PROMOTING AWARENESS OF INFORMATION NEEDS AND REALISING GAPS IN KNOWLEDGE

Examples from healthcare[1]

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▪ Recognition of information needs is the first step in information seeking. Information needs are, however, often not recognised. This might be one reason for on-going concerns and frustrations expressed by people lacking information e.g. patients and their families. Hearing their experiences expressed in their own words (voices) especially conveys the seriousness to attend to this. Information literacy training in the caring professions such as healthcare, social work and teaching can raise awareness of the need to recognise information needs as a first step in information seeking and to help people who rely on them to meet their information needs. This article briefly looks at the issues at stake when considering unmet information needs. Patients and their families are used as examples. It also briefly comments on the information literacy training of professionals in this regard with an emphasis on raising awareness of the need to recognise information needs.

▪ De (h)erkenning van informatienoden is de eerste stap in informatie zoeken. Informatienoden worden echter vaak niet herkend. Dit zou een van de redenen kunnen zijn van de voortdurende bezorgdheid en frustraties die uitgedrukt worden door mensen die op zoek zijn naar informatie, bijvoorbeeld patiënten en hun families. Het aanhoren van hun ervaringen, uitgedrukt in hun eigen woorden draagt ertoe bij om dit probleem "au sérieux" te nemen. Informatiegeletterdheidstraining in de zorgde beroepen zoals de gezondheidszorg, sociaal werk en onderwijs kan bijdragen tot een beter besef van de behoefte om informatienoden te erkennen als een eerste stap om informatie te zoeken en om mensen te helpen die op hen vertrouwen o voor hun informatiebehoeften. Dit artikel kijkt kort naar de belangen die op het spel staan wanneer men te maken heeft met informatienoden waaraan niet tegemoed gekomen /wordt. Patiënten en hun families worden als voorbeelden gebruikt. Het geeft ook even commentaar op informatiegeletterdheidstraining van/aan professionelen en legt specifiek de klemtoon op het ontwikkelen van hetbesef dat informatiebehoeften erkend moeten worden.

▪ La reconnaissance du besoin d'information constitue le premier pas dans la recherche d'information. Cependant, les besoins en information ne sont souvent pas reconnus, ce qui pourrait expliquer les continuelles inquiétudes et frustrations exprimées par des personnes à la recherche d'informations, comme les patients et leurs familles. Le récit de leurs expériences, exprimées en leurs propres mots montre qu'il s'agit d'un sérieux problème. L'éducation à l'information dans le secteur des soins, comme les soins de santé, l'assistance sociale et l'enseignement peut mener à une prise de conscience de la nécessité de reconnaître le besoin d'information comme un premier pas dans la recherche d'information, ce qui permettrait de mieux aider ceux qui comptent sur le personnel soignant, l'assistante sociale ou l'enseignant pour rencontrer leurs besoins d'information. Cet article examine brièvement les enjeux d'un besoin d'information non satisfait, en utilisant les patients et leurs familles comme exemple. L'article commente également de manière sommaire l'éducation à l'information des professionnels et souligne que ceux-ci doivent prendre conscience de la nécessité de reconnaître le besoin d'information.

In-spite of numerous studies on the information needs and information behaviour of patients and their families, and attempts to improve interventions for patient education and information provision[2], research reports reflect on-going concerns for the information needs of patients and their families not being met[3]. Such reports echo their frustrations. Reading about lists of information needs and lists of information needs not being met, brings such needs and issues to the front; it speaks to our senses of responsibility and care. For me it is the "voices" of patients and family members – "their own words" – that, however, truly reflect their despair, and the urgency to attend to their information behaviour.

