Conceptualisation of Nurses as Information Intermediaries for Patients in Palliative Care

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Abstract

It is argued that notwithstanding the life expectation of patients in palliative care, they still grapple with a wide spectrum of uncertainties for which they require answers to bring relief from anxiety. Nurses, appreciative of their role to relief anxiety, are often the only persons with whom patients have regular contact that can assist them in finding answers. Although nursing staff are well trained in palliative care, they often experience frustration when they fail to access the right information that will provide their patients' information needs. Despite evidence of numerous successful information provision interventions by nursing staff, the literature continues to report unmet information needs and frustrations of patients and their families. As a solution, this paper offers an exploratory conceptualisation of nurses and palliative care which can serve as a framework for further investigations towards enhancing nursing staff's information intermediary capacity.

Keywords:
Information Behaviour, Information Actions, Information Interactions, Information Intermediaries, Nurses, Palliative Care, Patients

Introduction

Palliative care is associated with diagnosis with a life-threatening disease or more often, the last phases of life – dying and death. It is mostly associated with ending curative treatment, such as focusing on quality of life while dying, hospice care, and coping with terminal illness (Pastrana *et al.*, 2008). It is, however, also associated by many with the mere diagnosis with a life-threatening disease (Fourie, 2008 citing the World Health Organisation; Pastrana *et al.*, 2008; Stayer 2012, p. 351). Patients in palliative care find themselves in a new, unfamiliar environment. Some gradually move into palliative care as their prognosis, after diagnosis with a life-threatening disease, worsens. For others, death may follow in a few days or weeks after diagnosis. Sometimes, palliative care applies immediately if curative care does not offer a solution (Fourie, 2008). Depending on their awareness of the diagnosis and prognosis, patients may expect to die; others may be in denial, or moving between awareness, acceptance and denial (Glaser & Strauss, 2005). Patients experience much uncertainty and anxiety in trying to cope, making sense of what is happening to them, and in maintaining something of their former lives. Their information needs and behaviour have been reported as complex, diverse and heterogeneous (Clayton, Butow & Tattersall, 2005; Fourie, 2008). For example, they find themselves in a context (palliative care) where they are facing death.

In this unfamiliar environment, patients share much of their lives and needs with healthcare professionals such as nurses. They depend on them for physical care, and to be informed about the diagnosis, prognosis and purpose of palliation (Bilodeau & Degner, 1996). Their families and informal caregivers rely on healthcare professionals for information and support (Carter, 2001; Bee, Barnes, & Luker, 2009). Of all healthcare professionals, nurses seem the people closest to interact with, and exchange information. Nurses seem

to be in the best position to support patients in their efforts to cope with their diagnosis and with prognosis, to make sense of what is happening with them, to try to maintain as much quality of life as possible (McCaughan & McKenna, 2007), and to make decisions (Beaver *et al.*, 2006; Bilodeau & Degner, 1996). Patients often prefer human information resources, trust nurses and find them more accessible than doctors (Neumann *et al.*, 2011). Nurses are expected to offer emotional support (Drew & Fawcett, 2002), and are called on for holistic patient care. For palliative care, the provision of information to patients and families can include: "The human rights of the moribund include liberty, dignity, personal integrity, information, assistance, and relief from unnecessary suffering" (Echeverri & Acosta, 1996).

Under these circumstances, it seems as if there is a need for nurses to adopt an information-related role. Information actions and interactions can range from providing factually correct and appropriate information on issues that deal with self-care and pain management to discussing the disease with lovedones (Davies *et al.*, 2010; Matti *et al.*, 2010; Wilkes *et al.*, 2000). Nurses should be able to act as soundboards for patients, answering questions and helping them to make sense of the information they receive. They may even be required to answer questions on related matters such as euthanasia and living wills. Within palliative care, there seems to be a need for nurses to serve as a link between information related to palliative care, other healthcare professionals and the patient and family. Although nurses can be specialists in their own right, not all are trained in palliative care, the complexities and ethical concerns of full disclosure on diagnosis and prognosis, and finding a balance with maintaining hope (Curtis *et al.*, 2008; Osuna *et al.*, 1998; Turner *et al.*, 2011). Although providing emotional support is very important for nurses (Fourie, 2008), they are not trained to balance this with patients' information needs and information behaviour. Often they need to develop their own coping mechanisms to distance them from the plight of patients and coping with their own emotional experiences (Menzies, 1993).

Many information-related actions have been ascribed to nurses such as: information sharing, giving, provision, dissemination, responding, communicating, connecting, exchanging, educating (i.e. patient education) and even empowering (Davies *et al.*, 2010; Drew & Fawcett, 2002; Fields *et al.*, 2006; Hustey & Palmer, 2010; Schultz, 2002; Wilkes *et al.*, 2000). Reports on these aspects acknowledge the needs of patients for support with their expressed information needs. However, such reports seldom reveal evidence of insights gained from Information Behaviour (a sub-discipline of Information Science). In spite of the time and effort going into information-related interventions, numerous unmet information needs and information-related frustrations are reported by patients and families (Kristjanson *et al.*, 2004; McCaughan & McKenna, 2007; Neumann *et al.*, 2011). These point to inadequate understanding of: (1) the information behaviour of patients (and their families); (2) how healthcare professionals can support the fulfilment of patients' information needs; (3) and how healthcare professionals can facilitate patients' information behaviour.

From the above, it is evident that there is increase in the number of patients diagnosed with life-threatening diseases such as cancer (Jemal *et al.*, 2011), people requiring palliative care, as well as those preferring to die in their own homes (Bee, Barnes, & Luker, 2009; Melin-Johansson *et al.*, 2008) all echo their uncertainties on nursing staff. Yet, nurses' training, as well as professional literature, prepares them only partially for their information role. It seems thus timely to conceptualise a role for nurses as information intermediaries.

