PATIENT ENGAGEMENT IN BREAST HEALTH EDUCATION INITIATIVE

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(PaCER)

October 31, 2017

Alberta Health Services

Strategic Clinical Networks

PaCER innovates

Table of Contents

PATIENT ENGAGEMENT IN BREAST HEALTH EDUCATION INITIATIVE 1

Background 3

What is PaCER? 3

Health Literacy and Patient Engagement 4

Methodology 4

Challenges in Patient Participation 5

Stage 1: Identifying Patient Needs for Standardized Education Booklet 5

Recruitment 5

Approach 5

Results 6

Stage 2: Patient Review of Standardized Education Booklet Draft 7

EDUCATION PRIORITIES OF BREAST CANCER PATIENTS IN ALBERTA 9

- Knowledge about my Cancer 9
- Feeling Assured about Day Surgery 10
- Understanding the Timeline of my Journey 11
- Preparing for Post-surgery Experiences 12
- Managing Side-effects of Tamoxifen 12
- Preparing my Family and Friends 13
- Taking Care of My Overall Health and Wellness 13

Conclusion and Recommendations 14

References 16

Acknowledgements 17

Appendix A 18

Appendix B 39

Appendix C 45

Background

A Provincial Education Scan done by the Cancer Strategic Clinical Network^{TM} (SCN 2017) of currently existing breast health education available to the women of Alberta across the Pre, Peri and Post-Operative stages has found that, although there is a large variety of breast health resources and educators across the province, the following gaps and inconsistencies exist:

1. Education provided by the different units is not integrated
2. Not all patients receive information when they need it
3. Patients in some regions do not receive current and comprehensive education
4. Access to comprehensive and allied health care, such as dieticians, physiotherapists, and Home Care, is also uneven
5. Effective web-based educational resources are absent

As part of its multi-year strategy to improve cancer care across the continuum the Cancer SCN is developing high quality, comprehensive, standardized provincial breast health education to address the above gaps.

Role of PaCER

The Patient and Community Research program (PaCER Inc.) was contracted by the Cancer SCN to consult women who had breast cancer surgery to find out what breast health education supports they had access to, what information they had found most useful and what else they would have liked to know about their preparation for surgery and aftercare.

The information gathered from patients would be used to inform a provincial breast cancer education prototype that would then be reviewed by patients. It was expected that at least one rural site and one urban site would be introduced to the prototype for final consultation.

What is PaCER?

PaCER is a patient engagement research program based at the University of Calgary, that trains patients and family members in qualitative health research, creating a new collective voice with, by, and for patients. PaCER's mission is to change the role of patients in their health and health care by bringing patient insight to the search for sustainable and effective health care. This means reframing the role of "patient" as a key stakeholder, partner, and colleague in health research and health care through an innovative co-design process. Key stakeholders of PaCER include the Strategic Clinical Networks, O'Brien Institute of Public Health, and the Department of Community Health Sciences and Rehabilitation and Disability Studies at the University of Calgary.

For the Breast Health Initiative's patient engagement project, PaCER explored how patients understand breast cancer surgery and the information they believe would help them from their

perspective as a breast cancer survivor. This patient voice often uncovers the flip side of traditional health literacy education (the anatomy, surgery and aftercare clinical procedures) by drawing attention to patient agency in education. This refers to the information patients need to be included in decisions, and to feel optimistic and confident in their ability to manage life after surgery. It is about understanding enough at every stage to cope with and make sense of surgery and its impact.
www.pacerinnovates.ca

Health Literacy and Patient Engagement

Initially understood as simply the ability to read and follow health-related text, the concept of health literacy has gained in breadth and complexity. Health literacy is now measured in terms of empowerment, agency, and health promotion; native self-determination; technology; culture and cultural knowledge. Patient engagement and health literacy are closely connected. As objectives of a stronger, more accessible, and equitable health care system, they demand a cultural change in the way that the role of patients is perceived in the health care system (Rootman and Ronson 2005).

The World Health Organization's policy brief (Coulter et al, 2008) outlines three interconnected aspects of patient engagement: health literacy; shared decision-making; self-management of chronic conditions. Health literacy is not just functional literacy or the ability to understand practical information, but it is also interactive and critical; that is, patients need "in-depth information," for long-term, independent self-care.

Methodology

Broadly following consultation principles and iterative, naturalistic inquiry, PaCER researchers explored the quality of patient education as patients experienced it in their cancer journey as a whole. This overarching review did not allow us to research thoroughly the best ways to serve patients to ensure support, safety, and well-being through the journey from being diagnosed to recovering at home after surgery. However, the use of open-ended conversations, rather than a "strengths and weaknesses" approach allowed us to explore what is most meaningful to patients and to identify significant areas for further consideration.

Stages

The engagement project was divided into two stages. The first stage included two focus groups and six individual narrative interviews. The focus groups were held in Calgary and Lethbridge. The purpose of this stage was to engage patients in a broad evaluation of educational materials available to them from their breast health clinics and/or healthcare team. Both as a group and individually, patients identified the resources they received from the perspective of how they experienced their journey through breast cancer, what concerned them most, what kinds of information they were able to use effectively, when they were able to use it, and where the gaps lay between patient needs and patient educational resources.

In the second stage, the draft of a standardized education booklet was taken to patients for review. This was also done through a focus group, where participants provided comments and suggestions based on the significant areas of information needs identified by patients in the first stage as well as their own perspectives on how those needs can be met.

This report outlines the results of each stage separately. However, the key priorities of patient education are presented here on the basis of a comparative and comprehensive analysis of both stages.

Challenges in Patient Participation

Contrary to expectation, the number of women who responded to posters, letters of invitation, and word of mouth was limited. We approached patient advisors' networks, health advisory networks, clinics, Wellspring in Calgary and Edmonton, and Compassionate Beauty. The main source of our recruitment were patient and nurse navigators. It is also important to note that the composition of our focus groups lacked diversity, particularly in terms of rural, indigenous, linguistic and ethnic minority populations.

