

**Information Needs Assessment:
Relevant and Reliable Information for
Longer-Term Breast Cancer Survivors**

Group Definition

My user group is breast cancer survivors, specifically women who are currently considered well and past all active treatments. They may or may not be on continuing medication, but chemotherapy and other intensive, regular treatments are finished. They are, in essence, cured of cancer. One of the things that makes this group an interesting information challenge is that having survived breast cancer is one of the few traits that they share. They can live in rural or urban settings, can be of a variety of ages and exhibit a wide range of socioeconomic, ethnic and marital characteristics. Though breast cancer affects primarily women, men can be breast cancer survivors, as well.

Information Needs of Breast Cancer Patients

Because this group is so diverse in its characteristics, its information needs and seeking behaviors are correspondingly diverse. Traditionally, however, all women with breast cancer have been treated the same, given the same exact information with little or no regard for the woman's individual circumstances. For example, single women may receive information about how their cancer will affect their husbands and a woman with Stage 2 cancer will receive information about Stage 1 cancer. I will first discuss the general information needs of women with breast cancer, then talk about the more specific

information needs of longer-term survivors. While there is significant overlap, women who are past the active treatment stage do have certain information needs that differ from those of newly diagnosed women.

There have been many studies of the information needs of women with breast cancer. These needs can be broken down into three categories: medical information needs, psychosocial and everyday-life information needs and “big issue” information needs.

Medical information is plentiful and widely available. “Many studies have identified that the majority of people with cancer want to be given all information related to the medical aspects of their illness and treatment” (Van Der Molen, p. 240). Yet all the studies reported a distinct lack of satisfaction on the part of breast cancer patients with regard to the information they received. The primary complaints were that too much information was shoved at them at the beginning, when they were still reeling from the shock of diagnosis, that information given lacked relevance to a woman’s own particular diagnosis or her personal circumstances and that the information was either too technical or too oversimplified. “The woman with breast cancer, to all intents and purposes, is reduced to a single, uniform entity where ‘one size fits all’” (Williamson, 18).

While information is generally associated with stronger coping skills on the part of patients, this kind of undifferentiated information pushing actually contributes to the stress of women by forcing them to sift through too much irrelevant information and asking them to remember information they may not need for months.

Breast cancer patients want information that helps them to cope with the psychological trauma of being diagnosed, as well as the lifestyle changes that occur.

“The desire for information also extended beyond the medical to encompass the psychosocial and support features available within the breast cancer community. In accordance with the published literature, many women reported that a diagnosis of breast cancer often resulted in major psychological and existential upheaval” (Manaszewicz, 8). Finding information on the psychological task of adjusting to being a breast cancer patient, as well as support groups, legal information and care resources like hospice care or home nurses were largely ignored in the information given to patients by their doctors.

One of the greatest unmet needs of women with breast cancer is having targeted, focused information for both informing and dealing with family and friends. Very little of this type of information has traditionally been available and very little study has been done on this user group.

What was especially clear from all of the literature is that the majority of breast cancer patients want as much relevant information as possible. The theme of relevancy came up repeatedly in the interviews and focus groups with breast cancer patients. “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]” (Williamson, p. 11).

Information Seeking of Breast Cancer Patients

Breast cancer patients receive the majority of their information, at least initially, from physicians or other medical personnel. However, “[d]octors do not receive adequate training in communication skills ... and consequently are ill-equipped to deal

with both their own emotional responses and those of their patients” (Van Der Molen, p. 240). Other primary sources of information identified by the literature include support groups and online resources. Again, this information needs to be targeted and relevant in order to actually fulfill the woman’s need for information.

Further complicating the information-seeking strategies of breast cancer patients is their traumatized mental state. “Until an individual is ready to accept they are living with cancer, they are unlikely to process information effectively” (Van Der Molen b, p. 52). Patients reported stuffing the information they had received into a drawer and never looking at it again.

The health system contributes to the difficulty of receiving adequate information. Patients frequently see a variety of specialists and receive care in a variety of venues, making it difficult to maintain a continuity of information. This lack of rapport with a caregiver combines with short appointments times to make it difficult for patients to feel comfortable asking questions and to have adequate time to get all of their questions answered without feeling like they’re imposing (Van Der Molen, p. 240).

Specific Information Needs and Behaviors of Longer-Term Survivors

Longer-term breast cancer survivors have some additional information needs, specific to their stage. These women are past the active treatment stage and are considered “well.” But “[t]he impact of illness continues to be considerable for most of the[se] women... Although most have got on with their lives after treatment, they nevertheless remain changed or compromised as a result of their experience with cancer” (Gray, p. 248). Interestingly, women’s information needs fall into the same three

categories as women who have just been diagnosed (medical, psychosocial and everyday-life and “big-issue”) but the specific needs are different.

