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## Proposal for Subproject:

### The information needs and information-seeking behaviours of young women with breast cancer in relation to the Internet

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*SSHRC Initiative on the New Economy (INE):  
The role of technology in the production, consumption and use of health  
information in varied settings: Implications for policy and practice.*  
(August 25 2004)

## **The information needs and information-seeking behaviours of young women with breast cancer in relation to the Internet**

### **Synopsis**

This project builds on a BC Cancer Agency (BCCA) initiative exploring the potential for telecommunications technologies to increase access to information, education and psychosocial support for people with cancer.

As the first phase of a longer study, this project explores the question: What role does the Internet play in the information-seeking behaviour of young women<sup>1</sup> who have or have had breast cancer. This population is of interest to us because of their unique information needs and the acknowledged unavailability of information relevant to those needs, as well as the extent to which this group appears to use the Internet for seeking health information. We will be exploring:

- 1) the general information needs young women have at various stages of their cancer
- 2) how they meet those needs (information-seeking behaviours)
- 3) to what extent existing information they access is meeting their needs (what are the gaps in both information and means of information delivery)
- 4) what their experience has been using the Internet – how central of a role it has played in information seeking; and to what extent it has been helpful and/or hindering.

Subsequent phases of the study will explore comparisons between this population and others with cancer. The research – qualitative in nature – will be conducted first by inviting participants to send online narratives, and then through online focus groups, which will allow us to test themes that emerge from the narratives. We will then go back to a subset of our initial participants in another online forum to discuss and clarify our findings, before producing a first phase report and recommendations for the next phase. Our report will discuss the information needs and information-seeking behaviour of young women with breast cancer, as well as the gap between what women say they need and via what means, and what is available. These recommendations will be relevant at both health agency and government levels, as well as providing initial qualitative data for further, more detailed study.

This research will be conducted in partnership with members of “the Young and the Breastless,” a group of young women who have or have had breast cancer. Their website

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<sup>1</sup> The term “young women with breast cancer” demands a definition. We draw on Thewes et al (2004), who reject the chronological definition often used in medical literature (under 50 vs. over 50), instead classifying “young” women using a functional definition: either pre-menopausal or having elementary school-age children.

will be used in the research for recruiting participants, and later, for posting the results of the study. Young women with breast cancer have been selected as a purposive sample for the purpose of the larger study (*SSHRC Initiative on the New Economy (INE): The role of technology in the production, consumption and use of health information in varied settings: Implications for policy and practice.*) Specifically, it is thought that young women with breast cancer tend to have unique and high information and support needs which to a great extent are not met by existing information for cancer patients. This population will also, for the most part, be familiar with information technologies such as the Internet.

We feel this project is timely for two reasons: firstly, governments and health agencies are spending a great deal of money on information technology, often without paying attention to the types of information people want and the ways in which they choose to access it, and often without involving users in the design and delivery aspects; and secondly, very little research of this nature has been conducted with this unique population, and with the breast cancer survival rate increasing, the information needs of more and more women will need to be taken into account and supported.

## **Background**

Although “information needs” are reported as high and “information searching” is reported as common among people with cancer, the literature suggests the kind of information desired and the mechanism through which it is accessed are highly dependent on the type of cancer one has, the stage of disease one is at, and even demographics and “personality type.” In other words, empirical research into information needs and information-seeking behaviour needs to “get specific.”

Although some research has been done on information needs of people with cancer, the literature is scant in two areas: young women with breast cancer, who it is suggested have higher and different information needs from their older counterparts, on whom most of the existing research has been conducted; and people who have finished treatment and are considered “survivors” but whose information needs may still be high and who still must cope with the constant threat of recurrence. Our research begins with the former population, but in subsequent phases we intend to work with other populations (e.g., older women with breast cancer) in order to do some “comparing and contrasting.”

Although breast cancer is primarily a disease that affects older women, 23% -- a significant number -- of women with breast cancer are under the age of 50. Using anticipated statistics for 2004, this means more than 4,800 of the 21,200 Canadian women diagnosed with breast cancer will be under 50. With death rates from breast cancer declining steadily over the past decade, clearly the needs and experiences of this group present an important area of study. To date, however, there has been very little research conducted on young women’s experience of having breast cancer. This is especially troubling given young women’s experiences of cancer are different from post-menopausal women’s experience in a number of ways: the diagnosis and treatment are often different, they exhibit more aggressive disease, and they suffer more recurrences. They are also coping with different “life challenges” than their older counterparts, likely involved in a career and/or taking care of a young family. It is not surprising, then, that

their information and support needs relate to family relationships, employment, and financial issues. What is surprising is that young women report that such information is simply not available: “All the information that we have is geared to women over 50” (Nothing fit me, 2002, p. 12) was a frequent sentiment expressed in a recent forum on breast cancer and young women.

In addition to the lack of information to meet these unique needs, much of the literature on “information needs” of people with cancer in general has been written from the perspective of the professional caregiver – what information he or she should “provide.” This literature focuses for the most part on *medical* information provided within a treatment setting. However, in an earlier collaboration with the “Young and the Breastless”, it was stated that information on other aspects of living with the disease -- how to talk to friends and family; how to coping emotionally and spiritually; where to find financial help – are also important. As well, understanding the process of “information-seeking,” as opposed to “information needs” is important and empirical research here is very limited.

