Breast Cancer Knowledge Online: Supporting the Information Needs of Rural Women

Rosetta Manaszewicz
Monash University
Australia

Julie Fisher
Monash University
Australia

Kirsty Williamson
Monash University
Australia

Sue McKemmish
Monash University
Australia

Manaszewicz Ms, Rosetta,
School of Information Management & Systems, Monash University
Level 7/26 Sir John Monash Drive,
Caulfield, Victoria. 3161.
rmanasz@optushome.com.au
Fisher Associate Professor, Julie
School of Information Management & Systems, Monash University (address as above)
Julie.Fisher@sims.monash.edu.au
Williamson, Dr, Kirsty
School of Information Management & Systems, Monash University (address as above)
Kirsty.Williamson@sims.monash.edu.au
McKemmish, Professor, Sue
School of Information Management & Systems, Monash University (address as above)
Sue.McKemmish@sims.monash.edu.au
BREAST CANCER KNOWLEDGE ONLINE: SUPPORTING THE INFORMATION NEEDS OF RURAL WOMEN.

ABSTRACT

One third of Australian women with breast cancer reside in rural areas. Timely information provision assumes even greater significance with geographic isolation and less direct access to services and support systems. This paper focuses on the results of an extensive user-needs analysis, the first phase of a major Australian research project - “An intelligent user-sensitive portal to breast cancer knowledge online”. The paper describes the potential role of the Internet and its applicability to the rural sector in providing differentiated, timely, evidence-based material, as well as psycho-social support designed to meet the diverse needs of the breast cancer community.

INTRODUCTION

I...realised very early on that rural is not some homogenous outpost beyond the last cappuccino machine. In other words, solutions to rural health concerns must be tailor-made to the existing situation – a simple nostrum but one which can be lost in a policy framework which tries to impose a ‘one-fits-all’ philosophy. (Best 1999, p.2)
For the woman diagnosed with breast cancer, or for her family, friends or carers, the ‘experience’ of being confronted with a life-threatening disease is anything but ‘homogenous’. Individual physical, psychological, financial, cultural and geographic factors all interweave to shape the personal cancer journey. Other variables further cloud the murky landscape of serious illness, e.g., disease stage, age, educational levels, available support systems, ethnicity, ‘optimism/fatalism’. The list seems endless. As reported in the literature, ‘rurality’ often compounds the complexity and overall impact of these variables.

A large body of research has documented the added burdens of living with a major illness in a rural or remote geographic location. Both national and international studies have focused on the numerous inequities associated with health care in rural/remote areas, such as: access to, and the availability of, specialist care (Kricker and Armstrong 2001; Tulloh and Goldsworthy 1997; McGrath et al 1999a; Van Dis 2002); the psychological stresses involved in travel to major centres for treatment(s) (McGrath et al 1999b; St.John-Larkin, et al 2002; Young and Byles 2001; Payne, Jarrett and Jefes 2000); issues of choice, privacy, confidentiality which are all exacerbated within the confines of a small rural town (Wilson 2000; Kelaher, Potts and Manderson 2001; Fitzgerald, Pearson and McCutcheon 2001) and the financial impostes (Butler and Howarth 1999) often incurred as a result of geographic isolation. Dr Best’s words are therefore, a succinct reminder of the imperative to look beyond a ‘one size fits all’ mentality; to recognise wherever possible both the unique characteristics of the individual community and, the diverse and often dynamic nature of the individual’s ‘health concerns’. 
The current research project entitled, *An intelligent, user-sensitive portal to breast cancer knowledge online* (BCKOnline: [http://www.sims.monash.edu.au/research/eirg/bcko.html](http://www.sims.monash.edu.au/research/eirg/bcko.html)) attempts to identify and meet these diverse medical, societal and decision-support needs through the development and prototyping of an ‘intelligent interface’ to an online repository of breast cancer materials. The overarching aim is the provision of timely and accurate materials to cater for, as far as possible, the differentiated information needs of users.

This paper reports on the first phase of the BCKOnline research project – an extensive user-needs analysis of the information needs of women with breast cancer and their families. The paper begins with a discussion of the literature in relation to rural women and breast cancer, followed by an outline of the BCKOnline project and the concept of the ‘intelligent portal’ and its particular significance for the rural sector given the importance of access to tailored, in-time information in making health and life-style decisions, as well as the role of information in the empowerment of patients and facilitating shared decision-making. Key findings from the research to date are presented and the relevance to rural health discussed.