Stage1: Identifying Patient Needs for Standardized Education Booklet

For this stage, PaCER set itself four guiding objectives:

1. Identify the educational resources that patients received and would need to receive
2. Understand if the education was received at the right time and in the right form
3. Assess what kind of education is most important to patients, where the gaps are, and what patients need to see included
4. Identify educational experience/needs of day surgery patients

Recruitment

With these objectives, patients who had been diagnosed and undergone surgery within the last two years were invited to participate in focus groups or individual interviews. Ten women attended the focus groups in Calgary and Lethbridge held in the Foothills Medical Centre and the Chinook Regional Hospital respectively. One face-to-face interview was conducted in Calgary and five telephone interviews were conducted with three patients in Edmonton, one in Vermilion, and one in Norglenwold (near Ponoka).

Approach

All participants were requested to review their educational package before focus groups and interview (only if it did not cause any distress) and think through questions, such as what they knew before being diagnosed; what they wanted to know most when they learned they had to have surgery; what their main source of information was and if their questions and concerns were addressed. We also asked them to consider how they would like to be informed should they have had day surgery. Finally, participants were also provided with selected educational materials by email and in hard copies before and during the meetings.

Patients were asked to recall major milestones in their cancer journey and the kinds of information they received at each stage. Patients were then engaged in a discussion of what information was useful to have, what they needed more information on, and when that information would be most usable (Appendix A).

Results

The main sources of patient education were the print materials they received from their cancer clinics and the teaching classes. Additionally, most benefited immensely from face to face and telephone contacts with their nurse navigator. Surgeons and oncologists also provided valuable information. Finally, patients conducted their own research through various national and international online resources. The results were presented to the SCN in the form of an interim report.

Two distinct yet closely interrelated types of education needs emerged. The first broad category which we entitled **Patient Experience of Clinical Education** included an overview of the education that patients had received from clinics, support centres, and their independent research. This section documented patients' experience with the range of education they were able to access and whether or not it helped them understand their diagnosis and treatment options, follow test results, prepare for surgery, and take care of themselves after surgery.
Following are the main results in this section:

(a) Print materials, although informative and useful, are overwhelming
(b) Teaching classes are excellent
(c) Percentages, graphs, and charts are confusing and generate anxiety
(d) Patients' state of mind makes it difficult to absorb the amount of information received
(e) Information needs to be spaced out and delivered in a modular way, relevant to the specific stage of their treatment
(f) Information needs to be timely, so that patients can prepare themselves
(g) Print information needs to be followed up with person to person guidance and check in
(h) Terms need to be explained at the start
(i) Test results need to be explained
(j) Side effects of drugs need to be explained (Neulasta, tamoxifen)
(k) Time with nurse navigator is most useful, comforting, and reassuring
(l) Need more clarity on how suitability for day surgery is determined

(m) More information needed on post-surgery complications (lymphedema, cellulitis, pain)
(n) Home Care essential for post-surgery drain care

In the second section, entitled **Patient Search for Education Leading to Engagement, Agency, and Self-Management**, we gathered patient responses that seemed to represent a broader and longer-term meaning of educational support. The topics that emerged are about understanding the impact of what they have gone through, what they can do to strengthen their chances and hopes for a cancer-free life. In other words, the questions and recommendations in this section reflect patient desire to seek education and information that would enable them to carry forward their own care and be able to turn their confusion, fear, and anxiety into positive actions.

Following are the results in this section:

(a) Education for patients and their family members to understand and respond appropriately to the changes that occur
(b) Personalized and targeted information to instil confidence and understanding of one's cancer
(c) A timeline for all the main steps and procedures with expected wait periods
(d) Explanation of whether cancer is a recurrence or will recur
(e) Sustained and workable information on diet, nutrition, exercise
(f) Advice on strengthening the immune system
(g) Detailed and accurate information on the effects of prolonged use of tamoxifen, letrozole, and other drugs
(h) Help and follow-up if one does not have chemotherapy
(i) Help and advice from "someone who has gone through the experience"

Rural Participants

At this point it was felt by PaCER researchers and the SCN that the rural perspective had not been represented adequately. It was, therefore, decided that efforts would be made to recruit patients for a focus group or interviews in Fort McMurray and Medicine Hat. Unfortunately, due to limited participant response and budgetary constraints neither option materialized.

From the interviews we were able to conduct with two rural patients, we were able to identify several concerns shared with patients in urban areas. What seemed different are that education needs are intertwined with the challenges of communication between centres, coordination of services, and accommodation of the specific circumstances of farming families.

Stage 2: Patient Review of Draft of a Standardized Education Booklet

A standardized educational booklet, *Your Journey Through Breast Cancer Surgery*, had begun to be drafted by the SCN with feedback from the Patient Education Working Group and other healthcare personnel. It seemed logical at this point to take the draft booklet back to patients for their evaluation of its usability in the context of their expressed education needs and priorities. We did not, however, go back to the patients with whom we had already consulted to assess how the booklet is able to address their concerns. Instead we conducted a focus group at the Misericordia Community Hospital in Edmonton, which has a strong presence of patient advisors. By engaging a broader group of patients and patient advisors, from those who were diagnosed within the last year to those who had had surgery ten years ago, we were able to conduct a review of the draft booklet from a number of different perspectives. We also conducted telephone interviews with two patients in Edmonton who were unable to participate in the focus group and with one patient in Fort McMurray.

In this final focus group, patient feedback was sought through four activities that traversed the whole patient engagement project:

1. Review and discussion of patient feedback in Poster format from the first stage of the project (Appendix B)
2. Review of draft educational booklet, *Your Journey Through Breast Cancer Surgery*
3. Writing responses to guiding questions on index cards
4. Recommendations for better usability of the booklet as well as for breast health education for patients in general (Appendix C).

The feedback provided by patients regarding the booklet have already begun to be incorporated

Analysis

Following is an integrated analysis of responses received from all three focus groups with 17 participants, and the individual interviews with 9 participants.

