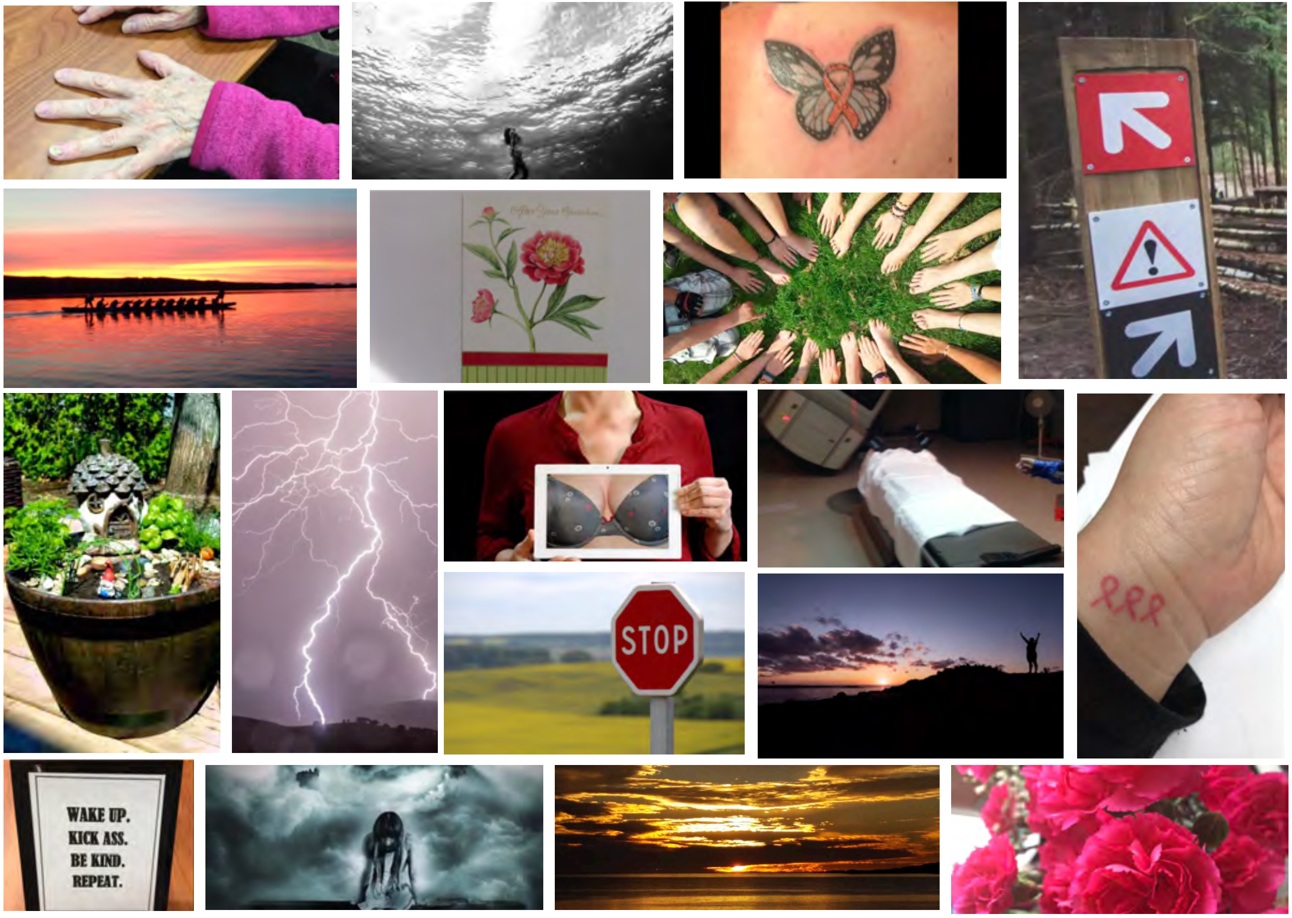
Patient-Oriented Research Breast Cancer Care

Using Digital Stories to Explore the Experiences of Breast Cancer Patients



Images from Digital Stories (DS 1-17)

Report

2019

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All photographs included in this report are from the digital stories created from this study and referenced accordingly.

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Executive Summary

OVERVIEW

Breast cancer is the most frequently diagnosed cancer in Canadian women with one in nine females estimated to develop breast cancer in their lifetime (1). The provision of care for breast cancer patients remains a complex undertaking. However, little is known as to what underlies patient choices regarding breast cancer treatment at Eastern Health. This document reports on the findings of a two-year funded patient-oriented research study that explored the experiences of breast cancer patients at Eastern Health using digital stories.

In health services, there is an increasing recognition for the need to listen to patients (2). Eastern Health's strategic plan identifies the significance of including "meaningful feedback on client experiences and using that feedback to continually learn and improve" as this helps shape programs and plans within the health authority (3). This study focuses on patient-identified priorities for improving the treatment experiences of women diagnosed with breast cancer at Eastern Health (4). A multidisciplinary team conducted the research in partnership with key stakeholders. This report presents findings and recommendations to improve systems and practices.

METHODS

The complex nature of decision-making in healthcare for both provider and recipient has prompted a movement towards innovative research approaches (5). Digital storytelling is a participatory method that combines the tradition of oral storytelling with technology. Patients combine photos, music, and personal narrative to create a short video about their experience. Digital storytelling is a novel approach to patient-oriented research with strong patient involvement (6-13). Digital storytelling touches on overarching commonalities and offers an accessible form of dissemination, while providing a rich source of data that allows for multiple ways to present details in one medium. Using a mixed-methods design, data included patient digital stories, screenings and questionnaires with healthcare practitioners at Eastern Health, and a subset of those practitioners participated in focus groups.


(DS16)

Executive Summary

FINDINGS

The digital stories created by patients identified determinants that influence breast cancer patient choices for surgery and treatment. The combination of digital stories and healthcare practitioner viewing responses allowed researchers to identify benefits and challenges to the delivery, format, and timing of information given to patients at various stages of their breast cancer care journey. Viewing and discussing the digital stories resulted in healthcare practitioners from Eastern Health identifying further opportunities related to optimizing decision-aids and process mechanisms in support of patient well-being at Eastern Health. Findings included:

Determinants influencing patient treatment decisions.

Determinants of patient treatment decisions included: 1) life stages and personal circumstances; 2) personal values; 3) previous experiences (family history, with self/others); 4) sense of control; 5) sexual health; 6) medical advice (from surgeon, healthcare staff, family and friends); 7) information patients received or sought out; and 8) the doctor-patient relationship. The doctor-patient dynamic was particularly instrumental in this process.

Patient identified priority #1: Focus on consistent information delivery to minimize emotional distress.

Patients indicated that accessible and consistent information delivery can mitigate emotional distress and support patient well-being during their breast cancer care journey. The delivery, format, and timing of information about diagnosis and treatment options can alleviate feelings of distress in breast cancer patients. Research suggests that making decisions about treatment is stressful and overwhelming: during this time, approximately 50% of newly diagnosed breast cancer patients experience significant levels of anxiety, distress, and depression (14). This study's findings further support this claim.

Patient identified priority #2: Develop the role of patient navigators to sustain access to consistent information during and after treatment.

Breast cancer patients and healthcare practitioners stressed the critical role of the patient navigator in ensuring continuity of care throughout the cancer care journey.

Patient identified priority #3: A whole person care approach is needed to improve overall patient well-being.

Consistent with psychosocial oncology, findings indicate there is a need to address the biological, psychosocial, and spiritual aspects of patient well-being both during and after treatment. This was indicated through three core areas: 1) patients' transitioning identities; 2) patients' mental health, and; 3) coping strategies and therapeutic supports both during and after treatment.

Creating and viewing digital stories: Overall Impact.

Viewing the digital stories had an impact on healthcare practitioners at Eastern Health: out of 117 survey responses from healthcare practitioners, 90.9% strongly agreed/agreed that viewing the digital stories increased their understanding of women's experiences with breast cancer treatment. Patients also indicated that developing their own digital stories and watching the stories created by others was an empowering and therapeutic process.

(Image citation of digital stories in order of presentation: DS9, DS9, DS17, DS3, DS7)

Executive Summary

OVERALL RECOMMENDATIONS

From the findings, the research team identified recommendations aimed at improving the experience of breast cancer patients at Eastern Health. Recommendations focused on information delivery, patient navigators, and whole person care. These recommendations were developed based on patient identified priorities and further informed by healthcare practitioner responses and feedback across phases two and three of the study. In addition to the recommendations, we have suggested timelines to support implementation.

1

Improve existing information resources and delivery processes to prioritize information access and clarify timelines. Create a visual decision aid to assist patients in understanding their options, timeline and wait times for treatments, and accessing resources.

1.1 Delivery in the form of a visual aid presented in a printable format for surgeons and patient navigators to review with breast cancer patients.

1.2 Delivery in the form of an App with a consistent web interface.

1.3 Explore wait time models that support consistent patient communication and an internal accountability of timelines.

2

Ensure there is a dedicated and resourced patient navigator to support breast cancer patients. The patient navigator should act as the primary contact for patients from diagnosis to treatment.

2.1 Surgeons provide patient navigator business cards with contact information to patients during their first appointment.

2.2 Develop and implement a patient navigator model where they connect face-to-face immediately following the patient's diagnosis. The patient navigator is the primary contact during transition of care across the breast cancer trajectory. This is consistent with the navigator model in person-centered care (15,16).

3

Prioritize patient education by creating information forums led by Eastern Health.

3.1 Information sessions prior to surgery.

3.2 Have a 24/7 hotline (on-call model) to respond/text answers, especially post-treatment.

3.3 Online resource hub (connect with App, as per recommendation #1). Include examples such as Bethechoice.org and Breastcancer.org

3.4 Increase post-treatment support: Both patients and healthcare practitioners indicated surgery should not be day surgery.

4

Whole person care: Develop, sustain capacity, and promote complementary therapies within Eastern Health with consideration given to key time periods during transitions of care.

