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Provision of cancer information as a “support for navigating the knowledge landscape”: Findings from a critical interpretive literature synthesis

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Abstract

Purpose of the research: Information is often seen as a crucial tool for the support of cancer patients, facilitating their involvement in care management and in decision-making. The importance of theory in guiding provision of cancer information has been widely accepted, but there is a growing need for critical reflection on the concepts underlying approaches to information provision. This paper presents findings from a critical review of literature related to information in cancer care.

Methods: Critical interpretive synthesis (CIS) was employed to review and synthesise published literature. 57 publications were selected in a multi-step systematic process. Their content was analysed and synthesised using established methodology consistent with primary qualitative research.

Key results: The synthesis identified and characterised a concept of cancer information provision as a “support for navigating the knowledge landscape”. This concept recognises the diverse, changing and relational nature of patients’ values, needs and preferences. It promotes a view of information provision as an ongoing and flexible process of navigating different resources, which in turn support the navigation of patients’ broader experiences of their health and care. This process recognises various levels of patient involvement with healthcare services, and ensures timely provision of selected and personally relevant information.

Conclusion: The concept of “support for navigating the knowledge landscape” offers a useful way of envisaging information services for people with cancer (and possibly also with other chronic illnesses), which would be responsive to patients’ needs and preferences.

Keywords

Patient information; patient engagement; healthcare professional – patient relationship;
critical interpretive synthesis

Introduction

Information is often seen as a crucial tool for the support of cancer patients. Its roles are thought to include facilitating patients' involvement in care management and decision-making (Department of Health, 2000; Department of Health, 2004a; Department of Health, 2004b; Department of Health, 2004c; European Commission, 2007), as well as providing reassurance and enabling autonomy (Åsbring & Närvänen, 2004; Browall, Carlsson & Horvath, 2004; Maliski, Connor, Fink & Litwin, 2006). It is now clear, however, that patients' preferences and needs for information related to their illness and care are highly varied, changing and context-dependent (Kennedy & Lloyd-Williams, 2009; McCaughan & McKenna, 2007; Ormandy, 2011; Pollock, Cox, Howard, Wilson & Moghaddam, 2008). These needs and preferences for information may differ between groups of patients, between individuals within a group, and within individuals over time. Patients demonstrate considerable diversity in the amount, details, and content of information they desire (Booth, Beaver, Kitchener, O'Neill & Farrell, 2005; Browall et al., 2004; Feldman-Stewart, Brundage, Nickel & Mackillop, 2001; Feldman-Stewart, Brundage, Hayter, Groome, Curtis Nickel, Downes et al. 2000), in their preferred patterns of information seeking and sources of information (Booth et al., 2005), perceived relevance of information (Maliski et al., 2006), general attitudes to and satisfaction with information (Pollock et al., 2008; Street, 2003), and broader orientations to communication (Street, 2003).

The role of healthcare professionals, and particularly nurses, in assessing and responding to patients' individual needs and preferences is now widely recognised (Booth et al., 2005; Browall et al., 2004; Fredette, 1990; Hardwick & Lawson, 1995; Harris, 1998). Many authors draw attention to a professional input in helping patients to articulate and refine their information needs and preferences, or supporting patients' interpretation of information in the context of their individual circumstances (Forrest, Plumb, Ziebland & Stein, 2006; Katz, Rice & Acord, 2004; Nanton, Docherty, Meystre & Dale, 2009; Ormandy, 2011). While the importance of theory in guiding such supportive activities

has been widely accepted (Padilla & Bulcavage, 1991; Rutten, Arora, Bakos, Aziz & Rowland, 2005; Street, 2003), the assumptions behind particular models of information provision often remain unexplained. We suggest that critical reflection on the concepts and principles underlying approaches to information provision is therefore needed.

In this paper we draw on findings from a critical review of published literature related to information in cancer care, and conceptualise patient information as a “support for navigating the knowledge landscape” of illness and care. We argue that this conceptualisation offers a useful way of envisaging responsive approaches to provision of information to people with cancer.

Methods

We undertook a critical interpretive synthesis (CIS) (Dixon-Woods, Cavers, Agarwal, Annandale, Arthur, Harvey et al., 2006) of literature related to patient information for people with cancer. This methodology links elements of conventional systematic reviews with interpretive approaches to analysis and synthesis of data typical for primary qualitative research. Both systematic and iterative in its approach, CIS is particularly useful for critical scrutiny of complex bodies of literature with the aim of generating new concepts, as well as recommendations for practice.

Review scope

Literature relating to providing information to people with cancer is large and diverse. It includes quantitative and qualitative empirical studies, theoretical and discussion papers, and policy documents, and draws on theoretical developments in various fields and disciplines, such as psychology, education, communication studies, sociology, anthropology, and philosophy. Acknowledging this diversity, rather than focusing our review on a particular narrow question, we sought to capture and critically analyse an in-depth picture of what is understood as patient information and what its perceived role in the care of people with cancer is. We were particularly interested in exploring these

issues in the context of an identified diversity and individuality of cancer patients' experiences, needs and preferences.

Sources and selection

We undertook a formal search of Medline (1950 to March 2010), Embase (1980 to March 2010), PsycInfo (1967 to March 2010), CINAHL (1981 to March 2010) and Web of Knowledge (1970 to March 2010), using combined thesaurus terms and free text natural language words for patient information, patient education, health communication and cancer (Table 1). This strategy was designed to ensure high sensitivity rather than specificity and yielded 6118 results.

