

Consumer health informatics: an overview of patient perspectives on health information needs

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Abstract

Patients are increasingly expressing their need for more information about their health. Different healthcare professionals provide a range of information to their patients during delivery of care. By means of a detailed literature search and a study of available evidence, this article explores patients' perspectives in gaining health-related information from the healthcare system, with particular emphasis on patients who come in contact with breast cancer services.

The literature review indicates that the main issues concerning health information available to consumers can be divided into the following sections: quantity of information (amount of information, number of sources, types and strategies for distribution); quality of information (validity, relevance, accessibility, understandability, timing of acquisition); and consumer/patient factors (age, health status, empowerment to make decisions). Information-seeking behaviour of consumers should be considered as part of a broader environmental and role-related context. The acquisition of information and the decision to seek information (either personally or using the help or services of other people) is affected by stress, perception of risk, hope for reward and perceived level of self-efficacy.

Keywords: *Health informatics; health information; consumers; information sources*

Introduction

In today's fast-paced and do-it-yourself (DIY) world, more and more people are becoming health conscious and hungry for information about their health. The sources of health information are multifarious and sometimes conflicting; consumers are constantly receiving information from the media, websites, friends and family as well as healthcare providers. The nature, content and quality of the information received by them could directly or indirectly affect their health. Informatics is a growing area that delves into these issues.

Medical informatics is described by Coiera (1998: 320) as

. . . the study of clinical information and communication processes. It is the rational study of the way we think about patients, and the way that treatments are defined, selected and developed. It is the study of how medical knowledge is created, shaped, shared and applied. Ultimately it is the study of how we organise ourselves to create and run healthcare organisations.

Consumer health informatics falls under the broad heading of medical informatics. Eysenbach (2000: 1713) defines consumer health informatics as 'a branch of medical informatics that analyses consumers' needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumer preferences into medical information systems'. Consumer health informatics could play an important role in today's world.

Among women, breast cancer is the foremost cause of cancer-related deaths in Australia. Breast cancer is also the most common cancer in women residing in NSW aged 40 or more (Estoesta, Supramaniam et al. 2000). The age-standardised incidence of breast cancer in women aged 50–69 years in NSW increased from 202.9 per 100 000 women in 1988 to 290.2 per 100 000 in 1998. In the year 2002 in NSW, 4008 new cases of breast cancer were diagnosed and the median age at diagnosis was 60 years (The Cancer Council

NSW 2003). Breast cancer information is available in differing quantities and qualities from various sources and there is a felt need for disseminating appropriate information and increasing breast cancer awareness among women.

The topic of breast cancer was used to explore the issues encountered by consumers with information currently available. This paper provides an overview of the issues.

Method

Literature on consumer informatics and breast cancer that had been published between January 1995 and December 2003 was sought through CINAHL, Medline and the Cochrane Library. The databases were searched using the terms 'breast cancer' and 'breast neoplasms', plus these terms in combination with other terms; 'information', 'informatics', 'patient' and 'consumer'.

The number of articles found using the terms 'breast cancer' and 'breast neoplasms' in a Medline search was 130 476. Of these articles, 37 were identified using combinations of the terms of interest. From the reference lists and bibliographies of the 37 articles, another nine articles were found relevant for this review. Thus, in total, 46 articles were analysed.

Results

The main issues that the literature review raised concerning health information available to consumers can be divided into the following sections:

- *quantity of information*: amount of information, number of sources, types and strategies for distribution
- *quality of information*: validity, relevance, accessibility, understandability, timing
- *consumer/patient factors*: age, health status, empowerment to make decisions.

In addition to the abovementioned main sections, information-seeking behaviour of consumers should be considered as part of a broader environmental and role-related context (Niedziedzka 2003; Wilson 2000). The acquisition of information and the decision to seek information (either personally or using the help or services of other people) is affected by stress, perception of risk, hope for reward and perceived level of self-efficacy (Niedziedzka 2003; Wilson 2000).

Quantity of information

In terms of information quantity, varying amounts are provided through a number of approaches; for example websites, decision aids, public seminars, counselling, doctor-patient communication, medical records, telephone helplines, books, journals, magazines, newspapers, TV and radio, self-help and support groups, databases and specialist health information services in libraries.

Websites

It is important to ascertain what sort of information patients are accessing online. This would help guide healthcare providers to impart required and appropriate knowledge to patients at the point of clinical care. A study which assessed the popularity, quality and accuracy of breast cancer-related websites found that popularity is significantly associated with type of content, the more popular sites being more likely than the less popular ones to contain information on ongoing clinical trials, other breast cancer research, and opportunities for psychosocial adjustments (Meric, Bernstam et al. 2002). The authors found that there was no relationship between popularity of websites and quality of information. Similarly, a study that evaluated online resources regarding Canadian breast cancer clinical trials indicated that online cancer data sources should strive to make access to information on clinical trials simpler and more reliable, particularly for residents of the country where the trial is conducted (Till, Phillips et al. 2003).

