



## Patient Education

## Development of multimedia informational tools for breast cancer patients with low levels of health literacy

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## ABSTRACT

**Objective:** To create informational tools for breast cancer patients with low levels of health literacy.**Methods:** Tools were developed through a three-stage process. (1) Focus groups were conducted with breast cancer survivors and interviews were held with health educators to determine content, source of information, format and medium of the tools. (2) Based on this feedback, a suite of tools was developed. (3) Focus groups were reconvened and health educators re-interviewed to obtain feedback and determine satisfaction.**Results:** We developed a suite of five informational tools using low health literacy principles, which focused on learning about breast cancer resources and learning about the members of one's healthcare team, understanding the "journey" or trajectory of care beginning at diagnosis, hearing from other breast cancer patients about their own journey, and becoming informed about what to expect pre- and post-surgery for breast cancer. The final products were rated highly by breast cancer survivors.**Conclusion:** The developed materials, designed for patients who read below an 8th grade level, reflect the informational needs reported by breast cancer patients.**Practice implications:** Healthcare providers must consider utilizing design principles and theories of adult learning appropriate for those with low health literacy.

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## 1. Introduction

Breast cancer is the second most commonly diagnosed malignancy among women in North America [1,2]. Following diagnosis, patients face a number of important decisions about treatment. Having accurate, reliable, and understandable information is crucial for breast cancer patients to make informed healthcare decisions. Unfortunately, about 25% of patients cannot obtain, process, and understand the written and verbal health information necessary to make appropriate decisions [3]. An additional 20% perform at marginal levels [3]. Being able to access and understand health information, termed health literacy, is vital to managing one's health [4]. Low health literacy has been shown

to be strongly associated with poorer physical health and risk of noncompliance with medical treatments [5–7].

The current state of information delivery and formatting can create barriers for cancer patients with low-health literacy to access and navigate the healthcare system, understand cancer-related information, and make decisions about cancer treatment [8,9]. Cox et al. [10] examined 14 different breast cancer education materials published by national organizations in the U.K. and determined they were above a 9th grade reading level, with over one-third written at a college level. Low health literacy may also affect satisfaction with care. For example, Livaudais et al. [11] found that breast cancer patients with low health literacy reported dissatisfaction with their decision-making responsibility, reporting either too much or too little responsibility. In addition, low health literacy has been linked to worse mental health, such as depression [6]. These data may reflect a connection between low health literacy, problems in comprehending cancer information, and unsatisfactory outcomes.

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Although the need for suitable information remains high across every stage, the initial stages represent one of the most critical periods [12,13]. Newly diagnosed breast cancer patients identify prognosis and treatment options as their most important informational priority [14–16]. As noted by Clayman et al. [17], cancer information studies have primarily focused on knowledge needed to decide between lumpectomy versus mastectomy. While undoubtedly this a crucial decision, many women also report unaddressed informational needs about the process and trajectory of care that can be tailored to their own experience of breast cancer [17].

Despite the plethora of written and electronic resources that provide facts about breast cancer and treatment options, surprisingly few interventions have been published that target low-health literacy breast cancer patients. One exception is Jibaja-Weiss and colleagues' [18] computerized, multimedia interactive patient decision aid (CPTDA) for low-literate, multiethnic women with early stage breast cancer. The CPTDA combines didactic soap opera episodes with interactive learning modules to teach women about breast cancer surgery options. The randomized trial was shown to improve patient clarity about their breast cancer surgical treatment decisions. However, tools appropriate for low health literacy populations that also address the trajectory of care and how to utilize one's healthcare team are still lacking in the public domain.

To address this gap, we developed a multimedia informational tool designed to increase patient understanding of: the breast cancer diagnosis, the healthcare team, what to expect pre-and post-surgery, and the typical steps in breast cancer care. Breast cancer is the most frequently researched cancer topic on the internet, with one study reporting over 2000 new postings in a four week period for the term "breast cancer" [19,20]. Despite the sheer availability, patients often lack the knowledge needed to locate reliable and healthcare professional-approved material about breast cancer. Consequently, we also created a module to improve access to breast cancer information in both electronic and print formats. The suite of tools was developed for women with lower levels of health literacy. A review of multimedia and print patient education materials for people with lower health literacy showed advantages for both types of formats [21]. Therefore, we developed a combination of audio-visual and text materials that used simple language interspersed with definitions of complex terminology, which has been recommended as a strategy to augment patient health literacy [22].