4.1 Expand and further invest in Eastern Health social workers to provide complementary therapies to breast cancer patients. Build on the work social workers are currently doing to provide complementary care by resourcing and supporting this work.

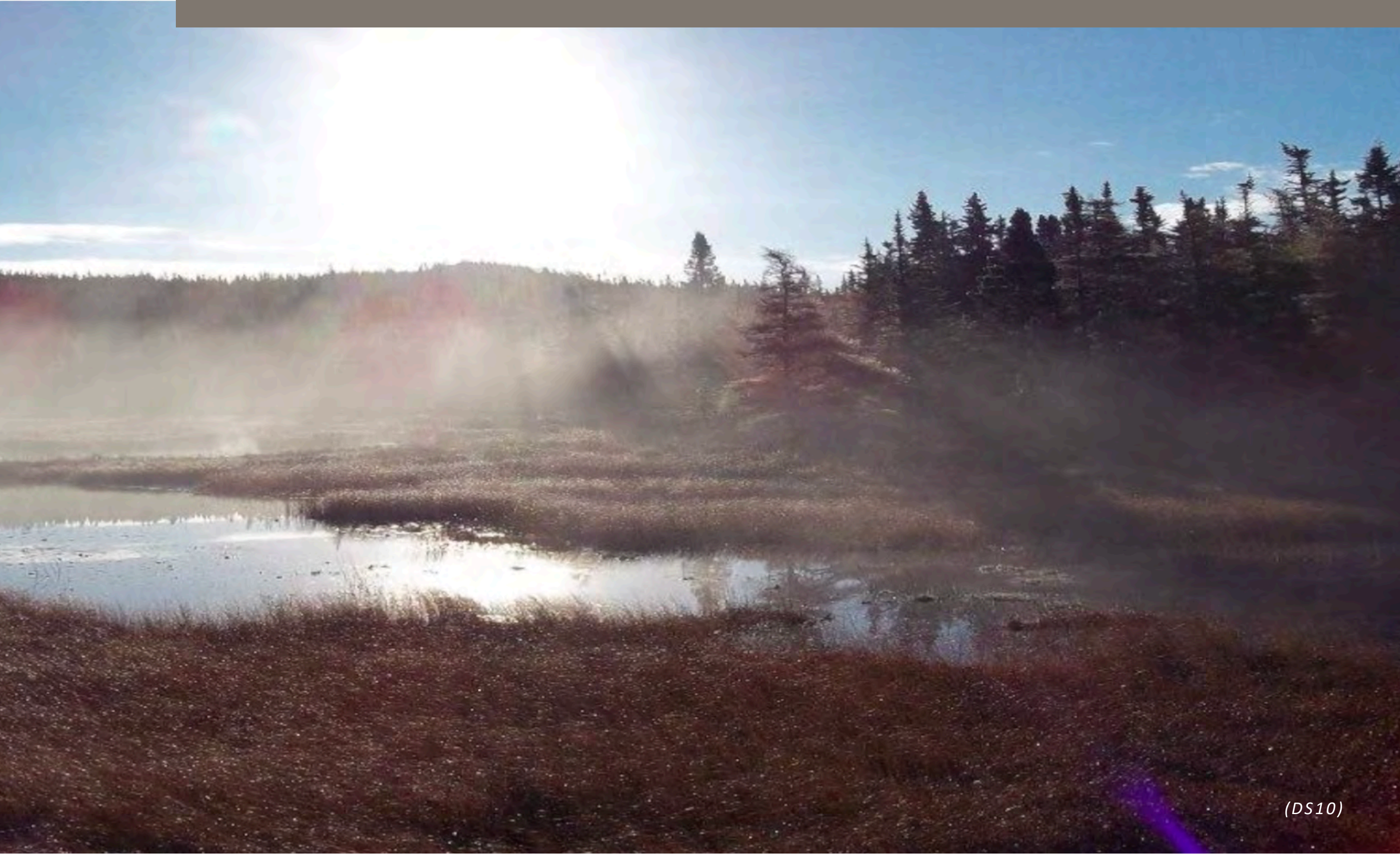
5

Educational applications and patient-interventions with digital stories.

5.1 Explore opportunities using digital stories as a pedagogical tool for healthcare practitioners and post-secondary students.

5.2 Evaluate digital storytelling as a program intervention for breast cancer patients (see recommendation #4).

While the study findings identify a number of strengths and opportunities within the existing practice, the recommendations focus on decision aids and process mechanisms in order to add further value to the critical work being done at the Cancer Care program at Eastern Health.



(DS10)

RECOMMENDED TIMELINE

Description	Q1	Q2	Q3	Q4
1.1 Develop, rework and assess printed visual aid	░			
1.2 App with website interface		■	■	■
1.3 Wait time models recommendations		░	░	░
2.1 Surgeons provide patient navigator business cards at initial patient meeting	■			
2.2 Review and revise patient navigator model	░	░	░	
3.1 Implement regular patient information sessions prior to surgery	■	■		
3.2 24/7 hotline for patients during and after treatment	░	░		
3.3 Online resource hub		■	■	■
3.4 Increase post-treatment support		░	░	░
4.1 Integrate, support, and promote complementary therapies provided by social workers	■	■		
5.1 Explore opportunities with health allied professions in using digital stories as an education tool at Memorial University	░	░		
5.2 Evaluate as a program intervention with breast cancer patients	■	■		

Background

INTRODUCTION

This report presents the findings of a two-year research project focusing on the lived experiences of women diagnosed and treated for breast cancer at Eastern Health in the province of Newfoundland and Labrador. This research was led by a team of researchers and supported by key stakeholders including representatives from Eastern Health. It was funded by a grant from NL SUPPORT, Strategy for Patient-Oriented Research (SPOR). This study was patient-centered and aimed at identifying applicable recommendations for improving the experiences of women who are diagnosed with breast cancer.

To identify these recommendations, the study had three phases: In phase one, women who had experienced breast cancer treatment at Eastern Health created digital stories about their cancer care experiences. In phase two, these digital stories, between three and 12 minutes in length, were then screened before an audience of healthcare practitioners (hereafter called knowledge users (KUs). In phase three, KUs participated in focus groups to provide greater insight into possible recommendations to improve breast cancer care. During each project phase, researchers gathered and analyzed data. The key findings from the analysis are presented in this report. In addition to the research findings, a series of applicable recommendations for improving breast cancer care at Eastern Health are included. The report is presented across the following four sections: 1) Methodology; 2) Findings and Recommendations; 3) Conclusion, and; 4) Appendices. Because of the technical nature of this research, readers can refer to the list of key terms in the appendices.

(DS9)

Background

QUESTIONS

As a project grounded in the lived experience of breast cancer patients, digital stories provided the foundational methodology for this work. Digital storytelling offers a research method that combines the tradition of oral storytelling with technology. In this collaborative process, participants combine photographs, music, and personal narrative to create a short video about a personal experience.

This research project was informed by patient-oriented research to better understand breast cancer patient choices and the factors influencing patient decision-making at Eastern Health. The study was guided by the following research questions:

1. What is the tone and content of the digital stories created by breast cancer patients? How do findings compare against existing research on determinants that influence patient treatment decisions?
2. What are the strengths and opportunities for information dissemination of surgical treatment options for breast cancer patients at Eastern Health?
3. What impact do the resultant digital stories have on viewers? Do they succeed in identifying opportunities for optimal decision aiding solutions for breast cancer patients at Eastern Health?

CONTEXT

Although breast cancer is the most frequently diagnosed cancer in Canadian women (1), the provision of care for breast cancer patients remains a complex undertaking. When making decisions about surgical treatment, breast cancer surgery options include breast conserving surgery (lumpectomy) or mastectomy. The rate of contralateral prophylactic mastectomies — the removal of the non-cancerous breast — is also increasing despite studies indicating little or no survival benefit (18-20). A combination of age, income, and travel time can influence variations in patients' treatment options and decisions (21), however, little is known as to what underlies patient choices regarding breast cancer surgical treatment at Eastern Health.

In health services, there is an increasing recognition for the need to listen to patients (2). Eastern Health's strategic plan identifies the significance of including "meaningful feedback on client experiences and using that feedback to continually learn and improve" as this helps shape programs and plans for Eastern Health (3). This project promotes patient-oriented research through the Cancer Care Program at Eastern Health. The process focused on patient-identified priorities and was conducted by a multidisciplinary research team in partnership with stakeholders that included representatives from Eastern Health.

Preliminary discussions with KUs at Eastern Health identified gaps in the delivery, format, and timing of information about surgical options for patients to make informed, deliberate decisions regarding surgical treatment prior to preadmission. Findings from several studies about decision-making instruments designed to present information on breast cancer surgical options indicated patients who were provided with such tools had more knowledge about their options and were more satisfied with their decision-making than those who did not receive such resources (22-25). While patients prefer simple and informative decision aids (26), there currently is not an up-to-date decision-making tool available for patients during their initial consultation with their respective surgeon.

Making decisions about treatment is also known to be stressful and overwhelming; during this time approximately 50% of newly diagnosed breast cancer patients experience significant levels of anxiety, distress, and depression (14). While patients decide on their surgical treatment during their first consultation with the surgeon, it is only during preadmission (approximately two to three days before surgery) that patients at Eastern Health receive detailed information about their chosen procedure. Thus the comprehensive educational component is provided after the choice is made, and only contains information pertaining to the patients' chosen option. Developing an understanding of patient choices and the factors influencing patient decision-making at Eastern Health, as well as gathering information to assist with the creation of a mechanism that provides patients accessible and comprehensive information prior to choosing treatments was a key objective of this project.

Methodology

As a form of patient-oriented research, a mixed methods design was used for this study. Data sources included: 1) digital stories, 2) questionnaires, and 3) focus groups.