**BREAST CANCER AND THE RURAL WOMAN**

To the best of the researchers’ knowledge, no Australian study to date, has specifically addressed the information needs of rural women with breast cancer, nor how these needs may be met through the application of technology. In fact, only a handful of reports have investigated the perceived psycho-social or decision support needs of those women and
their families confronted with a diagnosis of breast cancer. (See for instance: Stafford et al. 1998; Davis, Girgis, Williams and Beeney 1998; Girgis, Boyes, Sanson-Fisher and Burrows 2000). Even quantitative epidemiological/audit studies reporting on surgical work loads, mastectomy versus lumpectomy rates for example, or overall clinician patient loads, are a rarity (see Tulloh and Goldsworthy 1997; Mastoglio and Kristianson 2001; Furnival 1997; Back and Morgan 2000; Craft, Primrose, Lindner and McManus 1997). Given the fact that one third of all women diagnosed with breast cancer reside in rural or remote areas of Australia, (Australian Institute of Health and Welfare [AIHW] 1999) and a further 1.5 million rural women are at risk of developing the disease (Furnival 1997) this is a surprising omission.

Other ‘facts’ paint a sobering picture for the rural breast cancer woman and her family:

- breast cancer remains the largest cancer killer amongst women with 2,500 deaths and 10,000 new cases diagnosed annually (AIHW 1999)
- 5 year survival rates are lower for women residing in rural or remote areas than for their urban counterparts (AIHW 1998: 18)
- whilst overall mortality rates have decreased only slightly in the past decade, incidence rates have continued to climb (AIHW 1999)
- distance and the availability of radiation oncology units, remain an important factor in decisions regarding mastectomy versus lumpectomy and radiation therapy treatment (Kricker and Armstrong 2001: 2)
- only 17% of female GPs are located in rural areas despite the fact that ‘27% of the female population lives in rural or remote areas’ (Young and Byles 2001 p.1). This
statistic arguably becomes important considering the growth of ‘women’s health centres’ in most metropolitan areas and anecdotal evidence indicating a preference for female treating clinicians. Cultural and ethnic differences in dealing with such a ‘personal’ disease may also contribute to the desire for ‘gender-based’ treatment and management.

Other factors also play a contributing role in the hardships faced by rural residents. Chronic general practitioner shortages ‘in the bush’ have been well publicised. The ‘shortage’ however, extends to specialist care as well, often necessitating arduous trips to major centres for treatment. Strong, Trickett, Titulaer and Bhatia (1998) report that ‘more than 40% of visits to specialists in 1995-6 were to those based in capital cities. This percentage was even higher at 47% for people living in other remote areas’. (91), whilst overall access to specialist care, especially surgeons, is still ‘only 59%…and 17% respectively of the corresponding supply in capital cities’. (87) Given this need for travel, several studies (McGrath and Seguerra 2000; Davis Girgis, Williams and Beeney 1998, p.526) pinpoint the poor knowledge throughout rural areas of the Patient Travel Assistance Schemes (PATS). A recent Western Australian government report felt obliged to state:

_There is a strong need to improve the information available to the community regarding PATS. This includes providing education and awareness raising with General Practitioners, Health Service Staff and metropolitan hospital staff as well as ensuring that the general public are well informed._ (Department of Health March 2002, p.4)
Once treatment has been accessed, the literature also highlights other potential drawbacks to optimum care. Local hospitals are increasingly responsible for the administration of chemotherapy and ‘continuity of care’. Gilbar’s (2001) assessment that ‘the potential for errors in centres with little experience in chemotherapy administration would appear to be high’ (p.49) is further compounded by the fact that ‘limited experience in surgical management of breast cancer may be an impediment to ‘best practice’……(W)hile most urban surgeons now agree that breast cancer should be treated in a multidisciplinary setting by a specialist who treats many breast cancers, almost 50% of rural surgeons believe this is not necessary’ (Furnival 1997). Whilst such data may have altered marginally, individual clinicians’ preferences for treatment modality remains a vital factor in the woman’s choice of clinical pathway. (see Stafford et.al 1998: 515)

Given these above factors, information which is timely, accessible, accurate and, wherever possible, tailored to the specific needs of the individual women and her family becomes vital in facilitating improved psycho-social and health outcomes. The BCKOnline project and the concept of the ‘intelligent portal’ endeavours to meet these needs.

