in decision-making ([Ross et al., 2001](#)).

Cancer pain differs according to the cancer type, as well as the cancer site, for example, breast, prostate, lung or ovarian cancer, and stage of the disease ([Fourie, 2012](#); [Innes and Payne, 2009](#); [Deliens et al., 2012](#)). Generally, cancer pain manifests at various stages of the cancer disease trajectory – from diagnosis, throughout treatment and remission to end-of-life, and very often also in “survival” ([Bausewein, 2013](#); [Parker et al., 2007](#)). At different stages in the cancer trajectory and in different situations, patients experience different levels of uncertainty ([Hsu, Lu, Tsou and Lin, 2003](#)). Decker et al. (2007) note higher and lower uncertainties that then result in information needs.

Pain can manifest with other symptoms such as fever, nausea, lack of appetite, and sometimes even sexual dysfunction and pain during intercourse as well as psychological symptoms ([Coyle et al., 1990](#); [Edwards and Edwards, 2010](#); [Galloway et al., 1993](#); [Kaur et al., 2014](#)). Pain also has side effects – it can affect mood, appetite, and daily function ([Andersen, 2011](#)). The symptoms of pain, related to cancer as well as non-cancer afflictions, cannot be separated from the illness experience and psychological responses, and in some cases

there is co-morbidity of diseases so that the patient might have more than one type of pain to deal with ([Janke et al., 2016](#)). Some symptoms, or conditions such as cognitive impairment, may decrease the patient's ability to assess pain ([Hurley and Volicer, 2001](#)). And sometimes chronic pain can impact on patients' ability to attend to pain-related information ([Asmundson et al., 1997](#)).

Communication is very important in cancer pain management ([Vlok, 2007](#)). Cancer patients are expected to assess their pain, so that healthcare providers can treat and manage the pain; sometimes this can be problematic ([McGire et al., 2011](#); [Tate et al., 2012](#)). Intensities of pain can be rated on standardised scales ([Galloway and Graydon, 1996](#)), but this requires that patients are able to rate their pain intensity and type of pain ([Brunelli et al., 2010](#)). According to Anderson ([2011](#)) doctors need at least a minimal dataset to make decisions on pain management. Patients, however, often lack the knowledge and ability to assess their pain, and furthermore healthcare professionals are not always well trained in pain management ([Anderson, 2011](#); [Rana et al., 2011](#); [Oya et al., 2013](#); [Wang and Tsai, 2010](#)). Patients and healthcare providers may have different expectations of information on pain and may note different barriers ([Evan et al., 2006](#); [Hamers et al., 2012](#); [Jarrett et al., 1999](#); [McIntosh & Shaw, 2003](#); [Mortimer et al., 2004](#); [Stinson et al., 2013](#)).

As part of life experience, words are required to describe and label pain. Often patients lack the terminology to articulate their needs and experiences to the healthcare professional ([Bender, et al., 2008](#)). This inability also applies to the description of information needs related to pain: the ability to ask questions and express needs; the ability to recognise information needs, and language skills for clear and accurate articulation are very important ([Bender, et al., 2008](#)). It should be noted, however, that problems with recognising and expressing information needs are nothing new in information behaviour studies ([Taylor, 1968](#)).

Often family members and caregivers act as surrogates for patients in decision-making and in describing their pain or making decisions on treatment ([Oldham and Kristjanson, 2004](#); [Pyke-Grimm et al., 1999](#); [Tait et al., 2008](#)). They also need to take care of patients and support them in pain management. Patients and their families and caregivers, however, differ in terms of their information needs ([Resnizky and Bentur, 2006](#)). They also differ in terms of the chances that they will participate in educational events to address potential information needs and improve understanding, and in their perceptions of pain and pain descriptions ([Lynch-Jordan, Kashikar-Zuck and Goldschneider, 2010](#)).

With regard to pain, even more so than with other health-related information needs, it is often very difficult to distinguish between needs for information, and needs for actual help and support ([Keegan et al., 2012](#); [Snyder et al., 2008](#)). For example, Keegan et al. ([2012](#)) found that: '*The majority of AYAs [adolescents and young adults] who needed a pain management expert, physical/occupational therapist, mental health worker, or financial advice on paying for healthcare did not receive services*'. Research on cancer pain and information needs is also complicated by the difficulty to distinguish between a need for information and a need for support and a solution, in other words, a need for relief of pain.