PATIENT-ORIENTED RESEARCH

Patient-oriented research was a guiding principle of this study. The Canadian Institutes for Health Research defines patient-oriented research as research that engages patients, their families, and their caregivers in the research process, with the goal of focusing studies on patient-identified priorities (4). As a result, patients move from being an "active receptor" of healthcare services to a "proactive partner" (4). By focusing on patient-identified priorities and having patients help shape healthcare research, patients can impact health care practices and services, leading to better patient outcomes (4).

PHASE 1: DIGITAL STORIES

A total of 18 women (ages 30-74) who had made decisions about breast cancer treatment within the past four months to five years, and who had breast cancer surgery at Eastern Health within the same time frame, participated in the study. In small groups and one-to-one sessions, participants were asked to reflect on their personal experiences of breast cancer treatment at Eastern Health, including the advantages and disadvantages of information delivery, format, and timing, as well as various influences on their patient experiences.

After sharing ideas, participants created a total of 18 individual digital stories (ranging from three to 12 minutes in length). This was followed by a screening with other participants. Each participants received an honorarium and a digital copy of their story.

PHASE 2: SCREENING & QUESTIONNAIRES

Researchers held eight DS screenings, reaching a total of 117 KUs (including nurses, social workers, physicians, etc.) at Eastern Health. Screening locations included: 1) The Breast Cancer Clinic, 2) Newfoundland and Labrador Center for Applied Health Research (NLCAHR), 3) Cancer Care Social Work, 4) Continuing Education sessions with nurses at the Health Sciences Centre and St. Clare's Mercy Hospital (see Appendix for list of screenings). Screenings involved a sub-set of digital stories that together held all the themes identified from the phase one analysis. The research team surveyed the KUs who attended the screenings using questionnaires informed by the phase one analysis.

(DS7)

Methodology

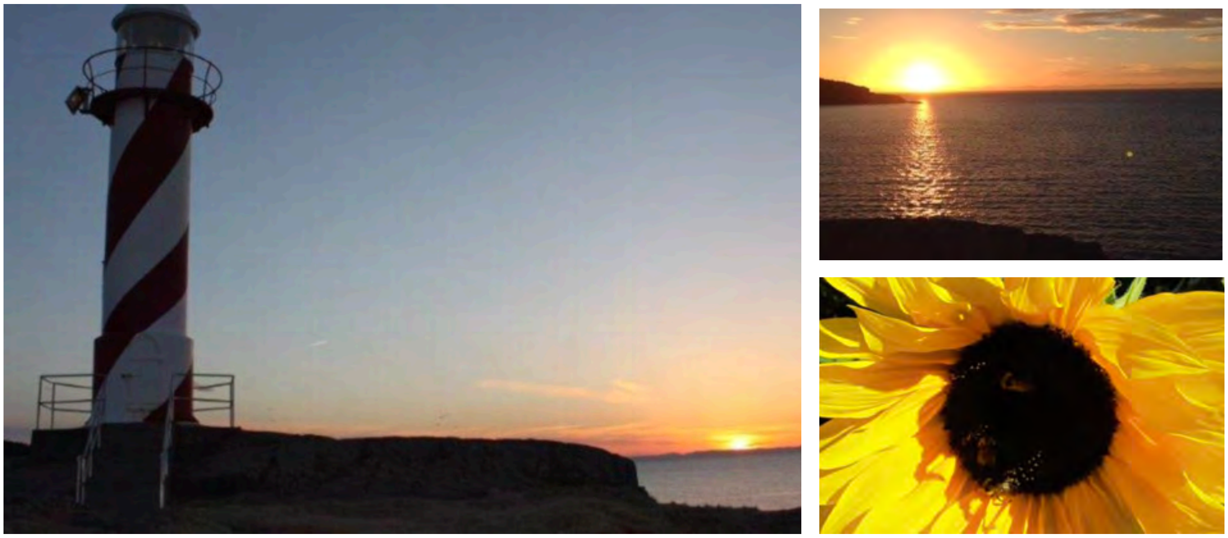
PHASE 3: FOCUS GROUPS

Following the screenings, 13 KUs participated in two focus groups aimed at identifying recommendations to improve the cancer care treatment experience at Eastern Health. Each focus group was 1-1.5 hours long and both were recorded and transcribed.

ANALYSIS

The research team analyzed the digital stories deductively based on the absence, presence, and variance of elements of the evidence-based patient choice (EBPC) framework (22,23,26,27). The stories were analyzed to understand the benefits and impediments associated with receiving information when deciding on surgical options, specifically: 1) timing of information received, 2) format, and 3) delivery method. The team also employed an inductive visual analysis to explore: 1) dominant imagery, 2) underlying narrative, 3) general tone, 4) content, and 5) overall framing of the digital stories. In line with standard procedure of visual analysis, the team analyzed differences across the stories and organized them into themes (28,29). The analysis included comparing findings against existing research on determinants that impact and influence breast cancer patient decisions relating to surgical procedures.

Findings from the digital story analysis informed the questionnaires administered during KU screenings, as well as the focus group questions. Questionnaires included Likert scale items to quantitively evaluate the impact and extent to which the digital stories succeeded in raising awareness and identifying opportunities for optimal decision-aiding solutions for breast cancer patients at Eastern Health. Questionnaires also asked if KUs were willing to participate in focus groups to further discuss the digital stories. Focus group sessions were transcribed, and researchers analyzed the transcriptions to identify major themes and sub-themes. These themes informed further recommendations presented in this report.



(DS4)

Methodology

QUALITY CRITERIA

Quality criteria for this research was informed by six validity criteria identified by The International Collaboration for Participatory Health Research (ICPHR). The ICPHR identifies the following validity criteria for participatory health research: Participatory, intersubjective, catalytic, contextual, ethical, and empathic (30)[1]. Participatory health research draws on the lived experience of those involved in the research. In this study, members of the research team included a patient advisor (with lived breast cancer experience) and KUs, including academic researchers in the areas of social work, medicine, and kinesiology, as well as healthcare practitioners in surgical oncology and perioperative care. The patient and KUs were involved in all stages of research, including design, question formation, and knowledge translation.

LIMITATIONS & CONSIDERATIONS

While the initial intent was to recruit women ages 50 to 74 who made surgical treatment decisions about breast cancer in the past six to 12 months at Eastern Health — as the largest number of new breast cancer cases occur within this age group — the researchers experienced challenges with recruitment. Recruitment criteria was expanded to include women ages 30 to 74 who had made surgical treatment decisions about breast cancer in the past four months to five years. Recruitment took longer as a result.

Although there were a number of themes identified by participants based on the broader impact of cancer on their lives, the primary focus of analysis was on the patients' cancer care treatment experiences at Eastern Health.

(DS17)

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[1] Participatory validity considers the extent stakeholders are actively involved in the research. Intersubjective validity is the extent the research is viewed as being both credible and meaningful to stakeholders whereas catalytic validity presents possibilities for public health action. Contextual validity relates to the local situation, ethical validity is the extent research outcomes are sound and just and empathic validity brings new interpersonal understanding.

Findings & Recommendations

The following section outlines the key findings from the study. The data for this section is drawn from the digital story analysis (phase 1), KUs screening responses (phase 2), and the focus groups (phase 3). Each finding includes a series of recommendations that focus on processes and supports for breast cancer patients at Eastern Health.

DETERMINANTS OF PATIENT TREATMENT DECISIONS

Determinants of patient treatment decisions included eight core areas: 1) life stages and personal circumstances, 2) personal values, 3) previous experiences (family history, with self/others), 4) sense of control in the decision-making process, 5) sexual health, 6) medical advice (from surgeon, oncologist, family doctor, healthcare staff, family, and friends), 7) information patients received or sought out, and 8) the doctor-patient relationship (See Diagram I).

1. Life stages and personal circumstances: Patients identified family, their future, geographical location, and financial considerations as significant factors in their treatment decisions. For example, treatment decisions were framed as a desire to see children and grandchildren grow up. One patient stated, "*I wanted to make the best decision to see my son grow up. I decided to get a double mastectomy*" (DS1)[2]. A number of patients included pictures of their children in their stories, emphasizing the role children had on their decision-making. The digital stories made evident that patients require information to help them make decisions about their cancer care needs, but information provided should consider their life stages and personal circumstances.

Financial constraints is also a key variable that impacts the cancer care journey. One patient explained, "*I went back to work after my fourth chemotherapy treatment because I ran out of sick leave. At this time, my oncologist voiced her concerns about me working given my severe side effects from the treatment. I felt like I had to go back to work*" (DS2). Effective continuity of care requires policy recommendations that remove financial barriers for patients.

2. Personal values: Life stages were closely connected with personal values, which played a central role in making treatment decisions. Examples included perspectives pertaining to wellness, mental health, complementary therapies, and a history of patients taking a proactive approach to their health (e.g. routine mammograms, regular check-ups), all of which shaped patients' treatment decisions.


(DS3)

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[2] A note about citations: Supporting literature is referenced with an individual number; digital stories are referenced with a DS in front of the number (for example, digital story #2 is DS2 throughout the report). The list of digital stories is included under the References.

Findings & Recommendations

Diagram I

Determinants Influencing Patient Treatment Options

Findings & Recommendations

(DS10)

3. Previous experiences with cancer: Patients' personal and familial experiences with cancer were a determinant in treatment choices. Family history held implicit expectations that patients could be diagnosed with cancer. Examples included choosing a bilateral mastectomy because a grandmother had a cancer recurrence after having a lumpectomy procedure and comparing family experiences and outcomes with cancer. One patient stated she chose a mastectomy based on a conversation she had with her mother:

> *I thought about a conversation I had with my mother when I was a teenager. She was a nurse. I asked her one time: Mom, if you ever had breast cancer, would you choose a lumpectomy, or would you choose a mastectomy? And she said to me mastectomies do better. Now I understand that was 40 years ago and great strides have been made in breast cancer treatments and everything, but I thought, 'why am I remembering that?'* (DS4)

4. Sense of control (or lack of) in the decision-making process: All patients reported that their level of inclusion in the decision-making process was a crucial factor in how they made decisions about their treatment. This varied from patient to patient. One patient described the stark difference between the treatment she received during a previous different cancer diagnosis and her breast cancer treatment. In her first experience, she had a multidisciplinary team that kept her informed and involved in various aspects of her care, which gave her a sense of control. In contrast, during her breast cancer care, she felt excluded in discussions concerning her diagnosis and treatment plan. She reported feeling unprepared for surgery and treatment and concluded that her breast cancer experience was overall "*… isolating. I felt like I was on a production line, like it was up to me to look up all the information, and I still did not feel that the surgical decision was mine*" (DS5).