Statement of the Statement

From the introduction, it seems evident that: (1) Within the palliative care context, patients develop needs for information in addition to the available factual information related to the specific life-threatening disease and care-giving (i.e. palliation); (2) Healthcare professionals and especially nurses may be in a unique position to act as intermediaries between information and patients to provide in their information needs (recognised information needs, expressed information needs, and dormant information needs) and to facilitate their information behaviour; (3) Healthcare professionals would need to develop the capacity to act as information intermediaries, understanding the full spectrum and complexity of the information needs, information behaviour and information practices caused by a

patient's (deteriorating) health status; (4) Healthcare professionals (e.g. nurses) need to understand how their information actions and interactions such as information sharing or information transfer can either increase patients' anxiety and fear or relieve it. (The concepts "information behaviour" and "information practice" are explained in a later section.)

Scope and Purpose of the Paper

To address the stated problem, this paper will clarify key concepts such as information behaviour, information practice, palliative care, and intermediary, before briefly reviewing selected findings on the information needs and information behaviour of patients in palliative care with specific reference to the role of nurses. Reports on the information-related role of nurses in other contexts will also be acknowledged. The paper will touch on the need for nurses to understand the spectrum of information behaviour and information practices of patients, the spectrum of information- related actions in which they can support patients, and the ability to contextualise each patient's individual needs in terms of information and other support (e.g. emotional support) required.

Clarification of Key Concepts

A section on the clarification of concepts is essential to ensure that the meaning attached to concepts clear to the researcher(s), readers and (when applicable) also research participants. Too often an intuitive understanding of concepts is assumed. Saracevic (1975, p. 324) refers to the "y'know" approach where it is assumed that everybody knows the meaning of key concepts. It should be kept in mind that people's worldviews are formed by their understanding of something which in turn influences their decision-making and willingness to think about difficult issues such as death and dying (Daveson *et al*., 2011). As Pastrana *et al*. (2008, p. 222) put it: "The use of the language is not just the way of transmitting meaning, but it constitutes what we do and how we do it."

Information Behaviour

Information behaviour is "conceptualised as complex human information-related processes that are embedded within an individual's everyday social and life processes with evolutionary and developmental foundations" (Spink & Heinström, 2011, p. xvii). It "encompasses information seeking as well as the totality of other *unintentional* or *passive* behaviours (such as glimpsing or encountering information), as well as purposive behaviours that do not involve seeking, such as actively *avoiding* information" (Case, 2007, p.5). Information behaviour can include being unaware and ignoring information needs (Wilson, 1999). Recognising the difficulty of defining "information needs", Wilson (2005, p. 32, 35) suggests that the term should be ignored and replaced with "information seeking behaviour", since behaviour is observable while needs are internal mental states that cannot be seen. It may, however, be difficult to ignore the concept of needs in information behaviour or to replace it with a completely different term since needs are a reality in human activities. Information needs are closely linked to challenges that individuals (such as patients in palliative care) experience in all facets of their lives. Information behaviour manifests in the work, research, study and everyday-life world. It is influenced by cognitive, conative and affective factors (Hepworth, 2007, p.41).

Information Practice

"Information practice" has been suggested as alternative to "information behaviour". According to Savolainen (2008, p. 4) "... information practice emphasises the role of contextual factors that orient people's information seeking, use, and sharing as distinct from individualist and often decontextualised approaches". "Information practice" features in studies in healthcare context, information literacy and information use (e.g. writing assignments). According to Byström and Lloyd (2012), information practice "as a social practice"… "is composed of a range of activities, e.g. to produce information, to seek and acquire information, to place value and evaluate information, to identify and compose information into meaningful combinations, to distribute and share information, and, in general, to put information into use." It can also include deliberately withholding or failing to provide appropriate information (Byström & Lloyd, 2012).

Apart from researchers noting information

practice as an alternative to information behaviour, these two key concepts are mostly not well aligned. This also applies to other information activities and information interactions, such as information giving, information provision, information dissemination and information transfer. Although noting this gap, this paper will not attempt to address it.

Palliative Care

A lack of conceptual clarity on palliative care and differences in country and cultural specific interpretations are often noted (Bosma *et al.* 2006; Meghani, 2004; O'Connor *et al.*, 2010). The World Health Organisation's (WHO's) definition of palliative care is a definition widely cited as point of departure for research projects (Fourie, 2008; Pastrana *et al.*, 2008). It defines palliative care as "... 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 American Academy of Palliative Care (AAP) definition (as cited by Stayer 2012, p. 351) for palliative care for children is also worth noting: "Sensitivity to and respect for the child's and family's wishes; palliative care includes the control of pain and other symptoms and addresses the psychological, social, or spiritual problems of children (and their families) living with life-threatening or terminally ill conditions; the goal of palliative care is the achievement of the best quality of life for patients and their families, consistent with their values, regardless of the location of the patient."

From these two interpretations, the following seem important when considering palliative care as concept: (1) improvement of quality of life; (2) the need to include patients and their families in palliative care; (3) dealing and coping with the problem of a life-threatening disease; (4) facing a disease that may be terminal; (5) the need to address physical, psychosocial and spiritual problems; (6) sensitivity and respect for the wishes of patients and families; (7) need to provide care consistent with the values of the patients and families; (8) need to ensure that the location of care does not have an impact on the palliative care provided. The need to support patients and their families is also stressed by Bee, Barnes and Luker (2009), Finlay and Jones (1995) and Meghani (2004). Although palliative care is often associated with terminal and end-of-life care, any diagnosis with a life-threatening disease may imply entitlement to palliative care from the time of diagnosis onwards.

Intermediaries and Information Intermediaries

Intermediation in its broadest sense implies dialogue where information in the form of advice or counselling flows from one person to another (or many). The emphasis is on facilitation. Rogers (Rogers & Shoemaker 1971, p.229) refers to an intermediary as a "change agent", stating: "[He] is necessarily a marginal man with one foot in each of the two worlds." According to Jinkook and Cho (2005), an intermediary is a human or non-human party that assists people in processing information.

The collection, organisation and distribution of information can also be included. Although Maglio and Barrett (2000) are concerned with non-human intermediation (i.e. the use of software), their observation that intermediation concerns "meaningful transformation of information" is especially important. According to them, information flows from one computer to another. Although it will not be pursued at this stage, it is noted that such "flow" might perhaps be further investigated against Csikszentmihalyi's (1997) theory of flow. However, fledging this out will require substantial further reading, reflection and cross-disciplinary research.

