
Interpreting the information behaviour of patients and families in palliative cancer care: a practical approach¹

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Abstract

An exploratory study on information needs and information behaviour was conducted with patients and families in a palliative cancer care setting in 2007 in South Africa. It showed differences between information needs reported by patients and families, and healthcare professionals' perceptions thereof. This article considers how healthcare settings with the support of libraries can make a difference in supporting the information behaviour of patients and families. It discusses support with unrecognised information needs, information needs occurring at different disease stages, information on emotional and psychosocial issues, information needs that are difficult to discuss, and the need for individualisation and contextualising.

Introduction

Noting an increasing number of patients being diagnosed with cancer, an increase in interest in the information needs and information behaviour of cancer patients and patients in palliative cancer care, an exploratory study was conducted in 2007 on the information behaviour of patients and families in a palliative cancer care setting in South Africa. The results reported by Fourie (2008) showed marked differences between the information needs reported by patients and family members, and the information needs and information behaviour of patients and family members as perceived by the healthcare professionals. This is in line with discussions by Docherty et al (2008) and Bartal, Barnoy and Zisser (2005). Similar to studies by Clayton, Butow and

Tattersall (2005), Docherty et al (2008), Fukui (2004), and Kutner et al (1999), Fourie (2008) noted numerous references to information needs in spite of information being provided by healthcare professionals, as well as concern amongst healthcare professionals for patients and their families using Google as an information resource.

This article offers a brief review of the setting of the exploratory study reported by Fourie (2008), before discussing how healthcare professionals, with the help of library and information (LIS) professionals, can support information behaviour in palliative care contexts on a practical level. It focuses on the following issues:

- allowing for dormant or unrecognised information needs;
- recognising that different information needs may occur at different stages of the disease;
- the need for information on emotional and psycho-social issues;
- issues patients and their families find difficult to address (for example, sexual well-being);
- the need for individualisation of information provision; and
- allowing for personal support in contextualising information.

Clarification of concepts

Two key concepts in this article are information behaviour and palliative care. Both are complex, with more than one interpretation. Palliative care can be interpreted as either care required since the time of diagnosis with a life-threatening disease such as cancer, or as the care of terminally ill patients to reduce pain but without curing the cause. The World Health Organisation (WHO) defines palliative care as

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 (cited by Fourie 2008).

The comprehensive definition of Wilson (1999: 249) is accepted for information behaviour: "the totality of human behavior in relation to sources and channels of information, including both active and passive information seeking and information use", and noting that information needs are not always recognised.

Setting of exploratory project and participants

As background to the suggestions in this article, the setting for the exploratory project by Fourie (2008) is briefly noted. The research was conducted at a private medical oncology clinic and two oncology wards at a private hospital in South Africa. They serve the same patients, most of whom were hospitalised. The study was based on semi-structured interviews conducted by an oncology social worker² according to a detailed interview schedule. Individual interviews were also held (by the author) with healthcare professionals (that is oncologists, a doctor specialising in palliative care and oncology nurses from both the clinic and the hospital wards) operating in the same setting. Table 1 reflects the demographic and cancer data of the patients and Table 2 reflects the data of the families. This article focuses only on suggestions to help patients and families.

Table 1: Selected demographic and cancer data for patients

| Gender | Type of cancer | Occupation | Language | Age | Qualification |
|--------|---|--|-------------------------------|---------|-------------------------------|
| Female | Breast and bone metastasis, no cure | Nurse | Afrikaans | 36 – 45 | Post school |
| Female | Inflammation breast cancer, no remission | Formerly a secretary | Afrikaans | 36 – 45 | Post school |
| Female | Ovary cancer and liver metastasis, no cure | Housewife, was active in local organisations | English | > 75 | High school not completed |
| Male | Testicle cancer and metastasis to lymph nodes, no cure | Electronic engineer | Afrikaans (German background) | 26 – 35 | Post school |
| Male | Differentiated non-Hodgkin lymphoma, passed away within two weeks | Pensioner | English (Indian) | 55 – 65 | High school completed |
| Male | Lung cancer, passed away within a month | Administrative post | Afrikaans | 36 – 45 | High school completed |
| Male | Multiple myeloma, passed away within a month. <i>Patient too ill to participate. Wife and son</i> | Depot manager | Afrikaans | 36 – 45 | Post school technical diploma |

| | | | | | |
|------|---|--------------|-----------|---------|-------------|
| | <i>participated.</i> | | | | |
| Male | Acute Myeloid Leukaemia, prognosis good, within the wider interpretation of palliative care. <i>Wife participated in the interview</i> | Business man | Afrikaans | 36 – 45 | Post school |