THE BCKONLINE PROJECT

The BCKOnline project, *An intelligent user sensitive portal to breast cancer knowledge online*, is a collaborative, multidisciplinary research study funded by an Australian
Research Council Linkage Grant, with matching resources from BreastCare Victoria - an initiative of the Victorian Department of Human Services - and the Breast Cancer Action Group, Vic. While the research team recognize that men can also contract breast cancer, this research project is focuses just on women. The BCKOnline project consists of the following components:

- an extensive user needs analysis, leading to the development of context-rich user profiles;
- identification, assessment, and ‘quality rating’ of information resources in accordance with evidence-based protocols and ‘best practice’ principles of web design;
- description of information resources with reference to the outcomes of user needs analysis, and requirements for value-added information about provenance, authoritativeness, quality rating, conditions and possible cost of access;
- development of a descriptive metadata schema to support user-aware resource description (metadata schemas define standardised elements to be used in resource description);
- exploration of how to provide differentiated access through an intelligent interface that matches user profiles to user-aware resource descriptions; and
- development and testing of an IT architecture which will provide a user-sensitive portal to breast cancer information resources online.

**Intelligent Information Portals**
The concept of an information portal is not, as pointed out by White (2000), a new concept. Online host services provided such facilities in the 1970s and 80s. Their aim was to provide a one-stop access point that pulled together data from a range of sources. White (2000) notes that the range of information portals is wide. He suggests ‘A feature of all these sites is that an expert, or a team of experts, in a particular area has created an information structure that assists the user in identifying relevant links.’ (356). Coiera (2000) argues that the exponential growth of the Internet and the information available, particularly low quality information, has resulted in users finding it increasingly difficult to locate accurate and timely information particularly in the health area. The development of intelligent information portals is to some extent a response to this problem.

Portal technology is now widely used, and there are some intelligent portals currently available. Murray (2002) describes two healthcare portals that provide searchable health information, WebMD and HealthCentral.com. Some of the portals, she notes, also provide users with the ability to personalise their Web interactions.

Providing personalized views for individual users is one of the major advantages to the deployment of a web portal. Personalization is achieved through the creation of personal profiles that contain user information and preferences. Portal access may be tailored by user preferences, need, security level and access authorization. (Murray 2002)

The innovative aspect of this project relates to its focus on delivering resources in customized ways to meet the individual needs of users from many different backgrounds. This involves the development of a metadata schema which supports resource description
that is sensitive to the diverse and changing information and decision support needs of a
target audience, and designing an intelligent portal which can use dynamic, context-rich
user profiles, and user-aware resource descriptions to provide timely access to relevant
online resources.

Most of the very limited reported research on intelligent portals focuses on improved
search facilities (White 2000). In the case of commercial sites such as Amazon.com,
current portal technology enables the development of profiles of users from past use, to
assist with future searches. One intelligent portal, Health Smart Library,
(http://www.hsl.wisc.edu/staff/webteam/health_smart.cfm) seeks to provide relevant
information for health professionals, sorted by research interest and the particular branch
of medicine. An Australian site http://www.healthinsite.gov.au presents information on a
range of health issues and collects limited user profile data but cannot yet be considered an
intelligent portal. By contrast, the proposed portal aims to provide timely and relevant
information to a much more variegated group of users. By necessity, it will need to draw
upon, and discriminate within, a much broader range of resources than those available
through well-established professional sources such as MEDLINE. Users will be presented
with ‘tiered’ information, which is tailored to their specific needs and backgrounds, such
as geographic location, age, literacy level and stage of disease. The development of ‘user-
profiles’ as a result of the user-needs analysis, is therefore a key component of the overall
strategy. The research methodology of this component is discussed in the following
section.
The user-needs component: Research method and analysis

The fieldwork for the study has involved the in-depth interviewing of 53 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 (Williamson 2000). 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. Three focus groups were held in rural locations in both Victoria and New South Wales, representing a third of the total participant numbers. As Australia is a multicultural society, it was also 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. Again, three of these nurses worked with patients residing in rural areas of Victoria.

