OUTCOMES OF PATIENT EDUCATION

IN BREAST CANCER

WHAT ARE THE OUTCOMES OF IMPORTANCE FOR

PATIENT EDUCATION IN BREAST CANCER?

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Lay Abstract

This thesis explores what are considered important outcomes of patient education in breast cancer. Firstly, a systematic review of all instruments created to judge patient education materials was completed and showed a lack of valid instruments for use in judging quality or outcomes in patient education. Secondly, a review of patient education studies in chronic conditions and cancer revealed a paucity of consistent or recommended outcomes for patient education. Lastly, the major focus of this thesis was a qualitative study that used focus groups to discover what breast cancer patients, physicians and nurses identify as important outcomes of patient education interventions at the Juravinski Cancer Centre. It identified that patients, physicians and nurse have five common beliefs about important outcomes of education interventions: improving knowledge, improving coping ability, providing an orientation to the cancer system, enabling shared decision making and helping to direct behaviour during cancer treatment.

<u>Abstract</u>

Patient education is an important component of quality cancer care. However, there remains much debate about its effects, merits and limitations. The primary objective of this thesis was to identify outcomes of importance for patient education interventions in breast cancer. Through the process of this inquiry, a systematic review of all patient education assessment instruments, a literature review of patient education studies in chronic diseases and cancer, and ultimately a qualitative study using interpretive description was conducted. The systematic review of assessment instruments revealed a lack of psychometrically sound instruments developed to assess quality and efficacy of patient education materials. There was also a lack of consensus as to what aspects of materials should be appraised to constitute good quality. The review of patient education intervention studies in both chronic diseases and cancer identified a general lack of consensus on the intended effects of educational interventions. Multiple outcomes were used without consistency and in differing combinations in the literature making it difficult to compare relative efficacy of interventions. To discover what key stakeholders in the process of patient education in breast cancer (patients, physicians and nurses) would identify as outcomes of importance, a generic qualitative study using interpretive description was conducted. Five common themes to all groups with respect to outcomes of importance were discovered: improving knowledge, improving coping ability, providing an orientation to the cancer system, enabling shared decision making and impacting behaviour during cancer treatment. Despite the surprising variability and inconsistency of outcomes discovered in the patient education literature, this qualitative study demonstrated that patients, physicians and nurses generally agree on what constitute important outcomes and serves as a first step in the process of developing validated outcomes for patient education interventions in cancer.

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Declaration of Academic Achievement

I, Ghazaleh Kazemi, declare that this thesis and the work presented in it are my own and have been generated by me as the result of my own original research.

INTRODUCTION

Approximately fifty percent of Canadians will be diagnosed with cancer during their lifetimes ("Canadian Cancer Statistics," 2017). Fortunately, outcomes following a diagnosis of cancer have improved over the last decade in part as a result of screening for certain cancers, and more importantly, as a result of significant improvements in therapy. Treatment decision-making is often a complex process for both patients and oncologists. Recent media coverage concerning potential overtreatment of premalignant breast cancer (O'Connor, 2015) highlights the complex world of information that patients need to navigate in order to participate in their health care. Physicians and nurses are no longer the only sources of health information. To this end, patient education interventions and education programs have become important components of quality cancer care. However there remains much debate about the objectives of these interventions, whether they are of benefit, and how they should be best evaluated. During my research fellowship in breast cancer, I planned to conduct an educational intervention study and assess its benefits. However, after conducting a thorough literature review I concluded that there was a lack of standardized outcome measures for patient education interventions in cancer care and that this reflected a major gap in knowledge. Hence, I conducted a qualitative research study to identify what health care providers and patients would identify as outcomes of importance in breast cancer education.