Patients' Information Needs and Information Behaviour

Before conceptualising a role for nurses as information intermediaries for patients in palliative care, findings on the information needs and information behaviour of patients in palliative care are briefly reviewed. (Considering length restrictions for the paper, findings on families is not considered).

Information Needs

Information needs have been linked to gaps in knowledge, the need to make sense of a situation,

an anomalous state of knowledge, and dealing with uncertainty (Case, 2012, citing the work of researchers such as Dervin, and also Belkin, Oddy & Brooks). Patients have been reported to need factual information on the disease (e.g. physical symptoms, emotional symptoms, stages, prognosis, cure), treatment (effect and success rate, side-effects, and alternatives), where to get help, diet, psychosocial care, complementary care, management of disease relapse, fatigue, sexual activity and sexual well-being, issues of genetics and hereditary diseases, cancer risks, drug information, coping strategies, weight-management, cancer screening, cardiovascular health, and euthanasia (Curtis *et al*., 2008; Mahon & Williams, 2000; Mason, 2005; Ohlendorf, Marianne & Ryan, 2012; Piredda *et al*., 2007; Watts *et al*., 2004). Patients need information throughout the illness, from the time of diagnosis, during dying, as well as close to death; sometimes the need is for professional advice or emotional support in contrast to information (Bee, Barnes, & Luker, 2009; Zanchetta & Moura, 2006).

It is clear that information needs sometimes differ according to disease and age groups. Ishibashi (2001) reports on the needs of children and adolescents with cancer for information and social support and Hughes *et al*. (2000) on the information needs of elderly postsurgical cancer patients during the transition from hospital to home. Posma *et al*. (2009) report on older patients. Beaver *et al*. (2006) report on the information needs of women with breast cancer and Matti *et al*. (2010) on multiple sclerosis – to name only a few studies. In a study on breast health information needs of women from minority ethnic groups, Watts *et al*. (2004) report that their needs appear to have been an "add on", and that healthcare professionals lack understanding about cultural beliefs, values and knowledge, together with racial stereotyping and misconceptions about cancer in minority ethnic groups. Neumann *et al*. (2011) refer to subgroups of information needs. When leaving the hospital for home care, issues arise such as: postoperative self-care, symptom management, clarifying the illness experience, psychological responses, coordinating follow-up care, community resources, identifying events that require physician notification, and pain management (Hughes *et al*., 2000). Patients differ in the amount of information they want: some desire as much

information as possible, while others want only the basics; information provided may be too advanced for their level of education or understanding; information may be in a language with which patients are not fully comfortable (Curtis *et al*., 2008; Rees & Bath, 2001).

Apart from factual information, patients desire information that will enable them to cope with their disease and treatment, and maintain quality of life. Information needs may differ according to the disease stage, e.g. newly diagnosed (Graydon *et al*., 1997) vs those close to end-of-life (Fourie, 2008; Zanchetta & Moura, 2006). Information is often aligned with primary needs such as social support (Ishibashi, 2001). Some researchers argue that information seekers should be given maximum information, and information avoiders should be given minimum information (Rees & Bath, 2001). According to Matti *et al*. (2010), it is important for nurses to understand the disease such as Parkinson's disease and understand the potential needs of patients. They must also understand why patients seek information. Rees and Bath (2001) report that women with breast cancer seek information to cope with breast cancer, to regain a sense of control, increase their feelings of confidence, and help facilitating the decision-making process. Their reasons for avoiding information include: escaping from worry, fear, feelings of negativity, and depression (Rees & Bath, 2001).

Nurses should be able to predict and prioritise information needs (Bilodeau & Degner, 1996). Many debates have been reported on the importance of keeping a balance between maintaining hope and the patients' desire for information (Curtis *et al*., 2008). To support patients, nurses need to understand the spectrum and diversity of patients' information needs (e.g. factual information vs information on copying). They also need to understand the impact of family relationships on information needs such as the needs of adolescent children or spouses of women diagnosed with breast cancer, or the wives of men who had a prostatectomy (Fitch & Abramson, 2007; Fitch & Allard, 2007; Kilpatrick *et al*., 1998; Kristjanson *et al*., 2004; Mason, 2005), or of the parents of children (Davies *et al*., 2010). Differences have also been noted between the information needs of patients and caregivers (Carter, 2001; Clayton, Butow, & Tattersall, 2005; Hasson *et al*., 2010; Nikoletti, *et al*., 2003).

Posma *et al*. (2009) note insufficient exploration of patients' personal situations and individual information needs. In a study on the information needs and understanding of 5-10-year old children with epilepsy, asthma or diabetes, Houston *et al*. (2000) report that the children with epilepsy had far more unanswered questions and felt excluded from discussions with doctors. They were more reluctant to tell their friends their diagnosis and felt stigmatised by their condition. Stigma is often also associated with HIV/AIDS and sometimes cancer where people are not prepared to discuss their disease.

A closer look at the nature of the different types of information needs identified above shows that patients' information needs are not only restricted to the type of life threatening disease from which he/she suffers, but also information about issues related to the implications for the patient within his/her current health status. Their information needs are complex, with many nuances, diversity, and antecedents (Johnson & Case, 2012), considering that the nurse who operates in a palliative care context should expect to regularly encounter these types of information needs and nuances among patients. It could be assumed that such regular encountering could be instrumental in encouraging nurses to be more proactive regarding where to find information that will support patients, and to accept a supporting information-related role.

Information Behaviour

The information needs of patients lead to different information actions that form part of their information behaviour. Nurses' awareness and perceptions of the information behaviour of patients will influence the information interactions they instigate – how they provide, give, share and disseminate information. The information behaviour of patients in palliative care is thus covered in the following paragraphs with specific reference to the role of nurses.

Patients have been frequently reported to prefer human contact when seeking information, with healthcare professionals, family members and friends as the most preferred sources; doctors and nurses are the most trusted sources (Neumann *et al*., 2011). Sometimes patients rely on others to search on their behalf (Abrahamson *et al*., 2008).

