

BREAST CANCER INFORMATION NEEDS AND SEEKING: TOWARDS AN INTELLIGENT, USER SENSITIVE PORTAL TO BREAST CANCER KNOWLEDGE ONLINE

ABSTRACT

Breast cancer features prominently in the medical expenditures of all western societies and remains the greatest cancer killer amongst women. Information regarding the medical, societal and psycho-social aspects of the disease are vital for informed decision making, patient 'empowerment', compliance and improved outcomes. Yet the literature consistently reports dissatisfaction with both the content and delivery mechanisms of breast cancer information. This paper presents a critical review of research on the information needs and information-seeking behavior of women with breast cancer. Results from the Australian Breast Cancer Information Needs and Seeking (BCINS) study are reported and affirm the importance of user-centered, contextual studies as a means of understanding the continually changing information requirements of a diverse target audience. The end-product of the BCINS study, an online 'intelligent portal', is described. Through the provision of quality, 'tailored' breast cancer resources, the portal is intended to meet the differentiated information needs of the breast cancer community.

INTRODUCTION

I...found that a lot of the time the information that you get until it suddenly is part of what you're going through is not relevant and therefore, ...you read a lot of information that you're not taking in. It's a process. [Participant 10]

These words emanate from a participant in the first stage of an Australian major project entitled, 'An intelligent, user-sensitive portal to breast cancer knowledge online' (1). The quote embodies the study's emphasis on the 'whole person' in investigating the diverse and dynamic information needs of women with breast cancer and their families. Since breast cancer features prominently in the medical expenditures of all western societies, this project assumes particular significance. In Australia breast cancer is the largest cancer killer amongst women with 10,000 new cases, and 2,500 deaths reported annually (2). Numerous studies have reported the continuing dissatisfaction with current information provision, both in terms of content and delivery mechanisms. Furthermore, the lack of timely and accurate information remains one of the two highest unmet needs of the woman with breast cancer (3 - 10). Given that information can play an important part in patient empowerment, satisfaction,

compliance, and ‘shared decision making’, the Australian project has the potential for far-reaching benefits.

Despite the importance of the topic, there appears to be a paucity of research about breast cancer information needs which adopts the contextual approach advocated by many in the information needs and seeking (INS) field (e.g. 11 - 17) and which is implicit in the opening quotation. Participant 10’s words suggest Wilson’s (11) and Wilson and Walsh’s (14) vision of the cognitive, affective and physiological domains as interdependent forces influencing the health seeker’s information needs, search strategies, and ultimate personal integration of knowledge. Whilst the literature on INS of cancer patients and, in particular, breast cancer patients has a long history, and ranges across numerous disciplines including the social and behavioral sciences as well as the traditional biomedical fields, the concentration on the actual users of information and their individual ‘living’ worlds is a relatively recent phenomenon in the literature. Generally, the overwhelming majority of studies adopts the quantitative mode of inquiry, where one-dimensional causal relationships are seen to have ‘statistical validity’. Too often in this literature the statistical ‘measurement’ of lives emerges as the ‘gold standard’, rather than the meanings that potential information seekers bring to their situations and needs.

This paper focuses on the first stage of the broader project, ‘An intelligent, user-sensitive portal to breast cancer knowledge online’. This first stage is a study in its own right and is referred to as the ‘Breast cancer information needs and seeking (BCINS) study’. The paper has the following purposes: to provide a critical overview of the research, to date, about breast cancer information needs; in the context of this research, to discuss the need for user-centered, contextual studies of the information needs of women with breast cancer; to discuss the potential of the Internet to assist in meeting breast cancer information needs; and to outline

key findings from the BCINS project. Quotes from participants in the BCINS study are included throughout the paper.

OVERVIEW OF THE AUSTRALIAN BCINS STUDY

In contrast to much of the other research in the literature, the BCINS study has the user at center stage and adopts an interpretivist/constructivist approach in an attempt to understand breast cancer patients' perceptions, values, beliefs and the 'meanings' they construct around the issue of information needs, seeking, and knowledge integration.