Table 2: Selected demographic data for family members

| Gender | Relationship | Occupation | Language | Age | Qualification |
|--------|--------------|------------------------------|-----------------------------------|---------|---------------------------|
| Female | Wife | Housewife | Afrikaans | 46 –55 | High school completed |
| Female | Wife | Administrative position | Afrikaans | 36 – 45 | High school completed |
| Female | Wife | Business woman | Afrikaans | 36 – 45 | High school completed |
| Male | Son | Manager at burger enterprise | English, had Afrikaans background | 26 – 35 | High school not completed |

The purpose of Tables 1 and 2 is to put the following discussion of issues of information behaviour and suggestions for LIS professionals in context.

Issues of information behaviour to be considered: a practical approach

In spite of a number of studies on the communication of information to patients in palliative care and guidelines on such communication (De Haes and Teunissen 2005; Back et al 2008), numerous concerns are still raised – which might be expected. As Williamson (2005) explains with regard to breast cancer, “one size does not fit all”. According to Carter (2001) the provision of information may appear to be straightforward, but information is often not provided or is provided in such a way that it causes more harm than being helpful. The following are some of the aspects healthcare settings such as oncology hospitals or hospital wards, oncology medical centres, general practitioners or general hospitals can consider when catering for the information behaviour of patients and families in cancer palliative care. LIS professionals with an understanding of user needs and information behaviour can help them succeed in this.

Dormant information needs

From the exploratory project by Fourie (2008) it appears that patients and their families do not always realise that they have a need for information or that information may make a difference. This is in line with Wilson's (1999) description of information behaviour and dormant information needs. They do not ask for information, not only because they may be shy or inhibited or because of cultural beliefs or lower educational levels (Fukui 2004), but because they do not realise that there is a need.

Patients and their families need to be made aware that there are many things for which they will not ask, but for which information is available and may make a difference. Information is not only about the disease or about prognosis (things they may be scared to explore or know about). Information is also about taking care of oneself, eating food suitable for the condition and knowing how to share feelings and needs with family (De Haes and Teunissen 2005).

Dormant information needs can be brought to the fore, for example, through a website, or brief surveys and information need audits at different stages of a patient's palliative cancer care journey. Burgers who conducted the interviews with patients and family members in the study reported by Fourie (2008) found that they are mostly keen to talk and that the detailed questionnaire actually helped her, as an oncology social worker, to establish rapport with them for follow-up sessions. By asking questions according to a checklist (especially focusing on things that research has shown that they do not note such as sexual well-being and difficulty in dealing with emotions), patients and their families may be prompted to think of information as offering solutions to small things, as small as getting a special mattress to prevent bedsores, and buying the right type and size of adult nappies.

There are also other means to raise awareness of information needs such as stories of people's experiences (Baker 2004), popular television programmes, information grounds (for example, informal discussions in consulting and hospital rooms; based on the work of Fisher and Naumer 2006), and books that can be read in hospital and consulting rooms. Urquhart and Fanner (2008) report on the value of bibliotherapy with regard to mental illness.

LIS professionals can help to make healthcare professionals aware of the need to deal with dormant information needs by disseminating reports of studies on information behaviour to them and promoting the idea of systematic reviews on

information behaviour. They can also help with literature searches, identifying books for bibliotherapy and identifying information resources and websites that can stimulate awareness of information needs.

Different information needs at different stages of the disease

Information seeking has often been described as an ongoing and iterative process. Satisfying one information need may lead to another. Changes in prior-knowledge and new gaps in a patient's knowledge base may appear, for example, learning that there are special mattresses that can help the prevention of bedsores, can lead to a number of questions (that is, needs for information) such as where can such mattresses be found and how much will one cost? Even to research on different brands of mattresses.

