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# Experience-based co-design: A method for patient and family engagement in system-level quality improvement

## **Cover Page Footnote**

We would like to acknowledge the Patient and Family Advisors at the Walker Family Cancer Centre, as well as the healthcare providers who participated in this project.

## Experience-based co-design: A method for patient and family engagement in system-level quality improvement

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### Abstract

Integrating patient and family member needs, wants and preferences in healthcare is of utmost importance. However, a standardized patient and family engagement model to understand these needs, wants and preferences in order to translate into high quality improvement activities is lacking. Experience based co-design (EBCD) is an approach that enables patients, family members and healthcare providers to co-design improvement initiatives together. In this study, EBCD was employed to: 1) assess the current state of information and educational resources at a local oncology center and 2) partner with patients, family members, and healthcare providers to create quality improvement initiatives targeting identified issues. Three focus groups were conducted: 1) patient and family member-specific, 2) healthcare provider-specific, and 3) all participants (including patients, family members and healthcare providers). Discussion questions were focused around current educational resources, barriers encountered throughout the cancer continuum, and recommendations for improvement. Six themes emerged from the two initial focus groups with patients and family members and healthcare providers: 1) patient-provider communication, 2) accessing information, 3) tailored information, 4) side effect information, 5) caregiver information, and 6) partners in care. Themes were presented to participants to ensure findings accurately depicted their experience and five quality improvement projects were created, aligning with the themes. This study provides an example of how EBCD helped to foster a safe environment, where patients, family members, and healthcare providers worked together in order to improve educational resources.

### Keywords

Experience-based co-design, patient engagement, patient-centered care, patient experience

### Introduction

In recent years, the patient experience has been a major focus of healthcare organizations internationally. The Beryl Institute describes the patient experience as “the sum of all interactions, shaped by an organization’s culture, that influences patient perceptions across the continuum of care.”<sup>1</sup> Initiatives focused on improving the patient experience have demonstrated improvements in clinical outcomes,<sup>2-5</sup> and health service delivery.<sup>5,6</sup>

One of the methods used to improve the patient experience is patient and family engagement.<sup>7,8</sup> Although patient engagement has been used to improve the quality of health services, change initiatives tend to be centred at the micro-level, guided by individual discussions with patients and family members or healthcare providers and clinicians.<sup>9</sup> In the last decade, involving patients and families in service improvement and re-design of processes at the macro- and system-level has been integral to the patient experience movement.<sup>10</sup> Despite the success of both patient and family engagement and healthcare

provider engagement to improve the patient experience, improvement initiatives have been limited to engaging either patients and family members or healthcare providers; rarely both. More recently, experience-based co-design (EBCD) has been used to amend this gap.

EBCD is an approach that enables patients, families and practitioners to co-design improvement initiatives together, in partnership. EBCD allows participants (i.e., patients, family members, and healthcare providers) to share their experiences of care through in-depth interviews, observations of group discussions, identifying key ‘touch points’ and assigning positive or negative feelings.<sup>11-14</sup> This method of data collection can help to inform health service development or improvements. In some initiatives, short edited films have been created from the participant interviews and are presented back to the participants to provide an understanding of how care is experienced.<sup>11-14</sup> Patients, family members, and healthcare providers are then brought together to explore the findings and identify areas for service improvement.<sup>11-14</sup> In most EBCD examples, patients, family members and

healthcare providers work together in small groups to implement quality improvement initiatives to address the outlined area of improvement.<sup>11-17</sup> Since its implementation, EBCD initiatives have been identified as best practice for leading improvements in health services, and have spanned a broad range of clinical areas.<sup>11-17</sup> Not only does EBCD collect data on the patient experience, but it uses the patient and family experience as well as the healthcare provider experience to make system-level improvements in practice.<sup>10</sup> Previous studies have indicated that the use of EBCD has improved engagement of both patients and healthcare providers, as they are able to share their stories and experiences in order to shape quality improvement initiatives.<sup>14-17</sup> Some of the successes of EBCD includes the consensus on areas for improvement,<sup>16</sup> and improved acceptability and sustainability of quality improvement initiatives by patients and healthcare providers.<sup>14, 15</sup>