The broader project, 'An intelligent, user-sensitive portal to breast cancer knowledge online', includes the following components: an extensive user needs analysis (the BCINS study); identification, assessment, and 'rating' of existing materials in accordance with evidence-based protocols and 'best practice' principles of web-design; the development of a descriptive metadata schema which will match user profiles with the identified resources; and finally, the development and testing of an IT architecture (a portal) which will lead to the creation of a user-sensitive interface to an online repository of breast cancer materials. The researchers believe that, while portal technology is widely used, and some intelligent portals are now available, the concept of providing *differentiated* access to breast cancer resources on the basis of matching user profiles and resource assessment is innovative. The project will advance understanding of how to develop user-sensitive intelligent interfaces supported by metadata schemas – another innovative contribution of the project.

The conceptual underpinnings of the BCINS study were influenced by both personal construct theory (18), which emphasizes the separate reality constructed by each individual, and social construct theory (19), which emphasizes the influence of society on individual reality. The researchers believe that, since each person's life experience is different and frames of

reference for interpreting the world are never identical, the focus should be on the individual. They believe, nevertheless, that there are shared experiences, values, and meanings within a particular culture. Giddens' (20) structuration theory sees culture as comprising both objective and subjective perspectives and the kinds of knowledge implied by both. When people share the experience of a certain disease within a particular society, it is likely that some shared meanings will emerge and that these patterns can be used to improve information provision.

The fieldwork for the study has involved in-depth interviewing of 34 women with breast cancer, either in focus groups or individual interviews, undertaken using a semi-structured interview schedule with a predetermined list of very broad questions. This approach allows probing and the follow up of leads provided by participants (21). The sample was a purposive one, selected to represent various age groups, disease stages, time since diagnosis, educational levels, marital status, urban and rural locations, as well as ethnic backgrounds. As Australia is a multicultural society, it was considered essential that the voices of women from diverse ethnic backgrounds (ie. Chinese, Italian, Greek, Lebanese and Aboriginal) be heard.

Participants were recruited via breast cancer nurses in both the public and private sectors, and through facilitators of healthcare centers and breast cancer support groups. In addition, a separate focus group of 11 breast care nurses was held. Of particular interest in the interviews was the information participants found most useful; their preferred information formats; their overall impression of the 'quality' of the information; the extent to which they used the Internet to locate breast cancer information; and, the gaps they perceived in information provision which is very important given the aim of presenting users of the portal with information which is tailored to their specific needs and backgrounds, e.g., geographic location, age, literacy level and time of diagnosis. An overarching aim was to identify the groups of people and types of information which should be specifically targeted in an online resource.

The gathering, coding and analysis of the qualitative data followed the grounded theory method, originally conceived by Glaser and Strauss (22), but as outlined by Pidgeon and Henwood (23). Analysis of data was a continuous process with the initial themes and categories, determined after the first few interviews, being continually reassessed and expanded as more data were collected. A matrix of demographic information has been developed, but cannot be included because of word limitations. The participant numbers referred to in the text come from this matrix.

RESEARCH FOCUSING ON BREAST CANCER INFORMATION NEEDS

Research focusing on the INS of cancer patients, and in particular breast cancer patients, has a long history and currently ranges across numerous disciplines including the social and behavioral sciences, as well as the traditional biomedical fields. The following presents a critical review of pertinent studies found in the literature.

Early research

Early studies were mainly from the biomedical and behavioral science fields and tended to work from a prescriptive model of communication where information was generally viewed as absolute and static. The patient, as the recipient of such ‘education’, was basically seen as part of a homogeneous group, often ‘ignorant’ and noncompliant (24). At the same time, the ‘support’ literature, largely from psychology and nursing, highlighted the role of information provision as an important component of ‘adjustment’ to a cancer diagnosis. Information and social support were seen as the basis for individual ‘control’ and ‘coping’ (25 - 26).

