



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

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A B S T R A C T

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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.

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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, 2004a, b, c; European Commission, 2007), as well as providing reassurance and enabling autonomy (Åsbring and Närvänen, 2004; Browall et al., 2004; Maliski et al., 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 and Lloyd-Williams, 2009; McCaughan and McKenna, 2007; Ormandy, 2011;

Pollock et al., 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 et al., 2005; Browall et al., 2004; Feldman-Stewart et al., 2001; Feldman-Stewart 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 and Lawson, 1995; Harris, 1998). Many authors draw attention to a professional input in helping

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patients to articulate and refine their information needs and preferences, or supporting patients' interpretation of information in the context of their individual circumstances (Forrest et al., 2006; Katz et al., 2004; Nanton et al., 2009; Ormandy, 2011). While the importance of theory in guiding such supportive activities has been widely accepted (Padilla and Bulcavage, 1991; Rutten et al., 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 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–March 2010), Embase (1980–March 2010), PsycInfo (1967–March 2010), CINAHL (1981–March 2010) and Web of Knowledge (1970–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 (Fig. 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

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 |

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. Fifty-seven 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.

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