Due to its very nature and complexity, coping with cancer pain requires more than information. It requires knowledge, understanding, and learning about such things as pain management and self-care ([Hughes, Knibb and Allan, 2010](#); [Hughes et al., 2000](#)). Brender et al. ([2008](#)), Krakowski et al. ([2008](#)), Martin et al. ([2014](#)) and Wong et al. ([2002](#)) report on patient education programmes, accessing the willingness of patients and caregivers to participate in educational events, and even on using the Internet as a support tool ([Kuziemsky et al., 2008](#)). Very few studies, however, move beyond the identification of self-reported pain-related information needs (exceptions being [Hughes et al., 2000](#)). Hughes et al. ([2000](#)) explore the importance of understanding. Very few studies recognise the complexities involved for individuals in identifying and expressing their information needs. These might be some of the reasons for the ongoing reports of frustrations that point to limited understanding of the often very complex symptoms experienced by cancer patients, and the difficulty to assess and verbalise such symptoms. In an attempt to address this lack, some patients turn to the Internet and online communities to meet with their information needs ([Park and Park, 2014](#); [Wittenberg et al., 2014](#)), and sometimes cancer patients can have an impact on pain treatment and policies ([Rogers and Todd, 2010](#)).

Clarification of key concepts

Information needs – from different approaches to an operational definition

Many attempts to define information needs have featured in research on the design of information services, information retrieval systems, and studies of information behaviour ([Cole, 2012](#); [Dorner, Gorman and Calvert, 2015](#); [Savolainen, 2012](#)). Taylor's (1968) arguments regarding different levels of awareness and expression of information needs have often influenced the work of others, for example, the work of Dervin (presenting information needs as a gap that needs to be bridged in order to make sense of a situation) (e.g., [Dervin, 1992, 1999](#); [Dervin and Nilan, 1986](#)) and that of Wilson and Kuhlthau who identify and address the anxiety and uncertainty that comes with information needs (e.g., [Kuhlthau, 2004](#); [Wilson, 1999](#)) (see also, [Case, 2012](#); [Ford, 2015](#)). According to Taylor (1968) expressions of information needs are all subject to different levels of awareness and expressions, namely, visceral, described as 'a vague sort of dissatisfaction' and therefore difficult to articulate; conscious, where the need can be articulated but only as 'an ambiguous and rambling statement'; formalised, where the need takes the form of a definitive and rational question describing the area of need in concrete terms; and compromised, where the need is redefined taking into account the nature of the information system being addressed. Therefore, to be the most effective, the patient's information needs should be expressed at the formalised level as a question requiring an answer (e.g., How long will the pain drug be effective?) or at the compromised level as an actual request for information (e.g., for a booklet on pain management, or a pamphlet on the side-effects of a drug). For the clinician, information needs can be revealed by a patient's choices on standardised instruments such as instruments for pain assessment ([Galloway and Graydon, 1996](#); [Ham, Kang, Teng, Lee and Im, 2015](#); [Marec-Berard, Gomez, Combet, Thibault, Le Moine and Bergeron, 2015](#)). Thus, it would seem that asking a question or asking for information requires patients not only to recognise a gap in their knowledge and a need for information but also hold a sufficient understanding and knowledge so that they can clearly and appropriately articulate it at the formalised level which demands the use of appropriate language and vocabulary. This is even more difficult for patients who are not communicating in their native language.

Information needs are, however, not always recognised or acted on. Sometimes the information needs are dormant ([Shenton, 2007](#); [Shenton and Dixon, 2004](#); [Wilson, 1999](#)) or ignored, or secondary to primary needs such as pain relief, self-care, post-operative self-care, rehabilitation ([Ford, 2015](#); [Kaur et al., 2014](#); [Wilson, 1999](#)), supportive care, and social needs ([Whelan et al., 1997](#)). Furthermore, there are expressions of actual information needs and expressions of perceptions of information needs (e.g., as reported in [Galloway et al., 1993](#)).

In summary, in the literature on cancer pain there is not always a clear definition of information need nor is there a distinction made between information needs, needs for learning (e.g., about cancer pain and pain management), needs for knowledge and understanding ([Bender et al., 2008](#); [Cappiello et al., 2007](#); [Hughes et al., 2000](#)), and needs for support ([Cappiello et al., 2007](#)). The situation is different in the literature concerning information behaviour in which information needs have been more specifically defined (e.g., [Case, 2012](#); [Cole, 2012](#); [Ford, 2015](#)), yet even in this body of literature there are difficulties; Shenton and Dixon (2004) highlight '[t]he lack of a common understanding of the term 'information need' ...in LIS writing' (p. 297) and that a 'problem lies in formulating a definition of information need that may be operationalized in researchable terms' (p. 306). If this is the case for a discipline in which information need figures prominently in the literature, it is not surprising to see confusion regarding the term in other disciplines.

Against the above discussion, this paper accepted an operational definition of information needs, namely that of Mackay (1960) who explained that information needs arise from the fact that the searcher has 'a certain incompleteness in his picture of the world—an inadequacy in what we might call his 'state of readiness' to interact purposefully with the world around him' (pp. 789-90).