Numerous studies have investigated whether ‘problem-solving coping’ with its emphasis on information and cognitive strategies - rather than ‘avoidant coping’ - facilitates adjustment, or

leads to greater distress and decreased quality of life for cancer patients (27). Another feature of the early literature was the emphasis on how much information cancer patients want or need (28 - 29).

The health consumer comes into focus

In the early 1990's the change in terminology from 'patient education' to 'patient information' symbolized the growing impact of 'patient-centered medicine' and the move away from the earlier prescriptive approach. Today's breast cancer patient has metamorphosized into a complex entity with differing physiological, cognitive and emotional needs in keeping with the early recognition of Wilson (11) and Wilson and Walsh (14). The literature of the past few years is punctuated with frequent admonitions to focus on the patient. As Luker et al (7) stated:

the service user's perspective is...of paramount importance if we are to provide adequate information to facilitate informed decision making. If we want to involve people with cancer in the communication process, then we need to find out from them what it is that they need to know (p.136).

Numerous factors have been attributed to this 'shift' in perspective: the rise in consumer advocacy; governments now intent on reducing spiraling healthcare costs through 'shared decision making' policies (see 30, 31); the deployment of 'evidence based medicine' protocols; telecommunications developments; and rapid societal changes. Many health care consumers now expect and accept a greater share of the responsibility for their own health care. This notion of autonomy and self-reliance was clearly expressed by Participant 30 of the BCINS study:

I've learnt that getting the information is all about taking more responsibility for your own health. I worked that out fairly early in the disease - that it's up to me to get what I need, work out what I want.

Concomitant with these factors, has been the general societal demand for accountability and the shift away from medical paternalism to patient/physician collaboration. Critics of the paternal approach point to the actual materials produced which have often been written in a language aimed at the lowest common denominator. As Coulter (32) postulated:

far too many of the information materials adopt the paternalistic view that patients cannot cope with bad news and must be kept ignorant of medical uncertainties. Patients are seen as ignorant children in need of instruction and reassurance, rather than as experts in their own needs and preferences (p.225).

Participant 15 expressed her frustration at the superficial level of information she was often confronted with:

I wanted the 'hard' information; I didn't want the 'fluffy, there, there' stuff at all. I wanted 'What does this mean? What's the pathology? What's the description of the medical condition? What's the background?

By the early nineties, a large body of research clearly pointed to the inadequacy of both the patient-physician communication processes and the growing dissatisfaction with patient materials. Increasingly the call was for 'shared-decision making' and the provision of materials which took into account patient needs and circumstances. Confusion and anxiety would be alleviated and patient satisfaction increased if patients were consulted about their information needs before materials were developed (33, p.319). Relevance of information and an awareness of patient 'context' form the backdrop to the following comments from participants in the BCINS study:

When I was first diagnosed they said I'd have to have a mastectomy and I was just agog. I just couldn't cope with that and the book...talked about 'your partner will still love you'. But yeah, what if you haven't got one? [Participant.22]

I know when I was in hospital after the operation I had a lady visit me [to give me information] ...and I don't mean to be horrid...but the woman was 80, old and she'd had hers done 21 years ago and I thought 'I don't want that. Leave me alone' ...I wanted someone who was my age, who was going through the same thing as me at that particular time. That's how I felt. [Participant 21]

Other studies have concentrated on the actual content of available materials, finding that many are contradictory (34) or inaccurate and 'lacking evidence' (33, p.320). The following comment from the BCINS study encapsulates this lack of satisfaction with current materials:

She gave me a whole wad of information. I was furious. It was basically a repeat of each other. It was extremely patronizing ...but it didn't actually talk about what it was doing biochemically. I wanted the hard data...I wanted diagrams. For the first time last week I actually saw what invasive (lobular) carcinoma looks like as opposed to a ductal or different type of cancer. [Participant 15]

