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Title: Understanding the information behaviours of carers of people with dementia: a critical review of models from information science

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Understanding the information behaviours of carers of people with dementia: a critical review of models from information science

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Understanding the information behaviours of carers of people with dementia: the potential offered by information science

Aging and Mental Health

Abstract

Aim

The aim of this review is to discuss how existing models of information behaviour from information science may help to improve provision of information to carers of people with dementia. The paper analyses existing models of information behaviour derived from information science, describes studies that have examined these models in relation to health, and discusses ways in which they help to understand the information behaviours of carers of people with dementia.

Methods

A comprehensive review of the literature on studies of information needs and a critical examination of models of information behaviours in relation to health were undertaken.

Results

Two dominant paradigms in information science research were identified, involving system-centred and user-centred approaches. System-centred approaches and studies are limited in that they have made assumptions on the types of information that people may require, the way in which information should be provided, the timing of information provision and have treated groups as homogenous, failing to take account of individual preferences. In contrast, user-centred approaches recognise the unique needs of individuals and that information needs are subjective and affected by a variety of factors. User-centred models of information behaviour, particularly Dervin's sense-making theory and

Wilson's Information Seeking Behaviour Models, could be useful in developing a better understanding of the information behaviours of carers of people with dementia.

Conclusion

Adopting a user-centred approach to studying the information behaviours of carers of people with dementia will take account of individual needs. Testing existing models of information behaviour within this group may help to develop interventions to meet the needs of individual carers and people with dementia.

Keywords: Information; sense-making; information-seeking; avoidance; monitoring; blunting.

Understanding the information behaviours of carers of people with dementia: the potential offered by information science

Introduction

Increased involvement of patients and carers in decision-making and long-term care is a priority for the National Health Service in the UK (Department of Health, 2004a). However, healthcare professionals, patients and carers must negotiate new roles, moving from the paternalistic doctor and the passive patient, to the open professional and the actively-involved patient or carer (Mead & Bower, 2000). An important aspect is the increased provision of information (Department of Health, 2004b): as people are encouraged to seek health information more actively, and information becomes more widely available through the world-wide web, so health and information professionals and voluntary organisations need to understand changing needs and how best to meet them. Dervin (2005) and Ginman (2000) suggested that this can be conceptualised from an information science perspective, but that it requires more than surveys to quantify the types of information needed by patients and carers. They proposed that understanding people's information behaviour, i.e., motivations for seeking information actively as well as reasons for information avoidance, the decisions people make about sources they consult, barriers to accessing information, the experience of information overload and how information is used when obtained, is equally important. The aim of this review is to explore how models of information behaviour may help to improve provision of information to carers of people with dementia. More specifically, the paper seeks to analyse existing models of information behaviour from information science, describe studies that have examined these models in relation to health problems, and to discuss ways in which they may be useful in understanding the information behaviours of carers of people with dementia.

This is particularly relevant for carers of people with dementia, as the UK Government's National Strategy for Carers makes clear:

“The government believes that information is central to meeting carers' needs. Without it they do not have the means to make choices or have control over their own lives” (National Strategy for Carers, 1999:43).

In this paper we describe and compare *system-centred and user-centred* paradigms, their origins and use in information science and highlight their strengths and limitations. This is followed by an analysis of studies that have adopted *system-centred and user-centred approaches to studying information behaviours in general and in relation to health*. We present an argument in favour of a *user-centred* approach to understanding information needs and behaviours, and discuss particular theories and models and how these may be useful in developing a better understanding of the information behaviours of carers of people with dementia. The essential features of these models are summarised in Table 1.

Approaches in Information Science: System- Centred Vs. User- Centred

Before discussing the relative merits of different model of information behaviour, we describe the two dominant paradigms in information science research proposed by Dervin and Nilan (1986)., The system-centred paradigm, which was heavily influenced by the information transmission model of Shannon and Weaver (1949), viewed information as an objective entity, and the user as a passive, mechanistic and homogenous consumer of information. Research adopting this paradigm aimed to optimise strategies for delivering the best information, as decided by the authoritative information transmitter, with minimal distortion of the message to the user (Talja, *et al.* 2005). The focus was centred on the system and the information conveyed, as it was thought that the same piece of information, given to different users, should have the same results (Johnson, 1997). Any failure in the information not achieving its aim, was attributable to ‘noise’ in the system. Predictors of information use were reduced to simple variables, such as education and gender (Savolainen 1995). Research on information needs of patients based on a system-centred paradigm, therefore, would examine the needs of the group as a whole, ignoring the differences between individuals, and focusing on interventions that, supposedly, meet everyone’s needs.