In a study I conducted in 2007 with the help of an oncology social worker, a nurse diagnosed with breast and bone metastasis (the metastasis affected her spine and liver and she was fully aware that no cure was foreseen) explained: *"You are caught unaware by the diagnosis… It seems as if people do not want to listen and give information when you say that you have cancer… It seems as if doors are closing when you tell them the diagnosis… and ask for information"*. She was looking for information to get her personal business in order, because she did not want to leave everything to her family when she got to the point when she could no longer take care of her own decisions. More about the voices of patients and family members from this study can be read in an article published in 2008[4]. A study reported by Davies et al.[5] on the information needs of parents with children in palliative care succeeds even better in capturing the desperation, pain, sadness and fear of parents whose children are dying. I include two quotations capturing the voices of parents from their study. The father of a child in palliative care explained: *"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"*[6]. 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"*[7]. Many more "voices" can be noted in the research literature.

I have no doubt about the fact that healthcare professionals such as doctors, medical social workers and especially nurses care very deeply about their patients[8], and that they themselves experience tremendous emotional stress due to their jobs[9]. I am also fully aware of the fact that they explore various means to provide information[10]. However, there are still too many shortcomings. Such shortcomings might be addressed by using information literacy training for healthcare professionals to raise their awareness for the reasons why information needs are not met, and for especially the difficulty to recognise information needs and to adequately express and formulate such needs as a first step in seeking information. Difficulties in expressing information needs are addressed by Taylor[11] amongst others; his work is often cited[12].

Although the "voices" cited here are from health contexts, I am sure that similar, perhaps less emotional, despair can be traced for numerous other contexts – academic, job-seeking and professional contexts. Also for these contexts, there are people who care (lecturers, teachers, social workers and employers) – but who do not understand enough of the problems to express information needs, and to help those they care for, to express their information needs.

Although patient education and information provision are the responsibility of healthcare professionals, librarians and information professionals are by nature of their training in information retrieval and information seeking, as well as studies of information behaviour and experience in reference services, better equipped to support healthcare professionals in supporting patients and families in recognising and meeting their information needs[13].

As I will point out in this article a big problem in information provision to patients and families is that patients often do not fully recognise the spectrum of issues on which they may need information, and that healthcare professionals may depend too much on patients' and families' abilities to recognise information needs and to express these adequately as questions and requests for information. The article will thus offer a few preliminary suggestions on how information literacy training of healthcare professionals can attempt to stimulate awareness for the spectrum of information needs that are often not recognised, and expressed as such. This is important in preparing healthcare professionals to provide patients and their families with information and in supporting them to seek information. The principles might also apply to other professionals such as teachers, lecturers and social workers.

This article will thus briefly look at the issues that are at stake when considering unmet information needs. Patients and their families will be used as examples. It will also briefly comment on the information literacy training of professionals, e.g. healthcare professionals, the difficulty in recognising gaps in knowledge as a major barrier in information sharing and exchange of information, means to raise awareness of information needs, and the difficulty to adequately express information needs.

Issues that are at stake when considering unmet information needs

Reports on information behaviour and reviews of studies of information behaviour often focus on the value of information. For patients and their families it is foreseen that information can enable them to take better decisions, to participate in decision-making, to deal better with stress and anxiety, and to make sense of their disease and their situation – among other things[14]. Approaching information provision from the opposite side, that is, looking at what patients and families are denied and the direness of their situation if they do not receive the right information or all information appropriate and relevant to their situation, may, however, offer a stronger picture of what patients and families are facing. They are *denied* the opportunity to take better decisions such as getting their personal business in order; they are denied the opportunity to plan where and how they want to spend time with love-one's; they are denied the opportunity to plan where they would prefer to die; they are denied quality of life by taking care of small things such as special matrasses to prevent bedsores or sucking ice cubes when receiving chemotherapy to prevent mouth sores (mucositis). Many reports have noted poor decisions because information on hospice care is not provided in a timely manner[15]. Parents with children in palliative care have especially been noted to suffer from long term grief due to feelings of guilt for not asking the right questions at the right time[16]. They are denied the opportunity to make sense of their situation and how to deal with it. The earlier mentioned nurse participating in my 2007 study noted that she felt fine when receiving chemotherapy: the oncologist explained the treatment and the side effects. Throughout the treatment she compared her situation to his explanation and she felt that she was doing fine… her situation was not quite as bad. For unknown reasons or merely an oversight, the same oncologist did not explain to her the side-effects of radiotherapy. She was totally unprepared. She (a qualified nurse) did not know what was happening: she felt as if she was losing her sanity, and as if she was dying. Expressing the lack of information in other contexts such as for school pupils and students in similar fashion might also reflect stronger pictures of the urgency to identify and address information needs.