Consistent with the methodological approach of CIS, three researchers (KK, ZS and SM) used a multi-step process to create a sample of studies to be included in the synthesis (Figure 1). In the first stage, we screened all the abstracts and developed a set of exclusion criteria to help manage the dataset (Table 2). After the initial screening and exclusion of papers deemed less relevant, we created a database of 704 publications. All the abstracts from this database were read again and coded according to the emerging thematic categories (Table 3). These categories were then used to guide the sampling of publications for full-text retrieval. We supplemented the initial database searches with other strategies, such as reference chaining, hand searches of journals and policy documents, and theoretical sampling of additional publications on the basis of key concepts identified in early analysis of literature. Those strategies uncovered a number of publications which, while not directly related to cancer care, made important contributions to theoretical arguments emerging from the cancer literature. Following the principles of CIS, which recognises the importance of adjacent literatures, we deemed these publications relevant to the review topic and included them in the final sample of 138 publications. The retrieved publications were appraised for methodological rigour and theoretical relevance by two reviewers (KK and ZS). However, consistent with the methodological approach of CIS, the priority was given to theoretical relevance. 57 of these publications were included in the final review and synthesis of literature. The

sampled publications included: qualitative and quantitative studies, reviews, theoretical and opinion pieces, reports and policy documents, as well as books (Table 4).

Data extraction and synthesis

For each study included in our sample we extracted information on its aims and methods, its relevance for the identified thematic categories, and a summary of its main conceptual contributions. We then conducted a thematic analysis of the content of the included publications. This analysis started with the close reading of the publications to identify main recurring themes, followed by the generation of the higher level themes capturing the phenomena described in the literature and mapping the relationships between them. This process involved constant comparison of the emerging theoretical structures with the data from the analysed publications. The analysis was undertaken by two members of the team (KK and ZS), with the initial reading and coding conducted independently and any disagreements discussed until consensus could be reached.

In our analysis we followed one of the essential principles of CIS: the critical scrutiny of literature. In this process, the synthesised literature became an object of inquiry and critique, uncovering and questioning the underlying notions and assumptions which informed particular representations of information in the care of people with cancer. This critical scrutiny of literature formed an integral part of the entire process of conducting the synthesis informing the sampling and selection of publications and playing a crucial role in generation of theoretical arguments. The analysis and synthesis of the retrieved literature was assisted by the use of QSR NVivo 8 software.

Results

In this paper we report on the key themes emerging from the literature synthesis which relate to the conceptualisation of provision of cancer information as a “support for navigating the knowledge landscape”. This concept has been used in the work of Daniels et al. (2007) which explored the use of the internet by cancer patients drawing directly on learning theory.

'We feel that it is helpful here to invoke the notion of navigation of knowledge landscape. By this we mean that doctors [and other healthcare professionals] invite patients / caregivers to consult wider sources of information about cancer so that they can begin to learn more about the relevant aspects of the disease and conavigate their understanding with an expert. This approach is in line with post-Vygotskian accounts of learning that stress the value of a dialogic form of practice to facilitate the development of patient understanding.' (Daniels, James, Rahman, Young, Derry & McConkey, 2007)

Consistent with CIS approach, we adapted and further developed this concept to synthesise various themes and arguments emerging from many other publications which suggested a similar conceptualisation of patient information, its place in clinical interaction, and its links with patient experiences of and engagement in healthcare.

In our synthesis the concept of a "support for navigating the knowledge landscape" represents the vision of information provision as an ongoing and flexible process of navigating different resources as part of patients' experiences of illness and care, which offers a contextualised and complex understanding of the roles of information in cancer care. Information provision is pictured as part of a dynamic, evolving practice in which patients actively interpret information relevant to them, drawing – if they choose to – on guidance and advice from healthcare professionals. The giving (and receiving) of information is understood as an ongoing and iterative process rather than a one-off action. The knowledge developed by the patient in this dynamic process is seen not only as acquisition of medical facts, but more broadly as a social practice linked to the broader contexts of healthcare interaction and the understanding of the roles, relationships and cultures that influence this interaction. This approach recognises that patients' reactions to and interpretations of illness may not necessarily be consistent with the medical model.

The conceptualisation of provision of cancer information as a "support for navigating the knowledge landscape" synthesises a number of themes emerging from the literature.

The following discussion explores these themes in more detail and is organised around three topics: the position of patient information in clinical interaction; the links between patient information and patient engagement in healthcare; and the relationship between patient information and cancer care pathways.

Patient information and clinical interaction

According to Daniels et al. internet-based information services (and presumably also other information tools) should not be perceived merely as sources of information but rather conceived of “as artefacts to be navigated by patients, with the crucial help of their doctors [and nurses]” (Daniels et al., 2007). This points to a crucial aspect of the conceptualisation of information provision as a “support for navigating the knowledge landscape”: the embedding of patient information in the communicative practices between cancer patients and healthcare professionals during the clinical interaction (Forrest et al., 2006; Kennedy & Lloyd-Williams, 2009; Nanton et al., 2009; Pollock et al., 2008; Street, 2001; Weiss & Lorenzi, 2005). In this concept, patient information is not seen in isolation but rather located in the broader context of the healthcare professional – patient relationship (Stokken, 2009).