Throughout my medical oncology training I observed that a significant portion of our new patient appointments were spent teaching patients about their diagnosis, staging, and treatment options. Patients appeared to be overwhelmed during these conversations

and often had a difficult time making treatment decisions. This often necessitated a second visit to see the oncologist one to two weeks later, termed a care plan, so that the patient could discuss the treatment plan after they have had time to absorb the information provided. I initially formulated a research question that asked whether providing internet-based education about the basics of diagnosis and staging of breast cancer to patients before the first consult visit with the medical oncologist, usually a two week timeframe, would improve educational outcomes. I planned to address this question through the design of a randomized trial. This proposal was to fulfill the requirements for my research fellowship project in breast cancer. However, when I set out to identify validated outcome measures to use in the conduct of this randomized patient education intervention study I had difficulty identifying methodologically sound outcomes. First, I conducted a systematic review of instruments aimed at assessing the quality of educational interventions. I was unable to find any consistent outcome measures that I could use in my study. Next, I conducted a literature review of patient education intervention studies, to see if there was a group of commonly endorsed outcome measures in these studies that could be used. Multiple systematic reviews of patient education intervention studies were identified but again there were no validated or consistent sets of outcome measures used or endorsed. Therefore, the focus of my research evolved to identifying outcomes for patient education interventions in breast cancer using rigorous methodology.

I conducted a generic qualitative study to identify outcomes of importance for patient education interventions in breast cancer using interpretive description. The design

included conducting focus groups of key participants in the cancer centre patient education process: patients, physicians, and nurses. Each group was asked to discuss their views on what they believed to be important objectives in patient education interventions provided at the cancer center. Transcriptions of the discussions were then coded for themes and subthemes regarding outcomes of importance. Themes were then analyzed across the groups for similarities and differences. Common themes across the groups included improving knowledge, improving coping, providing an orientation to the cancer system, enabling shared decision making, and impacting health behaviours such as self-care. A unique subtheme from the healthcare provider groups with respect to impact on health behaviour was improving adherence to management recommendations. Within the patient group, a number of unique subthemes emerged under the theme of improving knowledge, including using knowledge to counter popular misinformation, the need for tailored and specific information and the need to provide information on complementary care. Under the theme of improving coping, another unique subtheme for the patient group was the concept of gaining control.

In this document, the literature concerning outcomes for patient education interventions will be reviewed. The design, execution and results of an exploratory qualitative research study, which incorporated principles of adult learning theory, to identify what breast cancer patients, physicians and nurses identify as outcomes of importance in cancer centre patient education interventions will be presented.

BACKGROUND

The time of initial diagnosis of breast cancer is often overwhelming for patients. During initial consultations at the cancer centre, the oncologist discusses with the patient their diagnosis, the stage of the cancer, the prognosis and various treatment options. It is important to note that the literature in cancer care also shows that patients only recall about 50% of what was discussed in visits (Jansen et al., 2008). Despite this, to be able to participate effectively in management decisions, patients must have some basic knowledge of their cancer, prognosis, treatment options, and the risks of treatment. This is one of the major intentions of patient education in cancer care, to help patients improve their knowledge about their disease. However, is increased disease knowledge the only intended outcome? Currently there are no universally endorsed outcome measures for patient education interventions.

Patient Education

Patient education has been defined as "a systematic learning experience in which a combination of methods is generally used … which influence the way the patient experiences his illness and/or his knowledge and health behavior" (van den Borne, 1998). It has evolved from the field of health promotion. In the 1970s, the notion that individuals could impact their own health through lifestyle modification was introduced (Hoving, Visser, Mullen, & van den Borne, 2010). This concept identified the patients themselves as important participants, in addition to health care professionals, in determining their health outcomes. During this time, patients' rights advocacy groups and organizations

began emerging. These societal changes helped usher in the shift from the paternalistic model of healthcare decision making to the modern concept of shared decision making (Hoving et al., 2010). Patient education thus became an important driver in enhancing and enabling shared decision making in management of health care. The goal of patient education has been described as not only to enable the patient to understand their current health but to also gain the ability to make appropriate decisions and behavioural changes to improve their health (Syx, 2008).

In the field of oncology, there is considerable variability in the range of intended outcomes from patient education. Promotion of patient education as a method of improving a patient's ability to cope with illness has been another major driving force in its uptake into practice (Rutten, Arora, Bakos, Aziz, & Rowland, 2005; Van Der Molen, 1999). Bandura's theory of self-efficacy is a common theory used to support education interventions (Derdiarian, 1986; Gonzalez, Goeppinger, & Lorig, 1990; Kent et al., 2012; Rutten et al., 2005; Van Der Molen, 1999). The theory postulates that once given appropriate health related information a patient's self-confidence in seeking information improves and motivates them to positively impact their future behaviours and outcomes, thus helping them cope better with their illness (Gonzalez et al., 1990).