Instead of merely stating the benefits of receiving information, library and information professionals can analyse the content of reports on patients and families in various health contexts (cancer, palliative care, diabetes, renal failure, Alzheimer's, AIDS – and many others) to map what is happening to them if they experience failure in access to information and information communication. What happens to them cognitively (feeling confused, feeling over-whelmed), emotionally (feeling scared, alone, sad, anxious), and physically (experiencing stress related symptoms such as high blood pressure, insomnia). Other contexts such as academic and professional contexts might be analysed in a similar manner to identify what might be at stake when people do not get the right information.

Although numerous attempts are reported on improving patient education and the provision of information and information communication[17], there are some key issues that do not seem to be adequately acknowledged as barriers in addressing the information needs of patients. The issues I mention here are derived from the work of Wilson[18] on the concept of information behaviour, and reconfirmed in reviews on studies of information behaviour e.g. as reported by Case[19]. Wilson specifically notes that information behaviour includes active information seeking such as asking questions and looking for information, but more importantly for purposes of this article, it also encapsulates not recognising an information need or a gap in knowledge (i.e. dormant information needs), and recognising an information need and not doing anything about it, that is, not asking questions and not seeking for information[20]. There are also reports on people actively avoiding information[21]. Although patients and families may have good reason to avoid information on a diagnosis, prognosis or the success rates of a therapy, there may be many other issues that they could well receive information on e.g. on diet and nutrition.

Healthcare professionals rely strongly on patients to ask questions, and for patients to respond to prompts to ask questions. This also often came through in my 2007 study[22]. They report that patients often want very little information if at all. Many do not want to know about the diagnosis or the prognosis. Although this is all true, I think there are more to the information behaviour of patients and families. I would like to raise five issues for further reflection on failure in information provision. As I will point out at the end of this section, these issues can also apply to other contexts.

Patients/families do not recognise all gaps in their knowledge and needs for information. They cannot ask questions or seek for information about something if they do not even know that it is an issue. I am mentioning only two examples here: patients not expecting mouth scores (muscositis) when receiving chemotherapy will not ask questions on how to avoid it; patients believing that morphine may lead to addiction may be subjected to severe pain because they fear addiction – not knowing how poor their prognosis is, they may not think to ask if addiction matters when somebody is dying or whether the emphasis should be on quality of life rather than fears of addiction.

Healthcare providers do not always realise that patients/family members do not recognise all gaps in knowledge, and that there thus may be many issues on which they will not ask questions. The fact that patients are not asking questions is thus not only due to them not wanting a lot of information or trying to avoid information it is because they do not recognise the gap in their knowledge.

Healthcare providers mostly do not realise that their provision of information may not stimulate and enable patients/families to recognise what they need to know. A short discussion during consultation, a brochure, or a booklet may provide patients/families with enough information for the moment, but may not sufficiently help them to recognise other issues of concern. Referring patients to a number of authoritative websites may, however, stimulate their awareness of issues at stake. I am offering more detail on this in a section to follow. It is important to address insufficient stimulation of awareness.

Many studies have noted the difference between the information needs and information preferences of people who are ill and those of their families and caregivers. Many reasons have been explored such as the role and responsibility they take and differences in copying style[23]. This can actually be turned into a great benefit in trying to address frustrations with information provision. As mentioned in the first bullet patients and families do not recognise all their information needs (in fact this is true of all people in any possible context). Encouraging patients and their families to acknowledge their abilities and the differences in recognising what they might like/need to know may help healthcare professionals to fulfill a wider spectrum of expressed information needs (i.e. questions) as well as potential information needs. Information provision is often marked by insufficient exploitation of the differences between people and how collaboration and networking can help people to gain from such differences in order to recognise information needs.