‘Verbal information was embedded in the communication between patients and professionals and the relationships built up between them and through which patients monitored the trustworthiness and credibility of their clinicians.’ (Pollock et al., 2008)

Such an interpretation of patient information is grounded in the understanding of its use by patients and healthcare professionals in terms of (co-)navigation (Daniels et al., 2007). This is an interpretive process in which information providers may guide or support patients’ reading of information, and their understanding of their situation.

‘... health professionals can take on a more active role in anxiety reduction through direct and conscious, reframing and empowering interventions than by the

presentation of information in a neutral way with no direct attempt to influence the inferences which patients may make.' (Nanton et al., 2009)

This guidance and support may take on different forms, as healthcare professionals help patients to articulate their needs for information (Ormandy, 2011), or guide patients' interpretation of health information in the context of their individual circumstances (Forrest et al., 2006; Katz et al., 2004; Nanton et al., 2009).

'As individuals and groups are becoming more active, seeking out and creating their own information resources, they are increasingly, though not dramatically turning to physicians as expert guides and interpreters of the information they find as well as seeking reassurance or innovative steps from them.' (Katz et al., 2004)

Information provision is understood here as an essentially dialogic practice, requiring active participation of both the provider and the patient. This can be best illustrated by the "relationship-centric" design of healthcare communication systems described by Weiss and Lorenzi:

'... where the healthcare provider is one of the several communication channels utilised by the patient. In this design, it is critical for the providers to actively participate in the communication system [...] The providers must also recognise and address the fact that the patient and family have other communication needs and influences during the illness.' (Weiss & Lorenzi, 2005)

In this process, patient information takes on a role of a resource – one among many – employed by patients to deal with their experiences of cancer and the healthcare associated with it (Feldman-Stewart et al., 2000; Maliski et al., 2006; McCaughan & McKenna, 2007; Pollock et al., 2008; Tritter, 2009; Ziebland, 2004). Consistent with constitutive concepts of communication (Craig, 1999) information encompasses here both the content communicated by healthcare professionals or health education materials, as well as experiential knowledge drawn from experiences of other people, from media, and from incidental aspects of communication with healthcare professionals,

including tone of voice, eye contact, body language, perceived confidence and authority (McCaughan & McKenna, 2007; Pollock et al., 2008; Wyke, Entwistle, France, Hunt, Jepson, Thompson et al. 2011).

'Respondents were also sensitive to the significance of various cues provided by professionals and the light these could shed on their situation. Sometimes they interpreted body language while other cues were more directly expressed.' (Pollock et al., 2008)

So understood, information "produces and reproduces shared meanings" (Craig, 1999) providing not only "facts" (Nanton et al., 2009) but also "knowledge of roles, routines, cultures and practices" (Stokken, 2009). In this context, provision of cancer information and the resulting patients' knowledge are seen as social practices influenced by various social, economic and cultural contexts (Stokken, 2009; Street, 2003; Weiss & Lorenzi, 2005).

Patient information and patient engagement

The emphasis on the dialogic nature of the (co-)navigation of cancer information, and the co-production of shared meanings that is achieved in this process, points to another essential aspect of the conceptualisation of information provision as a "support for navigating the knowledge landscape": the understanding of patients' agency in the clinical interaction as essentially relational (Greener, 2008; Sherwin, 1998), and leading to various forms and levels of their engagement with healthcare services.

This concept envisages patients as agents engaged in different domains of activities: treatment decision-making (Feldman-Stewart, Brennenstuhl & Brundage, 2008; Hardwick & Lawson, 1995; Sinfield, Baker, Camosso-Stefinovic, Colman, Tarrant, Mellon et al., 2009; Squiers, Finney Rutten, Treiman, Bright & Hesse, 2005), care management (Adams, 1991; Daniels et al., 2007; Maliski et al., 2006; Pollock et al., 2008), information seeking and management (Booth et al., 2005; Meissner, Anderson & Odenkirchen, 1990), participation in peer support (Adams, 1991; Burt, Caelli, Moore &

Anderson, 2005) or even involvement in the design and evaluation of services (Daniels et al., 2007). But at the same time it recognises that their needs or preferences for information or participation may differ and depend on their individual characteristics and on the broader contexts of healthcare interaction (Booth et al., 2005; Butow, Maclean, Dunn, Tattersall & Boyer, 1997; Fallowfield, 1997; Feldman-Stewart et al., 2000; Nanton et al., 2009; Pollock et al., 2008; Vogel, Bengel & Helmes, 2008).

In this context, patients are pictured as interpreters of their experiences of health and healthcare (Dixon-Woods, 2001; Pollock et al., 2008), involved in many different interactions (Weiss & Lorenzi, 2005), making sense through practical interpretation of information drawn from many different sources, including the behaviour and experiences of other people (Pollock et al., 2008; Wyke et al., 2011). This process of interpretation may not always lead to an "expert" or even "correct" understanding of illness, or guarantee the adoption of adaptive coping strategies.

'Most information, whether sought deliberately or obtained serendipitously, is processed, rejected or selected (wholly or partially). For many it may be a necessary journey to undertake on their own as it is their lives they are trying to get back. In the process, they can become hopeful or depressed, they can pick up "good" as well as "indifferent" or "harmful" advice. They can also acquire useful insights, as well as misconceptions, about the disease and its treatments.'