Participant Characteristics

Location	# of Participants	Age range	Lumpectomy	Mastectomy	Day surgery
Edmonton	12	35-70	5	7	8
Calgary	5	47-64	1	4	
Vermilion	1	52		1	
Norglenwold	1	53		1	1
Lethbridge	6	43-73	3	3	2
Fort McMurray	1	60	1	1	

EDUCATION PRIORITIES OF BREAST CANCER PATIENTS IN ALBERTA

Knowledge about my Cancer

Patients' need for knowledge about their cancer stems from their desire to play an active role in their health care. They want information that is clear, consistent, and manageable. When patients read the information, however, depends on each person's physical and emotional condition. Most patients describe the moment from the period of diagnosis to surgery as a state of being "shell-shocked," "out of my element," and "overwhelmed with fear." Therefore, it may be well after surgery and during treatment that patients are actually able to read and absorb the information. The majority of our participants read through all the material they received in their blue, black, or purple bags, depending on their location. Most patients also did online research. Internet sources, although easier to navigate with specific subjects of interest, are often conflicting and confusing. Some physicians encourage patients to go to cancer sites, but many advise against it. The breadth and diversity of online sites also generate confusion and fear as patients try to relate information to what they are experiencing at the time with their own cancer. As a 43-year-old patient expressed tearfully, "I had no idea of metastasis and I'm hearing it and it's scaring me, you know?" Thus, patients expressed a preference for receiving suggestions from healthcare professionals about which sites to explore.

In reviewing the booklet *Your Journey Through Breast Cancer Surgery*, patients were asked how they would use the information in the booklet to understand their cancer. The answers to this question showed that knowledge and awareness about their cancer is tantamount to taking control over their journey. Patients felt the information in the booklet would help them "prepare," "manage," "understand," and "cope." It became clear that with better understanding of their cancer, patients felt more empowered to move forward without continued confusion, fear, and anxiety.

Making the Right Decision about Surgery

Throughout their cancer journey, patients must make many important decisions, all connected in various ways to their health and well-being. Many of these decisions require the ability to analyze information, compare options, and decide which one would serve them best. One area of concern shared by many is having to decide whether to have lumpectomy or mastectomy. Patients feel they are not provided with sufficient information regarding the outcomes, advantages, or risks to be able to make the decision confidently. It becomes particularly difficult when patients feel that their concerns are undermined either by their choice being denied or seen as irrelevant. For example, some patients wanting to go for mastectomy were refused; in one instance, the patient was told, "Lumpectomy, mastectomy, no difference in outcome, but purely for psychological reasons you can go for mastectomy." Patients are thus often compelled to go with their "gut feeling."

Patients deeply value shared decision-making through discussion and active involvement in choosing the right course of treatment. They unanimously suggested the following revision to the booklet under information on types of surgery:

Not
Your surgeon will review the best treatment option for you
But
"*Your surgeon will review options . . . that will help you understand best treatment, including surgical procedures, so you can make the best decision for yourself."*

How closely the experience of health is connected to patients' sense of agency and active involvement in the decisions they make is represented in this patient's words that were supported by many others: "Emotional support section [of the booklet] should include . . . You have the right to ask questions. You have the right to ask for a second opinion. You have the right to take control of and have more power over your journey."

• Feeling Assured about Day Surgery

Ten out of 23 participants had undergone day surgery—seven for lumpectomy and three for mastectomy. Discussion on the subject of day surgery as common practice in Alberta showed some remarkable differences. Most patients in Calgary, Lethbridge, and surrounding areas were not aware that breast cancer surgery is indeed common practice and the majority were quite sceptical about its advantages. Some women mentioned that since they felt quite fine after mastectomy, they might have been ready for day surgery but were not entirely sure. Two patients in their 40s who were scheduled for day surgery had to stay in hospital due to nausea and vomiting and "issues with warfarin." One of them lost consciousness on the way to the parking lot.

Most patients agreed that the opportunity to rest quietly and comfortably at home is far more preferable than staying in the hospital, which is often "annoyingly loud," making it difficult to get proper rest throughout the night. Contrary to some research findings that younger women who are otherwise healthy opt for and do well with day surgery (Saares & Suominen, 2005), both of our participants who had day surgery were over 65. One of them lives by herself.

What patients were most concerned about is not knowing how their suitability for day surgery was determined. It is significant that patients felt uncertain about how they were assessed as "good to go" and whether each one's personal circumstances was considered carefully. This uncertainty, as Eileen Jefferies notes, is critical in patients' confidence and sense of wellness:

> For many women, this post-mastectomy recovery is only the beginning of their connection with the healthcare system. Surgery, radiation, chemotherapy, and hormonal therapy are all possibilities that the patient may need to consider after mastectomy. . . . Planning for early hospital discharge means not only considering the patients' medical conditions, but also their unique circumstances (Jefferies, 1997, p. 32-33).

Women with younger children, or spouses who cannot help for various reasons, were unsure if they would be able to manage. As one person put it clearly: "If the patient is uncomfortable with same day surgery that has been decided for them by the doctor, then it is up to the healthcare providers to offer support and information needed for the patient to be comfortable about going home the same day."

• Understanding the Timeline of my Journey

This is another important indication that for patients the value of their breast health education lies in their ability to take control of their journey. All patients strongly emphasized their need for an overall timeline so that they would be able to pace themselves, understand which step to prepare for, and how to best manage their resources. For example, how soon after biopsy, surgery would follow, when they would be seen at the cancer clinic, how long they would have to wait to see their oncologist, when treatment might start and similar timed milestones are what patients want to know to get a sense of the whole trajectory at the very outset. As one person put it simply and clearly: "Right at the beginning I needed someone to say this is what's happening, this is what's next. I really could have used that."

It may be felt that as patients have different experiences and journeys, a timeline might not be applicable to all patients and, therefore, cause confusion. However, it appears that most patients would prefer to have a map, so that they can locate their own position within that map. Therefore, post-surgery treatment remains a critical piece of their education needs. The following questions express patients' need for a clear roadmap: when do I see my surgeon again? When would I start chemo? How long do I have to wait after chemo to start radiation? What to expect during chemotherapy and radiation? What are the long and short-term effects of radiation and chemotherapy?