Acknowledging terminological differences and interpretations in information behaviour and health-related disciplines, this exploratory paper focused on literature explicitly using the concept "information need(s)". (Adding terms such as patient education, learning, knowledge, understanding might also have been useful, but we decided to focus only on "information needs".) Although a body of useful sources might thus not be included in the literature review, this specific focus gave us a manageable number of articles to analyse at exploratory level and to make preliminary suggestions for further research. From the initial searches we did supplementary searches for literature to support specific statements, and we also drew on earlier readings of the literature on pain and information needs *per se*, as well as pain, palliative care and information needs. (Not all literature consulted are reflected in this paper.)

In offering suggestions for further research we extend suggestions for literature searches to related concepts such as “informational support needs”, “support needs”, and “learning needs”. Therefore the title reflects Ford’s ([2015, p. 17](#)) approach, namely, “information- related needs” and not just “information needs”.

Pain – an operational definition

Based on the definition of The International Association for the Study of Pain, pain for purposes of this paper is accepted as: “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. It is multi-dimensional, including physical, spiritual or religious and emotional pain (e.g. the pain of loss, changes of body image)” (The International Association for the Study of Pain). It has a cognitive dimension requiring the ability to recognise and articulate experiences of pain.

Palliative care – guided by the World Health Organisation’s philosophy

As a life-threatening disease cancer qualifies for palliative care which is

... an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organisation [WHO] as cited by [Fourie, 2012](#) and [Pastrana et al., 2008](#)).

Although most frequently associated with terminal care and the end of life, palliative care also applies to the early stages including diagnosis and treatment.

Methodology

Literature search

A search of key library and information science (Library and Information Science Abstract [LISA], Library and Information Source, Library and Information Science Technology Abstracts [LISTA]), healthcare and inter-disciplinary databases such as Aids & Cancer Research Abstracts, CNAHL, Health Source, Medline, PsycInfo, Thompson Reuter’s Web of Science and ScienceDirect found rather few articles when searches were conducted in November 2015 for cancer pain AND information needs. (We did not keep track of the exact number, and more articles were added to the reference management database at later stages to support specific factual statements). The words “cancer” and “pain” respectively had to appear in the title with information need(s) either in the title, keywords, or abstract. Articles were hand-selected for further analysis; they had to be in English and available as full-text. To keep the body of literature for analysis manageable it was decided not to include search terms for specific types of cancer where the term, “cancer” does not appear, for example, leukemia and Hodgkins disease. The search was also not extended to related terms such as “informational support” or “learning needs”.

Thematic analysis

In planning the thematic analysis we noted the work of Braun and Clarke ([2006](#)), Guest, Namey and Mitchell ([2013](#)) and Miles, Huberman and Saldaña ([2014](#)). We decided on a pre-determined list of issues to consider. These were deducted from the guidelines for palliative care which served as research lens (explained in more detail in the next section). Selected articles were studied and coded by the first author (familiar with work on palliative care) according to whether and how they covered key selected issues which could reveal the focus, adequacy as well as gaps in research on cancer, pain and information needs.

Rationale for palliative care as research lens for the literature review

Theories, models, research frameworks and research lenses can guide research including literature reviews. In preparation for the literature review we noted suggestions by Ford ([2015, p. 43](#)) allowing for information

needs leading to acts of information seeking as well as information avoidance needs, context in which information needs manifest, and cognitive, affective and psychological needs instigating information needs. We also took note of the 1996 model of Wilson depicting context of an information need and the person in context ([Ford, 2015, p. 102](#); [Wilson, 1999](#)), a revision of his 1981 model presented in 1999 acknowledging the context of an information need with specific reference to environmental context, social role and person in context (psychological, affective and cognitive states) ([Ford, 2015, p. 128](#); [Wilson, 1999](#)), and Godbold's model related to health information seeking ([Ford, 2015, p. 145](#); [Godbold, 2006](#)). Godbold (2006) acknowledges the person in context (as described by Dervin) and an information need (although not labelled as such in the model) is depicted as a gap. Johnson's comprehensive model of information seeking which has been tested with regard to cancer information seeking ([Johnson and Case, 2012, p. 40](#)) was also considered. Although this model focuses on information seeking, antecedents and information channels, it does not explicitly depict information needs. Although these models all hold value for studies of information behaviour and information needs, we decided to use palliative care as research lens for the literature review. Fourie (2012) reports on palliative care as context for studies of information behaviour. Her work as well as extended reading on palliative care and pain *per se* showed the need to work from the situation of the person in context experiencing cancer pain (or the caregiver). This context is palliative care that applies to all people diagnosed with a life-threatening disease such as cancer as well as their families – from the time of diagnosis, through treatment to end-of-life (and bereavement for families).