Apart from clinical trial information, the websites should contain comprehensive information about breast cancer in general. Patel and colleagues (2000) recommended that breast cancer specialists should either identify or create websites to this end for the benefit of their patients. Those studies that investigated online breast cancer information (Meric, Bernstam et al. 2002; Patel, Bradpiece et al. 2000; Till, Phillips et al. 2003) indicate that the consulting of Internet sources on health is becoming increasingly popular among patients and their families. The accessibility of online information provides an opportunity for patients and health professionals to function jointly, and ensures that patients have current and comprehensive knowledge about their disease and its management (Brotherton et al. 2002).

Decision aids (e.g. brochures, pamphlets and videos)

These sources explain choices that aim to help people in their awareness of healthcare options, to evaluate consequences of the potential advantages and disadvantages of the options, and to share in decision mak-

ing. Information that is provided in decision aids develops consumers' knowledge of the options, generates realistic expectations of the options, facilitates decision making and increases participation in the process (O'Connor, Stacey et al. 2003). However, appropriate strategies for distribution of decision aids need to be investigated.

Patient choice modules

An important source of information for healthcare providers has been systematic reviews. Holmes-Rovner and colleagues (2001) suggested that patient choice modules could be added to systematic reviews and to other key assessments of health technology. These authors proposed that the modules could be used as important information sources for developers of decision aids, for leaflets and for interactive websites used by patients.

Doctor-patient relationships

Traditionally, patients receive information from their doctors. Pivotal to this process is the doctor-patient relationship which provides an environment for the sharing of information. Building a patient's trust is very important from a provider perspective because the information shared has ethical and legal dimensions that could affect confidentiality and privacy issues (Thompson 2003). A survey of patients who had lodged a complaint about medical treatment found that 22% of complaints were related to poor communication or rudeness on the part of the provider (Daniel, Burn et al. 1999).

Healthcare providers have the means to play an important role in patient education. They could be involved in didactic provision of information or act as facilitators of information on a needs basis. Different types of patient education have been identified (Riemsma, Kirwan et al. 2002). These include providing information (such as by brochures and pamphlets), counselling (which provides an opportunity for patients to discuss their problems) and behaviour treatment (such as behaviour instruction, skills training and biofeedback).

Jones (2002:971) states, 'Providing people with medical conditions with information about their options is now an ethical requirement so that they can give informed consent . . . Information giving is an ethical obligation'. Providers could also empower consumers with regard to decision making by providing them with decision-making tools to access resources effectively and correctly (Huang 2003).

In many situations, communication problems could arise as a consequence of a healthcare provider concentrating on a patient's disease and its management rather than adopting a holistic approach. Rowan and colleagues (2003) propose a CAUSE model for communicating with patients about cancer risk. The CAUSE model includes: earning the patient's confidence; providing the patient with awareness of risk information; helping the patient deepen their understanding of cancer risk; building patient satisfaction with plans for coping with cancer risk; and motivating enactment of behaviour to overcome a cancer-promoting habit.

Increasingly, in today's world, there is marked emphasis on interventions (such as training) to help

healthcare providers promote a patient-centred approach in clinical consultations. A recent review concluded that interventions which promote patient-centred care within clinical consultations could significantly increase the patient-centredness of care (Lewin, Skea et al. 2003).

Patients not only need information about their health condition but also need to know about the potential uses of the information they themselves have given to their healthcare providers in confidence. Providing patients with as much information as possible about foreseeable disclosures of their confidential information could prevent ethical problems and uphold patient autonomy (Braunack-Mayer et al. 2003). Trust relating to the use of patient data needs to be earned by health professionals (Chalmers and Muir 2003).

Medical records

Allowing access to medical records enables patients to know what has been documented. Currently, patients in Australia have access to their medical records through the Freedom of Information Act. But, with the advance of time (especially, when electronic health records come into regular use in Australia), there could be issues related to confidentiality, privacy and ethical uses of information.

Quality of information

Validity and relevance

As for the quantity of information provided, information quality also varies among sources, health providers and types of consumers. Quality could affect and determine the usefulness of information. Validity and relevance of health information have been identified as factors that affect usefulness (Slawson and Shoughnessy 1997). Validity refers to the likelihood that the information is true, and relevance refers to applicability of the information to a patient's situation to enable them to lead a functionally satisfying life. Both validity and relevance have been used by doctors in a concept called 'Patient Oriented Evidence that Matters' (POEM) to indicate usefulness of information (Slawson and Shaughnessy 1997).