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 initially followed the grounded theory method, originally conceived by Glaser and Strauss (1967), but as outlined by Pidgeon and Henwood (1986). 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. The data was then analysed using a meta matrices as described by Miles and Huberman (1994). A matrix ‘is essentially the “crossing” of two lists, set up as rows and columns.’ (1994: 93). A database was developed and data were classified according to key themes that emerged from the interviews. The textual data was then classified and entered into the matrix. Participant’s comments are included throughout this paper and their randomly assigned numbers derive from this matrix.

**Breast cancer, the role of information and the Internet**

Governments both nationally and internationally now champion the inclusion of the health consumer as an active participant in her own health care. Information is deemed a vital ingredient in this partnership. Yet, whilst there is a plethora of breast cancer information available in both print and online, studies consistently report dissatisfaction with the content, provision, format and accessibility of such information. (McGrath et.al 1999a; Girgis, Boyes, Sanson-Fisher, and Burrows 2000; Jenkins, Fallowfield and Saul 2001; Luker et.al 1995; Luker, Beaver, Leinster and Owen 1996; Meredith et.al 1996; Fallowfield
To all intents and purposes the user is reduced to a single uniform entity where ‘one size fits all’. Variables such as disease stage, geographic location, ethnicity, educational levels, information needs and even age, are all too often ignored within the rigid parameters of the generic patient.

Arguably, such reductionism has in part, accounted for the phenomenal growth of the number and use of Internet health sites and disease specific bulletin boards and chat rooms. As of May 2000, there were an estimated 20,000 health sites (CyberAtlas 2001) and in 1998 at least 80,000 topic oriented discussion groups (Wu Song 2002: 41). Several studies have explored the reasons, motivations and information needs of the internet health consumer. 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 (American Medical Association, p.154) are some of the documented findings. In rapidly developing fields such as genetic testing, where the knowledge base of general practitioners in particular may be lacking, Taylor et al (2001) report that: ‘Respondents…looked for sites that provided clear and easily comprehensible information and a balanced view on treatment options’ (232), whilst for clinical trial participants the Internet ‘increased their understanding and thus their ability to talk with their providers’ (Ehrenberger 2001: 194) leading to greater informed decision making. Panjay, Hart and Tiwary (in press), exploring women’s use of the internet, report that ‘the emerging content of the internet provides reason to believe that there is an association between health needs and internet use’ and that ‘cutting down in information search costs entailed in the use of alternate modalities’ may be one evolving model of internet health use.
Due to word limit constraints it is impossible to report in any great depth on the impact of the Internet and its use by the health consumer. Suffice it to say that expectations are that by 2005, 88.5 million Americans (Ehrenberger 2001) will be accessing online health information. 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 (Australian Broadcasting Authority 2000: 2) whilst in the rural sector the Australian Bureau of Statistics announced:

At June 2000, an estimated 34%...of the 146,371 farms in Australia used the Internet. Although fewer farms used the Internet than used a computer at June 2000, a 91% increase in the number of farms using the Internet over the 15 months to June 2000 far exceeded growth in the use of computers for the same period. (Australian Bureau of Statistics September 2001)

Following is a discussion of the key findings from the user-needs analysis, and the potential applicability of the BCKOnline portal in meeting the perceived information needs of the rural breast cancer community. The research to date includes a number of elements such as the literacy level of users, education and language but these are issues that are applicable to all women not just those in rural areas. The following section focuses specifically on the findings that are pertinent to the information needs of rural women with breast cancer.

**KEY FINDINGS**
A divorced 46 year old mother living outside a large rural center in Victoria, provided the following observation when asked to comment on perceived gaps in current information provision.