In contrast, the user-centred paradigm supports the notion that information is dependent on the individual user and that ‘best’ information, as an objective reality, does not exist. The user is seen as a heterogeneous and complex individual, who actively integrates new information and constructs

knowledge in unique and individual ways (Dervin and Nilan, 1986). Furthermore, Savolainen (1993) argued the focus is not to understand whether information has been received accurately, but on how the user perceives the accuracy and usefulness of the information. , Dervin (1992) contended that information does not exist independently of human constructions of it, but that it must be understood through the eyes of the user. Wilson (1997) concurred that information need is inherently subjective and can only be researched through inference from behaviours or from personal recollections.

Research adopting the user-centred paradigm, therefore, would examine the needs of, for example, individual carers of people with dementia, and might examine how information needs varied over time so that interventions could be tailored to the specific needs of individuals.

There are similarities between the two paradigmatic approaches identified here and the patient education and patient empowerment discourses identified by Dixon-Woods (2001). Within the patient education perspective, the aim is for the authoritative health professional to transmit the objective message to the patient, who is expected to act accordingly (Johnson, 1997), whereas patient empowerment focuses on the unique meanings constructed by the unpredictable user, and aims to meet the affective, as well as the cognitive, needs of the individual. Dervin (2005) explicitly related this to the development of effective strategies for health information dissemination, moving away from health promotion and compliance to a more nuanced understanding of meeting individual needs and recognition that information will be used differently by different people.

Having introduced these fundamentally different concepts of information and information users, we describe system-centred and user-centre studies on information needs.

System-Centred Approaches to the Study of Carers' Information Needs

A number of empirical studies have attempted to quantify the level and types of information needed by carers of people with dementia (e.g., Thompsell & Lovestone, 2002, Wackerbarth & Johnson, 2002, Wald, *et al.* 2003). These studies, although not from information science, implicitly adopt the system-centred paradigm.

Wald *et al.* (2003), surveyed 100 carers of people with dementia. Participants were asked to complete a questionnaire containing closed questions, with pre-coded options about categories and types of information, when and in what format information should be provided should be offered. The majority of carers reported that they wanted most types of information at diagnosis, rather than at a later time, not at all, or as the need arose. Wald *et al.* (2003) recommended that information given to carers should be categorised, limited and offered in stages. This does not seem to match their findings that carers want as much information as possible, but rather seems to be a conclusion from preconceived ideas, inherent in asking the carers to identify their three most important types of information. Wald *et al.* (2003) advocated the rule of threes: at the time of diagnosis, carers should be given information about a maximum of three topics over a period of four appointments, in order to prevent information overload. This prescriptive approach does not take into account the individual preferences or situational context and appears to reinforce the notion of patients and carers as passive recipients of health information (Dixon-Woods, 2001), dependent on GPs to provide timely information. It also assumes that carers are a homogenous group, caring for a homogenous group of people with dementia, not taking into account how the information is used nor how needs may change over time.

Thompson and Lovestone (2002) recognised that carers are heterogeneous, hypothesising that family members would have different needs and information behaviours, depending on whether they lived nearby (within one hour) or further away from the person with dementia. They found that 31% of all participants were dissatisfied with the information given to them, but only 17% of the relatives who lived nearby reported this, compared with 48% of those that lived further away. There were also differences in the information required by relatives living further away: more wanted information about genetic risk and advice on behaviour and prognosis. Relatives who lived nearby more often obtained information from books and from the UK Alzheimer's Society. Those who used the Alzheimer's Society were found to be better educated than those who did not. Thompson and Lovestone (2002) concluded that the link between caregiver burden and information need was not obvious, as relatives living further away were unlikely to shoulder as much responsibility for care, but reported more unmet information needs.

Wackerbarth and Johnson (2002) surveyed 128 carers of people with Alzheimer's disease about their information needs. The survey was based on analyses of previously conducted qualitative interviews, leading to the development of a instrument, with the information needs section containing 20 items, under the headings 'general information', 'diagnosis and treatment' and 'legal and financial issues'. Respondents rated each information item on a scale of 0 (not at all important) to 3 (essential). Most of the items received an average rating of over 2 (important), with details about health plan coverage and how to find the best care rated the most important overall.