Another prominent argument for patient education interventions is to help improve patient recall (Finset, 2015). In oncology, given the high stakes nature of the initial consultation and high levels of anxiety associated with this, one might postulate that the previously reported recall rates of 50% are in reality much less in the context of patients that are newly diagnosed. Looking to the cognitive psychology literature,

cognitive load theory assumes memory is divided into a limited working memory, which

processes a small amount of information, and long-term memory, which is unlimited in

its capacity (Van Merrienboer & Sweller, 2010). If the capacity of working memory is

exceeded then it impedes learning and thus the person forgets what was taught. Based on

this theory, it is suggested that we are only able to process and retain 7 pieces of novel

information at a time which can be processed for long-term memory (Mayer, 2010). Two

types of cognitive load are described and are additive: intrinsic load (related to the

complexity of what is being learned) and extrinsic load (a result of the instructional

procedure/environment) (Van Merrienboer & Sweller, 2010). In the case of patients at

initial oncology consults, intrinsic load includes the discussion about diagnosis, prognosis

and treatment. For a large proportion of our population who have a limited background in

science, this discussion creates a large amount of intrinsic load. The extrinsic load in this

scenario includes stressors such as anxiety and unfamiliarity with the cancer system.

Thus, it is no surprise that recall rates can be so low given the high cognitive loads that

are imposed on working memory. To improve recall rates, some have proposed creation

of more structured teaching for patients (Langewitz et al., 2015). In fact, in the medical

education literature numerous studies show that breaking down complex learning tasks

into smaller chunks over time (decreasing cognitive load) significantly improves long

term knowledge retention (Mayer, 2010; Van Merrienboer & Sweller, 2010). If the

objective of patient education during the time of initial diagnosis is to improve patient

recall then we can apply the same principles that worked in health science education.

However, is improved recall the only objective in patient education interventions? A

review of the patient education literature in cancer reveals it is a common outcome measured, but it is seldom used alone to assess the effectiveness of patient education interventions (van der Meulen, Jansen, van Dulmen, Bensing, & van Weert, 2008).

In order to assess whether there were validated outcomes measures in patient education, I completed a systematic review of the literature looking at instruments used to assess quality and efficacy of educational materials. My hope was that if a validated instrument existed, then it might include a set of standardized outcomes for patient education interventions to measure efficacy.

Systematic Review of Patient Education Assessment Instruments

There is no universally endorsed approach for the assessment of quality of patient education materials, either in print or online. Some organizations have developed methods to assess quality, of mostly printed education material, independently, usually through the allocation of resources for input from patient education specialists. I performed a systematic review of the literature to review the quality of instruments developed to evaluate patient education materials with the aim of using the features of a validated instrument, if one was identified, for potential outcomes of importance in patient education interventions.

Methods

To identify instruments and evidence of their validity MEDLINE (1946-Jul 2016), EMBASE (1974 to Jul 2016), PsychINFO (1987 to Jul 2016), Healthstar (1996 – Jul 2016), Web of Science (1976 – 2016), CINAHL databases, and Health &

Psychosocial Instruments (1985 to Jul 2016) database were searched with the following keywords: "patient education.mp"; "patient education material. mp"; "assessment tool or instrument.mp"; "assess$ or appraise$ or quality$.mp". 628 articles were identified and after brief review of titles 581 were excluded for either being a duplicate, only addressing readability and not being about an instrument. 47 were selected for further abstract review. Only articles describing an instrument to assess quality of patient education material and/or describing the results of psychometric testing of instruments were kept. 25 articles were identified that discussed 12 distinct instruments through this method. References of the selected articles were then manually searched to identify further studies or instruments. A Google search with keywords "patient education and assessment tool or instrument" was performed and identified >200,000 results. The first 20 pages of the search were reviewed. Through this a further 6 instruments were identified. Then a subsequent Google Scholar and PubMed search was done using the respective instrument names as the search term to identify independent studies that used the instrument. The studies that performed and reported psychometric testing results were included in the analysis. In total there were 25 additional studies that had performed and reported psychometric testing of one or more of the instruments. In total 50 articles and 18 distinct instruments were identified for the review.