...a list of surgeons. A list of oncologists;... A list to say this doctor does one hundred plus a year. This doctor does three. Especially in rural areas. We might only have one doctor who does breasts, and if you’re put into the pathway... some women don’t know their options. There are other doctors who can do their surgery, who do breast surgery as a regular thing. And I think we need that... I think if you could go into (a) web site and know it was easy to look at... ‘Okay, that’s the area I want to go to. I don’t need to look at all that stuff. That’s all I’m interested in. That’s where I’m going to go’. And then I switch off my computer and walk away. And it’s not this overload of pamphlets. It’s being able to choose the information you want at the time. What’s right for you. (Participant 23)

These participant’s words embody several of the major themes emerging from the transcript and matrix analysis - the importance of timing and relevance of information materials; dangers of information overload; the need for ‘practical’ and localized information; and the potential for appropriate delivery mechanisms to empower the individual and hence contribute to improved decision making and knowledge integration. Each of these themes is discussed below.
‘Information overload’

For many women in both the rural and urban setting the handing over of a ‘wad of information’ (participant 18) usually at the point of diagnosis, was overwhelming. In both the urban and rural context where increasingly shortened hospital stays, especially for biopsies are common, the need to ‘get to the woman’ before she left for home exacerbated this situation even more (Chisholm et.al 2000: 113). Fearful of losing ‘contact’, the emphasis becomes to provide as much information as possible, often without reference to relevance, psychological impact, or the expressed wishes of the individual woman herself. The following comments from rural women illustrate the possible negative outcomes of this strategy:

*I was given, like everyone else, a lot of information when I was in hospital and I probably found that very daunting and unable to take it in. (Participant 25)*

*...as a young person there’s really a lot of information that you’re given (that) doesn’t cater for you. I mean I was given information that was just kind of put in my lap for me to read...which I never actually read...I think I might have got too much information. (Participant 15)*

From the perspective of several of the breast cancer nurses, the issue of information provision was complex requiring above all a recognition of the particular circumstances and individual preferences of the woman involved.
...sometimes people give everyone a huge big pack of information and I don’t think… it’s specialized…(W)hen you’re at Breast Screen why do you need the radiotherapy and chemotherapy literature?…I was in one surgeon’s practice and she gave this patient 10 different things. And yes, this patient was going to require all that treatment. But I thought ‘poor woman’. She’s just been told she’s got cancer and the surgeon thought she was doing a really good job giving her all this information.

For some women however, being in possession of all this information was comforting:

...I found the information that I received at Breast Screen was excellent and I still refer to that. There was a lot of it and I read what was relevant at the time because every booklet was for a different stage. ..The other day I just went back to that pack and I’ve been reading about reconstruction because it’s only... now that I’d consider looking at. So I found that really good. (Participant 27)

Unfortunately, not all women retain their ‘bundles’ of information. Many comments revealed that information was relegated either to the dustbin, or the bottom of bedroom drawers or cupboards, never to be looked at again. Apart from the sheer waste of such resources, and the costs involved in their production, some women also lamented the fact that many of these initial brochures were repetitive and hence failed to provide them with the necessary conciseness they sought. If nothing else, this clearly illustrates the impossibility of adequately catering for individual differences via a ‘one-size-fits-all’ approach.
Relevance of information

Many of the participants noted that the information and/or support provided to them was not relevant. 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 residing 30km outside of a small rural centre:

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 15)

Other women identified the lack of materials catering to their specific social circumstances and age-related characteristics, as evidenced by the following reflections:

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 6)

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
‘Localised’ information provision

The need for women to ‘know’ where they might obtain prosthesis, wigs, specialised physiotherapy assistance for lymphoedema, counselling, or even the existence of available support groups was evident across the entire sample. For the rural woman with breast cancer however, such needs were intensified by the sheer fact of distance, social and physical isolation, and the lack of access to timely and appropriate information sources. Findings from other Australian studies (Wilkes, White and O’Riordan 1999; McGrath and Seguerra 2000) which highlighted the lack of specific and accessible ‘local’ information was confirmed in the focus groups. For instance, Wilkes, White and O’Riordan found that for families caring for a seriously ill or dying relative, there was a need for ‘more detailed information on travel and accommodation when attending treatment in the city…(T)hey did not know information was available, or received it after the event’ (45). In the Girgis et.al (2000) study, ’10 of the 15 items with the highest frequency of moderate or high unmet need for help related to the health information domain and three were from the psychological domain’ (169). The call for basic travel and allowance information was a constant refrain from many rural participants as illustrated through the following reflections:

*I was told about it after I finished five months of travel. I was then told ‘Oh, there’s a travel allowance.’ So you don’t know where to look for it. And if you
don’t get told by word of mouth, then usually you don’t find out. (Participant 23)

You needed accommodation. You needed to know about travel systems. You needed to know about the grants out there for travelling, accommodation, et cetera...The very simplest question I was asked the other day – ‘How do you get there?’ (Participant 24)

During part of a discussion centring on the difficulty of discovering and accessing local services, the following exchange occurred:

**Participant 23**  If it’s on the web...it should be easy to find and it should be a whole list of all the allowances and grants and the eligibility and how you get it. It’s got to be a hell of a lot easier than relying on people to tell you word of mouth.

**Interviewer**  Then you’d have five million different forms I imagine

**Participant 25**  Even one phone call knowing that the questions (you) were going to ask, you could get the right advice.

**Participant 23**  Why can’t the pamphlet that you get for the travel assistance be on there with the form? Instead of having a hard copy pamphlet that you get, why can’t that be there with the form? The basic travel allowance form, the basic carer’s form.
Whilst the above extract clearly illustrates the potential role of the internet and the applicability of the BCKOnline database in facilitating information delivery of this kind, not all participants were equally enthusiastic in regards to their personal use of computers and the internet. This facet of the research is briefly addressed in the following section.

**Current Internet usage**

Of the 53 women in the study’s sample group, 19 reported to have personally searched for information on breast cancer via the Internet. Another 24 women indicated that if they themselves did not access the internet, then either their children, other family members or friends had recourse to the internet in order to locate specific information on their behalf. Perceived lack of computing skills, access difficulties, lack of time, or lack of interest were the major reasons cited for non-use of the internet as an information resource. However, what was most evident throughout the sample, and in particular, for women living in rural areas, was the ‘second hand’ nature of the use of information derived from the Internet. For example, women who received and read local breast cancer newsletters, or notice-boards in their health care centres, reported their awareness of the source of much of the information as the following exchange illustrates:

*Interviewer: M, you’re not using it? (the internet)*

*Participant 24: well...yes. At ..(the doctor’s) rooms he had folders...so they were there if you needed them. So I took them home and I read everything there. So I did use the*
Internet I guess in another way. I found that was most helpful because they addressed things that were bordering on, wasn’t just down the line. There were lots of things that I learnt that I would never have known about.

Interviewer: Do you remember what those things were?

Participant 24: One was lymphoedema at one stage, .....and there was another when Herceptin was being trailed.

I didn’t have a clue about any of that.

For another rural participant the Internet was not only an information resource for herself and her children, but evolved into a psycho-social support:

I think Pete is a very resourceful child and he looked up...the Internet. And if I was at his place he would...(say) ‘Look at this Mum’ or ‘Look at that’ which didn’t mean a thing to me at the time, but it did to him. It was what he wanted. (Participant 9)

CONCLUSION

Information, and access to that information, has long been recognised as the cornerstone of ‘patient empowerment’ and shared-decision making. For the individual in a small rural town, or in the vastness of the ‘outback’, knowledge of ‘best practice’ and/or available treatment options, the latest research results, or practical, directory-type information, become vital elements in fostering this ‘empowerment’. The current financial straits of
many hospital systems, plus 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 should be possible, is the identification of ‘patterns’ firmly grounded in the contextual world of the information seeker. Currently, information resources across the entire spectrum of disease 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 through an ‘intelligent portal’ to a range of differentiated quality resources, has the potential to meet the diverse information needs of the breast cancer community. The ‘intelligent portal’ prototype, based on the innovative matching of user-profiles with a user-centric metadata schema represents an important step in the ‘tailoring’ of health information and has wider applicability which may well feed into other initiatives and overall information policy. Through a detailed, contextual analysis of the ‘world’ of the user, it has been possible to determine patterns of information need across a diverse representative group of people. With its emphasis on the user, rather than simply the ‘information’, the BCKOnline portal will thus be an attempt to assist individuals in accessing information appropriate to their needs and contexts. For the rural breast cancer community, it is hoped the portal will redress the information inequities imposed by the ‘tyranny of distance’.

REFERENCES


http://cyberatlas.internet.com/markets/healthcare/print/0..10101_379231.00.html