However, when oncologists and surgeons acknowledged patient concerns and questions, patients felt included in the decision-making process. In these instances, patients also felt a sense of control in guiding their course of treatment. One patient used an image of a video game console to describe how the surgeon created a space where the patient was able to regain a sense of control: "*I was very fortunate to be assigned to a surgeon who gave me back some control*" (DS6). Another patient said, "*I met with my surgeon to discuss surgery. I was determined to get both breasts off and no one was talking me out of it... Thankfully, my surgeon didn't disagree*" (DS7).

"I was very fortunate to be assigned to a surgeon who gave me back some control" (DS6)

Conversely, when their comments were not valued, a patient's sense of agency diminished. One patient recalled, "*The Health Sciences Centre became my second home for the next year and a half. But I never really felt as though [sic] had much input into my care regiment...*" In order for patients to feel included, healthcare providers had to ensure that patients' voices and choices were valued and that any concerns or questions were heard and addressed.

5. Sexual health: Patients described their breasts as an important aspect of their identity in the areas of sexual health, femininity, and motherhood. One patient described how her chosen treatment impacted her identity as a woman and spouse. She reflected how her change in identity created difficulties, including the loss of sex drive, hormone imbalance, and memory-retention (DS1). While some doctors discussed breast reconstruction with patients, little or no information was provided by others. In these cases, women made decisions based on limited and incomplete information. Some women opted for reconstructive surgery as a way to retain femininity. Yet some patients shared feelings of regret due to lack of symmetry as the results were not what was expected. Some women were also surprised to find out that "*reconstruction [was] more aesthetically pleasing if both breasts were removed*"(DS8).

Findings & Recommendations

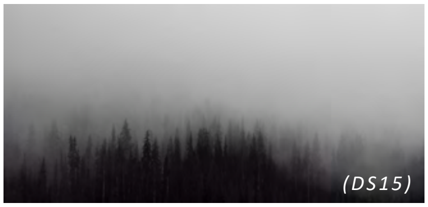
6. Medical advice from both formal and informal supports: While medical advice from healthcare practitioners and staff played a role for patients in their treatment decisions, information from family members and/or friends also strongly influenced patient decisions for their course of treatment. For example, one patient noted*, "throughout this whole process leading to the diagnosis, my oldest son [name] had said to me: Mom, I would rather have you here for 20, 30 years or more without your breasts than to have you here for a few years with them"* (DS3). Similarly, informal supports with a medical background were exceptionally helpful: through such familiar experts, patients felt more open to ask medical questions, receive advice, and learn how to better navigate the healthcare system.

7. Information: Pathology reports, medical tests, personal research and intuition were information sources that influenced patient decisions. Many patients went online to research their diagnosis and treatment options. One patient included an image of a Google search engine in their digital story to reflect how and where she secured the information she needed to guide her decision-making (DS2). Another went home after her diagnosis and "*googled breast cancer. This helped me to know what to ask the surgeon and what to expect*" (DS9). After her surgery and armed *"…with a detailed pathology report, I now continued to research terminology, so I was ready for follow-up treatments*" (DS9). Other patients' initiatives included exploring information with fertility specialists and hiring specialists in Central Canada to guide them through treatment options.

In contrast, lacking information about treatments also impacted the decision process. As one patient explained, *"…so we moved ahead with the left mastectomy. Though I still didn't feel that I had all the information on the procedure and especially the aftercare… I felt quite lost in the surgical process. Any questions I had on the surgical options were answered with 'you are not a candidate for that' or 'this this the usual process' without any full explanation or discussion…*" (DS5). This patient used an image of a maze to reflect how she felt navigating this step in her care. Similarly, another patient recalled, "*I didn't find the actual surgical staff were especially forthcoming with information. If you didn't ask specific questions about specific things, they sort of gave you the assembly line treatment: 'how are you this week?'*" (DS10).

Patients also relied on intuition as a source of information when making decisions about care. For some patients, decisions around treatment were guided by experiential knowledge, *"…there are many ways of knowing. Medical science is just one way. I learned after this to really listen to my own voice–so important. And trusting my gut. It was this that led me to making the right decision for myself*" (DS4). One patient considered a bilateral mastectomy because she "*didn't trust the right side was healthy. I had had the same sensations in both breasts over the past few months since my clear mammogram in March, tenderness and sensitivity... I no longer trusted the breasts I knew so well…*" (DS5). Patients who listened to their instincts, and felt supported by their healthcare providers, had a greater sense of agency and control in their treatment which positively influenced the rest of their cancer care journeys.

(DS5)



(DS15)

(DS8)

Findings & Recommendations

8. Doctor-patient relationship[3]**:** The relationship between the patient and their surgeon and/or oncologist played a key role in the decision-making process (see Diagram II). While positive relationships with family physicians improved the cancer experience, the relationship and guidance from oncologists and surgeons was critical. Descriptive examples include oncologists taking time to seek out different fertility treatment options, and patients who felt their surgeon was empathetic, responsive, and provided appropriate reassurances. For example, *"…my doctor has made my journey much easier because of their constant care and attention"* (DS11). Conversely, when patients felt a lack of mutual respect — which often coincided with poor interpersonal skills from their surgeon or oncologist — they indicated this had a negative impact on their cancer care experience. As one patient explained, "*everyone is unique and healthcare providers need to treat patients as they would want to be treated themselves or how they would want their family members to be treated and taken care of*" (DS12).

In the doctor-patient dynamic, accessibility referred to the doctor's ability to effectively and accessibly convey information about a patient's condition, treatment options, or next steps regarding surgery/treatment. Positive patient experiences were also connected to information delivery within the doctor-patient relationship that patients deemed accessible.

A core part of this dynamic was the notion of attentiveness. Being attentive to patients included active listening skills and validating patient concerns. Surgeons who possessed these traits were described as supportive, helpful, and compassionate. Patients also appreciated when surgeons engaged spouses in discussions about treatment options, as it provided a calming sensation in preparing for next steps. Patients who felt their oncologist addressed their concerns in a respectful manner also had a positive impact on a patient's cancer care journey. However, not all experiences were positive. When a lack of attentiveness was present amongst surgical staff, patients used terms like "*assembly line treatment*," "*production line*," and "*science projects*" to describe their experiences of breast cancer care.

While a number of determinants to decision-making were identified, patients also indicated they would have appreciated more guidance in the decision-making process. There is an opportunity to consider how further guidance can be provided while balancing various roles and information processes at Eastern Health. This will also be further explored in the subsequent sections (see Patient Priority #2).

Doctor-Patient Relationship

WHAT PATIENTS LIKE

- Being treated like a human being
- Attentiveness to their needs
- Are made to feel included
- Assumptions are not made about their knowledge
- When surgeons and oncologists ensure details are accessible

WHAT PATIENTS DON'T LIKE

- Being treated like a statistic
- Having no control: not feeling included in any type of decisions
- Feeling rushed
- Lack of accessible information

Diagram II

Doctor-Patient Relationship Preferences

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[3] Note: The use of the word "doctor" in this report is based on the language patients used in their stories. In some cases, the term "doctor" was used interchangeably in reference to a family doctor/physician, surgeon, or/and oncologist.

Findings & Recommendations

PATIENT IDENTIFIED PRIORITY #1:

A PLANNED FOCUS ON CONSISTENT INFORMATION DELIVERY IS NEEDED TO MINIMIZE EMOTIONAL DISTRESS

Providing consistent information that is timely, accessible, and digestible with various touchpoints throughout the breast cancer care journey should be a key factor for Eastern Health. Patients indicated what worked and what did not when it came to receiving and gathering information (see Diagram III). Addressing this priority will assist in mitigating emotional distress amongst patients from the early stages of diagnosis and decision-making around treatment options, to surgery, and transitions of care.

The role of emotional distress in breast cancer: Distress is defined as:

> *a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears, to problems that can become disabling such as depression, anxiety, panic, social isolation and spiritual crisis.* (31)

In addition to measurements of pulse, respiration, blood pressure, temperature and pain, emotional distress[4] is considered to be the sixth vital sign in cancer care (14, 32-33). While previous research indicates approximately 50% of newly diagnosed breast cancer patients experience significant levels of anxiety, distress, and depression (14), all participants in this study described some form of emotional distress.

Breast cancer patients indicated feelings of distress were further compounded or mitigated through several consistent areas in Eastern Health: 1) wait times, 2) information delivery, 3) quantity of information, and 4) timing of information during treatments and transitions.

1. Wait times: There were noted inconsistencies in wait times across patient stories, however most patients reported extensive wait times between diagnosis and surgery or treatment: "*Then we waited and waited a while longer …five months after my first mammogram*" (DS14). Patients said their emotional distress heightened during the waiting period that followed diagnosis. The lack of clarity about the wait times for surgery, between treatments, and seeing specialists compounded these patient concerns: "*The wait to get into the oncologist at the cancer clinic was the worst. It took over a month, why so long? Why didn't someone explain why I had to wait…?*" (DS7).