Similar to information needs, great diversity in information behaviour has been noted. Such differences depend on disease, age, context, culture and type of care, e.g. paediatric palliative care (Davies *et al*., 2010). Patients' information behaviour for various diseases has been studied; studies on breast cancer are especially prominent (Bilodeau & Degner, 1996; Fu *et al*., 2008; Nikoletti *et al*., 2003). Studies of information behaviour are very diverse. McCaughan and McKenna (2007) refer to "never-ending making sense" when discussing the information-seeking behaviour of newly diagnosed cancer patients. Mutch (2005) reports on young people in families where multiple sclerosis has been diagnosed; nurses need to be aware of the need to address myths on multiple sclerosis, and they should be willing to discuss the disease. Information can soothe anxiety but it can also increase anxiety.

Different processes such as dying and stages such as early in diagnosis or at end-of-life have been noted to impact on information behaviour (Bee, Barnes, & Luker, 2009; Gopal *et al*., 2005; McCaughan & McKenna, 2007). (This is also the case with information needs.) Information copying styles need to be considered (Nikoletti *et al*., 2003; Rees & Bath, 2001). Zanchetta and Moura (2006) report on self-determination and information seeking in end-stage cancer. According to them the following are important to understand the experience of being confronted with a terminal illness: expansion of awareness, life-facing knowledge contradictions, being open-minded and an active explorer of information sources, medical truth, and professional attitudes toward patients' information needs. It is evident that the information behaviour of patients in palliative care can be complex, and it reflects the perceptions of patients of the implications of the disease on their life styles. How they deal with their perception of their health status manifests in their information behaviour.

Knowledge of patients' information behaviour can better equip nurses to deal with situations and anticipate situations where patients need support. From the preceding review, there seems adequate proof that there is an underlying awareness among researchers that nurses are aware of to be their patients' information behaviour – in terms of their preference for specific information sources, personal beliefs about myths or medical truths and cultural differences.

Nurses are also aware of patients' needs and how their families and caregivers are affected by the implications of their health status, as well as professional attitudes towards patients' information needs. However, there is no evidence that nurses explicitly identify it as an area about which they should familiarise themselves to be better prepared in meeting patients' needs and facilitate their information behaviour – that is, to act as information intermediaries. Neither is there evidence that they acknowledge the complexity of information behaviour as portrayed in the Information Science literature (Case, 2012; Johnson & Case, 2012).

Seen from an Information Behaviour perspective the lack of understanding about cultural beliefs (Davies *et al*., 2010), the amount and level of sophistication of information required, when information is needed, and the language preference of patients are all indications of how important it is that nurses need to be familiar with the information behaviour patterns of patients (amongst many other issues) in order to be more successful in information interactions with patients.

Information-Related Support and Interaction between Nurses and Patients

From the preceding discussion on the information needs and information behaviour of patients in palliative care, it is evident that nurses are often exposed to patients in palliative care in need of information and how patients can respond to different levels of information. Insights gained on information behaviour of patients at the nurse/patient level might help nurses to improve how they meet patients' information needs with meaningful, relevant information, how they might facilitate patients' information behaviour (e.g. offering support in identifying information needs, seeking information, and using information) and also in preventing negative information behaviour such as seeking information from unreliable information sources, or information avoidance (Case, 2012).

To fulfil a role in this regard, nurses should be alert to the variety of information actions and interactions that may manifest in palliative care between themselves and patients and the situations where these can be instrumental (e.g. in reducing

anxiety) – an emotional condition, or in helping patients to cope, or make sense of their illness or dying. Furthermore, nurses should be able to interpret findings on information needs and information behaviour in palliative care. They should also have adequate information skills to find, evaluate, select, manage, repackage, and communicate information (amongst other things). Concerns have been expressed about their information literacy and knowledge of diseases. Duncan and Lorraine (2012) are concerned about the information seeking skills of senior students and especially their lack of ability to identify vocabulary to search for information, while Irvin (1997) is concerned about nurses' limited knowledge of diseases such as HIV/AIDS. Currently, the professional training of nurses working with patients in palliative care and their literature do not adequately prepare them for information related support manifesting as information actions and information interactions (i.e. apart from training in patient education and health communication). In the paragraphs to follow, some of the information actions and interactions taking place in palliative care between nurses and patients are noted.

Information actions can be explicitly labelled as such or implied by the choice of words. Explicitly labelled information actions include information sharing, information exchange, information giving, information provision, information dissemination, information transfer, and information communication (Bilodeau & Degner, 1996; Drew & Fawcett, 2002; Schultz, 2002). Information actions between nurses and patients in palliative care can, however, be implied by words and phrases such as responding, connecting (serving as a link), empowering, answering (e.g. questions), informing, explaining, contextualising, arguing or defending (e.g. on issues of euthanasia), acting as soundboard, discussing, encouraging, motivating, calming, bridging, and re-ensuring. Information actions can be proactive (before patients express a need for information) or reactive (in response to questions and concerns). The same applies to information interactions. For both, an understanding of the information needs and information behaviour of patients in palliative care is essential.

Apart from interactions such as discussions, information interactions include information interventions. In addition to a role to care for patients,

some nurses need to take on roles for patient education (Curtis *et al.*, 2008; Kilpatrick *et al.*, 1998; Posma *et al.*, 2009), and the planning and development of interventions such as telephone support, telephone help lines, information sessions for patients and their families, and information packages and booklets. Sometimes, these efforts are described as the empowerment of patients (Wilkes *et al.*, 2000), e.g. to participate in decision-making.