In addition, a timeline would mitigate anxiety caused by wait-times after certain tests. Waiting over a week after needle aspiration, bone density and other tests, without knowing why those tests are being conducted and what the results show have been described by some patients as "torture."

A few patients have also strongly recommended the booklet include information about Triple Negative breast cancer diagnosis, which is "terrifyingly scary." With information, they said, there is "hope."

• Preparing for Post-surgery Experiences

The post-surgery experience may include complications like clogging of drains, lymphedema, pain, and irritated wound or just the shock of the appearance of the incision and a temporary inability to look at the wound. Many patients felt unprepared for these after-effects. Here again, the timing of information becomes critical as many patients note that they did not know what to expect after surgery: "I never went to the clinic for pre-op. I had no idea what to expect for surgery," Or "When you go for pre-admission . . . they talk about nutrition and medication and take blood pressure and weight and height—but had they talked more about what to expect when you wake up from surgery . . ." Patients also felt the need to have more hands-on teaching about taking care of drains well before discharge.

Those who were able to attend teaching sessions on exercises, chemo, and radiation, for example at the Tom Baker in Calgary and the Breast Health Clinic in Lethbridge, benefitted immensely. A small number of patients noted that they found out they had been doing the exercises wrong on follow-up with the physiotherapist.

Home Care: Home Care is a critical part of post-surgery care and healing. The fact that 20 out of 23 participants chose to utilize Home Care services shows that patients felt the need for some kind of personalized help in the post-mastectomy stage. One woman said she "couldn't look at drains or incisions." Those patients who had problems such as pain, clogged drains, red and irritated wound, particularly appreciated having Home Care. Almost everyone expressed complete satisfaction with Home Care as a great source of comfort and reassurance not just for themselves but for their caregivers as well. A small number of women were quite comfortable self-managing and did not need Home Care at all. One patient reported being asked by Home Care to visit them at St. Albert, which the patient was unable to do soon after surgery. Most patients, however, felt confident enough after a couple of visits from Home Care to be able to manage themselves.

A source of anxiety for patients is the appearance of "other symptoms" that are not covered by instructions on drains. Research shows that uncertainty regarding what was acceptable and normal and reassurance from a health professional that they were doing the right thing is to be expected, due to "the lack of written instructions on what to look for if things were going wrong" (Boughton & Halliday, 2009, p.34).

• Managing Side-effects of tamoxifen

Many patients spoke quite frankly about this part of their journey. For some the side-effects of tamoxifen have been more difficult than for others. The emotional upheaval was so unpredictable and unexpected that one person decided to go off it to protect her family, although she remained unsure and anxious about the impact of that withdrawal. Those who expect to be on it for 10 years remain even more apprehensive of what side-effects they will have to face . Patients feel entirely unprepared for the effects of tamoxifen. Extreme fatigue, bouts of intense sadness, and a host of other issues affect work, family life, and every other aspect of self and identity. What patients seem to know or have heard about tamoxifen further accentuates the anxiety that patients already have about the drug. Those who want to go off it are told that, if premenopausal, they will face recurrence of cancer. Others believe that being on tamoxifen too long will bring back the cancer. Clarity and preparation for the side-effects are important for patients to manage the side-effects that are most likely to occur. One patient, who was offered letrozole did not feel any better: "there were so many symptoms from the drug, terrible side-effects. No one would help me or get back to me, so I told my nurse I was stopping."

• Preparing my Family and Friends

Patients discover that their family members and friends often do not know how to respond or react to their illness. Helping patients deal with the diverse reactions they are likely to encounter is extremely important for their psychological and emotional well-being. Those who have received meaningful support from friends and family have felt considerably strengthened in their journey.

> "The things I had to deal with. I would put my head down and tackle things head on. I had friends and immediate family to support me. Girlfriends took me to chemo. I felt I had one chance. I did not want to go back there again."

This appears to be a common concern among patients that is not addressed by the education they receive (Rozmovitz and Zeibland, 2003, p.60). One patient said, "I feel people think I am contagious. I am who I am, if not stronger." Another recalled that "everybody I knew who knew what I was going through was looking at me like they thought I was going to die."

It is noteworthy that the supportive friends and neighbours that our participants mentioned are either survivors of cancer themselves or are undergoing treatment. This "bosom buddy" approach may be an important resource to mobilize in future breast cancer support and education. A form of public education that friends and family can use was also highlighted by patients as a way for people to understand what patients are going through.

• Taking Care of my Overall Health and Wellness

For women with breast cancer, the journey goes far beyond surgery and means much more than getting the right treatment at the right time. In every case, women spoke strongly of the long-term issues of concern for them, such as their immune system, preventing recurrence, and understanding what their new normal might be. These issues are articulated in different ways, but they are directly connected to a sense of overall health and wellness. These are the areas where they feel they can play an active role in promoting their own health.

We asked patients what they thought they were least prepared for. Through the answers to this question, we sought to understand how education and information can help bridge the gaps in their understanding of the clinical pathways and the education they receive. The women spoke about chemotherapy, excruciating pain of dye testing, second degree burns from radiation, continued fatigue, and depression following tamoxifen. Common to all was the emotional trauma that persists and which each individual continues to fight in her own way. What one person said about her emotional state almost three years after her treatment reflects what all feel in varying degrees: "I still kinda crumble."

Psychological and emotional wellness is an integral part of physical wellness. The struggles with "the psychology of it all," "the thoughts," "going up and down," "the mental part," are concerns that do not follow a linear pattern, disappearing once the cancer has been treated. They absorb the patient from the very moment that the battle against cancer starts, becoming a part of the continued need for strength and hope that will enable them to manage their illness and move beyond it.

Conclusion and Recommendations

Patient education is an integral part of engaging patients actively in their treatment and journey towards health. When patients have the information and knowledge they need to make decisions, they feel more confident in analyzing options, problems, and outcomes.