(DS2)

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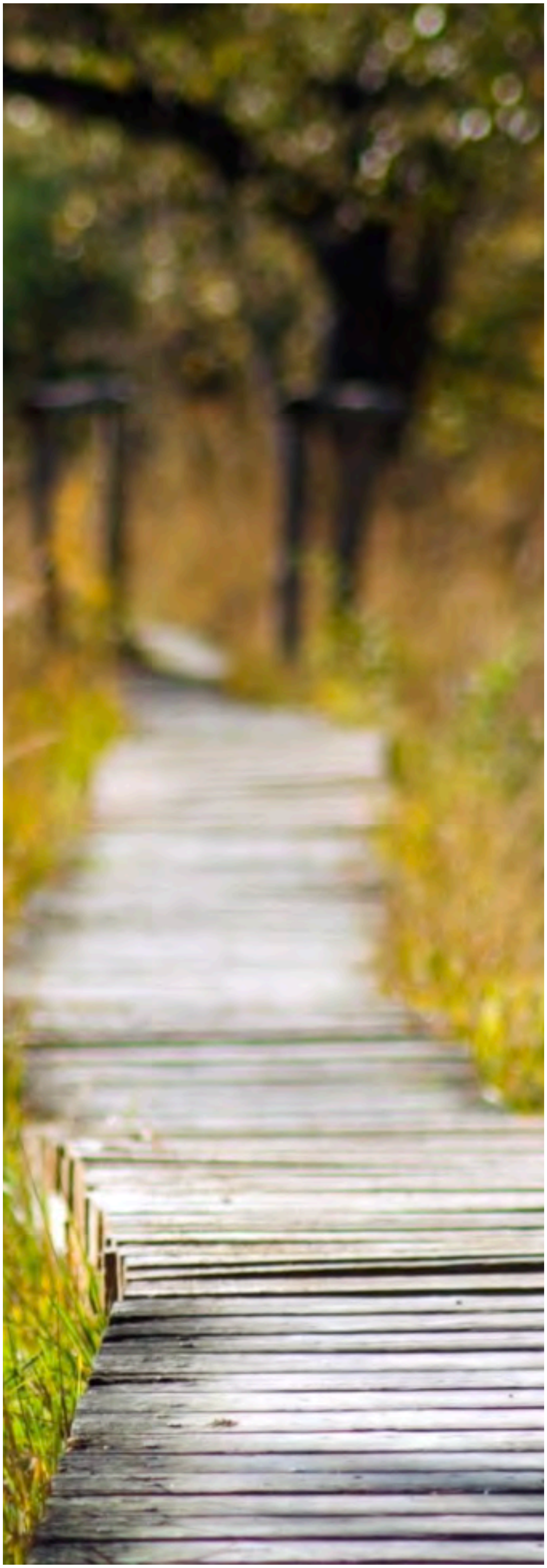
[4] Emotional distress is defined as: "a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears, to problems that can become disabling such as depression, anxiety, panic, social isolation and spiritual crisis" (31).



(DS13)

Breast Cancer Information at Eastern Health

What works

- The Internet as an information source
- Comfort in knowing next steps
- A consistent 'touchpoint' for information
- Knowing about available resources and supports immediately at diagnosis and at each stage
- Information delivery that is consistent, thoughtful, and accessible
- Having time to process and then ask questions
- 'Monday' clinics
- Patient-navigators reaching out first
- Information given face-to-face
- Information that is easily accessible

What doesn't work

- Inaccessible information: technical terms, excessive length
- Ineffective information
    - Pamphlet about post-surgery care
    - Book (too long)
- Large quantities of information at each visit is overwhelming
- Inconsistent information
- When the responsibility rests on the patient to know what information is out there and seek it out on their own
- Not having a social worker, nutritionist, or patient navigator at 'Monday' clinics
- Lack of information about resources

Diagram III

What works and what doesn't with breast cancer information at Eastern Health

(Image 1: DS13; Image 2: DS16)

Findings & Recommendations

2. Information delivery: Patient experiences were heavily impacted by how information was delivered and obtained. As one patient recalled during a post-surgery appointment, *"…bad news is they found some cancerous cells in the lymph nodes. But I left that damn hospital practically dancing because I was so elated and so happy. I was treated with respect and compassion and tenderness and I had time to process, time to think and time to talk*" (DS13). Conversely, another patient described her emotional distress when her family doctor delivered her cancer diagnosis over the phone, "*I felt like I was standing at the top of the Grand Canyon and I was pushed off the edge and was negotiating the Colorado River Rapids without lifesaving equipment and I can't swim!*" (DS2).

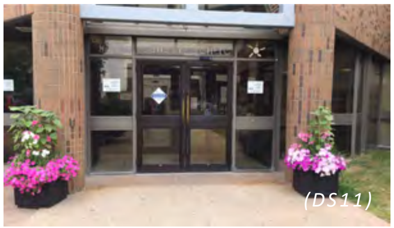
In general, patients received most of their medical information from their family doctors, surgeons, and/or oncologists. Patients also reported relying on the broader circle of care for information about treatments: "*I got the best information — choices of treatments, potential side effects, responses to drugs — important nuggets of information from health technicians, the chemo nurses, cancer center staff and the hospital pharmacists. They were amazing*" (DS10). This also included fertility specialists, health technicians, chemotherapy nurses, cancer center staff, hospital pharmacists, and social workers. Patients noted that they gained important medical information through support groups and at breast cancer conferences held within the province.

The diagnosis and treatment of cancer impacted patients' physical, emotional, spiritual, and psychological health. Understandably, a number of digital stories supported a desire for a whole person approach to cancer care. As one patient concisely noted, "*I believe that I would have really benefitted from a team approach to my illness. More of a holistic approach. I would have loved to talk to a social worker, a spiritual advisor — just to chat about life and death issues that come up when you are diagnosed with a serious illness*" (DS4).

Most patients in the study did not describe their experience as a holistic approach to care. However, one patient described her experience as an integrated and transparent team approach, *"...within two weeks I got a care team of physicians and surgeons, a nurse navigator, social workers, nutritionists, physiotherapists. I was given appointments, pre-admission dates. I began to move forward and my legs began to thaw. I walked again…*" (DS13). This approach had a positive impact on the patient's mental well-being and overall breast cancer care experience. This example reveals that there are instances of collaborative and holistic approaches at Eastern Health. How can Eastern Health ensure a whole person care approach becomes the norm, rather than an isolated occurrence? There is an opportunity for Eastern Health to consider bringing together various supports for breast cancer patients.

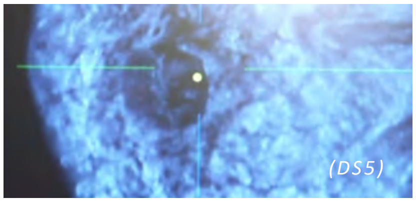
3. Quantity of Information: Patients described a lack of information about 1) post-surgery and/or post-treatment aftercare, 2) available supports/resources, 3) reconstructive surgery, and 4) complementary therapies. Yet, they also reported feeling overwhelmed by the volume of information provided during appointments, "*Every time I saw a doctor, there was so much information exchanged I came out overwhelmed*" (DS2). One patient used a blurry image of herself to express how overwhelmed she felt every time information was provided: "*I was given some information pamphlets, a book on cancer, and my cancer plan: chemo followed by surgery and radiation. Everything was a blur*" (DS1). Similarly, another patient noted how emotionally distressing her first day at the cancer clinic was, "*My first day at the cancer clinic and oncology appointments hit me harder than the first day that I found out that I had DCIS. So much information. I would need chemo. I would lose my hair. The drugs that they would give me may cause heart problems and on and on*" (DS14).


(DS11)


(DS11)


(DS11)


(DS14)


(DS5)

Findings & Recommendations

Most patients received material in the form of pamphlets and a book about breast cancer. Patients often reported the book being unused or unhelpful: "*I really did not find the book helpful and in hindsight it did not match how everything actually unfolded*" (DS16). Another participant indicated that the pamphlets she received about her mastectomy were not helpful in preparing her for her surgery, stating, "*a written pamphlet on aftercare with line drawings of the drain did not prepare me for the state I was in*" (DS5). Another patient said that while she did receive a box of printed material, she "*never got a chance to open the box or read its contents*" (DS15). There is a need to ensure that resources to support patients are in accessible formats, are digestible in content, and timely in delivery.

Patients reported being in shock when they received their diagnosis or during their follow-up visits. This made it difficult to take in any information during these appointments. While patients are encouraged to bring a family member to meetings, patients also shared that family members are also often in a state of shock or are unable to understand the information provided by the healthcare providers. This was best illustrated by a patient who brought her husband who *"…was supposed to take notes for me but mostly we both just sat there nodding at everything the doctor said like deer in the headlights. Trying to take it in, trying to understand*" (DS10). There is an opportunity in Eastern Health to explore how patients can be provided information in such a way that honours the need to process and digest what is happening.

During focus groups, KUs acknowledged patients are often overwhelmed by the large volume of information during appointments and that patient shock impedes the retention of information given at diagnosis. However, when asked about what information patients need to minimize emotional distress, KUs indicated there was a lack of information or understanding about a variety of factors including: Available resources, the meaning of their diagnosis, treatment choices and consequences, next steps in patients' treatment plans, as well as adequate information about aftercare following surgery or treatment. Focus group participants noted that there appeared to be some stigma associated with accessing the services of social workers. This was likely rooted in the lack of understanding of the role of social work. KUs described patients being unprepared to communicate their diagnosis and treatment to family or friends. KUs agreed that most resources and information provided to patients focused on the physical aspects of treatment and not on the psychosocial aspects of care.

KUs highlighted the challenge of balancing the need to provide essential information while not overwhelming patients. KUs suggested developing a consistent information plan that outlines and describes available patient resources and supports. This should include providing information in a simple and clear design that patients are able to refer back to (e.g. written documents, websites and/or voice recordings). KUs also suggested allowing and encouraging the use of recording devices during appointments.

(DS9)

(DS4)

4. Timing of information during treatment and transitions: The breast cancer trajectory is often described around core touchpoints pertaining to diagnosis – surgery – pathology – treatments – post-treatments. While patients often described a fear of the unknown at diagnosis, patients were also unclear about steps after treatment: *"What happens next? All the treatments are over. Doctors' appointments once every three months. Am I cancer free? Do I still have cancer? What happens next?"* (DS7).