Bearing the definition of palliative care accepted for purposes of this paper in mind, five themes featuring in the guidelines of the World Health Organisation for palliative care ([Fourie, 2012](#); [Pastrana et al., 2008](#); WHO) were identified for the thematic analysis: the research participants who are also the people affected by cancer, cancer type, cancer stage, cancer care such as treatment or palliation, and the care location or setting. Palliative care extends to the patient as well as the patient's family (i.e. caregivers) ([Pastrana et al., 2008](#)). As noted earlier family caregivers often need to take care of patients' pain management ([Chng et al., 2015](#); [He et al., 2010](#)), and studies of cancer and information needs in general have noted differences in terms of the information needs and information seeking of different groups, for example, in terms of age, gender, ethnic group and culture ([Fourie, 2008, 2012](#); [Johnson, 1997](#)). Cancer types differ significantly in terms of prognosis and symptoms such as pain, and therefore also in terms of the impact on information needs and information seeking ([Fourie, 2012](#)). Information needs at the time of diagnosis differ from information needs at an advanced stage such as cancer metastases ([Bausewein, 2013](#); [Aranda, Schofield, Weih, Milne, Yates and Faulkner, 2006](#)) or a terminal stage ([Coyle et al., 1990](#)). Different curative as well as palliation treatments are used in cancer such as chemotherapy, radiotherapy, surgery and palliative chemotherapy ([Halkett, Kristjanson, Lobb, O'Driscoll, Taylor and Spry, 2010](#); [Halkett, Kristjanson, Lobb, Little, Shaw, Taylor and Spry, 2012](#)). Differences in information needs have been found ([Bender et al., 2008](#)). The site of cancer care also has an impact on information needs. Patients treated in an oncology ward for example experience fewer anxieties, and do not need to be as concerned about self-care as a patient in home care, where the burden of care, and thus also all the uncertainty and anxieties fall on the caregiver ([Schumacher et al., 2002](#)). Healthcare professionals in a hospice have a far better understanding of palliative care, death and dying and also pain treatment. The intention of the review was to establish to what extent the complexities of these issues are covered and acknowledged in studies on cancer pain and information needs.

In addition the research designs of reported projects were analysed with regard to the research approaches, participants and sample sizes, and, research methods and methods of data collection, all important factors in deepening understanding.

Findings of analysis regarding the research focus of reported projects

Research participants – those people who are affected in some way by cancer pain

Information needs are influenced by many intervening variables or antecedents such as age, gender, education, socio-economic group, ethnic group, culture, and prior experience ([Case, 2012](#); [Johnson, 1997](#); [Johnson and Case, 2012](#)). Differences were also noted in studies on cancer information needs ([Docherty et al., 2008](#)). The choice of a participating group(s) is thus very important, as well as admitting differences between findings. The literature on cancer, pain, and information needs defines participants in various ways,

for example, in terms of their role (patient, family member, caregiver, healthcare professional), time since diagnosis (e.g. 5 years), cancer type (also referred to as cancer location), disease stage (e.g. newly diagnosed, advanced cancer patient, survivor, or terminally ill), or age group (children, young adults or the elderly), sometimes also in terms of culture or as a minority group in a specific country ([Case, 2012](#); [Fourie, 2012](#); [Johnson and Case, 2012](#)).

A cancer diagnosis and pain management affects not only the patients but also families and caregivers ([Decker et al., 2007](#)) and healthcare professionals ([Di Lorenzo, et al., 2005](#)).

Three groups of participants feature more prominently in the research on cancer pain and information needs: patients, caregivers and healthcare professionals. Patients experience the pain, but healthcare professionals need to determine and assess pain and prescribe treatment for pain management based on the location and intensity of pain, the type of pain, and side effects, thus requiring a “minimal dataset” ([Anderson, 2011](#)). Cohen and Botti ([2015](#)) report that in pain management and pain assessment, patient participation is very important as it will impact on treatment outcomes and quality of life. They also found that information was key to such participation and that patients experience barriers and facilitators. Caregivers are heavily involved in ensuring that patients adhere to pain management, often also taking care of their pain management ([Chng, 2015](#)). Sometimes they need to act as surrogates in explaining the pain. Studies covering differences between the information needs of patients and caregivers, as well as studies comparing reports on the information needs expressed by patients and caregivers with the experiences and perceptions of healthcare professionals are thus very important. Considerable differences have been reported ([Evan et al., 2006](#)). There are, however, few such studies on cancer pain and information needs. Exceptions are Wong, et al. ([2002](#)) who report on differences between patients and their caregivers.