(McCaughan & McKenna, 2007)

In receiving and using information patients are selective and creative, acquiring misconceptions as well as "authorised" information, adopting adaptive and maladaptive strategies (Åsbring & Närvänen, 2004; McCaughan & McKenna, 2007; Pollock et al., 2008; Tritter, 2009). Their preference to learn is closely linked to their emerging practical and emotional needs:

'Respondents wanted information which was specific to their personal circumstances and related to concrete advice, for example, what to expect during

treatment with chemotherapy, how to manage postoperative care and diet, or how to identify treatment side effects.' (Pollock et al., 2008)

While recognising the individuality of patients' experiences, needs and preferences, this concept avoids picturing cancer patients as atomistic, rational and self-actualising actors, or "knowledgeable agents who can account for their actions and know a great deal about the world in which they act" (Greener, 2008). Instead, it draws attention to the importance of relationships in shaping patients' attitudes to illness and healthcare, and their resulting actions (Sherwin, 1998; Weiss & Lorenzi, 2005). An emphasis is put, in this context, on the notions of care and trust which assume a certain level of interdependence between individuals.

'Human development is not just about the development of the capacity to become autonomous from others, but about combining autonomy with the ability to learn on how to depend on others.' (Greener, 2008)

In this vision, patients who prefer minimal information or do not choose to participate in medical decision-making may be interpreted as having made an "autonomous choice of dependency" (Butow et al., 1997) rather than signalling a system's failure to enable them to be free and "engaged". This understanding of agency and autonomy as relational, contextualised and situated (Sherwin, 1998) allows for the conceptualisation of patients' engagement as varied and shifting in response to the changes in knowledge, attitudes and relationships: from tenacious to resigned, active to passive, autonomous to dependent. This results in a vision of information provision as similarly "relationship-centric" (Weiss & Lorenzi, 2005) and context-dependent.

'A situated, tailored, and progressive method of information delivery was preferred, which helped respondents to deal with the practical issues and implications resulting from particular forms of treatment and their side effects as and when these were experienced. ... Patients did not seek to match professional expertise or question professional judgment.' (Pollock et al., 2008)

Patient information and patient journey of care

The highlighting of the changing and relational nature of patients' experiences of cancer and healthcare, and of the associated situated and progressive provision of information, draws attention to the final element of the concept of "support for navigating the knowledge landscape": the close connection between patient information and patients' experiences of their journey of care as represented in the notion of information pathways.

Closely linked to the clinical concept of cancer care pathways and an associated understanding of cancer experience as "a sequence of related events, proceeding from the first sign or symptom to hospitalisation and treatment and then to convalescence and cure or to recurrence and death" (Adams, 1991), information pathway has sometimes been interpreted as "a standardised protocol for providing written information materials to patients" (Pollock et al., 2008). The concept of "support for navigating the knowledge landscape" moves away from the vision of standardised tools and pre-defined stages in the continuum of care towards a more contextualised interpretation of patients' experiences which acknowledges the individual and dynamic character of their reactions to illness and care.

This interpretation is grounded in the sociological concepts of patient journey and illness trajectory, perhaps best defined by Nanton et al.:

'The term [patient journey] is in many ways analogous to the illness trajectory of chronic illness, described by Glaser and Strauss ... Included within the concept is the progression of the disease itself, the accompanying pathway of care and the individual's response to these over time.' (Nanton et al., 2009)

In their definition, Nanton et al. recall the aspect of personal meaning captured in Tritter's concept of the cancer journey as an epistemological journey in which "patients make sense of their cancer and act on the basis of their understanding" (Tritter, 2009). It has in turn its origin in Goffman's notion of "moral career" of the patient with mental

health issues understood as a “sequence of changes in his way of conceiving of selves, including ... his own [sic]” (Tritter, 2009).

Information pathways are, in this context, interpreted as ongoing processes of information provision unfolding alongside patients’ experiences of illness and healthcare, and are informed by a more fluid understanding of the continuum of cancer care (and of information) as individual, flexible and dynamic.

‘...information delivery is an ongoing process, which starts when the patient receives the diagnosis and continues during and after treatment.’ (Browall et al., 2004)

‘Questions, anxieties, and concerns regarding diagnosis, treatment, and outcome were embedded within the wider experience of dealing with the illness and its impact on their [patients’] lives.’ (Pollock et al., 2008)

This vision recognises the necessity of identifying patient information needs according to different stages of the continuum of care and timing its provision in response to these identified needs (Browall et al., 2004). However, it does not assume the uniformity of these needs or the possibility of predicting them:

‘...clinicians cannot expect to predict the information needs of any individual patient. The patient must be asked directly about the information that is material to his decision.’ (Feldman-Stewart et al., 2001)

‘...to maximize beneficence to patients, the process of informing patients must be flexible and patient-driven to a large extent in order to accommodate the variation in needs...’ (Feldman-Stewart et al., 2000)

The interpretation of cancer information pathways in terms of flexible processes rather than standardised protocols is closely related to the understanding of patient information as embedded in the communicative practices forming a clinical interaction, and to the broader recognition of the importance of relationships in shaping patients’ experiences of cancer and healthcare.