There are several limitations to these studies. First, although quantitative research aims to be objective, the measures used in the studies by Wald *et al.* (2003), and Thompsell and Lovestone (2002) to ascertain information needs, employed a pre-defined list of information categories. Only Wackerbarth and Johnson (2002) used a mixed-methods approach, in which categories of information need originated from in depth interviews with carers about their general needs. All of the studies asked respondents to rate the importance of items of information, which raises questions about the reliability of the results as this may yield results that do not accurately reflect real information needs, with the majority of items likely to be rated as very or somewhat important (Mills and Sullivan, 1999), and suggesting possible ceiling effects (Wackerbarth and Johnson, 2002). The findings could also be limited by the theoretical framework. Little reference is made to the context in which information needs arise, or how they may change over time. Carers are primarily treated as a homogenous group, with no distinction made between spouse and child carers, for example, or different types of dementia. The information uses of carers of people with dementia were not analysed, although studies by Polk (2005) and Paton *et al.* (2003), concerning how people understand dementia, have suggested that information is interpreted variously, as carers integrate new information differently depending on their preconceptions and life experiences. These limitations indicate the need to investigate further the information behaviour of carers of people with dementia, and as is advocated in the next section, new insights may emerge through the adoption of the user-centred approaches.

User-Centred Models of Information Behaviour

There has been a growing interest in developing methods and theories that focus on a user centred approach to understanding information behaviour, which incorporates information need, seeking and use (Tidline, 2005). In this paradigm, information exists as a fluid, changing and context-dependent entity, which is imbued with meaning by the user. The models and theories presented in Table 1 take this as their starting point, and demonstrate how this approach could increase understanding about the information behaviour of carers of people with dementia.

Insert Table 1 here

Dervin's Sense-Making

The idea of Sense-Making was developed to investigate and theorise information need and use (Dervin & Nilan, 1986). Dervin (1983) argued that sense-making provided a set of underlying principles and methods to understand the recognition and resolution of information need in the wider context of the way that people make sense of their world . The underlying assumption is that breaks in an individual's internal knowledge structure exist and it is by studying these that we can investigate how people need, seek and use information. As elucidated by Dervin:

“Sense-Making assumes that the discontinuity assumption is an important one to invoke in the study of human information use for those occasions when one wants to know about behaviour that is internally controlled”. (1992:62).

Dervin and Nilan (1986) emphasised that as people negotiate a constantly changing world, they will encounter new discontinuities that prevent them from reaching their desired state of certainty. The idea of Sense-Making suggests that at particular moments in space and time (situations) people may experience a gap in their knowledge, when internal sense has run out, prompting information seeking processes to bridge the gap and progress to the outcome (use), which is usually the reduction of uncertainty (Dervin & Nilan, 1986). Wilson (1999) adapted these stages and represented them figuratively, as is shown in Figure 1.

Insert Figure 1 here

The situation represents the context of the information need, and may arise in a number of different forms, all of which are assumed to have prevented the movement to the desired outcome (Savolainen, 1993). Gap is analogous to 'information need', and bridge is information seeking, during which it is

recognised that barriers may be encountered (Wilson, 1999). The outcome of information seeking is also included, referring to the uses for which the information is employed (Dervin & Nilan, 1986). This focus on how information is used once acquired allows questions to be asked about the value of the information to the individual, rather than the traditional assumption that acquisition of information is always beneficial (Dervin, 2005, Case *et al.* 2005). This is particularly relevant to health information, which may increase uncertainty and be perceived as threatening (Leydon *et al.* 2000 and Henwood *et al.* 2003). For example, women diagnosed with breast cancer, do not necessarily wish to receive information immediately, when coming to terms with a diagnosis (Rees and Bath, 2000a). Similarly, close family members of a person recently diagnosed with dementia may be coping with the news, and may be unable to utilise information at that time.

Another strength of the sense-making approach is its applicability to a variety of situations, both involving more formal types of information behaviour in relation to a professional role, and also the study of everyday life information seeking (Cheuk, 1999; Dervin, 1992; Harris, 1988; Savolainen, 1995; Savolainen & Kari, 2006). Several studies have focused on its application to studies of health information. Williams *et al.* (2003) employed the Sense-Making framework to explore the information needs and behaviours of female patients when visiting their GP.. and found few information needs reported by the participants. Often these were dealt with by avoidance, or relying on the instructions given by the doctor. In most cases information was viewed as threatening or distressing by individuals who preferred limited information. However, this study employed only elements of the sense-making framework, omitting the time-space component, seeing users as static and unchangeable, with their needs and use of information based on constant personality traits. As a disease or illness progresses, particularly a chronic condition such as dementia, the symptoms of a disease are likely to alter and the information required by individuals is likely to change.

Sense-making advocates naturalistic methods of inquiry to investigate information seeking (Case, 2002).. Odhiambo *et al.* (2003) investigated the information behaviours of informal carers, by asking them to recount gaps they had experienced in relation to critical incidents over a period of time.