Reports on age groups are important since diversity has been noted with regard to cancer and pain in general ([Hamers et al., 1996](#); [He et al., 2010](#); [Johnson and Case, 2012](#); [McDonald, 2009](#)). In studies of cancer pain and information needs the demarcation of age ranges are often problematic, very diverse, and very inconsistent. For example, Keegan et al. ([2012](#)) report on the information needs of adolescent and young adults (AYA) with their ages extending between 15 to 39 years, which, in terms of life experience spans a huge range. Other studies reporting on cancer pain and information needs according to age groups include Decker et al. ([2007](#)) reporting on adolescents and young adults and Hughes et al. ([2000](#)) on elderly post-surgical patients.

Fukei ([2002](#)) is one of few studies addressing cultural issues. The study with family caregivers in Japan found that caregivers of newly diagnosed patients normally get the information on the patients from health professionals before the patients are told the truth. Yamagishi et al., ([2012](#)) report a nationwide study in Japan. Kaur et al. ([2014](#)) report on Indian breast cancer patients and Larue, Fontaine and Brasseur ([1999](#)) on the French public’s knowledge and attitudes regarding postoperative pain, cancer pain and their treatments. They report on two national surveys over a six year period.

Some studies focus on healthcare professionals sharing their perceptions of the cancer pain-related information needs of patients and family members. Their perceptions are based on the questions they have to deal with and other experiences with patients and family members ([Mortimer et al., 2004](#)). They have reported on the problems patients experience in assessing and describing their own pain and expressing some of their pain-related information needs.

Types of cancer diagnosis and cancer site/location

As noted earlier information needs and information seeking are often influenced by the types of cancer (e.g., breast, lung, and prostate cancer) – sometimes with considerable differences in the urgency for information, type of information, reason for information need, et cetera ([Johnson & Case, 2012](#)). Furthermore, some types of cancer, along with pain treatment and management for them are also well researched, for example, breast and prostate cancer. However, studies of information needs reported, experienced, and perceived in relation to pain experienced with specific types of cancer are very limited. Most of the reports noted for this paper are about breast cancer ([Bender et al., 2008](#); [Cappiello et al., 2007](#); [Hovind et al., 2013](#); [Kaur et al., 2014](#)). Other cancer types covered in the review include colon cancer ([Galloway and Graydon, 1996](#)), lung cancer ([Galloway et al., 1993](#)), ovarian cancer ([De Kock et al., 2015](#)), pancreatic cancer (marked by high mortality and short survival) ([Coleman et al., 2005](#)), and rectal cancer ([Kunneman et al., 2015](#)). With prostate cancer

breast pain can for example be experienced as a side effect with gynaecomastia, a non-steroidal antiandrogen monotherapy ([Di Lorenzo et al., 2005](#)). De Kock *et al.* (2015) reporting on pain in ovarian cancer and found that 'Direct information from physicians remains the mainstay of communication'.

A few studies such as reported by Keegan *et al.* (2012) involved patients with various cancer types: lymphocytic leukemia, Hodgkin's lymphoma, non-Hodgkin's lymphoma, germ cell cancer, and sarcomas. Hughes *et al.* (2000) studied prostate, breast, lung, gastrointestinal, head, and neck cancer. They found that the information-need topics emphasised varied by site of cancer.

Some of the studies report on the type of cancer and the illness stage or the type of cancer and the treatment such as Kwua-Yun *et al.* (2010) reporting on lung cancer resurrection. For some cancers the focus is mostly on information needs related to prevention, for example cervical cancer where the screening method of Pap smears and diagnostic procedures such as biopsies have been noted as sometimes painful ([Hilzenrat, Yesovitch, Shrier, Stavakis and Deschenes, 2006](#); [Morgan et al., 1998](#)).

Two important issues not featured strongly in the consulted literature were the co-morbidity of diseases and multiple symptoms associated with some forms of cancer and the subject of pain intensity which can differ widely between cancer types.

Stages of cancer including the disease trajectory

Phases of cancer range from diagnosis to end-of-life and death; where diagnosis can be categorised as early diagnosis or advanced/late diagnosis; and where end-of-life might be preceded by a terminal phase ([Fourie, 2012](#)). There are also phases of treatment such as chemotherapy or radiotherapy or surgery (see [Kunnehan et al., 2015](#); [Kwua-Yun et al., 2010](#)) which are dealt with in more detail in the section on cancer care. Differences have been noted between the pain experienced at different stages (and in combination with the cancer location and treatment), as well as the information needs experienced overall at different stages ([Lynch and Paice, 2011](#); [Parker et al., 2007](#); [Deliens et al., 2012](#)).