The instruments and support of their validity for use were critically appraised by assessing the psychometric properties reported for each, specifically evidence of reliability and validity. Prior to implementation, an instrument should be proven to consistently produce the same results when applied to the same material (reliability) and

to measure what it is supposed to measure (validity) (Guyatt, Walter, & Norman, 1987).

An instrument might be reliable but not valid, however in order to be valid, it must

demonstrate reliability. There are multiple methods to test the reliability of an instrument

and these are outlined in table 1. For the purposes of this appraisal, instruments were

rated as having weak evidence of reliability if only percentage agreement between raters

was shown as evidence of inter-rater reliability, or if kappa <0.4, or if alpha <0.7

(McHugh, 2012; Streiner, 2003). Validity is broadly defined as the "degree to which

evidence and theory support the interpretations of test scores for the proposed uses of

tests" (AERA, APA, & NCME, 2014, p. 21). The traditional components of validity

include: face and content validity, convergent validity, construct validity and criterion

validity (table 2) (Del Greco, Walop, & McCarthy, 1987). An ideal instrument would be

shown to consistently rate an education material with the same score (high reliability) and

also be able to distinguish materials that have a poor versus good ability of educating

patients, demonstrated by showing "poor" scoring materials are less understood than

"high" scoring materials through standardized testing.

Table 1: Measures of Reliability

Inter-rater reliability (McHugh, 2012)	
A measure of how consistently raters score the same material. All of the following measure the degree of correlation between scores of two raters:	
Percentage of inter-rater agreement	Does not take into account the proportion scored the same by chance alone, thus can over-estimate true level of agreement
Cohen's kappa (κ)	Values of >0.40 considered as acceptable level of agreement
Pearson's correlation coefficient (r)	Values of >0.40 considered as acceptable level of agreement
Spearman's rho (r$_s$)	Values of >0.40 considered as acceptable level of agreement
Intra-class correlation coefficient	
Measures the level of agreement between each repeated test. The preferred method of reporting reliability (Guyatt et al., 1987)	
ICC	Values of >0.7 regarded as demonstrating good reliability (de Vet, Terwee, Knol, & Bouter, 2006)
Internal consistency	
Measures the extent to which scores within the instrument correlate with each other when assessing the same qualities.	
Cronbach's alpha (α)	Values of >0.7 regarded as demonstrating good reliability (Del Greco et al., 1987; Streiner, 2003)

Table 2: Measures of Validity

Component	Definition (Del Greco et al., 1987; Guyatt et al., 1987)	How components were interpreted in this review
Face and Content Validity	*Refers to whether the instrument appears to measure what it is meant to and whether all the relevant aspects of the domain that is being measured has been covered*	Instruments with a panel of patient education experts involved in the development or that described the use of an underlying education theory in guiding the development of the instrument
Convergent Validity	*Refers to how the instrument relates to other established instruments or measures of the same concept*	Instruments that showed significant correlation with other instruments, expert opinion or consumer opinion
Construct Validity	*Refers to ability of the instrument to measure the concept being studied. i.e. extent to which the instrument actually differentiates between good and bad quality patient education materials with its scores*	This can only be established through criterion validity – there is no direct measure of "quality"
Criterion Validity	*Refers to how the instrument relates to the gold standard measurement of concept being studied*	Significant correlation of the instrument score with measurements of patients' comprehension of the education material presented to them

Review of each instrument included: outlining the components of patient education material being assessed; the type of education material being assessed; the population for which the instrument was developed; and evidence of psychometric testing. The psychometric properties of the instrument and strength of their evidence were assessed. The criteria used were: how many individuals and patient education materials were included in the respective studies; the number of items in each instrument; and what types of reliability and validity testing was conducted and whether these were statistically significant. The most robust instrument would have evidence of face validity, good reliability as well as demonstration of further validity studies including convergent

and criterion validity.