Information actions and interactions can happen spontaneously, or as a result of pressure from patients (i.e. through questions). Davies *et al.* (2010) report on how information is shared about a child's daily life in the hospital, the families' daily life in the hospital, treatment, and end-of-life issues. Findings from studies on information needs and information behaviour can address some of the reported shortcomings of such actions and interactions. According to Carter (2001), information is sometimes provided in a way that is more harmful than helpful. Nurses often miss the need for holistic healthcare considering all facets of the disease, the patient's situation, the need for individualisation, and the need to incorporate caregivers (Carter, 2001). Information is also not always provided in a sensitive yet factually accurate manner (Carter, 2001), or with consideration of the patient's responsibility to his/her family (Kristjanson *et al.*, 2004) as it is the case with women with breast cancer. Often, additional types of information are required to reduce anxiety and increase understanding, e.g. videos or multimedia programmes. Bilodeau and Degner (1996) as well as Nikoletti *et al.* (2003) note the need to align information needs with an understanding of patients' or their family members' desired roles in decision making, and their copying styles (i.e. "monitors" for information seekers and "blunters" for information avoiders) (Case, 2012).

Information actions and information interactions as such do not represent a role as information intermediary. Each forms only a small part of such a role. To fully conceptualise an information intermediary role for nurses, each information action and information interaction manifesting between nurses and patients in palliative care needs to be identified and carefully studied. It also needs to be aligned with findings, interpretations, and models from information behaviour. At present, little is

known in this regard. Most models of information behaviour focus on information seeking and searching.

Wilson (1999) is one of few researchers that acknowledge information transfer as an information action forming part of information behaviour. Information actions are also too seldom addressed from an information behaviour point of view. An exception is Davies *et al.* (2010), reporting four patterns of information-sharing: no information, basic information, basic information plus implications, and basic information plus implications plus attention to parents' questions, concerns, and emotions (the latter happens in the minority of cases).

Information transfer is one of the information actions that hold much potential for a role as information intermediary – if fully understood and aligned with findings on information needs and information behaviour. In healthcare contexts, information transfer is discussed by Duffy *et al.* (2010), Madden *et al.* (1998), Hustey and Palmer (2010), and Keenan *et al.* (2006). Duffy *et al.* (2010) report a study on the impact of point of care documentation on the nurse-patient interaction. Such documentation reduces inefficiencies, decreases the probability of errors, promotes information transfer, and encourages nurses to be at the bedside. It can, however, also distract nurses' attention away from patients and compromise the nurse-patient interaction. Madden *et al.* (1998) report on an interface between nursing homes and emergency departments to improve transfer of information, and Hustey and Palmer (2010) on an Internet-based communication network for information transfer during patient transitions from a skilled nursing facility to an emergency department.

With concern for inadequate information transfer at shift changes, Keenan *et al.* (2006) report on a technological supported model for improving nursing handoffs. It focuses on the handoff as a focal point for not only information transfer but also reinforcing shared meaning and goals across shifts and units. Although useful, such research needs to be extended before it can fully reflect the potential role of nurses as information intermediaries. It should also raise awareness of the complexities of information transfer if it is intended to fulfil information needs and facilitate information behaviour. In the wider literature, many strengths of information

transfer have been stressed. Concerns have, however, also been expressed. Lee and Garvin (2003) criticise the one-way nature of accepted practices of information transmission. Much of the arguments on information transfer and information transmission is based on views originating from the field of sociology citing Freire's (Freire, 1970/1986) "banking concept" commenting that students (in an educational setting) become empty "containers" to be filled by knowledge of the teacher. Lee and Garvin (2003:451) warn that "Most health information transfer is characterised by this 'banking' approach".

According to Lee and Garvin (2003), there is strong resistance to the term transfer. There are, however, models such as the Interactive Communication Model of Havelock (Havelock 1986, p. 226) that can address some of the concerns, e.g. to ensure that there is no intention to "privilege expert over lay knowledge" or "transfer information as a monologue". This brief discussion of information transfer touches on its potential as an information action for which nurses can take responsibility in a role as information intermediaries. As noted, much more detail and understanding are required. Other explicitly labelled and implied information actions and interactions also need to be studied with care. A first step might be a content analysis of (1) which information actions and information interactions are reported between nurses and patients in palliative care, and (2) how these actions and interactions are reported with regard to addressing information needs and information behaviour.

Nurses as Information Intermediaries in Palliative Care

From an information behaviour point of view, a palliative care setting or situation can be viewed as a complex temporary context – temporary context as defined by Courtright (2007), where patients face existentialism. Here, nurses do not only take care of patients, but they also interact with patients. Such interaction needs to reflect empathy and support to alleviate anxiety among the affected patients. Findings from studies on the information needs and information behaviour of patients point to the importance of information and the inherent complexities of information behaviour and

information actions. Nurses, more than other healthcare professionals, seem to be suited to take on a role as information intermediaries. Their link with patients seems to be much more direct and therefore stronger than between the patient and other healthcare professionals. The nature of such a role, however, needs to be carefully studied. The conceptualisation offered in this paper is a first step in this direction. A few of the issues that need to be explored are noted here. (This is not intended as a comprehensive list; merely a point of departure.) Before continuing with this, an operational definition for an information intermediary in a palliative care context is proposed below. This builds on the section concerning intermediation and information intermediation.

An information intermediary in palliative care (a complex, fluctuating, temporary context where patients face existentialism) draws on advanced information literacy, communication and healthcare skills to act in a responsible and appropriate manner to ensure that meaningful, relevant information (as supplement to physical and emotional care) reach and support patients living with a life-threatening disease (e.g. making sense, coping, maintaining hope, making decisions). In fulfilling this role, an information intermediary employs a spectrum of information-related actions such as information transfer, information sharing, information giving, and information exchange. Intermediation can take the form of advice and counselling, but can also culminate to formal information interactions such as patient education. An information intermediary employs dialogue and communication skills, as well as knowledge of diseases and healthcare to ensure the appropriate and effective flow of information between sources (be that a healthcare professional, doctor or Internet resource) and to address the influence of antecedent factors on the information behaviour of patients. An information intermediary facilitates all information-related activities of patients, ranging from awareness for a need for information, to help in the formulation and expression of information needs, as well as help with the seeking, evaluation, interpretation and especially the contextualisation of information with regard to a patient's individual situation. In palliative care, all information actions of an information intermediary reflect empathy and cultural sensitivity, and foster trust in his/her ability to act as information intermediary.

In preparing nurses in palliative care to take on such a role, we can start by considering the following:

- Scope, purpose and nature of information actions and information interactions reported between nurses and patients in palliative care and the terminology used to describe these.