Newly diagnosed patients can have a range of information needs ([Fukui, 2002](#)). According to Decker *et al.* (2007) these new patients need information on future pain, the unpredictability of the different courses of the illness, responsibilities of staff, and when they [patients] will be able to take care of themselves. In a study conducted by Whelan *et al.* (1997), the patients identified social concerns as one of their self-perceived information needs. Pain was a major factor, reported by 42% of the 134 participants. Patients also reported other symptoms such as fatigue and psychological distress (confirming the co-occurrence of pain with other symptoms). Larue, Fontaine and Brasseur (1999) report on the French public's knowledge and attitudes regarding postoperative pain, cancer pain and their treatments.

Once a patient is in treatment they may transition from one phase to another ([Cappiello et al., 2007](#)) and there is likely to be a triggering of information needs regarding pain and other symptoms during ([Bender et al., 2008](#)) and after ([Capiello et al., 2007](#)) treatment; at discharge after surgery coinciding with increased uncertainty ([Galloway and Graydon, 1996](#)); as a part of follow-up care during the preparing of patients and families for which there is a need for advice on symptom management ([Hughes et al., 2000](#)); and regarding rehabilitation needs ([Kaur et al., 2014](#)). For those patients that are in advanced stages of cancer, there are often information needs regarding terminal illness ([Coyle et al., 1990](#)).

The information needs of survivors, for example, patients who have survived for more than five years, regarding pain have also been noted ([Decker et al., 2007](#); [Keegan et al., 2008](#); [Martin et al. 2014](#)) with Decker *et al.*, (2007) and Van den Breuken-van Everdingen (2012) reporting that survivors had higher anxiety, more unanswered questions, especially on what was wrong, as well as increased uncertainty due to multiple meanings of communication from doctors. 'Uncertainty is important to consider far beyond the treatment period, particularly assessment of information needs and acknowledgement of inherent uncertainty throughout cancer survivorship' ([Decker et al., 2007](#)).

Cancer treatment

Curative treatment such as chemo and radiotherapy and surgery is one of the stages of cancer as opposed to palliation aimed at the relief and management of symptoms and quality of life ([Pastrana et al., 2008](#); WHO).

Studies reporting on information needs regarding pain while patients are receiving these various types of treatment were noted under cancer stages. They are briefly repeated here to highlight treatment as an issue that specifically impacts on pain-related information needs.

A study regarding surgery for primary lung cancer noted discharge information needs ([Wang, 2010](#)). This also applied for a study after colon surgery ([Galloway and Graydon, 1996](#)). Hughes *et al.* (2000) report on elderly post-surgical cancer patients and laparoscopic surgery for endometrial cancer. Kunneman *et al.* (2015) note the numerous side effects such as pain women experience during intercourse after receiving preoperative radiotherapy. Kastania *et al.* (2009) report on the information needs of adult surgical patients regarding pain and pain management – ‘*what do they really want to know*’.

Wong *et al.* (2002) report on palliative radiotherapy and Di Lorenzo *et al.* (2005) discuss the effects of treatments such as non-steroidal antiandrogen monotherapy for prostate cancer which can cause synaecomastia and breast pain. Bosgraaf *et al.* (2013) report on psychological stress and information needs before and during colposcopy. This is in line with findings from other studies noting pain with treatment and diagnostic procedures ([Hilzenrat, Yesovitch, Shrier, Stavrakis and Deschenes, 2006](#); [Morgan, et al., 1998](#)).

Cull (1990) in the context of treatment such as chemotherapy, emphasizes the importance of helping patients understand the treatment so that they may provide informed consent. The presence of emotional expression and stress on the part of the patient are also discussed.

In a study of end-of-life care, patients receiving palliative radiotherapy given for treatment of advanced cancer identified the management of pain, fatigue, and home palliative care resources as the areas in which they continued to need additional information whereas caregivers showed greater interest in a range of topics in which to seek additional information ([Wong et al., 2002](#)). This reinforces the need for information regarding pain management at the end of life called for by Coleman *et al.*, (2005) and is similar to the assertions that during ([Bender et al., 2008](#)) and after treatment ([Capiello et al., 2007](#)) pain and other symptoms often trigger information needs.

Setting of care and treatment

Analysis of the studies indicates that setting of care is closely related to treatment and post-discharge healthcare needs ([Kwua-Yun, et al., 2010](#)). For example, Galloway and Graydon (1996) report that when patients were discharged from hospital ‘[a]n increase in uncertainty was significantly associated with an increase in discharge information needs’. In Norway, ‘[b]ecause of the short length of hospitalisation... breast cancer patients are left responsible for most of their own pain management’ ([Hovind et al., 2013](#)). Cohen and Botti (2015) report on information needs at the time of admission and during acute oncology in-patient treatment.