In Ontario, Canada, the patient experience of cancer services (i.e., physical comfort, continuity and transition, coordination of care, emotional support, information and education, respect for patient preferences, access, and family and friends)<sup>18</sup> is measured using the Canadian Ambulatory Oncology Patient Satisfaction Survey (AOPSS).<sup>19</sup> The AOPSS is a retrospective, paper-based, mailed survey that is designed to capture the experiences of patients who are currently receiving cancer treatment or who have received cancer treatment within the previous six months. The results are reported quarterly to the Walker Family Cancer Centre (WFCC), an outpatient cancer centre, and to Cancer Care Ontario (CCO). At the WFCC, patients consistently report lower than provincial average experience with information and education within cancer services. To this end, the current qualitative study describes the use of EBCD as a patient, family and healthcare provider engagement method in system-level quality improvement initiatives in an outpatient cancer centre to improve the patient and family experience of care.

## Methods

### *Setting*

The population of Ontario, Canada is 13.6 million, with approximately 88,000 new cancer cases expected to be diagnosed in 2017.<sup>19</sup> CCO funds and oversees the cancer system in Ontario, Canada, through established Regional Cancer Programs (RCPs) in every region (n=13) in the province. RCPs are networks of hospitals and agencies involved in providing prevention, screening and diagnostic and treatment services in the region.<sup>19</sup>

The WFCC is a small outpatient community cancer centre in the Niagara region, within the Hamilton Niagara Haldimand Brant Regional Cancer Program. The WFCC prides itself on putting their patients first, which is

highlighted through the many services they provide to patients and family members.<sup>20</sup> Radiation and chemotherapy are administered at this oncology centre, additionally, patients and their family members have access to an inter-disciplinary supportive care team, offering guidance in areas outside of cancer treatment, such as, social work, spiritual counselling, and pain and symptom management.<sup>20</sup>

### *EBCD Approach*

To improve the patient experience with information and education services at the WFCC, EBCD was used to meaningfully engage patients, family members and healthcare providers in the re-design of information and education services. The modified-EBCD process is further described below.

#### *Step 1: Patient and Family Member Focus Group.*

A focus group was conducted with cancer patients and family members (n=6) in order to solicit their experiences with information and education services at the WFCC. The questions were shaped in a way to help identify key emotional “touch points”<sup>11-14</sup> in the patient and family experience of care. The focus group was audio-recorded and transcribed verbatim to allow for data analysis.

#### *Step 2: Healthcare Provider Focus Group.*

A second focus group was conducted with healthcare providers (n=9) including: chemotherapy nurses, pharmacists, radiology nurses, social workers. Healthcare providers were asked about their experiences providing information, and education and effectively communicating with patients and families. The questions allowed the healthcare providers to share insights regarding enablers and barriers to patient information and education services at the WFCC. The focus group was audio-recorded and transcribed verbatim to allow for data analysis.

### *Data Analysis*

The focus group data from step 1 and 2 were analyzed inductively.<sup>21, 22</sup> Two independent researchers used a thematic analysis technique, including open-, axial-, and selective-coding to code the transcripts and organize the data into similar themes. A constant comparative method was used to allow the data to be grouped together and differentiated as themes were identified.<sup>21, 23</sup> From the process of thematic analysis, key themes and areas of concern were extrapolated and used to identify potential areas for quality improvement projects.

#### *Step 3: Patient, Family and Practitioner Focus Group.*

During the third step in the EBCD process, a joint focus group with patients, family members and healthcare providers (n=15) was held, in order to build consensus around the identified areas for improvement and gain acceptability of the quality improvement initiatives from all participants. The six main themes that were elicited from

the focus group sessions were presented to the participants. Additional discussions around personal experiences occurred among patients, family members and healthcare providers to reinforce the findings that were presented by the authors. This helped to look at improvement initiatives through an experience lens. Following the presentation, participants were asked to rank the priority areas from most important to least important. From the returned rankings, a master list of the quality improvement projects in ranking order was created. Following the joint focus group, quality improvement projects were developed that aligned with each theme that surfaced during the focus groups.