In recent years, there has been much controversy regarding the validity of information sourced from the Internet. Kiley (2002: 238) for example, states that 'Medical misinformation is a problem on the Internet. The danger is that vulnerable people will adopt unproved treatments at the expense of proved conventional ones'. On the other hand, no studies have yet found evidence that the Internet harms health (Smith 2001). The Internet is not the only source of varying qualities of information. Blaming the Internet for causing harm is synonymous with saying that books harm health (Doogue 2002).

In order to monitor whether the Internet does harm health, a database has been set up by the Research Unit for Cybermedicine and e-Health, University of Heidelberg, Germany (Eysenbach and Kohler 2002). Results are awaited from this database.

Another area of controversy is breast self-examination (Crossing and Manaszewicz 2003). Cancer organisations in Australia are in the process of chang-

ing the recommendation of 'breast self-examination' to 'breast self-awareness'. This change in semantics could create confusion among women and has the potential of delaying breast cancer diagnosis. Zorbas (2003) stresses the importance of disseminating comprehensible, evidence-based messages so that women are not given confusing health advice regarding breast cancer screening.

Quality of information: accessibility and understandability

The simplicity or difficulty associated with health-related information depends on numerous factors including accessibility (knowing that the information exists, knowing how and where to find it), and understandability.

Access to health information

This can be defined as how consumers can identify information appropriate to their needs; having the ability to find out who produced it, when it was produced and how it can be obtained; and consideration of accuracy and the different formats and distribution methods for information (Twyford Consulting 2001).

Regarding accessibility of existing information, a community-based study (Sadler, Dhanjal et al. 2001) conducted in ethnic women of Southern California found the favoured methods for receiving additional information about breast cancer were, in order of preference: mailed information (79.4%); health education programs (30.9%); and telephone calls (27.3%).

Understandability

Understandability of information is of paramount importance. Understanding the information could be in the context of the prognosis, risk factors, cause, pathophysiology, diagnostic tests, treatment and complications of the disease.

A study conducted in Sydney by Lobb and colleagues (1999) on how well prognosis was communicated to women with early breast cancer found that lack of understanding was responsible for women's confusion about breast cancer prognosis. They also stressed the need for healthcare providers to verify that the information they imparted was understood and suggested that a variety of techniques should be used to communicate prognosis and risk.

Misunderstanding of test results could also lead to patients' anxiety. On the subject of tumour marker reference ranges in cancer patients, Sundar and Symonds (2003) suggest that a clear and explicit explanation of the test results could reassure patients and thus allay anxiety.

Timing

Information should be available during the course of screening, diagnosis, treatment, recovery and discharge so that consumers can access and use it whenever they wish. Information on breast cancer should be provided at appropriate times. For instance, O'Neill and colleagues (2000) suggested that the time of biopsy may not be the optimal time for presenting complex educational material about breast health.

A study conducted by Shakespeare and Hobby (2001) aimed to investigate breast cancer patients' own opinions of the information provided about breast reconstruction prior to an immediate mastectomy or reconstruction procedure, and the acceptability of some aspects of their outcome after this surgery. They found that information about type and choice of prosthesis was considered by patients to be inadequate.

Demographic factors

Consumer's age

Age and other demographic and psychosocial factors have been found to be associated with health-related information needs. In a literature review, Sammarco (2001) examined the role of psychosocial stages in determining quality of life for women with breast cancer. The findings from this study indicated that planning and implementation of care must be tailored according to differences in age and in psychosocial life stage because life concerns can vary greatly in each decade of life. The demands of breast cancer can produce special needs in women for information, support, and communication or home care assistance.

A Canadian study which evaluated the needs of female BRCA1 (breast cancer 1 gene) and BRCA2 (breast cancer 2 gene) carriers undergoing genetic counselling found that age, education and previous diagnosis of breast cancer are important determinants in a woman's decision making after receiving positive genetic result. In this study, women with a previous diagnosis of cancer indicated that they needed more information relating to cancer treatment compared with women without cancer (Metcalfe, Liede et al. 2000). In another similar study it was concluded that genetic testing and counselling appear to produce psychological benefits and improve accuracy of risk perceptions, although women who were tested but declined to be informed of their results appeared to be at a greater risk of a worse psychological outcome (Butow, Lobb et al. 2003).