The settings where the studies presented in this paper were conducted differed, including: online groups/websites (site of care and treatment thus not known), in-patient oncology hospitals/units, and formalised support services such as the Supportive Care Programme of the Pain Service at Memorial Sloan-Kettering Cancer Pediatric Oncology Center ([Decker et al., 2007](#); [Wittenberg-Lyles et al., 2014](#)). For patient care, treatment times varied as well, from the short hospital stays for breast cancer surgery in Norway ([Hovind et al., 2013](#)) to the extended home care by nurses, especially in the case of post-surgery elderly patients reported by Hughes, *et al.* (2000). What did not significantly differ was the importance placed on the value of knowing about the information needs of patients, the barriers and challenges they often experienced in expressing them, and the need for interventions to address information needs and pain management to enable patients to recognise and articulate their questions and for the doctor to be able to answer them ([Bender et al., 2008](#)), providing comprehensive support ([Capiello et al., 2007](#); [Hughes et al., 2000](#)), and noting patients’ learning needs .

Findings on research designs

Research designs are important in determining what will be considered, noticed, found and learned. Considering the rather limited number of studies reporting more substantially on cancer, pain and information needs, with further limitations imposed by the foci as set out in the preceding sections, there are

also limitations of the research designs used in the studies. The following will specifically be noted: research participants and samples, and research methods and methods of data collection. Research approaches, as can be expected ranged between quantitative studies, qualitative studies, and mixed methods designs. Considering the complexity of experiences of pain ([Docherty et al., 2008](#)), and furthermore information needs ([Dorner, Gorman and Calvert, 2015](#)) there seems to be too few examples of mixed methods research.

Research participants and samples

Research participants and samples influence the validity and reliability of research findings. It makes a difference who participates. Studies with different groups of participants have noted overlap as well as differences in information needs and information behaviour. For example, Kunneman *et al.* ([2015](#)) in a study conducted with patients as well as doctors (i.e., oncologists) comparing their perceptions found ‘*substantial overlap between benefits/harms that patients and oncologists consider important to address during consultation, and at the same time poor congruence with daily clinical practice*’.

In terms of sample size, the studies presented in this paper, with a few exceptions, were very small, and often based on convenience, and/or purposeful sampling. For example, a study in Norway investigating women who had recently undergone breast cancer surgery Hovind *et al.* ([2013](#)) collected data from eight women. This is quite acceptable for qualitative research, but overall it means that understanding of cancer pain information needs is not sufficient.

Keegan *et al.* ([2012](#)) is an exception using 523 participants selected from a population-based cancer register, along with a study reported by Kaur *et al.* ([2014](#)) involving 154 patients. Specific groups are not well represented within the sample populations, an exception being Martin *et al.* ([2014](#)) who report on lower-income cancer survivors. Very few studies focused on more than one cancer phase, with the exception of Decker *et al.* ([2007](#)) who investigated patients in three phases: newly diagnosed, one to four years after diagnoses, and five or more years after diagnosis and Fukui ([2002](#)) who looked at 66 caregivers and their cultural differences.

Research methods and methods of data collection

Research methods include surveys (e.g., [Keegan et al. 2012](#)), phenomenological studies (e.g., [Hughes, 2010](#)), a study using Heideggerian hermeneutic phenomenology ([Hughes, 2010](#)), and another involving a content analysis of topics addressed by advanced practice nurses during four-week episodes of home care of 148 patients ([Hughes et al., 2000](#)).

Various methods of data collection were noted including combinations such as focus groups, semi-structured interviews, and questionnaires ([Krakowski et al., 2008](#)) and a semi-structured interview with a questionnaire ([Fukui, 2002](#)). Many used a single method of data collection such as semi-structured interviews ([Bender et al., 2008](#); [Cappiello et al., 2007](#); [Kaur et al., 2014](#)), in-depth interviews ([Hovind et al., 2013](#)) and an interview-administered analysis of frequently asked question (FAQ) postings (600) and interviews (the structure of which is not indicated) ([Galloway et al., 1993](#)).

In concert with the above methods, many studies used standardised scales in some form for the assessment of pain, symptom distress, and other issues, for example, the Karnofsky Performance Scale, Symptom Distress Scale, and Social Support Scale used by Kwua-Yun *et al.* ([2010](#)). Cohen and Botti ([2015](#)) used a questionnaire including a Control Preference Scale to determine patients’ preferences to participate. Galloway *et al.*, ([1993](#)) and Galloway and Graydon ([1996](#)) measured discharge information needs measured on the 50-item Patient Learning Need Scale (PLNS). Kaur *et al.* ([2014](#)) report on a descriptive cross-sectional study using a standardised instrument: a quality of life (QOL) functional assessment of cancer – therapy breast (FACT-B). Decker *et al.* ([2007](#)) developed a booklet of questionnaires based on Mishel’s uncertainty in illness scale; Kunneman *et al.* ([2015](#)) used a four-round Delphi study in combination with audio-taped consultations for comparison; and Galloway and Graydon ([1996](#)) interviewed 40 participants using the patient learning needs scale (PLNS). Other frameworks include the stress, appraisal and coping model of Lazarus and Folkman, the symptom distress scale, the psychological health status with general health questionnaire (GHQ), the day-to-day functioning with rapid disability scale, and the Sarason’s social support scale. Standardised instruments thus features very strongly.