Healthcare professionals should realise that there is no one-off need for information, and should ensure that this is acknowledged in the communication of information to patients. Offering an explanation at the time of diagnosis of the palliative stage and explaining the uncertainty of the time of death is not sufficient. As awareness and acceptance of the inevitability of death may deepen, needs for information may change, deepen or become less. Glaser and Strauss (2005) provide a very useful report on different levels of awareness of death. Patients and especially families may also face ongoing needs for practical information (Bee, Barnes and Luker 2008), and should be encouraged to continue looking for information through a variety of resources. Although word-of-mouth and personal contact is often preferred, the internet and conventional methods such as brochures may also be useful (Street and Ottmann 2007). The value of websites is such that patients can consult them in their own time and on a need-to-know basis. The frequent re-occurrence of some information needs such as how long somebody has before dying, or whether a person will have much pain, as well as the uniqueness of other information needs must be recognised by healthcare professionals. Although they might be aware of this (for instance, as noted in the research reports by Rose 1999), LIS professionals may be able to help them to deal with the dynamic nature of information needs, and providing for this.

It can be explained to patients and their families that the fact that they have been provided with information at the time of diagnosis does not mean that they will have all the information they need, and that they will never need to seek for information again. In fact, every small step along the journey can bring new

information needs. Spending a small amount of time at regular intervals, searching and using information may help a lot to sooth anxiety and uncertainty. Of course information is not the solution to everything, and it may in fact increase anxiety, for example, by learning more about the severity of the prognosis. It is important to understand anxiety in the context of palliative care (Adelbratt and Strang 2000), and that it can both soothe and increase anxiety. The information provided to patients should allow for different stages, for instance, if they are diagnosed as terminally ill with no cure, the purpose of palliative care, for example, using pain killers and sedation, as well as the fact that “addiction” is not an issue, need to be explained. Once they have to some extent accepted the reality of pending death, there may be different questions and information needs to be addressed. Patients and families should be encouraged to reflect on their own situation and efforts to cope with the final phases of cancer and pending death and their efforts to make sense of this. They should be made aware that often the efforts of coping and sense-making reflects gaps in their knowledge and understanding, and would therefore often also reflect information needs. Information needs as secondary needs as noted by Wilson (1999) in his arguments that information needs often follow on primary needs, for example, for physical comfort and safety, as well as the difficulty in aptly expressing information needs as noted in the different levels identified by Taylor (1968) (that is, visceral, conscious, formal and compromised levels), are also issues LIS professionals could bring to the attention of healthcare professionals, and about which they can gain acknowledge and share in communication with patients and families.

Although healthcare professionals seem to be aware that different information needs are experienced at different stages (Innes and Payne 2009), it is not always clear how they provide for this. It also seems as if they may not be fully aware of how much their perceptions of information needs may differ from what is reported by patients and their families (Docherty et al 2008; Fourie 2008). Through continued studies of information behaviour, healthcare professionals as well as LIS professionals can search for means to stress the value of information at each stage.

Information on emotional and psycho-social issues

When hearing about a cancer diagnosis, patients and family often think in terms of factual information: the type of cancer, what the disease may entail, the prognosis, treatment, side effects, alternative treatments, and perhaps some practical things such as personal care, hygiene and life style. These are also the

things stressed by healthcare professionals when providing information and explanations (Sapir et al 2000).

Emotional experiences are seldom expressed in terms of a need for information, for example, information on dealing with fear, not knowing how to share needs with family and friends, or not knowing whether it is good to cry in front of others or not (Fourie 2008; Back et al 2008). When in need of emotional support people may call on healthcare professionals who do not always have the time to fully deal with their needs. Apart from people offering advice, there are many other ways to find information to deal with emotional and psycho-social issues such as saying farewell, grief and bereavement. The availability of such information needs to be brought to the attention of cancer patients and their families. Information can be found in videos, webcasts, podcasts, and contact with other people through discussion lists, weblogs and support groups.

There is thus also a need to further explore information needs flowing from emotional issues and problems, how these can be addressed and especially the impact information may have on emotional experiences and problems. The book by Nahl and Bilal (2007) on emotion and information behaviour may be a good point of departure.