Healthcare professionals frequently express concerns about patients'/families' inability to retain and understand information. They stress that patients often want little information and that they are easily overwhelmed by information. Although they are deeply concerned about patients' well-being it does not seem as if they (healthcare professionals) feel a need to be specifically informed about studies on the information needs and information behaviour of patients and families or on how to support them with their own attempts to find information[24] (the latter is according to "my interpretation" not the same as providing them with information).

Inability to recognise all gaps in knowledge relevant to a situation where such gaps might be filled by information.

Lack of awareness of the impact of the inability to recognise gaps in knowledge and ability to make sense of a situation.

Information literacy programs for healthcare and other professionals… who need to support information needs

Many programs on information literacy for doctors and nurses, professionals from other care giving professions such as teachers, as well as workplace information literacy are reported[25]. These cover under-graduates, post-graduates and practitioners (as part of continuing professional development). Such programs focus on: aligning information seeking with evidence-based medicine and decision-making systematic reviewing of quantitative and qualitative research the elements typically associated with information literacy such as noted by SCONUL or the Big Six e.g. recognising a need for information, formulating the problem, evaluating and using information[26].

From reports on information literacy training it does not seem as if the inability of people to relate their needs to a gap in knowledge and a need for information is taken as point of departure. Standards and definitions of information literacy stress that an information literate person "can" recognise an information need, and adequately formulate this as a problem. Although there are many cases where such needs might be obvious e.g. what the disease entails, as well as the symptoms and possible methods of treatment, others might be less obvious. I would like to argue for more emphasis on the difficulties in recognising gaps in knowledge and adequately expressing such gaps as information needs.

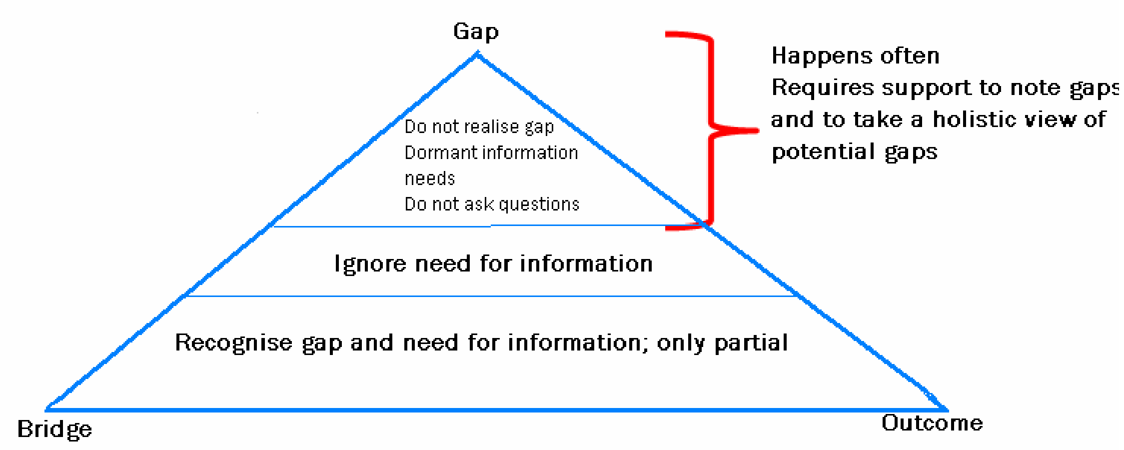

Fig. 1: Recognising a gap in knowledge that can be filled by information.

