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Review of Research on Information Behaviour in Contexts of Palliative Care with an Indication of Some Research Gaps

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Abstract

An increase in the number of people diagnosed with life-threatening diseases and affected by palliative care, as well as an increase in studies on information behaviour including information seeking, can be noted. With this in mind, the paper briefly reviews reports on research on information behaviour in palliative care in terms of: target groups and participants, settings, research methods and methods of data collection, components of information behaviour, and the factors influencing information behaviour. For each, some research gaps are noted. A few key findings on information behaviour in palliative care are highlighted. The intention is not to offer a comprehensive review; it is merely an overview to stimulate research in information behaviour in palliative care and to offer a point of reference. There are numerous research opportunities preferred.

Keywords

Information behaviour, palliative care, research, scholarly communication, information seeking, palliative care information needs

Introduction

An increasing number of people are affected by palliative care often associated with life threatening or life limiting diseases such as cancer, HIV/AIDS, chronic obstructive pulmonary disease and renal failure (Fourie, 2008; Veinot, 2009). With more people preferring to die at home, there is also an increase in reliance on communities to care for patients (Abernethy, Wheeler and Bull, 2011).

Research on information behaviour in palliative care is required to improve information systems and services for patients, as well as healthcare professionals (Abernethy, Wheeler and Bull, 2011; Johnson and Nelson, 2008; Sanderson and Tieman, 2010; Street and Ottmann, 2007; Wilkes, White and O'Riordan, 2000), to improve the quality and appropriateness of information provided to patients (Payne, 2002), and to empower patients through information (Zambrano, 2011). Timely and appropriate information can also help patients and families in dealing with dying and preparatory grief, and to take part in decision-making (Tomlinson, Burker and Soden, 2012). It can help with patient empowerment through information; especially if healthcare professionals take responsibility in determining what information is available and in identifying appropriate channels and means to share such information (Wilkes, White and O'Riordan, 2000). While we strongly focus on what is to be gained from information provision, we too seldom argue in terms of what is lost if information needs are not met.

Although there is a growing body of literature on information behaviour and palliative care, there are also many research gaps that need to be identified and filled, and which might be interpreted as a research agenda in this field.

Information Behaviour

Acknowledging a spectrum of definitions of information behaviour as portrayed by amongst others, Case 2007;:2012 and Fisher and Julien, 2009, this paper accepts the interpretation of information behaviour as ' active information seeking (directed, undirected, purposive, problem-based, conscious efforts), passive information seeking (unconscious efforts, which may include encountering information, serendipitous discovery of information, glimpsing, information exposure), browsing, semi-directed information seeking, scanning, information foraging, information discovery, information giving, information sharing, information use, information transfer, choice of information sources, preferences for information sources/channels, information avoidance and ignoring information needs (Case, 2007; 2012; Courtright, 2007; Wilson, 1999). It is “the totality of human behavior in relation to sources and channels of information” (Wilson, 1999:249).

Palliative Care

The definition of palliative care proposed by the World Health Organisation (WHO) and widely accepted (Doyle, 2003; Fourie, 2008) is “...an approach that improves the quality of life of patients and their families facing the problem 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”. The WHO also stresses that palliative care should address patients and their caregivers and ensure that they are supported throughout illness and death (Bee, Barnes and Luker, 2009).

Fourie (2012) citing a discourse analysis by Pastrana *et al.* (2008) summarises the several elements of interrelated conditions applying to palliative care. She points out that of 37 English and 26 German definitions revealed, no consensus on definitions of palliative care, only overlapping categories and common elements. These include the following: one or more problems, such as diagnosis with a life-threatening disease, and various sub-issues, such as pain and symptoms that require treatment; different phases of the disease, such as the time of diagnosis, progression to a more advance stage, moving from curative care to palliation, the terminal phase, and days before dying; specific purposes, objectives, and goals of palliative care, which are mostly related to palliation – relieving pain and aiming for quality of life and dignity in dying; tasks associated with palliative care, such as management of symptoms and comprehensive care; processes related to palliative care, such as dying and grieving; target groups affected by palliative care, including patients, their relatives and healthcare workers; a multi-disciplinary team approach drawing on physicians, nurses, social workers, councillors, dieticians, etc.; specialist expertise and skills, e.g. in breaking bad news and grief counselling; a specific setting to which patients are confined, e.g. hospice, cancer hospital ward or home care; elements of palliative care, such as ethics, disclosure, confidentiality, and palliative care structures, such as legislation on euthanasia and treatment policies.