Patients identified a lack of adequate information about aftercare and the after effects following surgery and/or treatments. For instance, one patient indicated that she went to emergency one day post-discharge due to complications with her incision and drain, because the pamphlet about post-surgery did not sufficiently prepare her to deal with the issues (DS5). Others said it was outside of a normative skill-set to adequately care for radiation burns post-treatment: "*I was left to care for them myself just with antibiotic cream… I didn't know how to care for my burns … How would I know how to take care of second-degree radiation burns?*" (DS14).

Findings & Recommendations

However, all patients indicated they benefited from – or would have benefited from – information about these different transition points in a digestible and accessible format. Information about transitions, such as: 1) potential wait times, 2) healthcare practitioners that are/could be involved at various stages, 3) what to expect at stages with regards to potential biological/psychological/sexual changes, 3) aftercare considerations, and 4) information about accessible resources and touchpoints between each of these stages. Information about transitions should also be available to patients in a format that they can regularly reference and easily read. There is an opportunity to create a visual aid that includes information about the breast cancer transitions in a digestible and accessible format.

During focus groups, KUs indicated patients should be provided with resources at different points of their cancer journey. Information delivery should include multiple formats for easy reference and retention. They also stressed the importance of providing information before surgery, as explained by one focus group participant: “I think if they get to surgery and they have nothing, I think we missed the boat.” Suggestions included modelling the TJ clinics: This refers to creating a regularly held group session where patients can get all the information they need before surgery. They can also make important connections to patient navigators, social workers, nutritionists and pastoral care. Information clinics would help with the consistency of information provided to patients as well as preparing patients for aftercare.
KUs suggested a 24-hour service available for breast cancer patients to call/text to ask questions about post-surgery, post-treatment, and/or aftercare that would provide in-the-moment responses to concerns.

PATIENT IDENTIFIED PRIORITY #1: RECOMMENDATIONS

The following recommendations stem from Patient Identified Priority #1: A planned focus on consistent information is needed to minimize emotional distress. There is a need to develop and implement a consistent information process in Eastern Health for breast cancer patients. Drawing on the findings, potential short- and long-term options include:

1. **Visual decision aid:** There is not an up-to-date decision-making tool available for patients during their initial consultation with their respective surgeon. An aid that includes a visual depiction of the treatment trajectory should be developed to assist patients in understanding their options and highlight the temporality of treatments (and wait times). This visual aid would also support consistency of care and information retention (see Appendix for visual example). The visual aid can be used by surgeons, oncologists as well as patient navigators and social workers as a tool to facilitate conversations with patients.

2. **Host information clinics for all breast cancer patients:** These clinics would provide an opportunity for patients to receive information they require prior to surgery. To emphasize whole-person care, clinic attendees would include social workers, nutritionists, patient navigators, and pastoral care (on call). Eastern Health staff would also provide patients with clear details about what to expect, particularly around timelines.

3. **Information access:** Stronger clarity about the overall process could be channeled through different mechanisms that use accessible language to communicate what to expect during surgery/treatment and post-surgery/treatment. Examples include:
   a. 24/7 hotline where someone is on-call to answer questions, particularly helpful for patients off the Avalon;
   b. Online Hub with links to easily accessible online sources (e.g. Be The Choice), including videos that explain the process (e.g. Breastcancer.org);
   c. Encouraging patients to record medical meetings (with permission)

4. **Internal accountability of timelines:** Patients need consistent communication about wait-times. A long-term recommendation is to create a document about the cancer care journey at Eastern Health with timelines and a process mechanism that also requires accountability of these timelines within the system (i.e. explore other models where this is implemented). Coinciding these wait times with complementary therapy options will potentially address emotional distress.

(DS18)

PATIENT IDENTIFIED PRIORITY #2:

THE ROLE OF PATIENT NAVIGATORS MUST BE FURTHER DEVELOPED IN ORDER TO SUSTAIN PATHWAYS FOR CONSISTENT INFORMATION ACCESS DURING AND AFTER TREATMENT

Breast cancer patients and KUs stressed the importance of patient navigators in providing continuity of care. A key theme in patient stories was the need for consistent information delivery: Patients don't know what they don't know. While some were able and/or willing to seek out evidence-based information to guide their decision-making process, there is a desire to have one consistent touchpoint. A navigator would be someone in the healthcare system patients could easily reach to ask questions about their surgery and treatment, who could provide support navigating the healthcare systems, and who could inform patients of resources. As noted by one patient, "*I would have liked to have had somebody who was knowledgeable to talk to so I could make informed decisions*" (DS2). In context, this was not a call for more time with physicians; the statement reflected the need for a practitioner within the Eastern Health structure to provide reliable and consistent information and support throughout a patient's care trajectory.

While Eastern Health does have patient navigators, they were only mentioned in one digital story. In this case, the patient shared the positive experience they had with the patient navigator. After viewing the digital stories, the other patients indicated they were unaware of the patient navigators.

Patient advocacy: Patients reported increased access to services when healthcare providers acted as advocates for resources. However, some patients also indicated their need to self-advocate to access medical supports post-surgery or treatment. Other patients felt that there were ineffective resources for post-surgery aftercare and stressed the need to have someone who is accessible to support breast cancer patients at every step: *"The medical profession needs to prepare women for this...there needs to be nursing staff or someone else who can talk to the patient and make sure they know what they are in for*" (DS5).

Informal supports: Patients are advised to bring someone with them for diagnosis and follow-up appointments. This was helpful when patients were dealing with information overload, "*It was so good that my daughter was with me as I only heard like Charlie Brown heard when the teacher talked to him: wha wha wha wha wha...*" (DS14). However, as highlighted in the previous section, patients' loved ones were not always effective at taking notes or processing information as they too were in shock. Formal supports through a patient navigator would address this reality.

(DS14)

(DS5)

(DS8)

(DS6)

(DS7)

(DS7)

Findings & Recommendations

PATIENT IDENTIFIED PRIORITY #2: RECOMMENDATIONS

1. Reevaluate the patient navigator model at Eastern Health with the goal of strengthening the breast cancer patient navigator program. Existing breast cancer care navigator programs that provide consistent support to patients through the cancer trajectory are well established in Canada, which can be helpful in determining different formats to meet the needs of breast cancer patients at Eastern Health to support continuity of care (15,16, 34-36). The patient navigator role should act as the primary contact for patients throughout surgery and treatment, and initiate patient contact immediately after diagnosis.
2. During their first appointment, surgeons should provide patients with a business card listing a contact phone number for the patient navigator at Eastern Health.
3. The patient navigator should attend Monday Breast Cancer Clinics and all relevant information sessions for breast cancer patients at Eastern Health.

(DS1)

(DS5)

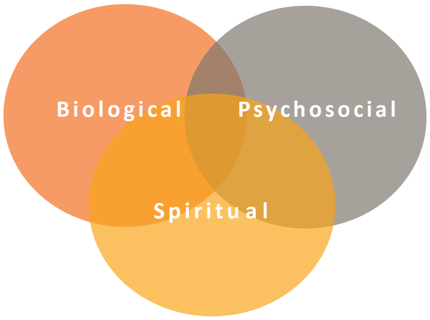
(DS7)

PATIENT IDENTIFIED PRIORITY #3:

THERE IS A NEED FOR WHOLE PERSON CARE INCLUSIVE OF COMPLEMENTARY THERAPIES TO IMPROVE OVERALL PATIENT WELL-BEING

Whole person care is based on the premise that: "...the best way to care for people with complex needs is to consider their full spectrum of needs – medical, behavioral, socioeconomic and beyond – in a coordinated and integrated way..." (37). Studies indicate that patients receiving whole person care "...have a better experience of care, as their needs are more fully addressed without having to navigate multiple programs and systems on their own" (37).[5]

Consistent with psychosocial oncology[6], findings indicate a need to focus on whole person care that addresses the biological, psychosocial and the spiritual aspects of patient well-being both during and after treatment. This is demonstrated through four core areas: 1) the patient's transitioning identity, 2) the need to support patient mental health, 3) coping strategies and supports patients can access during and after treatment, and 4) identifying the need for therapeutic interventions post-treatment.



1. **The patient's identity:** Psychosocial care acknowledges that a cancer diagnosis goes beyond the physical implications of the disease and treatment, as noted by one patient, *"...when a woman finds herself diagnosed with breast cancer, she is not only facing this scary reality of the disease, but of one that often directly impacts her identity and self-worth*" (DS16). Patients indicated that their breasts are an important aspect of their identity related to sexual health, femininity, and motherhood. However, many felt these aspects were not acknowledged during their cancer care; little attention was given to the psychological and emotional issues that arose post-surgery and treatment.

   For instance, one patient used a picture of a bright landscape turning into a dark forest to highlight the changes to her body during treatments (DS13). Another woman shared an image of shattered glass after being told chemotherapy would cause hair loss and infertility; she had felt unprepared for the long-term side effects of treatment (DS15).

2. **The need to support patient mental health:** Patients spoke about the ongoing psychosocial effects of cancer, defining their stress with terms such as distress, fear, anxiety, depression, and Post-Traumatic Stress Disorder (PTSD), that they experienced during and after treatment. As noted by one patient, *"...inside, there will always be a part of me that has been obliterated, never to be repaired*" (DS2). While sexual health is also an integral piece of whole person care, KUs indicated patients are afraid to talk about it with their healthcare providers. As a KU explained in the focus group: *Another thing we're really trying to promote [sic] we've all done the courses for specialized sexual counselling therapy...How to put it out there like nobody really knows...people are so afraid to talk about sexuality because 'the doctors might think we're more concerned about sex than our cancer,' that's the answers we're getting*."