Discussion and conclusions

In this paper we have presented and discussed a concept of information provision which synthesises various themes emerging from the published literature related to patient information for people with cancer. Picturing provision of cancer information as a “support for navigating the knowledge landscape”, this concept draws attention to the close links between patient information and the crucial elements of patients’ experiences of healthcare: their relationship with healthcare professionals, their engagement with services, and their experience of the cancer journey. We suggest that this concept offers a useful way of envisaging information services for people with cancer (and possibly also with other chronic illnesses), which would be responsive to the diverse, individual and relationship-centric nature of patients’ experiences, needs and preferences.

Using the method of CIS to synthesise the large and diverse body of literature related to information in cancer care, we uncovered and questioned underlying concepts and assumptions which inform the way that information is pictured in the academic literature and in policy documents. In doing so, we emphasised the importance of reflexivity and critical scrutiny in healthcare research and practice alike.

Applying these principles to our own work, we acknowledge the specificity of the methodological approach used in this synthesis, and its dissimilarity to traditional systematic reviews. Rather than providing an aggregative synthesis and quality appraisal of all available evidence, our CIS aimed at furthering the understanding of key concepts relevant to its topic. The resulting review process was exploratory, iterative and dynamic and was guided by a broad question which remained open for modification. The strategy for searching and selecting relevant sources was similarly flexible. While formal bibliographic searches were used, the inclusion criteria were flexible and evolved in response to the emerging theoretical arguments. Crucial to this process was the recognition that “literatures not directly or obviously relevant to the question under review” (Dixon-Woods et al., 2006) might further the understanding of certain concepts and arguments and could therefore be accessed. For instance, recognising the growing

links between cancer literature and a broader literature on chronic illness, we included some theoretically relevant studies which explored information needs and experiences in other chronic conditions. Rather than critically appraised for their methodological quality, the included sources were critiqued in the context of their theoretical contributions to the emerging constructs. This process was both critical and interpretive leading to the development of a synthesising argument which, while grounded in the evidence, was essentially a product of our "authorial voice". In this context, we recognise that the findings from our review, as well as some elements of its process, may not be reproducible. However, we believe that the arguments proposed in this synthesis reflect important themes present in the published literature and provide a useful reconceptualisation of the nature and role of patient information in the care of people with cancer.

This is important, because a view of information provision as a beneficial, benign and therapeutic healthcare intervention dominates (Nanton et al., 2009; Vogel et al., 2008), notwithstanding enduring concerns about risks that information may cause increased uncertainty and anxiety in patients (McCaughan & McKenna, 2007; Pollock et al., 2008). Academic literature and policy documents acknowledge the dynamic, equivocal and contingent nature of patients' experience of information in healthcare, picturing information as one of the important resources used by patients to deal with their experience of cancer (Feldman-Stewart et al., 2000; Maliski et al., 2006; McCaughan & McKenna, 2007; Pollock et al., 2008; Tritter, 2009; Ziebland, 2004). These resources extend beyond written patient information materials and direct factual knowledge presented by healthcare professionals and include "direct and vicarious knowledge of how cancer has affected others, information and representations of cancer in the media, and the interpretation of diagnostic and prognostic cues observed in their dealings with health professionals and services" (Pollock et al., 2008).

Cancer patients' information needs are dynamic and contextual because of the ways in which patients experience illness and information (Pollock et al., 2008), and because of

the nature and extent of changes that occur to the individual in the course of and in relation to illness (McCaughan & McKenna, 2007). Patients have varied, changing, and equivocal desires for information over time, and these desires may vary between and within individuals (Kennedy & Lloyd-Williams, 2009; Pollock et al., 2008). In view of the significant individuality and diversity of information needs and preferences, and the related uncertain possibility of predicting those needs on the basis of patient characteristics, the issue of personalisation of information services becomes paramount. Understood most commonly as the flexibility or responsiveness of information tools (Daniels et al., 2007; Department of Health, 2004a; Feldman-Stewart et al., 2001; Feldman-Stewart et al., 2008; Feldman-Stewart et al., 2000), this issue seems best addressed by a concept of information provision as an ongoing and flexible process of supporting the navigation of different resources, which in turn supports the navigation of broader experiences of health and healthcare. This process recognises various levels of patient engagement and autonomy, and ensures timely provision of selected and personally relevant information.

We propose that information provision is best conceptualised as an interpretive process “supporting the navigation of the knowledge landscape” in which patients’ understanding of information, and of their experiences of health and healthcare, is constructed and negotiated with the possible help and guidance from health experts, family members and other actors. This process is essentially dialogic, requiring active participation of both healthcare professionals and patients, and information is seen as a resource – one among many – employed by patients to deal with the experience of cancer and care. Patient engagement in healthcare and education is similarly best pictured as occurring along a continuum. The continuum encompasses various levels of patients’ autonomy and agency, expressed in different preferences for participation in care management and decision-making. It also acknowledges various levels of patients’ knowledge and understanding, including both “correct” information and misconceptions. Finally, it recognises patients’ varying reactions to the experience of illness, including adaptive and

maladaptive coping strategies. Information services and tools in this vision are conceptualised in terms of information pathways as flexible and ongoing processes of providing selected and personally relevant information at appropriate points throughout the continuum of care.