Initially, the participants described the information seeking process as a simple linear event of recognising a need and acquiring information, however, when questioned more closely about barriers and hindrances they encountered, a more complex pathway emerged. This involved being side-tracked, not knowing where to look, drawing on past experiences and incorporating these with information chanced upon by word of mouth, and eventually make some sense of the situation. Odhiambo *et al.* (2003) argued that the method of stepping through the information seeking process and identifying the bridges constructed for overcoming a 'gap' should help information providers to better understand how they can supply information to meet users' needs.

Finally, employing the sense-making framework prevents assumptions being made about the ways in which information will be used when obtained as it asks the user what sense the information enables them to make (Williams *et al.*, 2003), and may be important for carers to people with dementia.

Paton *et al.* (2004) and Polk (2005) explored the ways 'that people explain human behaviour' (Paton *et al.* 2004: 527) in the context of caring for a person with dementia. Both studies found that, even with full knowledge of the diagnosis, many carers did not attribute changed behaviours of the person with dementia to the illness. Instead, some carers believed it could be controlled if the person with dementia chose to do so, or was a result of childhood experiences or personality traits.

These studies demonstrate the importance of understanding how information is used and suggest that the concept of Dervin's Sense-Making may be usefully applied to all aspects of a carer's information behaviour.

Sense-making does not make explicit some of the factors that may influence needs for information in particular circumstances, but identifies a step-wise, cognitive process to be investigated. Sense-making, therefore, may lack explanatory power; however, if used in conjunction with other theories and models, it may be particularly suitable for studying individual information behaviour. (Tidline, 2005).

The focus on the individual's action of constructing meaning from information obviates the recognition of the role of social networks, as individuals do not act in a social or cultural void, but rather may be influenced by their wider surroundings (Talja, 2005). Furthermore, a focus on the

unique sense-making engaged in by individuals could be argued to limit the applicability of the research to providing solutions to problem situations. However, Dervin (1992) argued that it is the process of recognising the gap in knowledge and creating the bridges where similarities may be evident. It is less likely that characteristics of a person, such as age, gender or race, influence information need and behaviour as much as the nature of the gap, for example whether it is the result of the need to make a decision, overcome a barrier, or increase understanding (Case, 2002). Having discussed Dervin's sense-making, the extent to which other models provide explanations of the information behaviour experienced by carers are examined.

Wilson's Information Behaviour and Information Seeking Behaviour Models

Wilson developed and refined several user-focused models of information behaviour (Wilson, 1981; Wilson and Walsh 1996), ultimately describing a holistic model of information behaviour as a problem-solving process, in which uncertainty is ultimately reduced, but which is influenced by cognitive, affective and environmental variables (Wilson, 1999).

Wilson (1981) originally contended that the process of information behaviour begins with recognition of information need, which may prompt information seeking dependent on the relative risk of not having the full information, the ability to make a decision without further information, and the availability, cost and ease of use of suitable information sources.

Wilson (1981) produced a second model of information behaviour, into which he incorporated the context in which information seeking occurs, proposing that information behaviour may be affected by the environmental context, social role and personal role, all of which could act as aids or barriers to information seeking. Applying this to carers of people with dementia, it is not difficult to imagine potential barriers to information seeking; for example, caring for a spouse 24 hours a day will limit the opportunities for seeking and acquiring information independently. Wilson (1981) also posited that information needs were secondary needs, resulting from more three basic types of need: cognitive, affective and physical, each of which may result in different kinds of information behaviour. For example, an affective need for information to reassure may be sought verbally from a person, e.g.,

through discussion with other members of carer support groups, whereas a cognitive need to enhance understanding may be best met from written sources of information, e.g., patient information leaflets. Distinguishing between these three different types of need may be important for effective provision of health information. Caron *et al.* (2003) demonstrated that this may apply to carers of people with dementia, finding that decisions about palliative care were often based on the carer's own assessment of the quality of life experienced by the person with dementia, accompanied by feelings of uncertainty about what was best for their relative. Caron *et al.* (2003) reported that health professionals did not adequately support carers in this process, concluding that information should be offered to help carers deal with feelings of guilt or upset. Health professionals, therefore, need to understand that there are both cognitive and affective needs for information.

Wilson's original models were revised further to take account for the causative factors which may either motivate information seeking behaviour or affect how it is conducted (1999). The major adjunct in this new model, presented in Figure 2, was the consideration of activating mechanisms to prompt information seeking and influence the sources used. (Wilson, 1997).

Insert Figure 2 here

Wilson (1999) contended that the following were important in determining information behaviour:

"...stress/coping theory, which offers possibilities for explaining why some needs do not invoke information-seeking behaviour; risk/ reward theory, which may help to explain which sources of information may be used more than others by a given individual; and social learning theory, which embodies the concept of 'self-efficacy', the idea of 'the conviction that one can successfully execute the behaviour required to produce the desired outcomes'"
(1999:257).