Results

   Eighteen distinct instruments were identified in this systematic review. The characteristics of the instruments were varied and are presented in table 3a and 3b. Each used a combination of different features to assess quality. Some instruments that were developed for internet sources of education also addressed the resource's capacity for confidentiality, degree of sponsorship from private sources and navigation ease of the website. The critical appraisal of the psychometric properties of each instrument revealed that there was very limited evidence for reliability and validity in general. The results of this appraisal are presented in table 4. Of the 18 instruments reviewed, 9 had evidence of good reliability (Ademiluyi, Rees, & Sheard, 2003; Charnock, Shepperd, Needham, & Gann, 1999; Charvet-Berard, Chopard, & Perneger, 2008; Chong, Fraval, Chandrananth, Plunkett, & Tran, 2013; Clayton, 2009; Godolphin, Towle, & McKendry, 2001; Griffiths & Christensen, 2005; Helitzer, Hollis, Cotner, & Oestreicher, 2009; Hoffmann & Ladner, 2012; Irwin et al., 2011; Kang, Fields, Cornett, & Beck, 2005; K. Kaphingst, Zanfini, & Emmons, 2006; "LIDA tool," 2007; Mira et al., 2013; Moult, Franck, & Brady, 2004; Nasser, Mullan, & Bajorek, 2012; Patel et al., 2015; Rees, Ford, & Sheard, 2002; Shieh & Hosei, 2008; Shoemaker, Wolf, & Brach, 2014; Smith et al., 2014; Stinson et al., 2009; Taylor-Clarke et al., 2012; Wallace, Turner, Ballard, Keenum, & Weiss, 2005; Zellmer, Zimdars, Parker, & Safdar, 2015). Five had weak evidence (Adkins, Elkins, & Singh, 2001; Adkins & Singh, 2001; Adkins, Singh, McKeegan, Lanier, & Oswald, 2002; Bernier, 1996; K. A. Kaphingst et al., 2012; Mira et al., 2013; Myers & Shepard-White,

2004; A. N. Singh, Matson, Cooper, & Adkins, 2009; J. Singh, 2003; Wilson, 2000).

Four have no evidence of testing. Only 5 had strong evidence of both inter-rater

reliability and internal consistency: SAM, DISCERN, IQT, EQIP and PEMAT

(Ademiluyi et al., 2003; Charnock et al., 1999; Chong et al., 2013; Clayton, 2009;

Godolphin et al., 2001; Griffiths & Christensen, 2005; Hoffmann & Ladner, 2012; Irwin

et al., 2011; Kang et al., 2005; K. Kaphingst et al., 2006; Mira et al., 2013; Moult et al.,

2004; Nasser et al., 2012; Patel et al., 2015; Rees et al., 2002; Shieh & Hosei, 2008;

Shoemaker et al., 2014; Stinson et al., 2009; Taylor-Clarke et al., 2012; Wallace et al.,

2005; Zellmer et al., 2015).

Table 3a: Instrument Characteristics

Instrument	# Items	Content (language & style)	Graphics	Design (layout/ typography)	Motivation (reader engagement)	Cultural Relevance
SAM	22	X	X	X	X	X
RAIN	11	X	X	X		X
BIDS	35	X	X	X		
BALD	16		X	X		
DISCERN	16					
AHEC	17	X	X	X	X	X
IQT	21					
QS	7				X	
MIDAS	13		X	X		
EQIP	20	X		X	X	
ELF	22	X		X	X	
LIDA	41			X		
EVALPEM	46	X	X	X	X	X
SAM+CAM	22	X	X	X	X	
TEMPtEd	26	X	X	X	X	X
INDEX	63	X	X	X	X	
CDC CCI	20	X	X	X		
PEMAT	26	X	X	X	X	

Table 3b: Instrument Characteristics continued

Instrument	Author-ship	Accuracy	Currency	Sponsorship	Confident-iality	Navig-ability
SAM						
RAIN						
BIDS		X				
BALD						
DISCERN	X	X	X			
AHEC						
IQT	X	X	X	X	X	X
QS	X	X	X			X
MIDAS						
EQIP	X	X	X			
ELF		X				
LIDA	X	X	X			X
EVALPEM		X				
SAM+CAM		X				
TEMPtEd						
INDEX		X				
CDC CCI		X				
PEMAT						