## Results

Six key themes emerged highlighting focus areas for improvement targeting information and education services at the WFCC. Below, each of the themes are described in detail and supported with quotes in order to provide an in-depth understanding of the theme.

### **Theme 1: Patient-Provider Communication**

Patients and family members describe receiving a cancer diagnosis as overwhelming and “being stuck” not knowing what to think, feel, or say in that moment. Both patients and family members expressed feelings of uncertainty with regards to who to contact at the centre and how to get answers to their questions. This feeling of uncertainty was described as “paralyzing” to the patients and their family members to a point where, some did not even know which questions they should ask the healthcare providers. As such this was described as a limitation to getting the information they wanted or needed. A patient describes: *You're only going to get the answers to the questions you know to ask. At the beginning, you don't know what questions to ask.*

From the healthcare provider perspective, focus group participants reported that patients and their family members reported having a number of questions regarding their care. However, they were unsure as to which healthcare provider was the most appropriate to ask and therefore indicated that the patients and their family members did not ask any questions. A healthcare provider explains:

*When we talk to the patient and their family is there, [the patients say] “We have a ton of questions, we just don't know who to ask” So they [patients] don't ask them.*

This idea was further discussed as some healthcare provider's felt that the mental and emotional state patients find themselves in is often not conducive for a question and answer discussion. A healthcare provider expressed: *Actually, they [the patients] didn't give us a lot of information of what questions. They [the patients] were just sitting there dumbfounded with [not] even what they felt was enough knowledge to even come up with a question so they didn't have a clue what to ask.*

It is the desire of the healthcare providers to help the patients and their family members, by answering questions and addressing concerns. However, patient and family members are at times not able to communicate this with their healthcare providers. That is why, providing patients with foundational knowledge, support and encouragement through patient-provider communication was identified as an important first step to successfully guiding patients and family members through the cancer continuum. Participants expressed that an educational resource to facilitate discussions amongst patients, family members, and healthcare providers would be beneficial.

### **Theme 2: Accessing Information**

At the WFCC the main resource given to patients undergoing chemotherapy is an oncology binder. This binder includes a plethora of information such as the side effects of chemotherapy, roles of healthcare providers, and clinical definition of cancer. However, the wealth of knowledge from this resource is masked by the inability of patients and family members to understand the information, as it is not presented in a patient-friendly manner. A patient described the experience of reading and trying to learn from the binder:

*Personally, I went through my binder, it's almost like you [have to be] a Philadelphia lawyer at some point to understand it.*

Healthcare providers encouraged patients to read the information and come to them with questions, however had similar concerns with regards to the patient-friendliness of the information being presented in the oncology binder. A healthcare provider explains:

*[Patients] love the concept of the binder, [but] most of them said they really did not understand everything in the binder until the time they were finished because it took them that many times to get it.*

The concept of the oncology binder is well received by patients, family members and healthcare providers as it has been identified as a helpful resource during cancer treatment. However, the written content requires a high comprehensive understanding of health literacy, which fails to encompass all patients and family members receiving this educational resource. Participants recommended that the binder be re-created using appropriate health literacy levels, ensuring that plain language was present and that content was explained in a patient-friendly manner. The healthcare providers, patients and family members felt it would be important to “strip the binder of medical jargon” and create a resource that puts emphasis on clear and important information.

### **Theme 3: Tailored Information**

Patients and family members expressed great dissatisfaction regarding the level of specificity provided when receiving information from healthcare providers. Patients and family members recall “blanket statements and

educational resources that were not tailored to their specific cancer.” A patient depicted this theme as:

*A personal binder for that particular [cancer], your name is on this binder and the information goes in your binder specifically for your needs, whatever that may be.*

Patients and family members suggested that each oncology binder should be tailored to patient’s specific needs, wants and preferences. By personalizing the information in the oncology binder for each patient, unnecessary details can be cut out, ensuring that treatment information is specific to their individual. It was highlighted that each patient receives a diagnosis and a subsequent treatment plan, tailored to that individual patient, thus information should be presented in a unique manner. When asked about the usefulness of the resources provided, a patient referred to an educational resource that specifically spoke about her type of cancer as being more effective than the general binder everyone receives. A patient expressed:

*As far as understanding the diagnosis, I would say that it did not help in that way. There was another little book, I can’t remember what it is, that it’s specifically addressed breast cancer. That was more helpful than the [general] binder*

The suggestion to tailor the information that patients are receiving to cancer and diagnosis specific, was also coupled with the recommendation to add more visual aids to display information as opposed to full pages of written content.