Case *et al.* (2005) applied these activating mechanisms to the study of health information behaviour, arguing that the inclusion of stress/coping theory is important as it helps to explain why information may not be sought, e.g., if it is too frightening or stressful. Self-efficacy may be important because, if people do not feel confident that they can find or use information to help them improve their situation,

they may be reluctant to seek or use it (Case *et al.* 2005). A similar concept, 'mastery of life', proposed by Savolainen (1995), is the value that an individual places on items in their life, helping to instil a sense of coherence. People may seek information to feel in control of a situation; conversely, if they are unable to influence a situation they are less likely to seek or use information, e.g., when diagnosed with a chronic illness (Johnson *et al.* 2001).

Wilson's revised model of information seeking behaviour incorporated the context of the information seeking by labelling intervening variables as: 'psychological disposition', e.g., people who are curious are more likely to seek information than those who are risk averse, 'demographic', for example age or education might affect the sources of information consulted, 'role-related or interpersonal', e.g., whether someone is seeking information as a patient or as a carer, 'environmental', for example what sources are available, and finally 'source characteristics', e.g., accessibility and credibility (Case 2002). This refinement model also allows account to be taken of active and passive seeking of information, e.g., information may be chanced upon in everyday life, such as in a newspaper or by word of mouth (Wilson, 1999). Rather than assuming that information is always actively sought, or that problem-solving provides the context for all information behaviour, the model includes people coming across useful information serendipitously, an idea supported by McKenzie (2003).

Elements of Wilson's models have been applied to information behaviour research in a range of settings, and for different groups (Case, 2002). Williamson and Manaszewicz (2002) utilised the model to research the health information needs of women with breast cancer, asserting that this approach fits more closely with the patient-centred focus of health care, as it does not attempt to explain information needs and seeking as simple cause and effect, but rather draws on the notion that information, and meaning from it, is actively constructed and highly individualised. Williamson and Manaszewicz (2002) concluded that information provision to sufferers of breast cancer would be improved if the medical professional recognised that 'one size does not fit all' and that women with breast cancer should not be treated as a homogenous group. Similarly, the information and meaning for carers of people with dementia could be highly individualised, and dependent on the context, e.g.,

whether they are living with the person with dementia or visiting them everyday, what support services are available to the person with dementia and themselves, their existing ideas and conceptions of dementia.

Kuhlthau's Information Search Process Model

Kuhlthau (1993) developed a model based on research on undergraduate students. The model emphasised the meanings that different people give to the same information, based on their existing understandings and background and recognised that information is assimilated uniquely by individuals. Congruent with the theories and models developed by both Dervin and Wilson, information is not seen as an objective entity, but one which is viewed subjectively depending on past experiences and beliefs.

Kuhlthau (1993) described an affective model of the information search process, concentrating on the stages that an individual may go through as they move from uncertainty to understanding, with a particular emphasis on the accompanying feelings and emotions. It is posited that each stage should be accompanied by further uncertainty reduction as the individual progresses to a sense of greater understanding. In the first stages of uncertainty about the problem, feelings of anxiety and stress are likely; however, as the search proceeds and the information found is hypothesised to become increasingly relevant, feelings of relief, satisfaction and ultimately confidence are experienced.

Wilson wrote that the “association of feelings, thoughts and actions clearly identifies Kuhlthau’s perspective as phenomenological rather than cognitive” (1999:255), i.e., studying the way in which the world is experienced uniquely by individuals, as opposed to the investigation of objective reality (McCleod, 2001).

Kuhlthau’s model has had limited application to the study of health information behaviour. Warner and Procaccino (2004) employed Kuhlthau’s model to investigate the health information seeking behaviour of women, however its relevance remains unclear. Kuhlthau proposed a sense of resolution when information is found, however some researchers have questioned if this would always occur in a health information seeking context, when information may increase anxiety (Case *et al.* 2005).

McKenzie (2003) questioned whether this process model is suitable for capturing the richness of

information behaviour in 'everyday life situations', when there may not be only one information need to satisfy, but ongoing information needs. However, elements of the Information Search Process model may be relevant, particularly the notion of construction of knowledge through the assimilation of new information with one's past experiences, and the affective aspect of seeking information, which may or may not motivate further information seeking as a means of uncertainty reduction.

Johnson's Comprehensive Model of Information Seeking

Johnson's Comprehensive Model of Information Seeking (1997) had specific reference to cancer information seeking. It is depicted in Figure 3 and, similar to Wilson and Dervin, the context in which information seeking arises, shown in the model as the 'antecedents', is given primacy.