The conceptualisation of information provision as a “support for navigating the knowledge landscape” proposed in this synthesis has important implications for the design and delivery of information services in cancer care, and also for nursing training, practice and allocation of resources. The findings from this review suggest that nurses need to be aware of and responsive to the individuality of patients’ values, needs, preferences and experiences. Taking into account the dynamic character of patient needs related to information, static methods of information provision – such as simply making booklets or leaflets available to patients – may be insufficient to address patient needs. Adopting a more flexible approach, one that recognises information provision as an ongoing process unfolding alongside patients’ experiences of illness and care, is therefore needed. This approach does not exclude the use of standard information tools, such as leaflets, booklets, interactive computer programmes or internet resources, but recognises that they are to be actively navigated and interpreted by patients, who will come to their own views about how best they can act as a resource for them. Nurses need therefore to consider adopting flexible roles as supporters who facilitate patients’ use and interpretation of health information, and remain highly sensitive to the specifics of individual patients’ needs and preferences at any given time. In this context, it is important that communication skills training for nursing students and staff emphasises the significance of a flexible and contextual approach to information provision in cancer care embodied in the concept of “support for navigating the knowledge landscape”.

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Conflict of interest

None declared

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Table 1. Search strategy for Medline

1	exp pamphlets/
2	(pamphlet* or leaflet* or booklet* or brochure* or decision aid*).tw.
3	((patient or cancer or written or printed or multimedia or education*) adj2 (material* or information or tool*)).tw.
4	1 or 2 or 3
5	exp health education/
6	exp health knowledge, attitudes, practice/
7	exp information services/
8	exp communication/
9	exp mass media/
10	exp teaching materials/
11	exp decision support techniques/
12	exp decision making/
13	5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14	cancer.tw.
15	exp neoplasms/
16	14 or 15
17	4 and 13 and 16

Table 2. Exclusion criteria

Non-English publications

Oral presentations and posters

Publications focused on general health education or cancer knowledge, promotion and prevention (this category included publications that related to information directed to general public rather than specifically to cancer patients)

Publications focused on the lack of knowledge among patients as a rationale for the development of information materials

Publications focused on cancer genetic testing and screening

Publications on patient information for cancer clinical trials

Publications on psychological issues related to the disclosure of diagnosis and prognosis, and breaking bad news

Publications on prognostic tools in cancer

Publications on education and information tools for healthcare professionals

Publications focused on complementary or alternative medicine

Publications on cancer information in mass media (with the exception of the internet)

Publications on end of life planning and palliative care

Publications from paediatric oncology

Table 3. Thematic categories for the sampling of publications

Studies investigating the extent of variability of information needs within an individual (patient or significant other) over time (*i.e. studies looking at different types of information required at different stages of the patient pathway, or the use of different sources of information at different stages of the patient pathway*)

Studies investigating the extent of diversity of information needs between individuals at one or more time points (*i.e. studies looking at differences between different groups of patients and between individuals; studies looking at the tailoring of information according to different information needs, different cultural and linguistic characteristics; also studies looking at the information needs of partners, family members, caregivers, or studies looking at differences / similarities between information needs of cancer patients and their significant others*)

Studies relating to the use of multiple methods of providing information and support (*i.e. studies looking at complex patient education programmes or information and support networks; also studies examining the role of healthcare professionals, such as nurse specialists, in providing information and support*)

Articles presenting overviews of main theories within the field of patient information and health communication, or advocating new theoretical developments (frameworks) for providing information to people with cancer

Studies relating to the role of information provision in cancer care (*i.e. studies examining the role of information in increasing knowledge, supporting treatment decision-making, coping and psychological adjustment, influencing health outcomes and patient reported outcomes*)

Studies reporting the process of development of patient information and education interventions (*including studies looking at the patient input and evidence base for*

information)

Studies relating to particular types (content) of information (*i.e. illness and treatment related information, as well as information on social support, employment and economic effects of cancer, sexual concerns, diet and nutrition*)

Studies assessing the effectiveness of particular formats for information (*i.e. written, audio, audio-visual, computer assisted*) and presentation styles

Studies relating to health literacy, numeracy and competence (*including studies on patient use of medical terminology or consumer specific terminology*)

Studies relating to lay understanding of illness (*including studies on patient narratives*)

Table 4. Publications included in the synthesis

<i>Author/date</i>	<i>Source</i>	<i>Type of publication</i>	<i>Aims</i>	<i>Design</i>	<i>Participants</i>
Adams (1991)	database search	review	to discuss information / education needs of cancer patients during different phases of the disease; to discuss information needs of family members	N/A	N/A
Åsbring and Närvänen (2004)	reference chaining	qualitative	to give account of the strategies the women with CFS and fibromyalgia describe using to gain control over their situation during the health care process	semi-structured interviews	women with fibromyalgia and chronic fatigue syndrome
Beckjord et al. (2008)	database search	quantitative	to extend the research on the information needs of cancer survivors; to inform the development of psychosocial interventions	survey	survivors of non-Hodgkin's lymphoma, adult-onset leukaemia, bladder, colorectal cancer 2-5 years post diagnosis
Booth et al. (2005)	database search	quantitative	to explore number and content of patients' concerns, psychosocial distress and use of sources of information	survey	women with a first time diagnosis of a gynaecological cancer
Browall et al. (2004)	database search	quantitative	to investigate the information needs among women with ovarian cancer and whether these needs change over the period from diagnosis to 6 months after treatment	longitudinal study; postal questionnaire	women diagnosed with ovarian cancer who had undergone primary surgery