Difficulty in recognising gaps in knowledge

The difficulty to recognise gaps in knowledge seems to be a major barrier in information sharing and the exchange of information. The idea of information needs and information seeking as a result of a gap being experienced between what a person knows and what a person should know to make sense of a situation has been developed over many years in the work of Dervin[27]. Similarly the idea of an information need linked to an Anomalous State of Knowledge (ASK) has been raised in the work of Belkin, Oddy and Brooks[28]. Their interpretation is often cited by other researchers such as Ingwersen and Järvelin[29] and Case[30]. Figure 1 builds on Dervin's views[31] depicting a gap between what is known and what needs to be known for a person to make sense of a situation. If the gap in knowledge is recognised, and a person decides that information is required (i.e. needed) to fill the gap, he or she may start to seek information. As explained earlier, the problem seems to be that patients and their families, like many other people in situations that are not related to illness, diseases and health, too often do not recognise a need for information. A brief reflection on the complexity of what patients may face (taking breast cancer as an example) is reflected in Table 1; this should provide further support for the argument offered here. Similar examples might be noted when considering Bitso and Fourie's[32] finding on the information needs of teachers in Lesotho when they are expected to advise HIV/AIDS orphans[33].

Taking breast cancer as an example, potential gaps related to cognitive, affective and psychomotor issues are noted in Table 1. As explained

Tab. 1: Reflection of complexity of information needs – different types of information needs in breast cancer.

Needs for factual knowledge (*cognitive information needs*)	*Affective* (emotional) information needs
Cancer genetics related to breast cancer	Coping
Side effects of disease – i.e. breast cancer	Adapting
Treatment	Grieving
Side effects of treatment e.g. nausea, loss of hair	Sharing information with loved-ones
Danger of combining treatment, etc.	Dealing with emotions
Prognosis	Dealing with fear
Stages, etc.	Dealing with loss of confidence and issues of self-image, etc.
Needs for physical (*psychomotor*) knowledge (i.e. dealing with physical issues)	
Stress relief	
Adjusting to the loss of a body part such as with a mastectomy	
Dealing with pain	
Bedsores	
Sexual well-being	
Changes in tastes of food (due to chemotherapy)	
Clothes (e.g. special requirements for clothes after a mastectomy), etc.	

earlier in this article, these might not necessarily feature when patients express their information needs.

Information literacy training: raising awareness of information needs and the difficulty to adequately express information needs

Although information literacy standards offer excellent support for the planning of information literacy programs, additional means need to be found to raise awareness of gaps in knowledge and information needs and to strengthen the ability to express information needs. I will touch only briefly on a few possibilities.

The Internet offers numerous opportunities to gain insight in potential gaps in knowledge and thus potential information needs e.g. through browsing recommended websites, listening to narratives of other people's experiences, blogs, patients' discussion lists, content analysis of the subject literature, and the content analysis of questions set to healthcare professionals. Discussions in doctors' waiting rooms can also be useful sources of information.

Mind maps and visualisation can be useful means to offer abbreviated information on topics that might be of concern to patients, and to portray information needs or potential information needs. Using a mind map to portray the information needs noted in Table 1 might be more effective for some people.

Professionals such as nurses can be asked to keep diaries or journals of their experiences, questions they had to deal with, observations and concerns about patients and families. These might be translated as potential information needs.

Others' experiences in context such as stories, movies and popular TV programmes might highlight potential information needs.

Conclusion

The lack of awareness of information needs and the inability to recognise and adequately express information needs are serious barriers to fulfilling information needs. Although this applies to all contexts ranging from everyday-life and work to academic contexts, this is especially evident in healthcare contexts and in the words of patients/families as expressed in qualitative data collection. By highlighting the issues of concern and in adapting the information literacy training of healthcare professionals as well as others – especially those in caring professions such as teaching and social work – librarians and information professionals can raise awareness for the need to pay stronger attention to dormant information needs and information needs that are ignored. They can explore options for means to note potential information needs and to make sense of information. Only a few suggestions were noted in this article. Although the examples apply to healthcare, patients, families and healthcare professionals, the issues and suggestions can also be apply to other contexts.

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30 April 2013

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Notes

[1] This article is based on a paper with the same title delivered at the 13th EAHIL conference, Brussels, 4-6 July 2012. The sub-title expanding it from a focus on healthcare is, however, added here.

[2] Street, A. F.; Ottmann, G. Addressing online information needs in palliative care: An action research-inspired approach. *Systemic Practice and Action Research*, 2007, vol. 20, p. 151-165.

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