Insert Figure 3 here

Unlike Dervin, but similar to Wilson, these factors are made explicit, and grouped according to demographics, direct experience, salience and beliefs, all of which, Johnson (1997) argued, will be determining factors in the decision to seek health information. These factors are based on the health belief model (Becker, 1974), particularly the salience factor; if an individual believes that something is relevant they will be far more likely to seek information actively and act on it (Johnson, 1997).

Johnson (1997) contended that demographics, such as socio-economic status, may affect information behaviour as can direct experience, related to the degree of contact the person has had with a health issue. Johnson *et al.* (2001) proposed that a family member or friend having cancer may trigger earlier and more extensive information seeking, although it is the personal relevance factors of salience and beliefs that are probably the primary determinants in the decision to seek information, or not, once a gap has been recognised. Case (2002) also suggested that people often only seek out information that is compatible with their existing beliefs, so may be biased when selecting sources of information. Case *et al.* (2005) further suggested that information will be avoided or ignored if it requires people to alter their beliefs or causes uncertainty.

The second column of the Comprehensive Model of Information Seeking (CMIS) is titled 'information carrier factors', and is used to describe the various channels or sources of information

that a person can choose from. Johnson *et al.* (2001) suggested that these will vary for different people, and that there will be some interaction between them, as people make choices and combine sources to meet their information needs. People may have a preference for a particular source of information, for example verbal rather than written information,. Furthermore, in a similar conclusion to Leydon *et al.* (2000) , Johnson *et al.* (2001) suggested that cancer patients may choose information from doctors to meet their cognitive needs, but may turn to friends and family to meet their affective needs. Carers of people with dementia may seek or acquire information from healthcare professionals to meet cognitive needs, but may acquire other information from informal sources, e.g., carer support groups, to meet affective needs.

Information Fields and Social Networks

A factor that is not made explicit in the models and theories examined in the preceding sections, but that has been considered by a number of researchers, including Johnson (1997) to explain information behaviour of different groups is that of information field. defined as:

“...encompass[ing] the sources of information an individual is normally exposed to and the sources an individual would normally consult when confronted with a problem”

(Johnson,1997:23).

Johnson (1997) argued that the information field is an important component of the context of the information seeker, and constitutes not only the formal sources that will be consulted, but also informal sources accessed through the social network of the information seeker. Johnson (1997) conceptualised this as the physical space in which the communication of information occurs, and in which information is bound. Pettigrew (1999) investigated the role of nurses as information providers in the social network of the elderly, demonstrating that contact with weak ties, that is to say acquaintances who are outside of a close social network of family and friends, helped to widen the information field as, when attending a foot clinic, elderly people were serendipitously given information by both nurses and other attendees. In the early stage of dementia, the information field of the carer may include a large range of sources, including people in their social network and formal sources such as health care professionals. However the ability to seek information from informal sources may be limited by the willingness of the person with dementia or the carer to disclose the diagnosis to friends and relatives. Furthermore the information field may change over time, e.g., as people become more interested in a health matter, so they may deliberately

expose themselves to more sources of information, or may develop a wider social network of people who share the same interests and concerns (Johnson *et al.*, 2001). For a carer of a person with dementia, the information field may actually decrease rather than increase, as they have to devote more time to the role of caring.

Information Avoidance

Case *et al.* (2005) suggested that the concept of information avoidance has been lacking from many of the information seeking and behaviour models described above, as they are premised on the basis that if someone recognised a gap in their knowledge they would seek to close it by acquiring new information. This may be especially relevant to health information behaviour (Case *et al.*, 2005), where the motivation to seek information may be tempered by the fear of finding out something undesirable, or from a desire to put all one's faith in the medical profession. For carers of people with dementia the need to reduce uncertainty should not be assumed. Polk (2005) reported that often carers of people with dementia do not want to find out too much information about the course of the disease or the behaviours that are exhibited as it progresses, as this can lead to expectations of future behaviour and fears about what to expect.

Monitoring and Blunting

One approach that has been used in studies of health information behaviour, in an attempt to explain and predict information avoidance is the concept of 'monitoring and blunting' (Miller, 1987). The fundamental proposition is that the person's disposition remains constant and is given primacy (Miller, 1987). It focuses on the cognitive traits of an individual, postulating that people are either monitors, who will actively seek information in situations of stress, or blunters, who will distract themselves rather than seek information (Miller, 1987). Rees and Bath (2000) found that daughters of women with breast cancer who were classed as high monitors on the scale sought more information from cancer organisations and newspapers, than those women classed as low monitors.