- Ethical issues related to information actions and interactions in palliative care such as the right of patients to be fully informed (Osuna *et al.*, 1998).

- Need to maintain a balance in the use of information actions and information interactions and to help patients to maintain hope.

- Readiness to accept a role as information intermediary in addition to tasks of care and treatment. Nurses are already overworked, facing burnout and emotional trauma due to their work (Menzies, 1993; Fourie & Claasen-Veldsman, 2011).

- Requirements for successful and effective information actions and interactions such as good communication skills, adapting for individualisation, and empathy (Drew & Fawcett 2002; Turner *et al.*, 2011; Wilkes *et al.*, 2000).

- Depth and detail of information to provide and how to align this with patients' educational level, desire for information, readiness to receive information, etc.

- Awareness of and sensitivity to the impact of culture and ethnic differences in information interactions (Bilodeau & Degner, 1996; Gopal *et al.*, 2005).

- Recognition of the influence of antecedent factors and barriers in information interaction which can include educational levels, personal and interpersonal situations, available material and documentation, guidelines and policy, organisational structures, politics, resources and time, limited dialogue with patients, different priorities held by nursing staff, insufficient time to inform patients, and exploration of ways to address such barriers (Keatinge *et al.*, 2002; Piredda *et al.*, 2007; Mason, 2005).

Conclusion

Albeit the importance of information in a complex context such as palliative care, (including the close ties between patients and nurses, and the acceptance of nurses as information sources by patients), extensive research and reflection, is required before a role for nurses as information intermediaries can be fully pursued. Findings from studies on information needs and information behaviour in palliative care point to the need for information intermediaries. Who, better than nurses, can take on this role? The conceptualisation offered in this paper is, however, only a very small first step towards pursuing and establishing such a role for nurses. A stronger case needs to be made for nurses as surrogates for (or supplements to) formal library and information services. Regarding information behaviour, research has shown that "one size does not fit all" – that is, there is not a single solution in meeting information needs. It thus seems timely to investigate options for information provision to "fit different sizes of demand". Libraries and information services need to take up this challenge working from Information Behaviour as a sub-discipline to Information Science.

References

Abrahamson, J.A., Fisher, K.E., Turner, A.G., Durrance, J.C, & Turner, T.C. 2008. Lay information mediary behavior uncovered: exploring how non-professionals seek health information for themselves and others online. *Journal of the Medical Library Association*, 96(4) 310-323.

Beaver, K., Twomey, M., Witham, G., Foy, S. & Luker, K.A. 2006. Meeting the information needs of women with breast cancer: Piloting a nurse-led intervention. *European Journal of Oncology Nursing*, 10(5) 378-390.

Bee, P.E., Barnes, P. & Luker, K.A. 2009. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of Clinical Nursing*, 18(10) 1379-1393.

Bilodeau, B.A. & Degner, L.F. 1996. Information needs, sources of information, and decisional roles in women with breast cancer. *Oncology Nursing Forum*, 23(4) 691-696.

Bosma H., Apland, L. & Kazanjian, A. 2006. Cultural conceptualization of palliative care: a literature synthesis. *Journal of Palliative Care*, 22(3) 242-242.

Byström, K. & Lloyd, A. 2012. Practice theory and work task performance: How are they related and how can they contribute to a study of information practices. P*roceedings of The American Society for Information Science and Technology*, 49(1). http://www.asis.org/asist2012/proceedings/openpage.html. Accessed 14 February 2013).

Carter, P.A. 2001. A not-so-silent cry for help. Older female cancer caregivers' need for information. *Journal of Holistic Nursing*, 19(3) 271-284.

Case, D.O. 2007. *Looking for information: a survey of research on information seeking, needs and behaviour*. 2nd ed. Amsterdam: Elsevier.

Case, D.O. 2012. *Looking for information: a survey of research on information seeking, needs and behaviour*. 3rd edition. (Series editor: Amanda Spink). Bingley: Emerald Group Publishing.

Clayton, J.M., Butow, P.N. & Tattersall, M.H.N. 2005. The needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end- of-life issues. *Cancer*, 103(9) 1957-1964.

Courtright, C. 2007. Context in behaviour research. *Annual Review of Information Science and Technology*, 41 273-306.

Csikszentmihalyi, M. 1997. *Finding flow: the psychology of engagement with everyday life*. New York: Basic Books.

Curtis, J.R., Engelberg, R., Young, J.P., Vig, L.K., Reinke, L.F., Wenrich, M.D., McGrath, B., McCown, E. & Back, A.L. 2008. An approach to understanding the interaction of hope and desire for explicit prognostic information among individuals with severe chronic obstructive pulmonary disease or advanced cancer. *Journal of Palliative Medicine*, 11(4) 610-620.

Daveson, B.A., Bechinge-English, D., Bausewein, C., Simon, S.T., Harding, R., Higginson, I.J, & Gomes, B. (on behalf of Prisma). 2011 Constructing understandings of end-of-life care in Europe: A qualitative study involving cognitive interviewing with implications for cross-national surveys. *Journal of Palliative Medicine*, 14(3) 343-349.

Davies, B., Contro, N., Larson, J. & Widger, K. 2010. Culturally-sensitive information-sharing in pediatric palliative care. *Pediatrics*, 125(4) E859-E865.

Drew, A. & Fawcett, T.N. 2002. Responding to the information needs of patients with cancer. *Professional Nurse*, 17(7) 443-446.

Duffy, W.J., Kharasch, M.S. & Hu, M. 2010. Point of care documentation impact on the nurse-patient interaction. *Nursing Administration Quarterly*, 34(1) E1-E10.

Duncan, V. & Lorraine, H. 2012. Utilizing grounded theory to explore the information-seeking behaviour of senior nursing students. *Journal of the Medical Library Association*, 100(1) 20-27.

Echeverri, T.A. & Acosta, O.V. 1996. Palliative care: the hospice concept. *Pain Clinical Update*, 16(2). http://www.iasp-pain.org/ AM/AMT emplate.cfm?Section =HOME &TEMP LATE=/CM/Content Display. cfm& CONTENTID =7588&SECTION =HOME. Accessed 14 February 2013.