A study on motives for women attending familial breast cancer clinics in the Netherlands found most women wanted to be informed about the genetic nature of breast cancer, their own risk and their children's risks (van Asperen et al. 2002). The factors that appeared important were age, personal history of breast cancer, a BRCA (a breast cancer gene) mutation in a family member, and having borne children. Younger women were especially interested in their own risk and their options of prophylactic mastectomy. This study also appreciated a step-by-step approach used for decision making by women.

Consumer's health status

Patients' need for information could also depend on their current physical, mental and social wellbeing. For example, a patient with newly diagnosed breast cancer could need information on the advantages and disadvantages of various treatment options. Masood (2003) states the need for increasing awareness of breast-conserving therapy as an attractive alternative to mastectomy for patients. Recent studies also revealed that there is a clear need for information to be written specifically for women who are at high risk of develop-

ing breast cancer and who thus plan to undergo prophylactic mastectomy (Dobson 2003; Hatcher and Fallowfield 2003). The studies found that those women who went ahead with surgery were not adequately prepared for the level of postoperative incapacity.

For terminally ill cancer patients, palliative care is recommended. In most situations, palliative care involves a biomedical approach of pain and symptom management. As regards elderly terminally ill cancer patients, Ragan and colleagues (2003) proposed a holistic patient-centred approach to communicating palliative care. This should incorporate other terminally ill patients' narratives and lived experiences in the final stages of their life. Elderly cancer patients should be treated as active interpreters, managers and creators of the meaning of their health and illness (Vanderford, Jenks et al. 1997).

Consumer's empowerment factors

Empowerment indicates processes where patients are provided with opportunities to participate in their treatment management and to exert influence over their environment. It includes advocacy (intervention on behalf of persons in a systematic and competent manner) and 'voice' in decision making (O'Hair, Villagran et al. 2003).

Some consumers may choose to trust that their healthcare provider has provided them with all the information they need and thus not require any more information, whereas others actively seek out health information for themselves in addition to that supplied by their healthcare provider. There is a tendency towards enhanced consumer participation in healthcare decision making, and many patients like to know about the benefits and potential harm of various options available to them. Thornton and colleagues (2003) emphasise the need for availability of better information about screening, especially to increase consumers' awareness of the range of uncertainties as regards benefits and harm. Consumers are only able to make an informed decision when they have the relevant information. Similarly, in the context of having information versus not having it, a review of informed decision making about entering screening programs found that personalised risk communication, whether written, spoken or visually presented, was associated with increased uptake of screening tests (Edwards, Unigwe et al. 2003). Most of the studies reviewed addressed mammography.

Discussion

In this article I have identified issues relating to the information exchange that patients in general, and consumers of breast cancer services in particular, encounter. The impact of cancer diagnosis could affect the way patients seek information. The major issues could be classified based on quantity of information, quality of information, factors associated with procuring and collecting information (dependent on information need), and management and application of information.

The amount of information that patients would like and the information health professionals and the healthcare sector provides to them needs to be assessed at different times during the episode of care of

each patient. There is a definite need to develop appropriate strategies for distribution of information sources (O'Connor et al. 2003) but it is important to determine whether the strategies put in place are effective and useful for consumers. Continuous evaluation of strategies of providing information and the amount of information provided by these strategies need to be balanced by evaluation of patients' information needs at various times during their contact with the health system.

From the patient's perspective, the amount of information provided needs to be adequate; neither too much nor too little. The literature indicates that patients receive varying amounts of information from different sources. There is the possibility of information overload, deficiency (inadequacy) of information, and of overlaps or gaps. Therefore, there is a need for consensus building and for bridging the knowledge disparities that could arise within the system.

From a healthcare provider perspective, there is a distinct challenge in directing efforts to standardise ways in which information is provided to consumers while conveying appropriate medical knowledge and tailoring that knowledge to consumers, needs.

Regarding quality of information, health information provided to patients needs to be accurate and relevant to the patients' needs. The health sector needs to develop appropriate consumer information that patients are able to easily access and understand. The literature indicates that patients receive health information of varying quality.

It is also important to ascertain how consumers are interpreting and applying the information they obtain, and there is a need to find out how they perceive interacting with innovative computer-based informatics tools (Eysenbach 2000).

Future research could focus on both the quantitative and qualitative aspects of health information provided to consumers. In our healthcare system, more understanding is needed of the current inputs, processes and outcomes involved in the exchange of health information between providers and consumers. Future research efforts need to be directed in a way that would provide an understanding of whether health-related information provided by health professionals to consumers is increasing compliance to treatment and preventing adverse events and complications; has other tangible outcomes (e.g. reduced anxiety, increased satisfaction); is merely dispelling myths; or is not having any impact at all.

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