Table 4: Summary of the Psychometric Properties of Each Instrument

	Face + Content Validity	Good Reliability (# of studies)		Convergent Validity			Criterion validity
				Other instrument	Expert	Consumer opinion	
SAM	✓	✓	9				
RAIN	✓	↔	6				X
BIDS	✓	↔	1				
BALD	✓					X	
DISCERN	✓	✓	9	✓(QS, ELF, EQIP)	✓	✓	
AHEC	✓	↔	1				
IQT		✓	2	✓(QS)			
QS		✓	1	✓(QS, DISCERN)			
MIDAS	✓	↔	1	✓(ELF)			
EQIP	✓	✓	2	✓(DISCERN)	✓		
ELF	✓					↔	
LIDA		✓	1				
EVALPEM					X		
SAM+CAM	✓	✓	2				
TEMPtED	✓	✓	1	X (SAM)			
INDEX	✓	↔	1		✓		
CDC CCI	✓					✓	✓
PEMAT	✓	✓	3	✓(Readability score)			✓

✓ = significant results
X = failed to show significant results
↔ = weak evidence

The majority of instruments described some degree of face and content validity in the development process by including patient education experts; surprisingly 4 instruments (IQT, QS, LIDA and EVALPEM) had not described or published any form of face validity ("Assessing the quality of internet health information," 1999; Castro, Pilger, Fuchs, & Ferreira, 2007; Cullen, 2006; "Information Quality Tool," 2001;

Sandvik, 1999; Smith et al., 2014). Furthermore, 1 instrument (EVALPEM) had no evidence of any significant psychometric testing (Castro et al., 2007). Twelve instruments were tested for convergent validity where the comparator consisted of another instrument, expert opinion or consumer opinion (Ademiluyi et al., 2003; Baur & Prue, 2014; Castro et al., 2007; Clayton, 2009; Griffiths & Christensen, 2005; Hirsh, Clerehan, Staples, Osborne, & Buchbinder, 2009; K. A. Kaphingst et al., 2012; Mathew, Rajiah, & Sharma, 2013; Mira et al., 2013; Moult et al., 2004; Promislow, Walker, Taheri, & Bernstein, 2010; Shoemaker et al., 2014). Six instruments demonstrated significant evidence of convergent validity with another instrument, 3 with expert opinion and 2 with consumer opinion (Ademiluyi et al., 2003; Baur & Prue, 2014; Griffiths & Christensen, 2005; K. A. Kaphingst et al., 2012; Mira et al., 2013; Moult et al., 2004; Promislow et al., 2010; Shoemaker et al., 2014). Only two instruments, DISCERN and EQIP, showed evidence of convergent validity across greater than one comparator (Ademiluyi et al., 2003; Griffiths & Christensen, 2005; Mira et al., 2013; Moult et al., 2004; Promislow et al., 2010). Three instruments had evidence of criterion validity testing with 2 of them showing significant results (Adkins et al., 2002; Baur & Prue, 2014; Shoemaker et al., 2014). The PEMAT was the only instrument that had evidence of face validity, good reliability, convergent validity and criterion validity (Shoemaker et al., 2014). The aspects of the educational material assessed by this instrument for quality appraisal of interventions included domains that affect knowledge acquisition (language, graphics and design) and the ability to engage the reader.

Conclusion

My inquiry began out of the need to identify a validated instrument that could assess a patient education intervention's quality and efficacy in hopes of identifying standardized outcomes of importance. To identify such an instrument, I conducted a systematic literature review and critical appraisal of all published patient education instruments in any disease site and for any educational medium through the lens of evidence-based medicine. I was surprised to find a general lack of methodological rigour in the development of these instruments.