Along with the shift in focus to the patient, the breast cancer research literature of the mid to late nineties is characterized by wide-ranging methodologies adapted from numerous disciplines and an emphasis on patient/caregiver as the focus of study. Postmodernist theories of discourse analysis, phenomenology and sociology provide the theoretical frameworks for many breast cancer studies. To speak of 'coping style' (35), 'monitors and blunters' (36), 'social comparison theory' (37), or Lazarus and Folkman's 'Transactional Model of Stress and Coping' (38) in connection with the breast cancer information field would have been a rarity fifteen years ago. Yet, the continuous flow of studies reporting on patient dissatisfaction, as outlined above, make it doubtful whether information provision for the breast cancer community has greatly changed.

A true paradigm shift – or more of the same?

It is questionable whether many of the recent studies are any more applicable to the real world of the breast cancer experience, or less reductionist, than those originating from the more traditional biomedical research paradigm. For example Miller's (39) 'monitoring and blunting' theory and the Miller Behavioral Style Scale (MBSS) has been used in a number of different medically-related situations, including the Rees and Bath (36) study of the information-seeking behavior of women with breast cancer. Miller's division of personality types is established on the basis of responses to four hypothetical scenarios: a visit to the dentist, being held hostage, being laid off work, and being in an airplane which goes into a deep dive, plus a series of questions to determine the 'monitoring' or 'blunting' personality.

In the Rees and Bath study (36) it is considered that, for 'high monitors' information facilitates coping '... because it provides them with increased certainty, helps them to attach appropriate meanings to their experiences, and enables them to rehearse or work through their experiences' (p.900). This is opposed to 'blunters' who 'avoid or distract themselves from information in threat-relevant situations' (p.901). MBSS was used in the mailed survey component of the research with participants being categorized into 'high and low monitors' (p.902). Participants in the other component of the study – the focus groups - were divided into these personality groups '...on a median-split procedure, leading to individuals being categorized depending on other individuals' scores, rather than on individuals' personal characteristics' (p.903). Even if one accepts this as a valid approach, the question must be asked: How reliable are reactions to Miller's hypothetical scenarios in relation to the life experience of having breast cancer? Moreover, although not Rees and Bath's conclusion, the focus group findings appear to cast serious doubt on the usefulness of dividing individuals into 'monitoring' or 'blunting' personality types:

The theory that information seeking follows a consistent or habitual approach is not supported by the findings of the focus group discussions. Instead, these suggest that individuals may fluctuate between seeking and avoiding information, with the process being dependent on situational variables, such as how controllable the threat is perceived to be (p.905).

Participant 27 echoes this oscillation:

...when I was first diagnosed I didn't want to know anything because when I came home after the operation...I was 'cured'. I didn't need to know anything. It's only since then that I've sort of got a little bit braver...

Researchers have also 'borrowed' from the field of education and applied 'readability' formulae to patient information materials in order to assess their efficacy and relevance to the target audience. Such formulae have also been used as criteria in the production of patient information materials. Several studies (40 - 42) assume that 'patient education materials should be aimed at the eight grade level or below; however, most patient education materials are still written at the 10th grade level or higher' (41, p.807). In fact neither level is appropriate to all information seekers. For example, Participant 2 would require a higher than 10th grade level for her information. She would not be alone given that, in May 2000, 30% of the Australian population had completed tertiary education (43):

I need the twofold - both sides - the emotional and the factual. But in a lot of depth. Not the brief little pamphlet stuff... don't want the throwaway type of article. I want the deep scientific type that I can take in. [Participant 2]

The emphasis on 'readability formulae', rather than providing choice of reading levels for information seeking, makes the patient the passive recipient of information, rather than an individual 'constructing the meanings of texts' (24, p.1424) by bringing her own experiences

and values to the task of ‘sensemaking’. Nor does such a reductionist view of comprehension allow for the role of diagrams, pictures, or multimedia enhancements as aids to understanding. The role of the visual in breast cancer resources was emphasized numerous times in the focus group discussions:

Look, the most important thing for me was to go and... see someone else’s reconstruction. As soon as I saw that reconstruction I was completely at peace about having it... [Participant 29]

Such tests also do nothing to accommodate the use of medical jargon, which worried some participants, as indicated by the quote from Participant 14, an older woman in her 70s:

...I wouldn’t understand it [technical medical information] anyway. It’s a long while since I did science and things like that. And I’ve never been interested in it...I wouldn’t understand the scientific terms.