It is important to note, however, that while standardised scales are very useful when involving larger numbers of participants, the “voices” of the participants are not heard, thereby omitting potentially rich data that could inform future research studies.

Hovind *et al.* (2013) used in-depth interviews to solicit data from the eight women one year after breast cancer surgery. They reported that ‘[t]he interviewees had expected pain in the acute postoperative period, but had not expected that pain would persist. None of the women recalled having received information about pain’. Hughes, Knibb and Allan (2010) discovered that patients’ information needs should be considered with other issues; that fear and lack of knowledge play an important role in entrusting the surgeon with the responsibility for most of the decision-making. It was also reported that individual, unmet information needs focussed on the practicalities of treatment and being in an unfamiliar situation and environment, reinforcing the need for practical information and that for elderly post-surgical cancer patients, information needs during the transition from hospital to home were extensive. This also applied to information needs regarding cancer pain. The following needs were specifically identified: information about community information resources, identifying events that require physician notification, and advisement on pain management.

Suggestions for future research

Based on the review of research on cancer pain and information needs, the authors recommend the development of an extended framework to guide future research. It should be noted, however, that as the scope of the review is limited, these recommendations only address issues that are directly related to the findings.

The major finding that arose from the examination of the studies on cancer pain and information needs covered in this review, and extensive prior reading on pain and information needs as well as pain in palliative care, was the complexity of cancer pain, especially in the context of information needs. Cancer pain information needs have at least three layers to consider, physical, cognitive, and emotional. If these layers are considered in relation to Taylor’s (1968) levels of information needs and the difficulties in recognising, expressing, and articulating cognitive information needs, the complexity of pain-related information needs becomes even more evident. In addition, for cancer pain information needs, a “belief” layer referring to the impact of health beliefs, religion, and the need to maintain hope might also apply. Furthermore, such layers seen in relation to levels of information needs (i.e., Taylor’s interpretation) are not unique to cancer pain; they might also feature in other healthcare contexts such as childbirth, surgery, or disease conditions such as diabetes and dementia. In this sense, this exploratory review holds value beyond discrete studies of cancer pain information-related needs.

In addition to complexity, six other things stood out regarding cancer pain information-related needs:

- The need for contextualisation of pain (cancer related, side-effect related, chronic or acute pain, pain location, and intensity, etc.);
- Recognition of pain *per se*, the importance of sharing information on such recognition, and the potential value of information;
- Expression and appropriate articulation of pain experiences and information needs;
- Actions taken to fulfil (or ignore) pain information-related needs;
- On-going re-assessment of pain as well as information needs during the disease trajectory – from pain experienced during diagnostic procedures and treatments, to advanced stages of cancer. Emotional and spiritual pain also need to be acknowledged.
- Recognising the layered nature of cancer pain information needs, and the need to address different information behavioural domains in studies of cancer pain information needs (i.e., the physical, cognitive, and affective domains).

In summary, a framework for further study should not only build on the criteria for palliative care and components of a typical research design to develop a suitable and adaptable research methodology which includes appropriate data collection instruments, but also should address all three information behavioural domains: physical – types of cancer diagnosis and cancer site/location, stages of cancer and the corresponding disease trajectories, settings of cancer care and treatment and the various cancer treatments; cognitive – differing terminologies on a broader extent between disciplines and in a narrower context,

between patients and healthcare practitioners, abilities in pain assessment and information processing; and affective – the difficulties patients often experience when articulating their information needs, especially in relation to pain assessment and the role that emotions play. Additionally, the framework needs to go beyond simply asking cancer patients about their information needs and pain-related information needs. It must incorporate alternative methods such as deducing potential information needs from other sources such as guidelines on pain management and cancer (i.e., what patients should know), their questions and actions. Studies of question and answer (Q&A) websites on pain might extend this exploratory study before moving to empirical work with cancer patients.

Conclusion

Although much has been published in a variety of disciplines on cancer and information behaviour and information needs respectively, the literature is scant on cancer pain in relation to information needs. This is true for expressed information needs, perceptions of information needs, and information needs potentially implied by other needs such as pain management and self-care, and the feedback from standardised instruments on pain and pain management. The limited, diversely scattered, and narrowly focused research reports about cancer pain and information needs might be prohibiting understanding of complex experiences, thus causing on-going frustration for cancer patients and their families and/or caregivers. This review of research on cancer pain and information needs is used to suggest some components necessary for future research. We recognize, however, that as an exploratory review many more factors need to be considered.

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