Burt et al. (2005)	database search	qualitative	to explore in-depth men's experiences after radical prostatectomy and their expressed postoperative needs; to collect descriptive data about clinical indicators of incontinence after prostatectomy	semi-structured telephone interviews; in-depth interviews	men diagnosed with early stage prostate cancer undergoing surgery
Butow et al. (1997)	reference chaining	quantitative	to examine stability of cancer patients' information, involvement and support preferences over time, and to explore possible predictors of these preferences	questionnaire	cancer patients
Coulter (2002)	theoretical sampling	book	argues for the end of paternalism as a defining characteristic of British medical system	N/A	N/A
Craig (1999)	theoretical sampling	theoretical	examines different traditions of communication theory; reconstructs communication theory as a dialogical-dialectical field according to two principles: the constitutive model of communication as a metamodel and theory as metadiscursive practice	N/A	N/A
Daniels et al. (2007)	database search	quantitative	to examine patients' use of, attitudes to, and beliefs about the Internet as an information source, compared with other media, as well as those of their relations and caregivers	interviews	patients recently diagnosed with any type of primary cancer and caregivers of cancer patients (groups not necessarily related)

Department of Health (2004a)	searching websites	document	set out to make information an integral part of healthcare; describes a new relationship between people and the knowledge the health service holds	N/A	N/A
Dixon et al. (2008)	searching websites	report	to raise awareness of the challenges for the NHS and the government in achieving the full engagement of individuals in health care	N/A	N/A
Dixon-Woods (2001)	reference chaining	review	to investigate discourses about the use of information leaflets for patients	N/A	N/A
Donaldson (2003)	reference chaining	editorial	to discuss the expert patient programme	N/A	N/A
Fallowfield (1997)	reference chaining	review	to examine what benefits, if any, have occurred as a result of encouraging women to become more involved in clinical decision-making; to ask whether or not the assumptions about what women want and need, as far as treatment choices are concerned, are correct	N/A	N/A
Fawzy and Fawzy (1994)	database search	manual	to standardise a structured short-term psychoeducational intervention for breast cancer patients	N/A	N/A
Feldman-Stewart et al. (2000)	reference chaining	quantitative	to find out whether there is an agreement between patients on what questions they want answered; to identify the 'core questions'; to identify the reasons for wanting information	survey	patients diagnosed with early-stage prostate cancer

Feldman-Stewart et al. (2001)	database search	quantitative	to determine what information should be incorporated into decision aid for early-stage prostate cancer; to determine the extent of agreement between patients	survey	early stage prostate cancer patients
Feldman-Stewart et al. (2008)	database search	quantitative	to determine if the information needed by early-stage prostate cancer patients for decision-making had changed since first survey (over 10 years earlier)	survey	early stage prostate cancer patients
Forrest et al. (2006)	reference chaining	qualitative	to identify children's awareness and understanding of their parent's cancer, their reactions to being told the diagnosis and treatment, what information they would have liked to be given and seemed to need	semi-structured interviews	breast cancer patients and their children
Fredette (1990)	database search	theoretical	to examine patient education within the context of how emotional responses to cancer affect learning; proposes a model for cancer patient education	N/A	N/A
Green (2006)	database search	theoretical	describes the transportation theory of narrative persuasion and the ways in which transportation into narrative worlds can lead to cancer relevant belief and behaviour change	N/A	N/A
Greener (2008)	theoretical sampling	theoretical / review	presents a critique of the Expert Patient programme (and of Giddens' work) asking why the approach has appeared at this specific time, and problematising its use in the context of recent evidence and evaluations of its use	N/A	N/A

Hardwick and Lawson (1995)	database search	review	to discuss the caregiving family's need for information and learning, as identified by research, and describe the implications this has on the way the nurse interacts with the caregiving family as they support an adult patient with cancer	N/A	N/A
Harris (1998)	database search	review	to identify a sample of literature regarding the information, education and communication needs of patients with cancer and their families	N/A	N/A
Heldal and Tjora (2009)	theoretical sampling	qualitative	to investigate the active patient role from a perspective of sensemaking	case study; interviews	staff from haematological out-patient clinic
Holman and Lorig (2000)	reference chaining	editorial	argues that the partnership between patients and health professionals is a prerequisite for effective and efficient health care	N/A	N/A
Holmström and Röing (2010)	theoretical sampling	review	to explore and compare the concepts of patient-centeredness and patient empowerment, and clarify a possible relationship between the two from the perspective of the encounter between patients and their healthcare providers	concept analysis	N/A