Proctor *et al.* (2002) assessed the correlates between carers' ($n=50$) knowledge of dementia and self-reported levels of anxiety and depression, using the Miller Behaviour Style Scale (MBSS) to ascertain

whether carers were monitors or blunterners. They found that those who scored higher on the monitoring subscale were more likely to be anxious and more knowledgeable about dementia. According to Proctor *et al.* (2002), individuals may respond differently to information, dependent on their coping style and information preferences. Graham *et al.* (1997) found that increased knowledge about biomedical aspects of dementia was linked to higher levels of anxiety. However, it could be argued that those who try to find out more about the disease do so because they are naturally more anxious, and therefore have a greater need for information and support. The causal effect in this relationship is not obvious.

Williamson and Manasewicz (2002) have criticised the dichotomy of categorising people as either monitors or blunterners in terms of their information-seeking preferences, that this is an oversimplification that does not take account of contextual factors, or the fact that people's preferences may change over time or according to the situation. They contested whether people's reactions to hypothetical situations will have a bearing on how they will cope in real life situations (Williamson and Manasewicz, 2002). That is not to say that the concept of monitoring and blunting does not contribute to understanding health information needs. Viewing information behaviour and needs as a response to a stressful situation may be a valuable concept to draw upon, and it is pertinent for the medical professional the concept of focusing on individual information needs, rather than treating all patients as a homogenous group who will react to information in the same way,

Conclusions

This review has explored several models and theories from information science and has suggested ways in which these might help understand the particular needs of specific groups of patients, as well as the carers of people with dementia. 'Information behaviour' involves a complex range of processes from recognition of an information need and active searching, to incidental acquisition of relevant information. Many of these models also examine the way that information is used, positing that information should reduce uncertainty, but also recognising that new information can increase uncertainty and cause anxiety. While it is clear that these models have the potential to help understand

the needs of carers of people with dementia, empirical research is required to examine the extent to which these models can be used to develop interventions to meet the needs of this group.

Figures

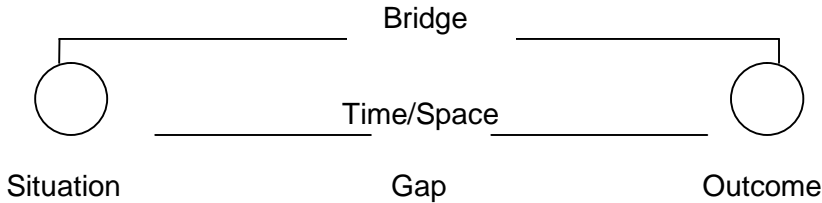


Figure 1: Dervin's Sense Making framework modified (Wilson, 1999:254)