#### **Theme 4: Side Effect Information**

The healthcare providers identified that information regarding the classification of side effects, common or severe, is not clearly explained, leading to increased hospital emergency room visits that in many cases, could be avoided. A healthcare provider stated:

*There [are] different messages in terms of when to call the clinic even though we go over it in the class.*

As such, there is a misunderstanding among patients and family members as to what is considered a severe side effect, for which emergency care should be sought, in comparison to a common side effect as a result of treatment that does not require immediate attention.

This was further expanded on by the patient and caregiver’s, as they experienced a manifestation of side effects, leaving them unable to cope. A participant stated: *“I didn’t feel I had enough understanding, as I mentioned before, about the side effects from both the chemo and then the drugs that were supposed to address the side effects. They created their own.”*

To provide effective care, make efficient use of resources and improve the patient experience at a system-level, improvement in educational information regarding common and severe side effects should be explored.

#### **Theme 5: Caregiver Information**

Patients very distinctly described the importance of a support system and the integral role loved ones played throughout their treatment. Healthcare providers were in agreement, also expressing the fundamental role of a patient’s family support system, during cancer treatment, however limited information and educational resources exist specific to the caregiver’s perspective. A healthcare provider indicated:

*They want it in their words, instead of patient’s words. They want it to actually direct them because I think they are just as overwhelmed.*

Caregivers indicated that they would read the pamphlets or booklets with the patient every night and were left without a firm understanding of the material. The family members who participated in the focus groups indicated that they were hesitant to ask the patient for clarification on the diagnosis, symptoms or treatment and would have preferred to have a resource tailored to their needs, as a family member. A family member expressed:

*All information was for the patient. There was no information for the caregiver. What to expect? How to handle certain things? You’re not the focus. The patient is.*

Caregiver support is important in the patient’s cancer care; however, these individuals require different types of information. Participants recommended the development of educational resources tailored to the caregiver perspective, including psychosocial aspects related to caring for an individual with cancer.

#### **Theme 6: Partners in Care**

Traditionally, patients are the recipients of care and the healthcare providers are the decision makers. As one participant expressed, *“I just put myself in the hands of my doctor go to it. You know what you’re doing. Right or wrong, that’s what I did.”* However, participants expressed the desire to shift that paradigm to a shared decision-making model, as patients and family members want to form a partnership with their healthcare provider in order to discuss important issues such as treatment options.

Deciding on a course of treatment is an important step in cancer care and patients felt that they were not included in the conversation.

Patients and family members recalled times of frustration regarding the definitive nature of the treatment decision. A patient expressed:

*I was told like; this is what you’re going to do. You have chemo and you have your radiation and we’ll see then. There was no discussion.*

Patients and family members wanted to partner in the decisions regarding their care, however they were not engaged by healthcare providers during this process. To this end, patients and family members wanted healthcare providers to recognize their role on the healthcare team

and highlighted the importance of considering all perspectives, especially the patients.

### **Quality Improvement Projects**

Through EBCD, patients, family members and healthcare providers identified core information and education-based themes that required improvement in the WFCC. These themes guided and helped to inform the quality improvement initiatives developed by the WFCC healthcare providers, and the Patient and Family Advisory Council (i.e., patient and family advisors who have an experience with the cancer care system and advise on the direction and content of current and future strategies and system-level initiatives that directly impact the cancer centre).

Inviting all the participants (patients, family members, and healthcare providers) to collaboratively discuss the project's themes and participate in a discussion about potential quality improvement projects was an important step that was taken by the research team. The relevancy of the quality improvement projects created through this third focus group was strengthened as each stakeholder's perspective was present. There was a realization that occurred during this focus group that fueled the conversation between patients, family members, and healthcare providers that centered on the paralleling nature of each participant's concerns and recommendations. It was found that patients, family members, and healthcare providers have a similar goal, to help the patient, however their differing perspectives and roles added depth to the

conversation and aided in grounding the quality improvements projects.