Despite the dearth of research in the foregoing areas, the Internet is increasingly being promoted as a means to disseminate health information to patients and their families. Yet lack of information is not a problem: young women have reported being “bombarded by pamphlets and booklets” (Nothing fit me, 2002, p. 11) but still their needs are not met. Badly needed is an understanding of the extent to which people actually *want* what types of health information – from the Internet and otherwise – and when, and how they undertake and prefer to seek it, as well as to what extent their needs are met.

Building on the above-mentioned BCCA initiative, our project will allow us to achieve a fuller understanding of these and other aspects of the issue of “information needs and information-seeking behaviour” of one group in particular, young women with breast cancer. By focussing on the experiences of the women themselves and allowing their insights to guide our project, we will be able to explore some significant assumptions made by governments as well as many health agencies and health professionals when they talk about the importance of “information.”

These assumptions include

- that patients need a lot of medical information (in fact they may prefer not to be overwhelmed with information)
- that “information” is a simple product offering, when actually there are many different types of information, many different styles and tones in which it can be offered, and many different “voices” in which it may be written and interpreted
- that information needs cease once the person has finished treatment

Besides leading directly to the second phase of our study, the results of our phase one project will have immediate relevance for The Young and the Breastless, a group that is seeking to design its Web site to meet information and support needs of young women with breast cancer across Canada. There will also be immediate relevance to BCCA, providing evidence for how the organization can more effectively meet or support the

information needs of young women with breast cancer. The project will also have implications, both in this phase and subsequent phases, for other health agencies and government offices whose mandate is to support the health care of Canadians through the provision of health information.

## **Method**

Our project will be qualitative and iterative, building upon as well as informing other aspects of the INE study related to its “Theme I”: lay-user consumption of health information.

We will advertise the study through a number of community sources such as the *Abreast in the West* newsletter (see Appendix 1). Interested participants will be directed to the *Young and the Breastless* website for more detailed information about the study (see Appendix 2). Women interested in participating, or seeking further information, will be directed to email one of the investigators. An electronic copy of the Information and Consent form will be sent to interested participants for initial review. If they agree to be in the study, they will be sent the consent form by regular mail, with a stamped, addressed envelope, and asked to complete and return the form (see Appendix 3). We aim to recruit approximately 45 women through this method. Our population will 1) have or have had breast cancer, 2) be either pre-menopausal or have preschool or elementary school-age children, and 3) have access to an email account.

We will first ask participants to “tell us your story about what you needed to know and how you went about finding answers to your questions”. In other words, they will be asked to write a narrative about their information needs and information-seeking behaviour. Questions will be included to structure their narrative (see below). They will be directed to send the narratives via email in a Word processing document or email.

Using a grounded theory approach to analyzing the data will allow us to begin the study inductively, allowing themes to emerge from participants rather than generating them a priori. Such an approach will aid us in our attempts to unveil meanings that participants themselves assign to their experiences. The strengths of a qualitative research study in such settings cannot be overestimated when the intent is to do research on little-understood phenomena. Grounded theory has been used with great success in a number of studies where researchers are exploring communicative processes to extract emergent themes and where there is little existing information about a topic.

Questions on our interview survey will include:

- what kind of information did you feel you needed in the weeks after being diagnosed with cancer? During treatment? After treatment?
- from whom and/or where did you prefer to get the different types of information, and how did you seek it?
- what was your experience in seeking and receiving the information?

- did getting the information help, and if so, how? If not, do you know why not? (ask for each source of information)
- in general, how did your information needs change over time?
- Do you use the Internet to get information? Which types of information?
- What is your experience in using the Internet?

Our rationale for leaving the Internet questions until the end of the survey is that in much of the research that has been conducted on information needs of people with cancer and information technologies, the Internet has been assumed to be the preferred method of delivery, and the question has been “how best do we make it happen?” In contrast to that, we want to first find out about the information needs and information-seeking behaviours of our participants, before finding out how the Internet may – or may not – play a role.

After analysing the data and extracting themes, we will conduct several focus groups (we cannot say how many at first, since a grounded theory approach suggests we keep doing research until reaching saturation – until new themes do not emerge) with the people who submitted narrative interviews. In the focus groups, we will ask participants to discuss the themes, and to answer questions derived from the original analysis in order to test the ideas that emerge and generate new data where necessary. We will also explore further any issues that arise in the focus groups that seem to need clarification or explication.

Our focus groups will be conducted on line, using “WebCT” technology. Such technology is very different from monitoring online activity without participants’ knowledge. All our participants will be online voluntarily, and will have filled out a consent form and have participated in the first stage of the project (the narrative). Secure accounts will be created for all participants, which they will access via their own user names and encrypted passwords. Participants will be given pseudonyms so that the researchers will not be able to tell whom the responses are coming from. Data will be removed from the site in a timely manner so that they will not be backed up inadvertently into a less secure site. A similar process will be used as our participants submit their initial surveys to us, and as we go back to them to discuss our findings.

## **Workplan**

- Ethics approval: September 2004
- Participant recruitment: beginning October 2004
- Data collection: completed February 2005
- Data analysis: mid-April 2005
- Final report and recommendations for further research: end of May 2005

## References

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