Invariably, such tests achieve little except to categorize the patient/information user and run the risk of ‘disenfranchising’ a large sector of the population.

Even in a ‘patient-centered’ study, where constructs from psychology and sociology were melded to develop a questionnaire designed to ‘elicit women’s perceptions of informational needs’ (44), the patient ironically had little input into the development of the instrument. As participants in the BCINS project pointed out:

All our cancers are different. They’re all breast cancers, but they’re different. You’re all at different stages; you’ve got different cultural backgrounds. It’s all very complicated. It’s only when you come to these sorts of things and you realize ‘wow’ there’s no one answer for everybody. [Participant 16]

I don’t think any of us would have sought identical information because we all do it in different ways and our personalities handle it in different ways and we progress at a different speed with the level of information that we want. [Participant 2]

The need for more user-centered, contextual studies

Whilst the studies, reviewed above, to some extent represent a departure from the earlier biomedical approaches, the inclusion of methodologies from other disciplines has not led to a contextual analysis of breast cancer information needs. It appears that often ‘the agenda for exploring information needs has...been set by the investigators and not the individuals with cancer themselves’ (38, p.241). Overall, the perspective remains narrow and invariably ignores the multiple realities of the breast cancer experience which is richly textured, overlapping and intrinsically complex.

During a discussion in one of the focus groups of the BCINS, regarding the importance of ‘relating’ to one’s clinician, both as a prerequisite for asking questions and gleaning information, several participants noted that they had changed their doctors. The following quote emerged from this discussion and epitomizes the complex interrelationship between motivation, external circumstances (e.g., financial situation), emotional response and physical capability:

It’s hard while you’re searching, (for another doctor), because emotionally.....you haven’t got the energy to drag around to different surgeons and also simply the cost.... ‘No, I don’t really like you!’ and forking out some more money going to another surgeon. [Participant 22]

If we accept that ‘the experience of illness is a profoundly social one’ (37, p.205), then quantitative methods alone are insufficient to understand the ‘experience of need’. As Wilson (12) has pointed out, a broader, multiple perspective which eschews the reductionism of single causal factors is essential if we are to understand the user’s psychological, social and physiological ‘context’ (p.552). There is considerable scope for qualitative studies such as

the BCINS study to provide richly textured understandings of the information needs and behaviors of people with breast cancer and the potential role of the Internet in assisting to meet such needs. Further findings of the study follow the next section on the potential role of the Internet.

THE POTENTIAL OF THE INTERNET TO MEET INFORMATION NEEDS

According to Harris Interactive (45), ‘the internet serves as a powerful lever for instigating patient involvement in care decisions’ (p.1). There are cogent reasons why there is considerable potential for delivery of quality information about breast cancer via the Internet. The first of these is the increasing use of the Internet for health information acquisition. For instance, in America, it is estimated that 52 million adults, or 55% of those with Internet access, have used the Web to locate health or medical information (46, p.3) with women ‘more likely to seek online health information’ (p.6). Other research (47) revealed that once people have access to the Internet ‘the health information digital divide tends to disappear’. Furthermore, Brodie (47) reports that there are no significant statistical differences in people below, or above, 60 years of age and their online health seeking habits: ‘Once people gain access to the internet, its use at home to get health information is similar across income, education, race and age. Therefore the number of persons using the internet to access health information should rise along with computer use’ (p.262). Some forecasters believe that by 2005, 88.5 million adults in America will be using the Internet to find health information (48). In Australia, figures also indicate a rapid uptake of Internet technology. As of August 2000, 61% of adult Australians had some access to the Internet (49, p.2).