Figure 1 provides an overview of the quality improvement projects, which are further described below. The sixth project is still under development.

### *Commonly Asked Questions*

The recommendation from the Patient-Provider Communication theme was to develop an information resource, outlining commonly asked questions to help patients identify questions to ask healthcare providers to jumpstart a conversation.

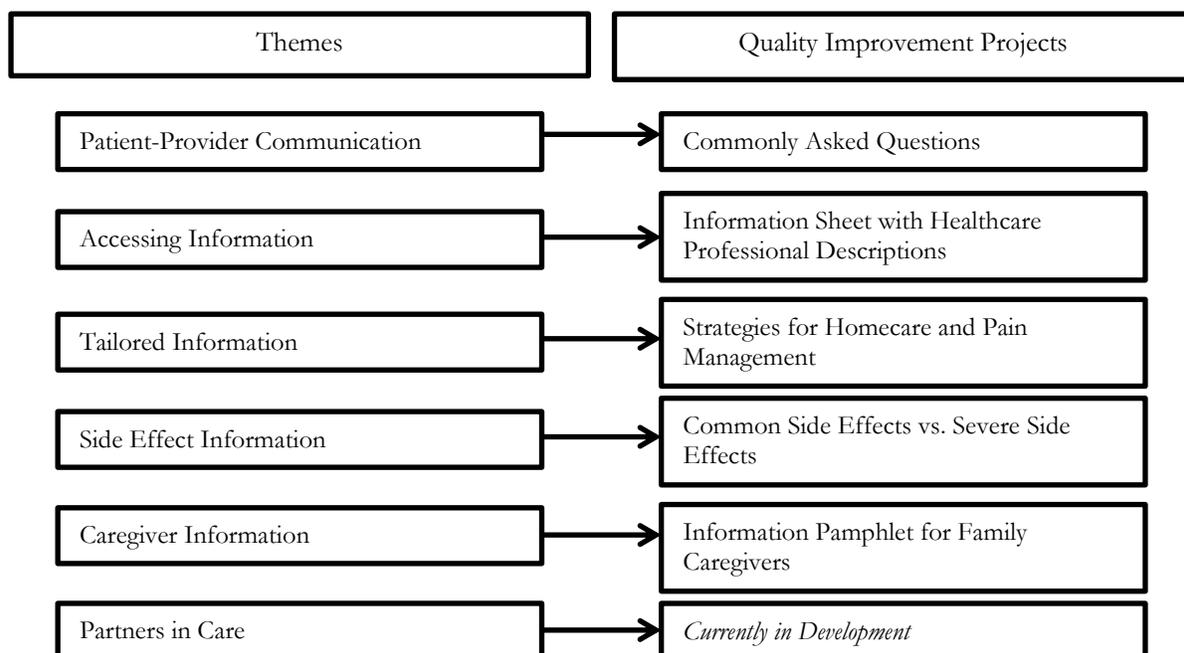
### *Information Sheet with Healthcare Provider Descriptions*

Based on the Accessing Information theme, patients, family members and healthcare providers recommended the development of an information sheet that would include a description of each healthcare provider at the WFCC, with a clear role description outlined in plain language, including contact information.

### *Strategies for Home Care and Pain Management*

The Tailored Information theme highlighted the importance of individualized care plans that are unique to each patient. The patients, family members and healthcare providers recommended a toolkit including information around home care and pain management, to empower patients and their caregivers to care for themselves in the comfort of their own home, fostering independence and enhanced quality of care.

**Figure 1. Themes and Quality Improvement Projects**



### *Common Side Effects versus Severe Side Effects*

Based on theme 4, Side Effect Information, an informational resource outlining the difference between common side effects and severe side effects was developed. This provides patients with the necessary information to make informed decisions about symptom management.

### *Information Pamphlet for Family Caregivers*

With regards to the Caregiver Information theme, it was recommended by patients, family members, and healthcare providers that a quality improvement project focus on developing an educational resource specific to the caregiver role and perspective.