How the WHO’s definition of palliative care, the inter-related conditions for palliative care and other definitions and descriptions of palliative care can be used to conceptualise palliative care as context for studies of information behaviour is currently under investigation by the author. This can have an important impact on the scope and demarcation of research studies, data collection and the interpretation of participants’ responses. It is very important that researchers working on information behaviour in palliative care are clear about their interpretations and that they check the interpretations of people participating in their studies.

Research on Information Behaviour in Palliative Care

The following sections will give a brief review of the *status quo* of research on information behaviour in palliative care as reflected in reported studies. The intention is not to be exhaustive or to offer a systematic review, but merely to stimulate interest in the field and to offer a point of departure.

Target Groups and Participants

Studies of information behaviour in palliative care mostly focus on the information needs and information seeking of patients (Clayton and Tattersall, 2005; Fourie, 2008; Innes and Payne, 2009; Johnson and Nelson, 2008).

An increasing number of studies are also reported on the information needs of families. This include, studies on the information behaviour of parents of children (Davies, Contro and Lason, 2008; Davies, Larson and Contro, 2007), and children of parents who are patients (Kennedy and Lloyd-Williams, 2009). The interpretation of “family” has, however, been noted to be problematic (McClement and Woodgate, 1998). Some studies include a variety of family members (depending on who is available to participate), and some also include more than one family member in the same study (Fourie, 2008). Although such studies can collect richer data, there is also the danger of getting contradictory views. Studies combining patients and family members – and even caregivers, are also noted (Kirk, Kirk and Kristjanson, 2002; 2004). Fourie (2008) also reports on the South African context, while Lin and Tsao (2004) report on family caregivers in Taiwan. They are highly involved in their ill family member's symptom management and must stay at the bedside to share the nursing and care giving tasks in the palliative care unit. The six domains for which family members participating in their study needed specific information included the basic tenets of care giving, the disease, the social welfare of the patient, psychosocial issues, palliative care, and spirituality/religion. Wilkes, White and O'Riordan (2000) report on the support needs of families (primary needs), which might be interpreted in terms of (secondary) information needs.

An increasing number of studies are reported on informal caregivers (Bee, Barnes and Luker, 2009; Fukui, 2004; Lin and Tsao, 2004). The information needs of informal caregivers are especially important in ensuring that they receive sufficient support. Mazanec, Ferrell and Prince-Paul (2011) report on the experiences of distant caregivers of parents with advanced cancer.

Only a few studies have been reported on the information behaviour of healthcare professionals including the work by Sanderson and Tieman (2010) on information for general practitioners. Clayton *et al.* (2005) worked on the needs of patients and their caregivers. Fourie (2008) also involved patients, families and healthcare professionals; the emphasis was, however, on healthcare professionals' perceptions of the information behaviour of patients and families.

Some of the studies address not information behaviour, but issues underlying information behaviour. Clayton *et al.* (2005), for example, report on the discussion of end-of-life issues with terminally ill cancer patients and their caregivers.

More research is especially needed on the information behaviour of other stakeholders forming part of the multidisciplinary team taking care of patients in palliative care such as social workers and social councillors, religious/spiritual advisers, and medical aid workers. Research on the information behaviour of employers and colleagues might also shed light on the supporting infrastructure for patients. These people can play an important role in meeting the information needs of patients, and in supporting their information behaviour. They can also act as information intermediaries in giving and providing information to patients and families and also in patient education. They furthermore can fulfill an advisory role and they can also do proxy searching on behalf of patients.

Settings

Although a variety of settings feature in studies of information behaviour in palliative care, most studies focus on hospices (Johnson and Nelson, 2008). Studies of patients in home care (Bee, Barnes and Luker, 2009) are also reported. Lin and Tsao (2004) and Tomlinson, Barker and Soden (2012) report on palliative care units, Mazanec, Ferrell and Prince-Paul (2011) on a comprehensive cancer centre.

Considering that the setting such as a hospice might influence patients' and families' awareness of an illness and pending death, there seems a need for more cross-sectional comparisons between different settings. This can be combined with studying patients from various backgrounds and ethnic groups (e.g. how many patients from different ethnic groups are treated in hospice care), and alternatively in home care. Cross-country comparisons might also be useful such as reported by Kirk, Kirk and Kristjanson (2002).