The standardized education booklet, *Your Journey Through Breast Cancer Surgery*, is a step in this direction. It has started to address some of the educational needs and priorities identified by patients. By dividing the information into stages that correspond to the common stages of a patient's journey from diagnosis to surgery, the booklet has created a clear and concise resource for breast cancer patients.

By sharing with us their experiences with breast cancer educational support, patients have provided valuable insight not only about what their cancer education means to them but also what it could mean. They have shown the possibilities of health literacy going beyond basic, functional information tied to immediate healthcare needs. Patients want to use their health education to build and enhance their capacity for active participation in decision making, wellness, and management of care.

Therefore, a standardized educational resource should be supplemented and supported by other resources which are listed below:

1. **Strengthening the interactive and critical literacy** of both patients and healthcare teams by focusing on ways to make patients an integral part of planning and promoting their care through the cancer journey
2. **Extending the presence of nurse navigators** who play a vital role in the tremendous guidance, comfort, and education they provide to patients. There are many patients who are unable to have that individualized connection with a nurse navigator beyond a phone call or two. One patient advisor noted that her "volunteer group saw 600 patients last year and many of them had no nurse navigator at all"
3. **Recognizing and building the role of patient navigators** as an important resource to aid nurse navigators in addressing the need for "someone who has gone through it," especially in helping cope with the emotional struggle: "It's hard to go through a double mastectomy, you are bald, and losing your breasts. . ."
4. **Ensuring patient access** to teaching sessions on drain care, exercises, prosthesis use, chemotherapy, and radiation in person or online. These sessions were reported as most effective to address targeted issues related to the patient's specific stage of treatment
5. **Preparing effective** education for families of patients
6. **Personalizing education** for patients depending on individual differences and needs
7. **Coordinating information sharing** between clinics and support centres for consistent and non-conflicting messaging

Continued patient engagement in developing and implementing these resources will ensure their effectiveness and usability.

Finally, understanding the specific education priorities and gaps of rural and ethnic/linguistic minority patient communities as well as patients with low literacy will be critical to developing a truly comprehensive, inclusive, and usable breast health education.

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Acknowledgements

The researchers are grateful to the Cancer SCN for the opportunity to participate in the Breast Health Education Initiative and would like to acknowledge the contribution of all who gave their time and support to the patient engagement component of the Initiative.

We would especially like to thank the following:

All patients and advisors who participated in the focus groups and interviews, working with great care and involvement to review educational materials and give us their invaluable feedback;

Angela Estey, Executive Director, and Shandra Harman, Senior Project Manager Cancer SCN, for their leadership and insights;

Caroline Martin, RN, for advice and support in reaching out to breast cancer patients in Lethbridge;

Jennifer Anderson and Jessica Dollard, Cancer Control, Alberta; Darryl Lacombe and Jessica Lamb, Strategic Clinical Networks for assistance in reaching both urban and rural patients;

Nancy Marlett, Director, Patient and Community Research Program, for guidance and support throughout the project; and

Cathy Riam for her patient and resourceful help in hosting the focus groups

Appendix A

Breast Cancer Surgery Focus Groups - Participant Posters

Calgary, Foothills Medical Centre, June 6, 2017 Participants (4):

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Lethbridge, Chinook Regional Hospital, June 8, 2017 Participants (6):

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Focus Group – CALGARY – June 6, 2017

PARTICIPANT 1

EVENT	INFORMATION RECEIVED/ PROVIDED BY	INFORMATION MISSED	NOTES:
Breast Cancer Diagnosis 1993		Received no information. Nothing on chemo, radiation	
Diagnosis Metastatic Breast Cancer 2011	Tom Baker: **Exercise** – met **Dr Reed** and thus went to BEAUTY (see below)	Received no information for nurse or oncologist	**GREEN** – noted as GOOD on poster
	Tom Baker: Nutritionalist – Handout (2011)	For me, not enough on fruits and vegetables	
	Alberta Cancer Foundation – **My Journey** (journal)– good but general		
	BEAUTY Program - Exercise – 3 Levels – very good - Diet – stressed fruits & vegetables and what to avoid – good - Sleep – good - Stress reduction – good		
	WEBSITES: - Food for Breast Cancer http://foodforbreastcancer.com/ - Breast Cancer Care (UK site) https://www.breastcancercare.or		

	g.uk/ - Living Beyond Breast Cancer (US) http://www.lbbc.org/ - Medscape http://www.medscape.com/ - AHS – see Alberta Prevents Cancer http://www.albertapreventscancer.ca/		
	Workshop – Inspire Health (BC) – https://www.inspirehealth.ca/		
		Bummer 'faux pas' – Went to a workshop at Tom Baker Cancer Centre 'Reforming Hope' – received a Green Sleeve (personal directive)	Frown drawn on poster next to this remark

Focus Group – CALGARY – June 6, 2017

PARTICIPANT 2

EVENT	INFORMATION RECEIVED/ PROVIDED BY	INFORMATION MISSED	NOTES:
Sept 2014 – Found lump, went to GP			
5 Days – Needle sample by surgeon			
4 Days – Surgeon called	Surgeon – results showed malignant cells		
3 Days – Signed consent for bilateral mastectomy	80% lymph node negative Lumpectomy & mastectomy with regard to outcome & envelope with info on breast cancer	Info needed – immediate reconstruction possible/communication with plastic surgeon/images of bilateral vs immediate reconstruction	
7 Days – Oct 2014 – Bilateral mastectomy - overnight stay	- Dressing changes - Emergency phone numbers - Exercises	- Signs of cellulitis - Next step/ timeline (when results in/ referral to cancer centre)	
10 Days (?) – Saw surgeon – had cellulitis			
7 Days – Surgeon	- Discussed pathology with surgeon - (provided) Cancer types/stage/receptors - (diagnostic) Needed chemotherapy	- When opportunity for cancer centre would be, when chemo would start	