Information on issues difficult to discuss

There are many issues cancer patients may prefer not to discuss, for example, sexual well-being and the experience of death. Means need to be found that can make patients and families aware of the need to address such issues (if they are so inclined) and to direct them to sources they can consult, for instance, after or before a personal discussion with a healthcare professional. Before a discussion it may help with identifying information needs, and the words to express these³. After a discussion it can help to expand and deepen understanding. As a last alternative, information sources can be used to replace a personal discussion with a healthcare professional or an expert councillor.

LIS professionals can help healthcare professionals, as well as patients and families to identify appropriate resources to address such problematic information needs and to identify the terminology and actual information needs.

Individualisation and tailor-made approaches

The provision of tailor-made information “packages” for individual patients and their families may seem like a daunting task for healthcare professionals who are already working under difficult circumstances. If offered, for instance, via a portal where they can select from a variety of electronic resources to make up their own packages according to information packages prescribed by doctors, oncologists, social workers and oncology nurses, it might be easier. Kirk, Kirk and Kristjanson (2004) stress the importance of individualising information delivery to patients with specific attention to the process at all stages of the illness, while Street and Ottmann (2007) discuss the involvement of patients and families in the development of an online information resource based on action research. Again LIS professionals can help to identify useful information sources and websites. Volk (2007) wrote an excellent book on information for cancer patients.

Personal support in contextualising information

Research has also stressed the importance of helping patients and their families to contextualise information according to individual situations and needs (Fourie 2008). Regardless of a wealth of information that may be provided, patients and family often cannot fully apply it to their own situation. Lewis, Pearson, Corcoran-Perry, Narayan (1997) explored the scope of decisions encountered by elderly cancer patients and their family caregivers and found that they also needed clarification on information, reassurance about their decisions, a listener, permission to change the treatment, and help with communication. In this regard it would be useful to help healthcare professionals find methods to help patients and families to contextualise information (for instance, methods in addition to one-on-one sessions). It seems as if healthcare professionals might be aware of this. However, often patients and families need more information than can be provided during a one-on-one consultation session.

What else can LIS professionals do?

The people who are closest in supporting cancer patients and their family members are oncology healthcare professionals such as nurses, social workers, and oncologists. In an indirect manner there are, however, many ways in which LIS professionals, especially those specialising in cancer, can offer a service to

oncology healthcare professionals. The following are a few suggestions in addition to what has been mentioned:

- Bringing research on information needs, information seeking, and information behaviour to their attention, for example, by means of systematic reviews.
- Encouraging them to subscribe to alerting services to note the latest information, for instance, the email alerts or RSS feeds of tables of content (TOC) of key journals such as *Palliative medicine*, *Supportive care cancer*, and *Journal of palliative care*, to monitor the websites of relevant professional associations, to monitor weblogs, and if they do not have time, somebody can do it on their behalf (Fourie and Claasen-Veldsman 2007 wrote on WWW current awareness services (CAS) for oncology nurses).
- Explaining theories of information behaviour stressing that not all information needs are recognised or if recognised, reacted on, and that information needs are often secondary to other needs, as well as the dynamic and iterative nature of information seeking (Wilson 1999).
- Explaining that people will have different needs for information in the same context, and different ways in dealing with information.
- Explaining that it might be easier if information is made available, for example, through the web and patients can choose when, how, where and how much information they want in addition to personal support with contextualisation.
- Bringing concerns and advice on the provision of information to their attention (for instance, as explained by Docherty et al 2008).

Conclusion

With an increase in cancer diagnoses, and patients receiving palliative care, as well as the growing interest in using the internet as an information resource, LIS professionals should support healthcare professionals in realising that information behaviour in palliative cancer care contexts is complex and entails more than questions and requests for information. Addressing the complexities of information behaviour, including dormant information needs, the recognition of different information needs at different stages of the disease, the need for information on emotional and psycho-social issues, allowing for information provision on issues patients and their families find difficult to address, the need to consider tailor-made information, and allowing for personal support in contextualising information according to individual situations and needs, would

be essential in keeping patients and their families from using Google as a first resource in dealing with their need for information.

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Endnotes

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² Wilna Burgers, an oncology social worker with a Master's degree in Medical Social Work, conducted the interviews with patients and family members. She is a staff member of the Mary Potter Oncology Centre, Pretoria, South Africa.

³ The four levels of expressing information needs identified by Taylor (1968) and the problems in expressing information needs have been noted earlier in this article.