Research Methods and Methods of Data Collection

Both quantitative and qualitative research methodologies feature in research on information behaviour in palliative care, with an increase in mixed methods or triangulation, using both methodologies. LaDonna (2011) also argues for the value of qualitative research. Good examples of qualitative research include the study by Clayton *et al.* (2005). The latter offers an excellent report on culturally-sensitive information-sharing in paediatric palliative care, and how the parents of children in palliative care are affected. Reading the words of parents made me realise how strong the voices of people can be to reflect their lived experience. The following is but two examples: “The doctors would tell you exactly what was happening. They talk to you, but they don’t explain… telling me [only] facts means ‘that’s it,’ [that’s all] they can do. That doesn’t make you feel better.”

During a month’s stay, a Spanish-speaking mother of a child in palliative care washed in her child’s bathroom sink because she received no orientation regarding available facilities. She feared asking questions. “I didn’t know. I thought if I asked someone they would answer me in English, and I wouldn’t be able to communicate”.

Questionnaires are frequently used, and often these are standardised instruments from the health sciences such as questionnaires on needs, information needs, well-being, quality of life, and experiences of pain. Questionnaires can be distributed by hand, or by means of email or online via a website. Although questionnaires are mostly self-administrated, there are also studies where a structured questionnaire is used to guide interviews with participants. In such cases, the questionnaire is completed by the interviewer, and the interview is recorded with consent from the participant(s). Fourie (2008) reports a study where structured interviews were conducted by an oncology social worker with a Master’s degree in Medical Social Work. Tomlinson, Barker and Soden (2012) report the use of focus groups, followed by inductive, thematic analysis. Focus group interviews were also used by Clayton *et al*. (2005), and Tomlinson, Barker and Soden (2012). Examples of studies based on individual interviews include Clayton *et al*. (2005). Bee, Barnes and Luker (2009) report on a systematic review of informal caregivers’ needs in providing home-based end-of-life care to people with cancer.

Tomlinson, Barker and Soden (2012) report on participants’ views on an issue such as written information, their experiences, and their thoughts on the value of the written information. Chassignol (2008) argues for a participatory approach to palliative care and providing Information: “The participatory approach allows the global care of patients and takes into account the suffering of healthcare professionals”… “This participatory approach to palliative care, which includes the process of keeping patients informed, is not possible without a service proposal that includes a system of care centred on patients, the role of intercommunication forums, anticipation and ethical decision-making.”

Participation is also evident in the reports by Street and Ottmann (2007) on participatory action research in the design of a portal to meet information needs in palliative care. To deepen understanding of the complexity of information behavior, a combination of quantitative and qualitative methods is necessary. Although quantitative methods can deepen our understanding of the numbers of people affected (e.g. in hospice care) or involved (e.g. using the Internet as their main information source), qualitative methods can deepen our understanding of “lived experiences” through the eyes, hearts and voices of the people. In particular, we need more very large scale quantitative studies – over a spectrum of target groups and settings. Expert statistical help can be called in for this. It would also be useful if post-doctoral researchers would be willing to engage in larger scale qualitative studies to gain findings that lend themselves more to generalisation. The value of quantitative and qualitative research methods, as well as different methods of data collection when studying information behaviour in palliative care, thus needs to be considered in their own right. As for methods of data collection, I would like to suggest that the potential of narratives and storytelling (including digital storytelling) is investigated. Some studies are labelled as exploratory and descriptive (Fourie, 2012). Too many such studies can hinder research progress in the field of information behaviour. However, if followed-up by full-scale studies building on findings and insights gained, it can turn out to be very valuable in expanding research approaches and scopes. Ethical issues are very important in research in palliative care and need to be dealt with, with great sensitivity. Kvåle (2007) offers good advice on this.

Components of Information Behaviour

The components of information behaviour as discussed in this section are noted against a wide interpretation of information behaviour. At present, studies of information behaviour in palliative care mostly focus only on information needs in general (Lin and Tsao, 2004), or information needs in combination with a specific element or condition of palliative care. Krik, Kirk and Kristjanson (2002) report on whether we are meeting the information needs of palliative care patients and their families. McConigley, Kristjanson and Nikoletti (2001) address information and support needs. They identified four trial information related needs: understanding foundational information, conflict of interest issues and financial implications of trial participation. For many studies on information needs participants are questioned on their information needs, without acknowledging the inability of participants to recognise information needs (i.e. dormant information needs as explained by Wilson 1999), or to adequately explain information needs. Problems with the latter, are captured in Taylor's (1968) seminal article on questions and answering where he notes four levels for the expression of information needs: visceral, conscious, formalised and compromised needs.