Fields, S.D., Wharton, M.J., Marrero, A.I., Little, A., Pannell, K. & Morgan, J.H. 2006.

Internet chat rooms: Connecting with a new generation of young men of colour at risk for HIV infection who have sex with other men. *Journal of the Association of Nurses in Aids Care*, 17(6) 53-60.

Finlay, I.G. & Jones, R.V.H. 1995. Definitions in palliative care. *British Medical Journal*, 311(7007) 754-754.

Fitch, M.I. & Abramson, T. 2007. Information needs of adolescents when a mother is diagnosed with breast cancer. *Canadian Oncology Nursing Journal*, 17(1) 16-25.

Fitch, M.I. and Allard, M. 2007. Perspectives of husbands of women with breast cancer: information needs. *Canadian Oncology Nursing Journal*, 17(2) 79-90.

Fourie, I. 2008. Information needs and information behaviour of patients and family members in a cancer palliative care setting: an exploratory study of an existential context from different perspectives. *Information Research*, 13(4) paper 360. http://InformationR.net/ir/13-4/paper360.html. Accessed 8 February 2014

Fourie, I. & Claasen-Veldsman, R. 2011. Exploration of the needs of South African oncology nurses for current awareness services available through the Internet. *Information Research*, 16(3) paper 484. http://InformationR.net/ir/16-3/paper484.html. Accessed 8 February 2014.

Freire, P. 1970/1986. *Pedagogy of the oppressed*. New York: The Continuum Publishing Corporation. (translated from original Portuguese manuscript in 1986, copyright 1970 by Paulo Freire).

Fu, M.R., Axelrod, D. & Haber, J. 2008. Breast-cancer-related lymphedema: information, symptoms, and risk-reduction behaviors. *Journal of Nursing Scholarship*, 40(4) 341-348.

Glaser, B.G. & Strauss, A.L. 2005. *Awareness of death and dying*. New Brunswick: Aldine Transaction.

Gopal, R.L., Beaver, K., Barnett, T. & Ismail, N.S. 2005. A comparison of the information needs of women newly diagnosed with breast cancer in Malaysia and the United Kingdom. *Cancer Nursing*, 28(2) 132-140.

Graydon, J., Galloway, S., Palmer-Wickham, S., Harrison, D., Rich-van der Bij, L., West, P., Burlein-Hall, S. & Evans-Boyden, B. 1997. Information needs of women during early treatment for breast cancer. *Journal of Advanced Nursing*, 26(1) 59-64.

Hasson, F., Kernohan, W.G., McLaughlin, M., Waldron, M., McLaughlin, D., Chambers, H. & Cochrane, B. 2010. An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. *Palliative Medicine*, 24(7) 731-736.

Havelock, R.G. 1986. Linkage: key to understanding the knowledge system. In Beal, G.M., Dissanayake, W. & Konoshima, S. (Eds). *Knowledge generation, exchange and utilization*. London: Westview Press, pp. 211-243.

Hepworth, M. 2007. Knowledge of information behaviour and its relevance to design of people centred information products and services. *Journal of Documentation*, 63(1) 33-56.

Houston, E.C., Cunningham, C.C., Metcalfe, E. & Newton, R. 2000. The information needs and understanding of 5-10-year old children with epilepsy, asthma or diabetes. *Seizure - European Journal of Epilepsy*, 9(5) 340-343.

Hughes, L.C., Hodgson, N.A., Muller, P., Robinson, L.A. & McCorkle, R. 2000. Information needs of elderly postsurgical cancer patients during the transition from hospital to home. *Journal of Nursing Scholarship*, 32(1) 25-30.

Hustey, F.M. & Palmer, R.M. 2010. An internet-based communication network for information transfer during patient transitions from skilled nursing facility to the emergency department. *Journal of the American Geriatrics Society*, 58(6) 1148-1152.

Irvin, K.L., Ferguson, E., Cox, T. & Farnsworth, W.J. 1997. Nurses' evaluations of sources of information about HIV and AIDS. *Journal of the Royal Society of Health*, 117(5) 298-303.

Ishibashi, A. 2001. The needs of children and adolescents with cancer for information and social support. *Cancer Nursing*, 24(1) 61-67.

Jemal, A., Bray, F., Center, M.M., Ferlay, J., Ward, E. & Forman, D. 2011. Global cancer statistics. *Cancer Journal*, 61(2) 69-90.

Jinkook, L.J. & Cho, J. 2005. Consumers' use of information intermediaries and the impact on

their information search behaviour in the financial market. *Journal of Consumer Affairs,* 39(1) 95-120.

Johnson, J.D. & Case, D.O. 2012. *Health information seeking.* New York: Peter Lang.

Keatinge, D., Bellchambers, H., Bujack, E., Cholowski, K., Conway, J. & Neal, P. 2002. Communication: principal barrier to nurse-consumer partnerships. *International Journal of Nursing Practice*, 8(1) 16-22.

Keenan, G., Yakel, E. & Marriott, D. 2006. HANDS: A revitalized technology supported care planning method to improve nursing handoffs. *Studies in Health Technology and Informatics*, 122, 580-584.

Kilpatrick, M.G., Kristjanson, L.J. & Tataryn, D.J. 1998. Measuring the information needs of husbands of women with breast cancer: validity and reliability of the Family Inventory of Needs-husbands. *Oncology Nursing Forum*, 25(8) 1347-1351.

Kristjanson, L.J., Chalmers, K.I. & Woodgate, R. 2004. Information and support needs of adolescent children of women with breast cancer. *Oncology Nursing Forum*, 31(1) 111-119.

Lee.R.G. & Garvin, T. 2003. Moving from information *transfer* to information *exchange* in health and health care. *Social Science and Medicine*, 56, 449-464.

Madden, C.C., Garrett, J. & Busby-Whitehead, J. 1998. The interface between nursing homes and emergency departments: a community effort to improve transfer of information. *Academic Emergency Medicine*, 5(11) 1123-1126.