Many participants in the BCINS focus groups commented that they, or a relative on their behalf, had found helpful information on the Internet. For Participant 17, the ability to directly access authoritative and current medical journal articles was valuable:

I felt more comfortable with them (articles) than with some of the information that I was reading in the books I was borrowing.

For other women, the vast array of information available through the Internet represents choice and an aid to decision making:

I was really looking (for) information about the causes of the disease; about different treatments on offer...what are the latest treatments? What else is on offer other than what the doctors tell (us)...[Participant 34]

On the other hand, there was doubt expressed about the quality, authority and currency of some of the information and the skills required to find reliable and suitable information:

...how do you know which one (web site) has credence and which one doesn't? I mean, if you're going to go into the Internet and try to find a site that's going to tell you something, how do you know that that's not valid information? [Participant 27]

This view is in keeping with much of the recent research which is devoted to assessing website 'quality' in terms of accuracy, source identification, readability, and authority (See especially 50 - 51). Other findings by the California Healthcare Foundation (52) reveal that 'consumers must sift through a lot of irrelevant material' (p.11) and that search-engines, which are the user's basic strategy, are 'inefficient tools' (p.11) for locating information.

Several studies have concentrated not on the content of websites, but on the reasons, motivation and information needs of the health consumer in order to understand the phenomenal growth in Internet health-seeking behavior. Several reasons are proffered: frustration or disappointment with current or previous physicians; the failure of other therapies; the desire for latest research news and the ability to remain anonymous (53, p.154).

In rapidly developing fields such as genetic testing, where the knowledge base of general

practitioners in particular may be lacking, Taylor et al (54) report that: ‘Respondents...looked for sites that provided clear and easily comprehensible information and a balanced view on treatment options’ (p. 232), whilst for clinical trial participants the Internet ‘increased their understanding and thus their ability to talk with their providers’ (48, p.194) leading to greater informed decision making.

FINDINGS OF THE BCINS STUDY

Analysis of the interviews and focus group transcripts affirmed the highly personal and dynamic nature of the information-seeking patterns of the woman with breast cancer. Whilst common ‘themes’ did emerge, the transcripts above all indicated the complex nature of the individual information-seeking process. Reactions to content, format, sources and, preferences for the timing and delivery mechanisms of information, all highlighted the individuality of human preference and the intricate interplay of the physiological, cognitive and affective domains. To attribute such diversity to simple demographic variables, or psychometric constructs of adaptation to cancer, or even notions of ‘patient control’ is to diminish human experience. Yet a large proportion of the breast cancer literature adopts this reductionist/positivist approach to information needs and seeking. In doing so, such literature perpetuates the implicit assumption that what cannot be measured is scientifically less valid. More importantly, it fails to address the issue with which the BCINS study, and most of the INS field, is ultimately concerned - how best to provide access to information which addresses such diverse needs.

The Australian project, in contrast to most other research in the literature, involves suitably qualified people who have experienced breast cancer, including the Research Fellow who works full time on the project. Some of the findings from the BCINS study have been

mentioned throughout the paper. Further discussion follows - under the headings: delivery mechanisms; content and format of information; and complexities of information need.

Delivery mechanism

Several findings from the BCINS study are highly pertinent to the issue of facilitating information provision and informing system design. For instance, most participants reported that the usual initial method of obtaining information was verbally through the health care professional. This was then supplemented by the handing over of a ‘wad of information’ (Participant 15) irrespective of user preference. Inability to control the flow or type of information, led to the feeling of ‘information overload’ or an ‘avalanche’ (Participant 15) at a time when many of these women were at their most vulnerable:

I guess the main thing is too many booklets, too much stuff to read ...and to find out the information, the specific information that you need to have, you have to read, you have to read through too many things...[Participant 10]

Content and format of information

Perceived gaps in content were evident in various areas, particularly in metastatic (secondary tumours) disease; genetic testing; accurate risk assessment for family members; information dealing with complementary and alternative medicines; and, significantly, directional information on available local support and financial services.