Many studies focus on information seeking where the emphasis is often on preferences for sources such as preferring doctors or nurses, or intimate personal circles or social networks. A few studies on using the Internet have also been reported, including Willis, Demiris and Oliver (2007) reporting on Internet use by hospice families and providers. Zanchetta (1998) reports on self-determination and information seeking in cancer recurrence. Hardly any studies refer to "information behaviour" as the umbrella concept as depicted in the definition by Wilson (1999) and the discussion of Savolainen (2007) who also introduces the concept "information practice" into the terminological debates of information behaviour. Examples of studies explicitly referring to information behaviour are Fourie (2008; 2010; 2012).

A substantial number of studies report on the needs and preferences of patients and families to be informed (Clayton *et al.*, 2005; Kirk, Kirk and *Kristjanson, 2004)*. How patients have been informed and their awareness of the disease prognosis and pending death may have an influence on their information behaviour.

The need and preferences to be informed is mostly not emphasised in definitions of information behaviour, or as the focus of studies conducted in Information Behaviour as a sub-discipline to Information Science and related to Library Science. There are studies, however, reporting on the preference of some people to avoid information and especially "bad news"; these also apply to health in general (Brasher, Goldsmith and Hsieh, 2002; Lambert, Loiselle and MacDonald, 2009). There is increasing recognition of the importance of good communication between healthcare professionals and patients facing cancer or end of life (Friederichsen, Strang and Carlsson, 2000; Kennedy and Lloyd-Williams, 2009; Turner, Payne and O'Brien, 2011). An extensive body of studies on information communication with regard to advanced diseases, cancer and palliative care can be noted such as De Haes and Teunissen (2005). The focus is mostly on the need for excellent verbal communication within the palliative care setting (Tomlinson, Barker and Soden, 2012). In addition, there are many studies reporting on communication in disease phases such as near the end of life (Clayton, Butow and Tattersal, 2005). Mazanec, Ferrell and Prince-Paul (2011) report on the lack of communication and control experienced by distance caregivers of parents with advanced cancer, while Turner, Payne and O'Brien (2011) report on mandatory communication skills training for cancer and palliative care staff, asking "Does one size fit all?".

Effectiveness of communication with general practitioners regarding palliative care is addressed by Taubert and Nelson (2010) exploring information exchange and communication issues, while Mazanec, Ferrell and Prince-Paul (2011) report on a lack of communication and control, and providing written information in palliative care; according to them this leads to a gap between the legislation and the nature of the physician-patient relationship in palliative care. Studies reported on patient education imply "information giving", a component of information behaviour which seldom features in studies labelled as information behaviour or outside the healthcare disciplines. In the healthcare literature, reports on patient education and providing or giving information to patients and families, are, however, not linked to information behaviour as sub-discipline. Tomlinson, Barker and Soden (2012) report on the experiences of cancer patients in palliative care and their preferences for the provision of written information. In addition to the current studies of a spectrum of information- related activities captured in the concept of information behaviour, what seems to be required are studies focusing specifically on the searching and retrieval of information, i.e. the search terms, search strategies and interaction with electronic information sources such as search engines. Studies on searching for images and using social media such as blogs might especially be useful. Studies are also required about the role and manifestation of browsing, foraging, information use, information sharing, collaborative information seeking, and information encountering in palliative care.

Factors Influencing Information Behaviour

Many factors that can influence information behaviour have been noted in reviews of the research field e.g. Case (2006; 2007; 2012), Courtright (2007) and Fisher and Julien (2009). These include age, education, gender, ethnic group or culture, and experience. With regard to palliative care the following can be highlighted as factors influencing information behaviour that have been studied with regard to palliative care (some of these factors feature explicitly in the titles of studies):

- Role, such as care giving (Fuiki, 2004; Lin and Tsao, 2004). Mazanec, Ferrell and Prince-Paul (2011) explore the complex phenomenon of distance care giving regarding an advanced cancer population.
- Relationship, e.g. spouse, parent, child (Davies, Contro and Larson, 2008; Wilkes, White and O'Riordan, 2000).
- Cultural/ethnic group. Davies, Contro and Larson (2008) offer an excellent report on giving information to Latino and Chinese families in paediatric palliative care.
- Type of palliative care, e.g. paediatrics (aimed at children) or geriatrics (aimed at elderly people) (Davies, Contro and Larson, 2008).
- Country specific differences. Fukui (2004) reports on Japanese family caregivers, and Kirk, Kirk and Kristjanson (2002) on a comparison between the perspectives of Canadian and Australian palliative care patients and their families. McConigley, Kristjanson and Nikoletti (2001) report on information and support needs in palliative care in Western Australia.
- Setting, such as hospice, hospital, or home care (Bee, Barnes and Luker, 2009). The impact of "setting' is also addressed in an earlier section.
- Disease such as HIV/AIDS (Veinot 2009) and chronic neuromuscular disease (LaDonna, 2011).
- Disease stage such as advanced cancer (Innes and Payne, 2009; Mazanec, Ferrell and Prince-Paul, 2011). Zanchetta (1998) reports on cancer recurrence. There are also reports on the terminal phase (Fukui, 2004).
- Disease location such as different types of cancer has also been studied with regard to information behaviour.