	Look Good, Feel Better class - Excellent		
Nov 2014 – Saw oncologist at the Holy Cross site	Excellent review of prognosis, chemo, side effects	None – but later added: Classes at Wellspring (Tai Chi & Yoga); Compassionate Beauty - shaving head - wig - prosthetic	
March 2015 – Chemo completed	Referred to Genetics for BRCA testing Referred to plastic surgeon	Needed: Importance of diet, low stress, exercise in preventing recurrence	
May 2015 - Breast reconstruction (implants)	Plan for saline injections Info on implants	Pain with injections due to high volume	
Jan 2016 – Nipple construction (plan: 3D tattoo)		- Nipple necrosis signs - Alternatives now because developed nipple necrosis	

Focus Group – CALGARY – June 6, 2017

PARTICIPANT 3

EVENT	INFORMATION RECEIVED/ PROVIDED BY	INFORMATION MISSED	NOTES:
May 2014 Physical, diagnosis with routine mammogram	Compassionate care given by my doctor. He said stay positive.		
	Radiologist said – it is so tiny you would not have found it thru self exam		I felt comforted, radiology staff excellent
Doctor did biopsy	He warned, "hurts him more to do this to me – but needs to be done"		Friendly professional excellent staff
Radioactive dye			Wonderful doctor
Surgeon	Information given - super		Amazing, love him and gratitude Care given 5 star Pre-op and operation excellent
'Chateau' Rockyview – Surgery June 19			Rockyview – 10 Star The care having an enclosed room Wonderful care and extra care re: Warfarin Very quick treatment after diagnosis Oncologist was super as well

Follow up care - GP - Surgeon - Oncologist		Woman who gave info lesson, as though she didn’t want to teach us (having a bad day?) Prosthesis not well displayed in box Not feminine, just a rubber thing in a basket Would have liked to see an actual nice clean bra and demo how you “put the stuff in the bra”	
		Would have appreciated free parking, gas allowance	
		Heads up for family and friends – what to expect when they are not educated on my cancer needs	
		What programs and assistance are available	
		A more simple overview	Also a “little” pampering, ie: A cookbook with title, “Your road to healing”, recipes, positive quotes, life lessons – taking care of you! It’s never too late, etc.

Focus Group – CALGARY – June 6, 2017

PARTICIPANT 4

EVENT	**INFORMATION RECEIVED/ PROVIDED BY**	**INFORMATION MISSED**	**NOTES:**
Mammogram May 2016			No signs before mammogram
Biopsy end of May 2016			
Diagnosis end of May 2016	Received medical blurb about IDC (Invasive ductal carcinoma) from doctor		
Breast Health Clinic/Surgeon	- Received a briefcase full of pamphlets - Received package from Rockyview about surgery – **this was the most helpful** - Had nurse practitioner - Had pre surgery class – **very helpful**	This was an overwhelming amount of information. I am shell-shocked. I don't know what to ask.	**GREEN** – noted as HELPFUL on poster
Two surgeries June 28 and July 19 2016 – Lumpectomy	Had Post Surgery class - **very helpful**		
Appointment with Medical Oncologist Put on Hormone treatment and Radiation	Found out about treatment August 2016 Took classes at Tom Baker - **these classes were helpful** More pamphlets		

Radiation Sept 6 – Oct 6, 2016			
Follow up appointments - Surgeon - Family Doctor - Radiation oncologist - Medical oncologist			

PARTICIPANT 5

Note that other participants added coloured stickers to each others' posters.

EVENT	INFORMATION RECEIVED	INFORMATION MISSED	NOTES:	DOTS:
Found lump, went to doctor, ordered mammogram				**H**
Then Biopsy, Diagnosed with Breast Cancer				**H**
Met with surgeon who was amazing in explaining everything, and setting my mind at rest	Got binder with all information. Had information session with nurse who explained what would happen.			**G**
Next, Surgery, went well, healed quite well. Some pain, especially when exercising.	Had pre-op session before surgery. Went over everything with nurse who gave me info on aftercare, and pamphlet with all info.		Note that other participants added coloured stickers to each others posters. (In this case the **M** was added by another.)	**M**
Met with Radiologist who recommended Radiology.				
Met with oncologist, no chemo	All Doctors were very good and explained everything so that I could understand.	Lots of info, quite over-whelming. But helpful. Found the waiting was very stressful.		
Had to have other test done…		… but no info as to why!!!, or results	Green dots added by other participants as info needed	**H H**

PARTICIPANT 6

Note that other participants added coloured stickers to each others' posters.

EVENT	INFORMATION RECEIVED/ PROVIDED BY	INFORMATION MISSED	NOTES:	H,G,M,U
I found a lump on my left breast				
Went to my doctor				H
Sent me right away to Radiology –				
Found the cancer				
Sent me to the Cancer Clinic				
Saw the oncologist - spoke a lot with Caroline	(Info from) Nurse - Information very direct and comprehensible		May have meant surgeon instead of oncologist here	
We decided that a lumpectomy was necessary	(Info from) Doctor		Doctor and I	
Came for the surgery	(Info from) Doctor			
Find also some lymph node	(Info from) Doctor			
Need chemo and radiation	Checked internet. Booklets at the hospital. Spoke with nurses.			

In between they put in a port - oncologist	(Info from) Oncologist			
Start chemo – (3 months) was quite sick	(Info from) Doctor			
And went for radiation	-			
I saw a dietetist	Here at hospital			G
	ONLINE – American, Canadian Cancer, French Cancer sites.		Other information sources	
	Pharmacist		Other information sources	

Focus Group – LETHBRIDGE – June 8, 2017

PARTICIPANT 7

Note that other participants added coloured stickers to each others' posters.

EVENT	INFORMATION RECEIVED/ PROVIDED BY	INFORMATION MISSED	NOTES:	**H,G,M,U**
Biopsy showed precancerous cells				
Dr (oncologist) said nothing further to be done				**M**
1.5 years later went for mammogram and ultrasound				
Ultrasound tech found lump				**G**
Sent for another biopsy				
Biopsy showed cancer				**H**
Decided to have mastectomy	Cancer was stage 1 – lymph nodes were clear			
	Oncologist said I could take Tamoxifen for five years or do nothing			
I am currently taking Tamoxifen			Another participant added (pharmacist about side-effects Onco-Typo)	**H**

	Breast Health Clinic		Between diagnosis and mastectomy I went to breast health clinic and received much information and help.	**H**

Focus Group – LETHBRIDGE – June 8, 2017

PARTICIPANT 8

Note that other participants added coloured stickers to each others' posters.