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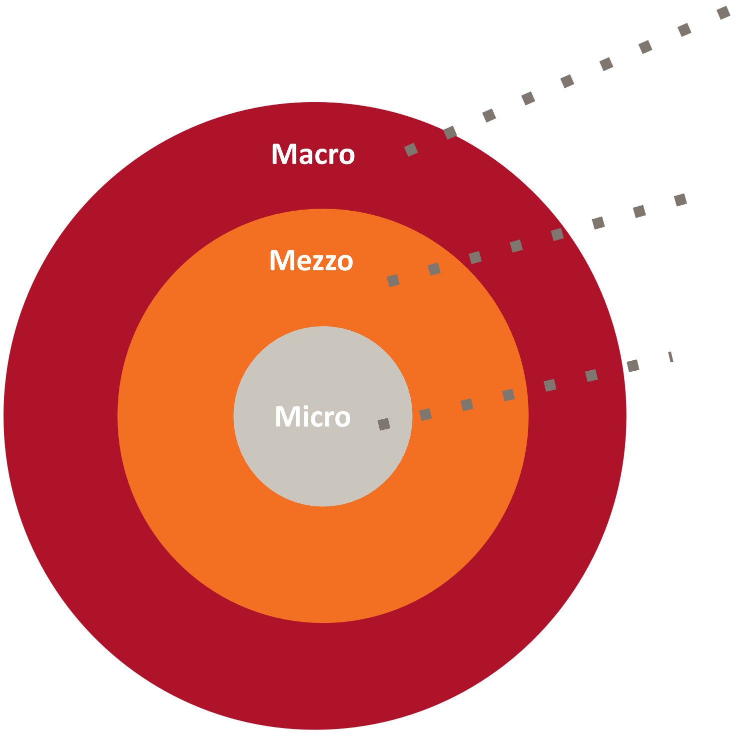
5. KUs defined whole person care as patient-centered care. Key attributes included:
   - Recognizing and valuing patient choice and patient voice;
   - Patients must have options—and adequate information regarding those options—thereby allowing them to choose needed supports and resources;
   - Patients can choose to take the lead in decisions regarding their care, or they can choose to let their healthcare provider make decisions regarding their care;
   - A whole person care approach recognizes the value of complementary therapies in treatment. Examples of complementary therapies identified included art therapy, sex therapy or counselling, meditation, yoga, and exercise.
6. Psychosocial oncology is a whole person-centered approach to cancer care. Psychosocial oncology recognizes that the impact of cancer and its treatment extends beyond the physical implications of the cancer experience (39-40). It is a specialty in cancer care focused on understanding and addressing the effects of cancer on the social, psychological, emotional, spiritual, functional and quality-of-life aspects of patients, their families, and professional caregivers (39-40).

Findings & Recommendations

Multiple patients suggested that transitions in care were critical periods to bring in emotional or mental health supports. Patients expressed feelings of isolation and loneliness, especially during radiation treatments, with one patient noting, *“…chemo always included good company, card games, treats and brightness. I was not prepared emotionally for the stark contrast that would be radiation. Being completely alone and uncomfortably still with only my thoughts & the whirl of the machines, my mind raced…”* (DS17). Another participant reported that after surgery and treatment, *“…I didn’t know what was happening to my body”* (DS1). Length of time between surgery and the pathology report without contact also contributed to emotional distress.

Both patients and KUs indicated that breast cancer surgery should not be day-surgery, and suggested this needed to change. Patients and KUs stated the need for at least one overnight in the hospital following a mastectomy, as one patient stressed, “*a mastectomy is a very big surgery, it is emotionally big, psychologically big and physically big. It is not day surgery*” (DS5). KUs also indicated further benefits and program efficiencies to an overnight stay, as the additional time would be beneficial to the patient’s mental health, it offers an opportunity to extend and improve patient training and preparation regarding aftercare, and the added time would also present extended opportunities to connect patients to complementary health support services.

3. **Coping strategies and supports accessed by patients:** Most patients navigated their emotional issues on their own, outside of their regular cancer care. One patient noted, “*I had to learn how to cope in the best way possible…*” (DS12). Most patients sought out supports and explored creative means to make the time pass. The following diagram highlights the coping strategies and supports that patients accessed at the individual level (micro), the group level (mezzo), and within Eastern Health (macro):



MACRO (Eastern Health): Nurses, surgeons, oncologists, staff, social workers, nutritionists, other patients (particularly during chemo)

MEZZO: Support from spouse, family, friends, community, SOS, Avalon Dragons

MICRO: Creative means, exercise, meditation, pets, art, humour, food (dietary), attitude (fight/accept)

Diagram IV

Coping strategies and supports accessed by patients at various times during their breast cancer care

Findings & Recommendations

A common theme in all the digital stories was the critical role of supports. The supports were either formal (medical and non-medical related supports), or informal (family, friends, and support groups). Support varied through the course of care and included general encouragement, spiritual support, practical support, emotional support, etc. The following excerpts illustrate some patient views regarding the support they received:

"Love and support from those close to me held me up through nausea, hair loss, muscle spasms, bone pain and sleeplessness." (DS17)

"These are really hard days but these people make it better for me because I feel cared for. I feel cared for by friends, my family and my medical teams. They circled the wagons and they kept the wolves at bay. I am going to be safe, I'm going to be okay." (DS13)

"I feel like I have made it out of the Colorado river with the help of a rope my husband and daughter threw to me, a life-jacket my surgeon got to me, a dingy and oars my oncologist and other health professionals gave me." (DS2)

Peer-support groups held great importance during decision-making and transitions in care. Patients noted value in having someone who understood exactly what they were going through: *"Connections to other women, travelling the same path as I was travelling, coupled with the love and positive energy from my family and friends became my lifeline…To have someone entirely understand the devastation and fear was such a blessing"* (DS17). Two community-based peer support groups mentioned by patients included the Avalon Dragons and Sharing our Strength (SOS).

(DS3)

Findings & Recommendations

A number of coping strategies patients pursued also aligned with complementary therapies, yet patients did not indicate they accessed these therapies through Eastern Health. However, focus group KUs suggested there are current attempts to offer and address these needs within Eastern Health, such as regularly offering complementary programs including art therapy, yoga, meditation, exercise, and sexual health counselling. Yet these efforts are often challenged by a lack of capacity within the current structure.

To support complementary therapies and incorporate aspects of whole person care within program delivery for breast cancer patients, KUs indicated the need to expand the definition of 'care' within the Eastern. Health framework. Suggestions to address this need include an investment in developing capacity in whole person care, recruiting volunteers to run support programs when financial constraints prevent Eastern Health employees from doing so, and providing information to family doctors about resources to support the mental health of cancer patients throughout the cancer trajectory (including post-treatment).

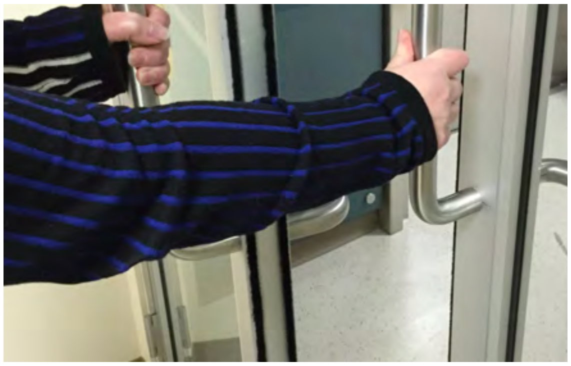
4. **The need for therapeutic interventions post-treatment:** Many of the patients advocated for support before, during, and after treatment. They pushed for peer support groups, psychologists, or spiritual advisors to be provided for the mental well-being of patients. Otherwise, women were left to wonder, *"…how do I pick up the pieces and start over…?"* following discharge from the cancer clinic (DS12). Similarly, focus group KUs echoed comments that patients often feeling unprepared for life after cancer treatment or surgery, as explained by one KU, "*Patients feel cocooned when they're going through their treatment phase but then when that's over, then what?*" KUs noted that patients' emotional distress often peaked post-treatment, highlighting the importance of ensuring continuity of care.

PATIENT IDENTIFIED PRIORITY #3: RECOMMENDATIONS

There is an opportunity to support whole person care within Eastern Health to improve patient well-being. Recommendations include:

1. Develop, sustain, and promote capacity in complementary therapies within Eastern Health, particularly during critical transition periods. Research in the area of complementary therapies indicates offering such services have a positive outcome on patient mental health.
    - Conduct a needs assessment of the types of complementary therapies and supports needed across micro, mezzo and macro areas.
    - Connect patients with peer-support groups at Eastern Health and within the community.
    - Explore sustainable options that provide supports for patients who live off the Avalon.
2. Better access to follow-up care post-surgery and post-treatment.
    - Overnight stay after breast cancer surgery.
    - A 24/7 hotline where someone is available (on-call) to answer questions about post-treatment concerns via phone/text.

(DS1)



(DS15)

Findings & Recommendations

CREATING AND VIEWING DIGITAL STORIES: OVERALL IMPACT

Digital storytelling is a powerful research intervention that draws on the lived experience of participants. Digital stories have an impact not only on those who create them, but also on those who view them. This was evident in the feedback from KUs who attended the digital story screenings. From the 117 questionnaire responses from KUs who viewed these digital stories, 90.9% strongly agreed/agreed that viewing the digital stories increased their understanding of women's experiences with breast cancer treatment. As one KU indicated in the survey, "*listening to the women's experiences of going through treatment for breast cancer opens my eyes to what some of their needs are. This will help healthcare professionals provide better care*." Another KU indicated that the videos provided a more complete picture of the process, "*It was a very emotional experience watching the videos and hearing these stories. I felt I got the whole experience of the patient rather than pre/post op when they come to our floor and I can care for them*."

Of the responses, 65% indicated that they would change how they interact with patients.[7] For instance, one respondent stated, "*I will be more open to listening to patients and ask them if they have questions. I will not assume that they have the knowledge on what to expect after a mastectomy*." Another response included, "*In my profession, there is a great deal of emphasis placed on patient understanding but often after time one becomes lazy. Reminds me I need to check in more to clarify understanding*."