## 2. Methods

### 2.1. Participants

#### 2.1.1. Focus groups with women treated for breast cancer

We recruited breast cancer survivors through the St. Michael's Hospital outpatient oncology clinic in Toronto, Canada. Oncologists reviewed their daily patient lists and identified patients whom they thought might have low health literacy (based on difficulty in information processing during treatment, English as a second language, prior difficulty understanding information about breast cancer). Health literacy was not formally assessed in clinic. From this list, patients who had already completed treatment were approached for recruitment in one of two focus groups. Nineteen women were approached during regular clinic hours. Of those, a convenience sample of eleven agreed to participate and attended the focus groups.

#### 2.1.2. Interviews with health educators

We recruited cancer healthcare educators who had provided services to women with breast cancer for at least one year and also

had specific expertise in working with low-health literacy populations. Four cancer healthcare educators were recruited from breast cancer centers in two Toronto hospitals. All four health educators completed individually conducted interviews, as described below.

### 2.2. Overview of procedures

Prior to conducting focus groups, we assembled an interprofessional team consisting of a social worker and clinical psychologist trained in psychosocial oncology, a nurse patient navigator, and a family physician to identify the format and content of breast cancer information typically provided to newly diagnosed patients as well as health information tools geared toward low health literacy patients. This team met three times to identify health tools and to develop the focus group questions. In each of the two focus groups with breast cancer patients, we first asked participants to identify what information was difficult for them to understand and obtain when they were undergoing breast cancer treatment. Participants rank-ordered the information they found the most important during their breast cancer journey (Table 1). Next, participants reviewed seven previously developed health information tools (Table 2), such as videos of breast cancer patients talking about their treatment, breast cancer informational slideshows on the internet (e.g., Canadian Cancer Society website), informational comics about cancer, as well as narrated slideshows and podcasts developed specifically for those with low-health literacy for other chronic illnesses, such as diabetes [23]. We also presented informational pamphlets typically provided in breast cancer clinics (e.g., 24,25). Participants were asked to select their three most preferred options from all of those presented using a structured exercise. Participants rated the tools for their usefulness/usability, and then rank-ordered the tools in terms of preference for format and presentation. Each participant received colored voting stickers (unique colors were used for identifying first, second, or third choices) to indicate their rank order of tool preference. After voting concluded, participants were invited to provide comments about the rationale for their selection, which further allowed the research team to understand preferences about the tools. Health literacy levels and education attainment were not formally assessed, but most participants described being completely overwhelmed with too much information at the time of diagnosis as well as not receiving "the right kind of information." In addition, patients noted the importance of being equipped with tools that they could revisit at various points in the cancer care continuum in order to learn at their own pace.

In the interviews with healthcare educators, participants reviewed the identical breast cancer informational tools as shown to patients in the focus groups. Healthcare educators were asked to comment on the type, content, and format of information important to women with breast cancer who also have low levels of health literacy. Both the focus groups and individual interviews were digitally recorded and transcribed. The transcripts were used

**Table 1**  
Survivor focus group rankings of topics considered most important ( $n = 11$ ).

Topic	Title of topic	Rank
1.	Encouraging messages of hope and coping	1
2.	Who are the important healthcare team members?	2
3.	How can I use my healthcare team and <i>who</i> do I call <i>when</i> ?	3
4.	What are some available and legitimate resources?	4
5.	What are the treatment options?	5
6.	What do I need to know at each stage of the journey?	6
7.	Tailored information – How will <i>my</i> cancer be treated?	6
8.	What can I expect after surgery?	7
9.	Preparing for appointments – What can I expect?	7

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