Nor was there any single approach to the type of information required. As mentioned previously, some women felt aggrieved by the lack of detail and biochemical information contained in many of the resources provided to them, whereas others felt they would like

information to be ‘simplified’ [Participants 29 & 32], and more direct. The issue of ‘relevance’, however, was emphasized numerous times. Often materials, more appropriate for the older, married woman, were provided for single women. Women also felt a distinct lack of information for their partners and families. Many participants stated that they would have appreciated specific information directed towards their children and spouses. Most importantly, there was a perceived lack of material with which women felt they could identify. This was particularly evident with some of the ethnic groups and is typified by the following comment from an Aboriginal participant:

Maybe the printing of material needs to be done to cater more for Koori women ...to break down the barriers a bit...why can't we have a brochure with Koori women? To make Koori women feel it's okay to come into this place (hospital) and get their treatment. You want to encourage people, not to make them feel frightened and not follow something through. [Participant 30]

The desire for ‘positive’ information highlighted the imponderables of human communication. Many of the women reported the perceived need to remain ‘positive’ in the face of a life-threatening situation, yet simultaneously rejected empty platitudes from either their clinicians, friends or printed materials:

You see, it's interesting. I was getting that sort of negative feedback from people dying (in the support group), but then on the other hand, I at least wanted to know, or not to be told that everything is going to be absolutely okay. Because then I felt that I was being lied to. It's interesting isn't it? It's a very difficult process to go down about giving information to people. Making sure that it's balanced and it's what they want. You're looking for positive feedback, but on the other hand, you don't want to be given misinformation. [Participant 34]

How would Miller’s Behavioral Scheme classify the above woman? Would she be a monitor or blunter? Or would she be displaying ‘mal-adaptive coping’ strategies according to some

psychological testing criteria? How can any single positivist approach fathom the complex, but all too human responses, embedded in the above quotation?

CONCLUSION

The interpretivist methodology, with its emphasis on discerning perceived meaning, provides an insight into the complex, multi-layered world of the individual's information needs. Only by coming to some understanding of the contextual 'realities' of the breast cancer world, can we provide information delivery mechanisms which seek to address the diversity of these worlds.

The current financial straits of many hospital systems, the time demands on health care workers, and the sheer volume of available materials make designing information provision strategies to meet each individual's unique needs an impossibility. What is possible, is the identification of 'patterns' firmly grounded in the contextual world of the information seeker as has been achieved in the BCINS study. Currently, information resources and their mode of delivery fail to distinguish such patterns. The woman with breast cancer, to all intents and purposes, is reduced to a single, uniform entity where 'one size fits all'.

Internet access to an 'intelligent portal' of differentiated quality resources, which will be the 'end-product' of the BCINS study, has the potential to meet the diverse information needs of the breast cancer community. Firstly, it will provide a 'one-stop' entry point, alleviating the inaccuracy of current search engine retrieval systems, as well as obviating the need for highly proficient searching skills by the consumer. Secondly, it will facilitate access to the latest research 24 hours per day in the privacy and anonymity of the individual's home, whether this be in an urban or rural/remote location. There will also be easy access through public libraries, hospitals and doctors' rooms. Thirdly, it is the woman with breast cancer who will

be able to control the flow of information, and to decide exactly how much she requires at which particular point in time and at a level suited to her needs. Finally, multi-media enhancements will provide for individuality as far as it is possible to do so, e.g., for people with low literacy skills, those who prefer visual or aural information, or people from non English speaking backgrounds. The 'intelligent portal' will thus be an attempt to assist individuals to select their own information according to their needs and contexts.

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