Maglio, P. & Barrett, R. 2000. Intermediaries personalize information streams. *Communications of the ACM*, 43(8) 96-101.

Mahon, S.M. & Williams, M. 2000. Information needs regarding menopause – Results from a survey of women receiving cancer prevention and detection services. *Cancer Nursing*, 23(3) 176-185.

Mason, T.M. 2005. Information needs of wives of men following prostatectomy. *Oncology Nursing Forum*, 32(3) 557-563.

Matti, A.I., McCarl, H., Klaer, P., Keane, M.C. & Chen, C.S. 2010. Multiple sclerosis:

patients' information sources and needs on disease symptoms and management. *Patient Preference and Adherence*, 4, 157-161.

McCaughan, E. & McKenna, H. 2007. Never-ending making sense: towards a substantive theory of the information-seeking behaviour of newly diagnosed cancer patients. *Journal of Clinical Nursing*, 16(11) 2096-2104.

Meghani, S.H. 2004. A concept analysis of palliative care in the United States. *Journal of Advanced Nursing*, 46(2) 152-161.

Melin-Johansson, C., Odling, G., Axelsson, B. & Danielson, E. 2008. The meaning of quality of life: narrations by patients with incurable cancer in palliative home care. *Palliative & Supportive Care*, 6(3) 231-238.

Menzies, I.E.P. 1993. *The functioning of social systems as a defense against anxiety: a report on a study of the nursing service of a general hospital.* London: Travistock Institute of Human Relations.

Mutch, K. 2005. Information for young people when multiple sclerosis enters the family. *British Journal of Nursing*, 14(14) 758-760.

Neumann, M., Wirtz, M., Ernstmann, N., Ommen, O., Längler, A., Edelhäuser, F., Scheffer, C., Tauschel, D. & Pfaff, H. 2011. Identifying and predicting subgroups of information needs among cancer patients: an initial study using latent class analysis. *Supportive Care in Cancer*, 19(8) 1197-1209.

Nikoletti, S., Kristjanson, L.J., Tataryn, D., McPhee, I. & Burt, L. 2003. Information needs and coping styles of primary family caregivers of women following breast cancer surgery. *Oncology Nursing Forum*, 30(6) 987-996.

O'Connor, M., O'Brien, A.P., Griffiths, D., Poon, E., Chin, J., Payne, S., & Nordin, R. 2010. What is the meaning of palliative care in the Asia-Pacific region? *Asia-Pacific Journal of Clinical Oncology*, 6(3) 197-202.

Ohlendorf, J.M.W., Marianne, E. & Ryan, P. 2012. Weight-management information needs of postpartum women. *The American Journal of Maternal Child Nursing*, 37(1) 56-63.

Osuna, E., Pérez-Cárceles, M.D., Esteban, M.A. & Lune, A. 1998. The right to information for the terminally ill patient. *Journal of Medical Ethics*, 24(2) 106-109.

Pastrana, T., Jünger, S., Ostgathe, C., Elsner, F. & Radbruch, L. (2008. A matter of definition – key elements identified in a discourse analysis of definitions of palliative care. *Palliative Medicine*, 22(3) 222-232.

Piredda, M., De Marinis, M.G., Rocci, L., Gualandi, R., Tartaglini, D. & Ream, E. 2007. Meeting information needs on cancer-related fatigue: an exploration of views held by Italian patients and nurses. *Supportive Care in Cancer*, 15(11) 1231-1241.

Posma, E.R., van Weert, J.C., Jansen, J. & Bensing, J.M. 2009. Older cancer patients' information and support needs surrounding treatment: An evaluation through the eyes of patients, relatives and professionals. *BMC Nursing*, 8. http://0-www. biome dcentral. com. innopac. up.ac.za/content/pdf/1472-6955-8-1.pdf; accessed 14 February 2013).

Rees, C.E. & Bath, P.A. 2001. Information-seeking behaviors of women with breast cancer. *Oncology Nursing Forum*, 28(5) 899-907.

Rogers, E.M. & Shoemaker, F.1971. *Communication of innovations: a cross-cultural approach*. 2nd Edition. New York: Free Press.

Saracevic, T. 1975. Relevance: a review of and a framework for the thinking on the notion in information science. *Journal of the American Society for Information Science*, 26(6) 321-343.

Savolainen, R. 2008. *Everyday information practices: a social phenomenological perspective*. Lanham, Maryland: Scarecrow Press.

Schultz, P.N. 2002. Providing information to patients with a rare cancer: using Internet discussion forums to address the needs of patients with medullary thyroid carcinoma. *Clinical Journal of Oncology Nursing*, 6(4) 219-222.

Spink, A. & Heinström, J. 2011. Introduction: new directions in information behaviour. In Spink, A. & Heinström, J. (Eds.) *New directions in information behaviour*.

Bingley: Emerald Group Publishing, p. xvii

Stayer, D. 2012. Pediatric palliative care: a conceptual analysis for pediatric nursing practice. *Journal of Pediatric Nursing*, 27(4) 350-356.

Turner, M., Payne, S. & O'Brien, T. 2011. Mandatory communication skills training for cancer and palliative care staff: Does one size fit all? *European Journal of Oncology Nursing*, 15(5) 398-403.

Watts, T., Merrell, J., Murphy, F. & Williams, A. 2004. Breast health information needs of women from minority ethnic groups. *Journal of Advanced Nursing*, 47(5) 526-535.

Wilkes, L., White, K. & O'Riordan, L. 2000. Empowerment through information: supporting rural families of oncology patients in palliative care. *The Australian Journal of Rural Health*, 8(1) 41-46.

Wilson, T.D. 1999. Models in information behaviour research. *Journal of Documentation*, 55(3) 249-270.

Wilson, T.D. 2005. Evolution in information behavior modeling: Wilson's Model. In Fisher, K.E., Erdelez, S. & McKechnie, L. (Eds.). *Theories of Information Behaviour*. Medford, NJ: Information Today, p. 31-36.

Zanchetta, M.S. & Moura, S.L. 2006. Self-determination and information seeking in end-stage cancer. *Clinical Journal of Oncology Nursing*, 10(6) 803-807.

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