Patients indicated that developing their digital stories was an empowering process. Patients were also able to identify connections amongst one another in sharing their experiences.

CREATING AND VIEWING DIGITAL STORIES: RECOMMENDATIONS

There are opportunities to explore digital stories as a pedagogical application in healthcare settings, including continuing education and across post-secondary healthcare disciplines. While digital stories were applied as a method of data collection, there is also the potential to evaluate the process as an intervention strategy amongst cancer care patients. Recommendations include:

1. Explore the capacity of digital stories as a pedagogical tool at Memorial University and within Eastern Health continuing education programs.
2. Conduct a pilot program to evaluate digital stories as an intervention strategy amongst breast cancer patients.
3. Based on the digital story screenings, the material may be difficult to hear and view for audience members. We recommend only screening 2-3 digital stories at one time, followed by a discussion. We also recommend informing audiences about the content prior to any screenings.

(DS12)

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[7] While 65% of KUs indicated they would change how they interact with patients, a significant number of the remaining respondents identified that they were already working well with patients and had implemented many of the recommended changes identified in the digital stories.

Conclusion


(DS11)

Breast cancer is the most frequently diagnosed cancer for women in Canada (1). As reflected in the digital stories at the heart of this project, diagnosis often comes as a shock. Breast cancer patients must become experts about their disease and treatment options. They also need to learn how to navigate a complex healthcare system and find support where it is available. This research focused on how breast cancer patients make decisions about their care and treatment at Eastern Health. In addition to hearing firsthand from women who have undergone treatment, we also heard from KUs – healthcare providers, nurses, social workers, doctors, oncologists and others who work closely with breast cancer patients.

This report summarizes the key findings from this research. In addition to presenting research findings from the analysis of patient-created digital stories, surveys, and focus groups, the report identifies a series of concrete recommendations. These recommendations are aimed to support improved care for breast cancer patients as they navigate their treatment.

The quality of care throughout a patients' cancer journey is under-reported (17). This research therefore addresses this need by reporting on patient experiences in their breast cancer care journey at Eastern Health. Along with this report, the outcomes from this project included: 1) 18 digital stories regarding cancer patient care, 2) eight screenings with 117 KUs, 3) recommendations for a visual-aid (see page 35), 4) a participant screening of digital stories with patients and their family members, 5) conference presentations (SPOR-CIHR Summit and Participatory Health Conference), 7) invited presentations (People's Health Matters, M3 Speaker Series, Arts & Health NLCAHR), 8) forthcoming academic papers detailing findings, and 9) a research-based theatre production based on the digital stories (performed in November 2019).

The research team would like to thank all who were involved in this research, with a special thanks to the patients at Eastern Health who shared their stories and experiences to inform this research.

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Appendices

DEFINITION OF KEY TERMS

KNOWLEDGE USERS (KUs)

Individuals who are “likely able to use the knowledge generated through research in order to make informed decisions about health policies, programs and/or practices. A knowledge user can be, but is not limited to, a practitioner, a policy maker, an educator, a decision maker, a healthcare administrator, a community leader or an individual in a health charity, patient group, private sector organization or media outlet” (38). In this study, included healthcare practitioners, such as nurses, social workers, clerical staff, physicians, etc.

PATIENT-ORIENTED RESEARCH

Research that engages patients, their caregivers, and their families in the research process with the aim of identifying patient priorities and ultimately improving patient outcomes (4).

DIGITAL STORYTELLING

A participatory research method that combines the tradition of oral storytelling with technology. In this collaborative process, people combine photographs, music, and personal narrative to create a two- to five-minute video about a personal experience. The underlying philosophy of digital storytelling is that people are experts in their own situations (13).

WHOLE PERSON CARE

Patient care that considers an individual’s full spectrum of needs, including medical, behavioural, socioeconomic and beyond, in a coordinated and integrated way (39-40).

PSYCHOSOCIAL ONCOLOGY

A specialty in cancer care focused on understanding and addressing the effects of cancer on the social, psychological, emotional, spiritual, functional and quality-of-life aspects of patients, their families, and professional caregivers (35-36). Psychosocial oncology recognizes that the impact of cancer and its treatment extends beyond the physical implications of the cancer experience (39-40).

SEXUAL HEALTH

This term refers to “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence” (41).

(DS18)

DECISION MAKING AID
TEMPLATE

BREAST CANCER TREATMENT AT EASTERN HEALTH

▨ The grey boxes are examples of potential information.

Diagnosis → Surgery
Estimated Time:

Type of Surgery:
MASTECTOMY: removal of the whole breast
LUMPECTOMY: removal of the cancerous tumour and some surrounding healthy tissue. You may need surgery to remove lymph nodes from your armpit. Your surgeon will help you with these decisions.

Planning:
Generally, the first step in breast cancer treatment is surgery. However, some people might first require additional treatment.

When you meet with the oncologist, you might want to ask to record the conversation so you can refer to it.

After Surgery:

Signs Incision Has Healed:

Pathology → Additional Treatment
Estimated Time:

Additional Treatment Options:
Depending on the type of cancer and surgery, you may need one or more forms of treatment. Your oncologist will go over these options with you:

RADIATION THERAPY:

CHEMOTHERAPY:

HORMONAL TREATMENT:

TARGETED THERAPY:

Potential Side Effects:

Follow-up & Aftercare →
Estimated Time:

Reconstruction:

Estimated Time of Referral:
With a plastic surgeon, you will decide if you are a good candidate. It is important to talk about the type and timing of surgery, the recovery process, how your new breasts will look and feel, as well as your own expectations.

Follow-Up Plan:
Make a plan with your oncologist to monitor side-effects and symptoms.

Decision Point
Type of Surgery

Decision Point
Additional Treatment

Decision Point
Reconstruction

Healthcare Supports:
Connect with Eastern Health's Patient Navigator:
http://cancercare.easternhealth.ca/patients-and-family/patient-navigation/

Community Supports:
To help you through these decisions visit: https://bethechoice.org/en/

Healthcare Supports:

Community Supports:

Aftercare:
Through your healing, you will experience physical and emotional changes. There are supports you can access, including complementary therapies, social workers, and counsellors. Health, local, and provincial supports are available to help you develop strategies to lead your life after breast cancer.

Healthcare Supports:

Community Supports:

Appendices

DIGITAL STORYTELLING SCREENINGS

JANUARY 2018
ONCOLOGY DEPARTMENT
CANCER CLINIC
HEALTH SCIENCES CENTRE

FEBRUARY 2018
EASTERN HEALTH STAFF AND PRACTITIONERS
NEWFOUNDLAND AND LABRADOR CENTRE FOR APPLIED HEALTH RESEARCH (NLCAHR)

FEBRUARY 2018
SOCIAL WORK DEPARTMENT
CANCER CLINIC
HEALTH SCIENCES CENTRE

MARCH 2018
NURSING EDUCATION DAYS
ST. CLARE'S MERCY HOSPITAL

APRIL 2018
DAY SURGERY AND OPERATING ROOM NURSES
HEALTH SCIENCES CENTRE

APRIL 2018
DAY SURGERY NURSES
HEALTH SCIENCES CENTRE

APRIL 2018
NURSING EDUCATION DAYS
ST. CLARE'S MERCY HOSPITAL

APRIL 2018
RECOVERY ROOM NURSES
ST. CLARE'S MERCY HOSPITAL

THEATRE PERFORMANCE & PANEL DISCUSSION

NOVEMBER 2019
The Cut of It
Written by Meghan Greeley
Produced by White Rooster Theatre
Artistic Director Ruth Lawrence
Directed by Lois Brown
Based on the digital stories from this research project

white rooster theatre
PRESENTS
THE CUT OF IT
NOV 7–9, 8PM & NOV 10, 2PM
LSPU HALL
FREE ADMISSION

WRITTEN BY MEGHAN GREELEY
BASED ON RESEARCH CONDUCTED BY DR KATHLEEN C SITTER
DIRECTED BY LOIS BROWN

FEATURING
YOLANDA BLISS LAURA BRADLEY MARY COSTELLO LILY HALLEY-GREEN
AMY KAVANAGH-PENNEY ALLISON KELLY ALEXIS KOETTING
RUTH LAWRENCE WENDI SMALLWOOD

RESERVATIONS RECOMMENDED
FOR TICKETS, CALL 753-4531 OR VISIT LSPUHALL.CA

Appendices

RESOURCES

Eastern Health – Cancer Care

The Provincial Cancer Care Program

http://cancercare.easternhealth.ca/about-us/

D. H. Bliss Murphy Cancer Centre: 1-709-777-7480

Cancer Patient Navigator St. John's: 1-855-848-3888

Aboriginal Patient Navigator: 1-709-777-2199 or 1-709-777-2110

Social Worker: St. John's: 1-709-777-7604

http://cancercare.easternhealth.ca/cancer-care-services/social-work/

Financial Resources Available for Cancer Patients:

http://cancercare.easternhealth.ca/wp-content/uploads/sites/2/2018/08/BR_Financial-Programs-Brochure_2018-05.pdf

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The Canadian Cancer Care Society

Information about breast cancer

http://www.cancer.ca/en/cancer-information/cancer-type/breast/breast-cancer/?region=on

Daffodil Place

Travel and accommodations during treatment when living 50km+ from St. John's, NL

NL Division of the Canadian Cancer Society

1-888-754-6520

Community Supports

Sharing Our Strength (SOS)

Peer Support Group. Email for online and offline options for support

Sharingourstrength.nl@gmail.com

Avalon Dragons

Dragon boating for breast cancer survivors in St. John's, NL

https://www.avalondragons.com

Online Resources

Be the Choice

https://bethechoice.org

A tool for patients to become aware of breast cancer treatment options

(Canadian site)

BreastCancer.Org

https://www.breastcancer.org

Includes podcasts and videos about understanding breast cancer

(American site)