More studies are, however, needed on a cross-analysis of various factors such as role, setting and coping style; or culture and age. Studies are also needed on the Internet as orientation tool in supporting information behaviour in palliative care. In multilingual and developing communities, the impact of mother tongue and the medical terminology used by healthcare professionals and the information provided to patients and families can be studied. Although health information in countries such as South Africa is mostly available in English, the country in fact has eleven official languages. For the majority of South Africans, one of these is their mother tongue; often this is not English – the language in which health information is mostly made available. Multiple languages might also be a problem in other African countries.

Key Findings

Although a spectrum of findings are noted by studies on information behaviour, we are still touching only the surface of a complex phenomenon (information behaviour) in a very complex context (palliative care). I am mentioning only a few findings in order to stimulate interest in the research field:

- Although there are some commonalities, information behaviour in palliative care is very diverse, and very individual: one size does not fit all (Fourie, 2008). In particular, tensions are often revealed in the wishes of patients for general advice versus specific information (Payne, 2002).

- When receiving or finding information relevant to their information needs, patients and families often still experience a need for contextualisation (Fourie, 2008). Various preferences for receiving information have been noted, and preferences may frequently range between a preference for no information, to some information, to a preference for as much information as possible (Innes and Payne, 2009; Kirk, Kirk and Kristjanson, 2004; Payne, 2002). Research findings with regard to preferences for receiving information especially focus on the time of diagnosis. In addition, preferences with regard to receiving information on the prognosis also feature strongly. Clayton *et al.* (2005) compare the needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end-of-life issues. Clayton *et al.* (2005) explain: "Discussing end-of-life issues is of key importance to terminally ill cancer patients and their families, and a challenging topic for both healthcare professionals and patients/carers."
- Differences in the information behaviour of people in the same palliative care situation have been noted, e.g. differences between the information behaviour of patients and their spouses or caregivers. It does not seem possible to predict the nature such behaviour may take (Fourie, 2008).
- According to Wilkes, White and O'Riordan (2000), families often only become aware of needs for information at the time when a crisis occurs.
- The information needs of patients and families change and diverge as illness progress and communication between them becomes less verbally explicit.

Comments on a Research Agenda for Information Behaviour in Palliative Care

Although considerable progress has been made with regard to research on information behaviour in palliative care, and although this paper is putting some issues on the table, I am not feeling quite ready to propose a research agenda for studies of information behaviour in palliative care based on this. For the moment, there are, however, some first steps I think should be taken. These include:

- A conceptualisation of palliative care (as defined in the Health Sciences).
- A conceptualisation of context (as defined in information behaviour literature) that can be taken with a conceptualisation of palliative care to conceptualise context of palliative care as framework for research on information behaviour in palliative care.
- A next step would be to consider contexts in specific environments/spheres/situation(s), as well as specific incidents/moments, and to consider a diversity of multiple, overlapping contexts (Fourie, 2010; 2012).
- Systematic reviews reflecting the *status quo* on various issues related to palliative care e.g. issues related to specific diseases, treatment and quality of life (at end-of-life); this might also help to reflect research gaps.
- Mapping the research settings/locations of palliative care in terms of population groups receiving palliative care.
- Mapping the multi-disciplinary team that participates in palliative care.
- Mapping the people affected in and by palliative care.

Before-mentioned issues might shape research on information behaviour in palliative care, and might help to gain a better picture of the *status quo* before moving on to theories and models that can direct research.

Conclusion

Although a wide spectrum of issues is covered in research on information behaviour in palliative care, there seems to be much that requires further understanding. Following an argument by Fourie (2010, 2012) to consider multiple, overlapping contexts of palliative care such as "context of awareness", "contexts of pain", and "context of informing", it seems as if publications on palliative care in general such as textbooks on palliative care, as well as publications on key issues such as books and articles on quality of life (Yang and Mahon, 2011), might shed light on issues to address in research if being read through an information behaviour lens.

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