EVENT	INFORMATION RECEIVED/ PROVIDED BY	INFORMATION MISSED	NOTES:	H,G,M,U
3 biopsies prior	Negative, lot of calcification			
Felt lump March 2015				
Series of ultrasounds	Told normal breast tissue Sept 2016			
Insisted on removal of lump as it had changed				H
Lump removed Nov 14, 2016				
Was called Nov 24	Breast cancer margins not clear			
Saw my doctor Nov 25 – he arranged for a mammogram and ultrasound as lump initially not found on mammogram	GP confirmed breast cancer, said I needed more surgery and treatment			G
Saw surgeon following week	Breast Health Clinic gave me large info package			

Surgery (left lumpectomy Dec 22)				
Started Tamoxifen (10 years) Jan 27			Tamoxifen	G
Problems did not heal til 3rd week of March			Met surgeon twice from Dec – March as I reacted to sutures	
Started radiation April 6, ended April 28				
Severe radiation burns, still struggling			Radiation did not apply to another participant	U
	Lots of coping info from social worker at various stages			

Focus Group – LETHBRIDGE – June 8, 2017

PARTICIPANT 9

Note that other participants added coloured stickers to each others' posters.

EVENT	INFORMATION RECEIVED/ PROVIDED BY	INFORMATION MISSED	NOTES:	H,G,M,U
March 15 felt lump in the shower – made an appointment				
Did mammogram/ultrasound	Yes cancer March 20			
Biopsy	Reading on internet			
Met with surgeon	Confirmed breast cancer. Right after meeting with surgeon met with nurse – she explained about radiation, chemo . . . had to make decision about going with lumpectomy or mastectomy. She gave me a binder with some info. I used web to get more info to help with my surgery decision. Friends were also getting info.			
Did my lumpectomy April 26				
Week after got my result back	Clear nodes but not clear margin. Used web and found out			U

	I might have to go for more surgery (2 or even more) to get clear margin. My friend's husband who is a doctor helped me to make the decision and go with mastectomy			

EVENT	INFORMATION RECEIVED/	INFORMATION MISSED	NOTES:	H,G,M,U
Decided on mastectomy			Good choice because there was a pre cancerous part in my breast which didn't show in ultrasound or mammogram	
Mastectomy on May 16	Nurse called to get some info from me I asked her for consultant and dietician to meet. Got a book which was better info.			
Will meet with my oncologist June 15				

Focus Group – LETHBRIDGE – June 8, 2017

PARTICIPANT 10

Note that other participants added coloured stickers to each others' posters.

	PROVIDED BY			
Found lump in right breast				
Wait 6 months. Went to family Dr. Had first mammogram and ultrasound that afternoon. End of Jan.				
Middle of Feb had biopsy				
Diagnosed end of Feb				
Saw surgeon mid March	Most information gained here at Breast Health Clinic, oncologist and radiologist. Chemo education.			**H H**
PICC line inserted for 3 rounds of chemo				
PICC line removed, remaining 9 treatments through IV				
	Surgery education, physio education			**H H**

Double Mastectomy on Sept 1 2016				
Heart condition discovered				
Physiotherapy	Radiation class			H M M
16 Rounds of radiation completed Dec 12, 2016				
Put on 5-year hormone therapy plan				

APPENDIX B

BREAST HEALTH EDUCATION: WHAT ARE PATIENTS SAYING?

Report from Focus Groups and Interviews

AT DIAGNOSIS

Right at the beginning I needed someone to say this is what's happening this is what's next

This is how they will take you though it. Here are the choices you will need to make and the drugs you might need to take

I needed a counsellor. Not a support group. I just got my diagnosis

Doing the research when looking up stuff online. It's confusing and different information on all these different sites

PRE-SURGERY

Educational Resources

- BINDER
- SESSION WITH NURSE; SESSION WITH SURGEON
- FRIENDS; OTHER PATIENTS

Decisions

- LUMPECTOMY OR MASTECTOMY
- DAY SURGERY OR HOSPITAL STAY
- HOMECARE

My mastectomy wasn't a recommendation, it was a personal choice

I had to make a decision within a week regarding lumpectomy or mastectomy and all the options, it's not in this binder

He said lumpectomy was the way to go but it turned out to be bigger

I preferred being at home in my own bed and own space

I live alone, was offered homecare but didn't take it

I went to homecare to make sure everything was healing ok

Stressors

- TOO MUCH INFO
- NOT TARGETED INFORMATION
- WAIT TIMES
- TESTS

Even though I had a medical background it was totally out of my element

I was too shell-shocked to ask questions

Did the mammogram, did the needle aspiration. I had to wait 8 days. It was torture

Day surgery? I don't know. They kept me in worried about bleeding

Went in for day surgery but had to stay overnight

If there was an FAQ of common concerns . . .

DAY OF SURGERY

Educational Resources

- Discharge instructions

Stressors

- Pain and bleeding
- Reactions of friends and family members

I think pain management is really important, especially when you add that on top of the stress

There was bleeding all night and I don't think lumpectomy should be day surgery

If family members are unable to deal with the body after surgery, it can turn into a very distressful time

No one ever mentions that. Preparing us for how people close to us will act would be helpful

Everybody I knew who knew what I was going through was looking at me like they thought I was going to die

Information needed

- lymphedema
- services and classes

I was not prepared how to take care of myself once I got home

I wish they had talked more about what to expect when you wake up from surgery

POST-SURGERY (1)

Resources

- Homecare
- Physiotherapy
- Exercise classes

Decisions

- Attending classes

Stressors

- Pain
- Irritated Wound
- Fatigue
- Waiting
- Tests
- Clear nodes but not clear margin; more surgery

After your surgery, they ask you to go for these bone density tests and other tests, but they don't tell you why

I was worried about other symptoms, whether the drainage was enough or clogged

I didn't have any information on timelines, next steps, when biopsy results would be in, or referral to oncology

Saw surgeon after ten days, had cellulitis

I had trouble healing and couldn't lift my arm. But I was doing all the exercises in the book wrong

If you live alone you don't have the incentive to do all the exercises

POST-SURGERY (2)

I think I had PTSD, needed counselling after surgery, what all happened to me

I am going through this emotional up and down and I am wondering why they did not tell me

I wanted to know what my new normal would be

I didn't want to deal with the fear of recurrence

They only mention 5 year survival rates and I want to live a lot longer, when I started looking at numbers, survival and treatment I got really anxious

I mentioned my anxiety to my nurse navigator but she was kind of busy

Wellness afterwards is a big gap

Needed more information on diet, stress, exercise, and preventing recurrence

Is it going to come back and will they catch it as soon

Am concerned about other breast. Want the other one out too.