## **Discussion**

The purpose of this study was to examine the use of EBCD as a patient-, family- and healthcare provider engagement method for system-level quality improvement, in an outpatient cancer centre, with the hopes of improving the patient experience. As such, focus groups were conducted with patients, family members, and a wide range of healthcare providers at the WFCC, to gain their unique experiences with information and educational resources within the centre. The EBCD method facilitated interactive discussions among patients, family members, and healthcare providers. Many important themes, such as patient-provider communication, accessing information, tailoring information, side effect information, caregiver information, and partnering in care, were identified using EBCD, which may not have surfaced otherwise. Understanding the patient, family and healthcare provider experience with information and educational resources emphasizes the importance of developing quality improvement projects together “with patients and family members”, as opposed to being created in isolation “for the patient”, fostering a patient-centred approach to improvement planning at a system-level. Those impacted directly need to be involved with the discussion, formation and creation of new healthcare initiatives.

As Coulter et al. stated, most engagement initiatives have been isolated; either adopting a ‘bottom up’ or ‘top down’ approach.<sup>10</sup> This project is an example of how quality improvement projects, can engage and create a harmonious partnership between patients, family members and healthcare providers, facilitating a perfect blend of bottom-up and top-down, through the EBCD approach. Although previous engagement methods have been successful, generally the patient and family member experiences have been kept separate from those of healthcare providers. Alternatively, EBCD has provided a means to create a shared perspective among all participants.

An emerging practice within the healthcare system has been the formation of collaborative partnerships between patients, family members, and healthcare providers, in order to capture a well-rounded perspective of healthcare services.<sup>24</sup> In oncology care specifically, there is a strong emphasis put on bringing together a diverse group of people to help meet the needs of the patient.<sup>25</sup> Aligning with current literature, the inclusion of patients, family members, and healthcare providers in our final focus group was essential, as an environment was created where multiple perspectives could be heard. The quality improvement projects were made stronger as the experiences of users and providers of oncology services were considered and integrated. Furthermore, the use of EBCD meant that the experiences of patients, family members and healthcare providers could be viewed together for a more holistic understanding, leading to recommendations viewed as acceptable by all.

The common purpose of this EBCD project acted as the connective tissue to encourage consensus on the quality improvement directions, ultimately ensuring the created projects targeted key issues and concerns that were not only supported by patients and family members but were also reinforced by healthcare providers, similar to previous studies.<sup>14-17</sup> As such, system-level transformation is able to occur.<sup>10</sup>

This study adds to the literature on EBCD, by highlighting its use as a patient, family member and healthcare provider engagement method to develop system-level quality improvement initiatives.<sup>11-17</sup> EBCD brings together patients, family members, and healthcare providers to plan, design and implement system-level service improvements.<sup>14</sup> It allows for more inclusive practices of patient and family engagement, and provides the opportunity for patient and family perspectives to be voiced, resulting in quality improvement projects that are aligned to the needs, wants, and preferences patients, family members, while considering healthcare provider perspectives.

## **Limitations**

The first limitation is that this study was conducted at a small local oncology centre. The results of this study may not be generalizable to other centres. However, the methods used in this study could be replicated in other cancer centres to identify priority areas of improvement.

The second limitation is that not all types of cancer were represented in the patient and family member participant sample. As a patient’s diagnosis determines treatment, prognosis, and has been known to influence their experience of care, this may not be representative of the full spectrum of patient and family member experiences of information and education services as WFCC.

## Conclusion

The current project demonstrates how patients, family members and healthcare providers were engaged to identify system-level quality improvement projects using an EBCD approach to improve cancer services. EBCD was seen to be an effective approach that led to an understanding of core information and education gaps at the WFCC. EBCD allowed for open discussion with those who use and deliver the services at this cancer centre. Through the sharing of experiences and narratives, six quality improvement projects were developed, that are grounded in the reality of patients, family members and healthcare providers at this cancer centre. EBCD facilitated collaboration and partnerships between patients, family members and healthcare providers. Not only did EBCD empower patients, family members, and healthcare providers to share their stories and experiences but also allowed for those experiences to be transformed into quality improvement initiatives that will improve the patient experience of cancer care.

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