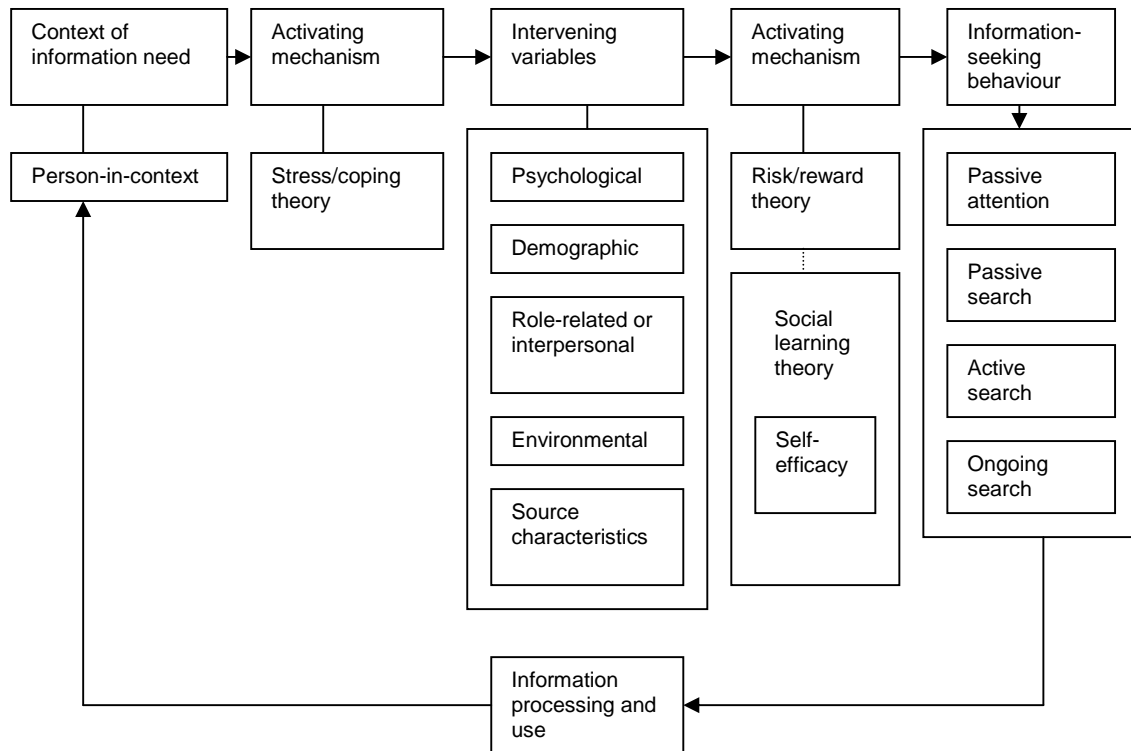


Figure 2: Wilson's 1996 model of information behaviour (Wilson 1999:257)

ANTECEDENTS

**INFORMATION
CARRIER FACTORS**

**INFORMATION
SEEKING ACTIONS**

Background Factors

Demographics

Direct
Experience

Personal Relevance Factors

Saliency

Beliefs

Characteristics

Utilities

Actions

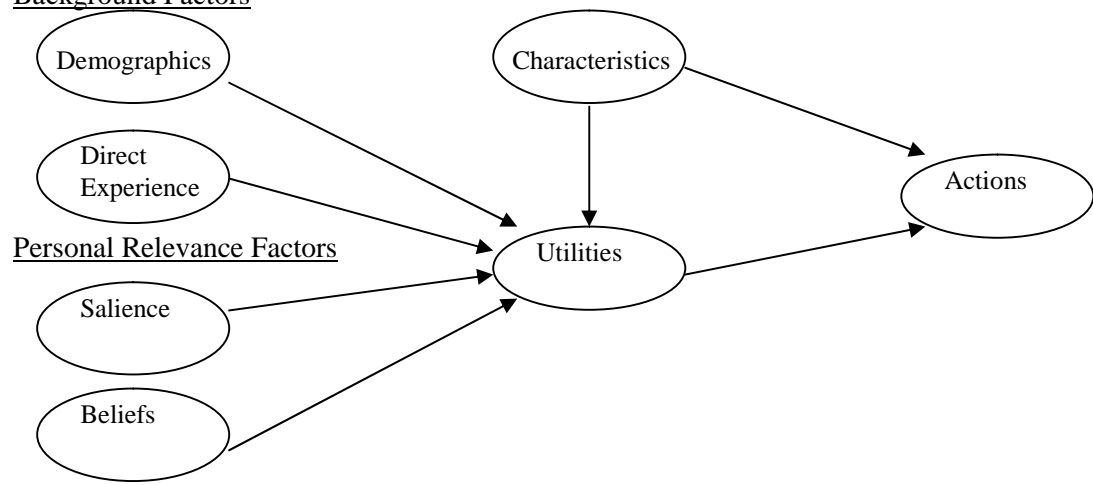


Figure 3: Johnson's Comprehensive Model of Information Seeking (1997)

Table1: Key features of user-centred theories and models of information behaviour

Theory/ Model	Origin	Focus of Research; Phenomena of Interest	Underlying Philosophies/ Theories	Methods of Research	Application to Health Information Behaviour Research
Sense-Making (Dervin, 1983)	Communication Studies	Context of user; bridges to overcome gaps in knowledge; information use and interpretation	Sense-Making	Critical Incident Technique; Micro-Moment Timeline Interview	Odhiambo <i>et al.</i> (2003) Williams <i>et al.</i> (2003)
Integrated Model of Information Behaviour (Wilson, 1997)	Information Science	Problem solving; information seeking behaviour; information seeker characteristics; barriers to seeking	Stress-Coping Theory; Self-Efficacy; Risk-Reward Theory	In-depth interviews with users; participant recall of behaviours	Williamson & Maneszewicz (2002) Beverley, Bath and Barber (2007)
Information Search Process Model (Kuhlthau, 1993)	Information Seeking Behaviour of Undergraduates	Stages of information seeking and accompanying emotions; reduction of uncertainty	Phenomenology; Constructivism	In-depth interviews with users	Warner & Procaccino (2004)
Comprehensive Model of Information Seeking (Johnson, 1997)	Cancer Information-Seeking Behaviour	Antecedent factors affecting information seeking; information channels and sources; information fields and social networks	Health-Belief Model	In-depth interviews with users	Johnson <i>et al.</i> (2001)
Monitoring and Blunting (Miller, 1997)	Psychology	Psychological pre-disposition to information seeking and use; information avoidance	Monitoring and Blunting	Monitoring and Blunting subscale, objective measure of attitudes to hypothetical situations	Rees & Bath (2000) Proctor (2002)

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