Janz et al. (2008)	database search	quantitative	to examine if treatment and survivorship information needs of women with breast cancer differ by race/ethnicity; if there are racial/ethnic differences in perceived difficulty understanding information; if support received from other women with breast cancer differs by race/ethnicity	survey	women diagnosed with breast cancer
Katz, Rice and Acord (2004)	reference chaining	book chapter	to reflect on early experiences with e-health, to evaluate e-health networks and suggest areas for improvement	N/A	N/A
Kennedy and Lloyd-Williams (2009)	database search	qualitative	to identify communication and information needs of children where a parent has advanced cancer	semi-structured interviews; write-draw technique for children	persons with advanced cancer who had dependent children, well parents and children from their families
Lupton (1997)	reference chaining	qualitative	to explore the ways that people think and feel about medicine and medical profession	in-depth interviews	lay people
Maliski et al. (2006)	database search	qualitative	to describe knowledge, information received, information sources used and information desired by prostate cancer patients and to explore differences in information received and acquired among men of different ethnicities	focus groups	men diagnosed with prostate cancer

McCaughan and McKenna (2007)	database search	qualitative	to explore the information-seeking behaviour of patients newly diagnosed with cancer over 3-month period to uncover social-psychological processes for a substantive theory of information-seeking	in-depth interviews	patients with a first cancer diagnosis
Meisser et al. (1990)	database search	quantitative	to examine information needs of significant others of diagnosed cancer patients as reflected in their telephone calls to Cancer Information Service	content analysis of telephone call records forms	callers to CIS
Mol (2008)	theoretical sampling	book	N/A	N/A	N/A
Nanton et al. (2009)	database search	qualitative	to elucidate the experience of uncertainty at different stages of disease trajectory; to investigate interrelationships between information, problem solving and cognitive reframing in mediating the effects of uncertainty	focus groups; semi-structured interviews	men diagnosed with prostate cancer
Ormandy (2011)	expert opinion	theoretical	to identify a working definition for the term information need; to expose the key concepts surrounding information need; to highlight the potential contribution that models of information behaviour / need can make to health and health research	N/A	N/A
Padilla and Bulcavage (1991)	database search	review	to discuss a variety of theories related to cancer prevention, early detection behaviour, theories of stress, coping and adaptation to disease and treatment	N/A	N/A

Parsons et al. (2010)	searching websites	review	to review the quality of patient engagement in primary care, how to measure it, and developments in patient involvement in primary care	N/A	N/A
Pollock et al. (2008)	database search	qualitative	to evaluate Cancer Back Up project of patient information which aimed at mapping cancer pathways and devising standardised protocols of delivery of information; to explore experiences of information provision	longitudinal qualitative interview-based case studies	newly diagnosed patients with lung or head and neck cancer and their relatives
Rutten et al. (2005)	database search	review	to synthesise research on patient information needs and sources to discern patients' information needs and sources from which they receive cancer-relevant information throughout their cancer journey	N/A	N/A
Sherwin (1998)	reference chaining	book chapter / theoretical	presents a feminist analysis of autonomy, making vivid both the attraction to and distrust of the dominant interpretations of the concept	N/A	N/A
Sinfield et al. (2009)	database search	review	to describe available evidence about issues that are important in patient and carer experience of prostate cancer care across phases of disease	N/A	N/A
Squiers et al. (2005)	database search	quantitative	to better understand the information needs of Cancer Information Service users and determine the most effective ways to address those needs	content analysis of telephone call records forms	cancer patients; CIS callers

Stokken (2009)	theoretical sampling	qualitative	to investigate the role and value of knowledge in the relationship between patient and health professional	in-depth interviews; focus groups	patients (various conditions); health professionals (various)
Street (2001)	reference chaining	theoretical	presents a linguistic model of patient participation in health care	N/A	N/A
Street (2003)	database search	theoretical	to examine the potential of interactive health communication (IHC) for improving quality of cancer care and cancer-related health outcomes	N/A	N/A
Tritter (2009)	reference chaining	book chapter / qualitative	to explore cancer patients' needs for support and self-management	focus groups; questionnaire	cancer patients
Vogel et al. (2008)	database search	quantitative	to analyse breast cancer patients' information needs and experiences with information received in the course of the first 6 months of treatment; to investigate the stability of decision-making preferences and experiences over the same time	self-administered questionnaire; longitudinal study	newly diagnosed breast cancer patients
Volk (2002)	database search	overview	to describe the Patient Education Research Centre at the University of Michigan and highlight its innovative services for patients throughout their cancer journey	overview of services	N/A
Weiss and Lorenzi (2005)	database search	qualitative	to understand the communication needs of cancer patients and their caregivers	semi-structured interviews	patients with various cancer diagnoses

Willems (2000)	theoretical sampling	theoretical	discusses anthropological and philosophical features of the use of self-management plans by patients with chronic disease, focusing on patients with asthma	N/A	N/A
Wood and Wood (1996)	reference chaining	theoretical / review	examines research into individualised tutoring and uncovers common principles that govern such tutoring	N/A	N/A
Wyke et al. (2011)	expert opinion	report	to examine the kinds of information that people need, prefer and use in relation to choice; their response to, and use of, different types of information available in different formats; and whether views, preferences and reported use of information vary systematically by social group	N/A	N/A
Ziebland (2004)	database search / theoretical sampling	qualitative	to explore in detail how two participants from DIPEX prostate and breast cancer studies talk in their narratives about how, when and why they used the Internet within the context of their experience of cancer	narrative interviews	2 patients with breast and prostate cancer
Ziebland et al. (2004)	reference chaining	qualitative	to explore the use of Internet by patients diagnosed with cancer	narrative interviews	patients with prostate, testicular, cervical, breast and colorectal cancer

Figure 1. Process of study selection