Women who have survived breast cancer still have a significant need for medical information. Not only are they generally still dealing with side-effects of treatment, most are now hyper-aware of every twinge and need to know what constitutes a worrisome symptom and what is to be expected from a post-cancer body. Other information needs revolve around what sort of lifestyle may help a woman’s body stave off a recurrence and what alternative therapies are available and how effective are they? Perhaps the greatest information need, however, is how to stay current on the medical literature, as well as how to effectively evaluate that information.

Psychosocial and everyday life issues revolve mainly around dealing with the trauma breast cancer survivors have been through and how to deal with family and friends. Other needs in this area include legal issues such as employment, health and life insurance, and financial assistance for rebuilding lives devastated by a long illness.

As survivors of a disease that causes others to succumb, women who are past the active treatment phase frequently deal with a lot of “big-issue” questions. Why did I survive while others did not? How does being a cancer survivor change my life and my way of living? How can I give back to a community that supported me during my illness?

Information behaviors differ, as well. Women in this group appear to be more confident about information-seeking and more able to process what they find, possibly because of a reduced anxiety level as well as lessened physical effects of the disease and treatment. “The search for information among longer-term survivors did not follow a

predictable pattern of progression. Most were strongly oriented to physicians as important sources of information. Yet, the women expressed a prevailing opinion, based on their experience, that they could not count on physicians to provide a comprehensive approach to information, and that, therefore, they needed to find complementary sources” (Gray, p. 249).

Women were frustrated not only by this lack of consistency in receiving information, but by the lack of consistency in the literature itself. They didn’t understand how different sources and different studies could have completely different results, nor did they have the ability to evaluate which studies were properly done or which were relevant to themselves (Gray, p. 252).

Given this, I have identified the following specific information needs and applicable information literacy skills for longer-term breast cancer survivors. At a very high level, all information needs can be described as “Find, evaluate and apply relevant information.” I have tried to be more specific and describe more concrete, lower-level information needs of this particular group, as well as specific skills that can be developed to meet those needs. A skill listed in one area maybe be applicable to a subsequent area, but has only been listed once.

Medical Information Needs:

Breast cancer survivors need to be able to find reliable, relevant, authoritative scientifically-based medical information.

- *Sub-Need:* Evaluating medical studies for both validity and relevance
- *Sub-Need:* Information about what symptoms are normal and which require medical attention

- *Sub-Need:* Information about what lifestyle choices will make staying off cancer more likely, as well as what complementary therapies might be effective
- *Sub-Need:* Finding information that fits the woman's needs in terms of relevancy to her personal situation, as well as the desired level of details and desired format
 - *Skill:* Effective search engine use
 - *Skill:* Evaluation of authority of a source and reliability of information
 - *Skill:* Evaluation of information's relevance to searcher and her personal situation
 - *Skill:* Finding and evaluation of breast cancer portals
 - *Skill:* Evaluation of information's currency and acceptance by the medical community
 - *Skill:* Ability to read scholarly literature and evaluate the process by which a study was done
 - *Skill:* Ability to analyze the statistical significance of study's results
 - *Skill:* Ability to recognize whether or not a study is relevant to the woman's personal situation
 - *Skill:* Ability to describe symptoms in medical language
 - *Skill:* Ability to compare symptoms to those described in medical literature and make a decision as to whether symptoms warrant a medical visit

Psychosocial and Everyday Life Information Needs

Breast cancer survivors need to be able to find relevant information that meets their needs for psychological and logistical support, as well as the needs of their friends and families.

- *Sub-Need:* Finding a support group of women with similar experiences and information about how to deal with psychological stress of being a cancer survivor
- *Sub-Need:* Finding practical information like legal rights, employment and discrimination laws and insurance information
- *Sub-Need:* Finding information for family and friends
 - *Skill:* Evaluating and using web searches, cancer portals and user group directories like Yahoo Groups to find the right group
 - *Skill:* Evaluating web groups for trustworthiness
 - *Skill:* Evaluating legitimacy of advice and information from support groups
 - *Skill:* Using web searches, cancer portals and user groups like Yahoo Groups to find the right information for family and friends' needs
 - *Skill:* Evaluating the information needs of friends and family

Big-Issue Information Needs

Breast cancer survivors need information that helps them deal with the existential angst that comes from surviving a potentially deadly disease.

- *Sub-Need:* Finding information about how to help other women with breast cancer
- *Sub-Need:* Finding ways to deal with uncertainty of living as a cancer survivor
- *Sub-Need:* Finding ways to deal with how surviving cancer has changed a woman's outlook on life

- *Skill:* Using web searches, cancer portals and user groups to find volunteer opportunities and reach newly diagnosed women who may need support

Survey URL:

<https://catalysttools.washington.edu/tools/survey/?sid=25287&owner=brolland>

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