TREATMENT AND FOLLOW-UP

Resources

Pharmacist
Wellsprint
Thrive
Compassionate Beauty

Decisions

Radiation

Tamoxifen

Stressors

The one area I struggled with was the radiation . . . and that was the biggest weight and cause of anxiety

Recovery from radiation—second degree burns and the fatigue

The chemo. It was the worst and the psychology of it all. You know the thoughts.

For me, it's not the fear it will come back, my fear is what I have to go through again to get rid of it

Women don't know about the side-effects of Tamoxifen. My family couldn't live with me I was so emotional

Period of being really sad---did not know how to cope, unhappy, tired, crying a lot. Wanted to get off Tamoxifen, was told will have breast cancer if you go off it

Appendix C

Section by Section Review of *Your Journey Through Breast Cancer Surgery* with guiding questions

Section One: Coping with Breast Cancer Surgery	**Information needed**	**Actions Recommended**
Day Surgery	Don't agree, not sure day surgery is common practice How is day surgery determined? Possible complications to be aware of? How can I prepare for after-care? Can I stay longer if complications develop? Where would I get help if I needed it after going home? When do I see my surgeon for follow-up?	1. Explain advantages of day surgery 2. Explain why day surgery is becoming common practice 3. Should have something about wait times 4. Replace "exceptional circumstances" with conditions under which overnight stay may occur
Emotional support		Section should include... "You have the right to ask questions. You have the right to ask for a second opinion. You have the right to take control of and have more power over your journey"
Finances		Delete: "your doctor can help you access the supports you need." Clarify info re insurance,

		parking, and transportation: doctors and surgeons won't know about insurance, it is difficult to get them to fill out proper forms; parking is not recoverable unless strict tax guidelines are followed
Fertility	What about brand new mums getting breast cancer? What about the BRCA gene?	Create spaces throughout book for thoughts, questions
SECTION 2: About Breast Cancer	**Information needed**	**Actions Recommended**
Anatomy of Breast	Where in the breast is my cancer? Lobular cancer or in-situ? What is the sentinel node's relation to the tumor? How to prepare myself to ask proper questions of the surgeon?	Make illustrations clearer, more useful Great illustration in *Support Knowledge Hope: A companion and reference guide for women with breast cancer* "Your Breast," instead of "Anatomy of Breast"—less intimidating Channels of the dye—better visuals
Stage and Grade	Excellent information	Provide legit links You can record sessions Bring a family member or friend
Hormone Receptors	Excellent information	
Section 3: Breast Cancer Surgery	**Information needed**	**Actions Recommended**
Types of Breast cancer surgery	How do we make decisions—lumpectomy or mastectomy?	Change wording to: Your surgeon will review options . . . that will help you understand best treatment,

		including surgical procedures, so you can make the best decision for yourself" Expand the "Margins" section on its own—put it before Breast Reconstruction Surgery. this is important information that should be included under its own heading (top of p. 9) Note: chemo may come before surgery Timeline: If you know how long, you can pace yourself.
Breast reconstruction Surgery	What makes one an eligible candidate? What are what are the reasons for not being a good candidate, such as high-risk—smoking, diabetes, obesity What about conflict? Surgeon strongly urges exercise; plastic surgeon is thumbs down	
Lymph node surgery		Introduce this section appropriately
Sentinel Lymph Node Mapping	Why would you require more than one appt?	Information on pain and discomfort during dye testing
Axillary Lymph Node Dissection		
Section 4: Preparing for Surgery	**Information needed**	**Actions Recommended**
Checklist		Update info based on current

		surgical practices
FAQ	How will I feel post-op and how will I help myself? Telling me upon discharge is too late. Will I get pathology report from surgeon?	friends and family should be knowledgeable before surgery Some type of encouragement to help both patients and their families and friends to make them ready for the change
Day Before Surgery	How long will drains stay? How will my many after-surgery questions be answered? What to wear? What about sex?	Remove Hemovac drain info (old technology) Nail polish removal – not required— Outdated comments that, although might not be harmful, are still outdated and can cause additional minor anxiety
Section 5: The Day of Surgery	**Information needed**	**Actions Recommended**
Post anesthetic	Would I open my eyes? Will anything hurt?	Follow-up plan Patient should be aware of what to do if she experiences problems Take out "call your surgeon"—go to Emerg
After Surgery	How will chest look after mastectomy?	Before leaving hospital, you may have homecare arranged
Pain Measurement Scale	Excellent	
Section 6: Going Home	**Information needed**	**Actions Recommended**
When to Call Your Surgeon	Misinformation: p.27	None has direct number for

	Facial itching	their surgeon. You would have to see the general surgeon on call. Even if you come to emergency, it will be the on-call surgeon. Not your surgeon. This information should be corrected You may meet your team—not always
	Understanding chemo/radiation. Future plans	
Section 7: Follow-up	**Information needed**	**Actions Recommended**
		overall timeline: e.g. surgery 2/S2 follow-up 4-6/S2 follow-up at cancer clinic section on exercise and diet in accordance with Canada Health Guide
		Radiation – long term side effects (damaged nerves, pain for years on healthy tissue, itching) Chemotherapy
		Value of one on one connection