The major finding of this review is that there is a lack of psychometrically sound instruments developed to assess the quality of patient education materials. Despite this, there are a large number of publications discussing a variety of these instruments and using them in research. The focus of the literature has been on establishing face validity and reliability, but in general there is a lack of the usual types of testing to ensure validity. It is not surprising that instruments which focus on assessing the same domains of material, such as authorship, accuracy and currency as used in DISCERN, IQT and QS instruments, show convergent validity. This only confirms that they are all in fact testing similar domains. However, showing that two instruments measure similar domains does not demonstrate that they are also able to differentiate low from high quality educational materials that have differential effects on the learning outcomes of patients. To effectively demonstrate this through convergent validity, one of the instruments must have also independently shown that it was able to do the above, i.e. have established criterion validity. As such convergence with another instrument alone is not sufficient support for an instrument's validity. The DISCERN and EQIP instruments have further

strengthened their validity by demonstrating convergence with expert rating of materials, which in most institutions is the gold standard of assessment. The only instruments that have shown the ability to distinguish materials that have low ability to teach patients from ones that have high ability are the PEMAT and CDC Clear Communication Index. Unfortunately, the CDC instrument has no evidence of reliability testing, thus compromising its credibility. Currently, the only instrument that has shown sufficient evidence for its use is the PEMAT. Although, it also has limitations in its psychometric properties – criterion validity was only established in a small group of patients reading about inhalers and asthma. PEMAT was not able to distinguish between poor and high-quality material in the group of patients reading about colonoscopies. This may be largely reflective of the small number of patients used and the high literacy rate of the group in general. It has been previously shown that the quality of patient education intervention has the greatest effect in groups with low health literacy (DeWalt et al., 2006; Williams, Baker, Parker, & Nurss, 1998).

An older and more traditional description of the concept of validity was used in assessment of these instruments with an emphasis on establishing criterion validity. More modern theories of validity in assessment, such as Samuel Messick's unitary theory of validity (Messick, 1995) and concepts of political validity (Patterson, Lievens, Kerrin, Zibarras, & Carette, 2012)**,** have promoted further important and necessary steps in validating an instrument before wide implementation and use. Messick (1995) has described the concept of validity more comprehensively with the view that in addition to demonstrating the above types of validity described that assessments instruments should

also provide proof of comprehensive construct validity. He described that "validity is not

a property of the test or assessment … but rather the meaning of test scores" (Messick,

1995, p. 741). He emphasized the need to integrate considerations of the content of

assessment, criteria used in the assessment and the social consequences of the assessment

into the construct validity framework. Political validity relates to the concept that

multiple stakeholders may influence the design, development and ultimate interpretation

of scores (Patterson et al., 2012). To establish political validity there must be generalized

acceptance of the assessment and its interpretations by the population where the

assessment will be used. To properly demonstrate this type of validation a patient

education assessment instrument, after having established reliability and criterion

validity, should be tested in multiple types of educational materials and in differing

populations to ensure that what it is measuring is in fact the ability of the material to

teach readers and not another aspect. Unfortunately none of the instruments reviewed

discussed any type of testing that would address this more modern definition of validity.

Is it valid to use criteria from clinical medicine on judging the psychometric

properties of an instrument and apply them to the patient education literature? In fact, the

same criteria are endorsed and widely adopted in other areas of education, such as

medical education (Cook & Beckman, 2006; Norman & Eva, 2010). As such this lack of

rigour seems to be unique to patient education. In fact, there is very little consensus as to

what components are required to gauge an educational patient resource as good quality.

This was reflected by the wide variety of domains used by each instrument to assess

quality of the patient education materials. Some rely heavily on the resource's use of

language, use of graphics and overall design while others do not assess these aspects and only focus on the material's trustworthiness and accuracy. The latter are instruments developed for assessment of online resources (DISCERN, IQT, and QS).

There is a need to improve on the methods for evaluating the quality of patient education materials. If clinicians aim to engage patients in shared decision-making and to respond to patients expressed desire for increased information early in their disease (Degner, Kristjanson, Bowman, & et al., 1997; Jenkins, Fallowfield, & Saul, 2001; Luker, Beaver, Lemster, & Owens, 1996), access to good quality education materials is important. However, if there is a lack of validated methods for differentiating good quality from poor, there is a risk of providing inappropriate resources to our patients and hindering efforts of patient engagement. There is a need for consensus on what aspects of an educational material are important for rating its quality and efficacy. Second, there is a need for more emphasis on research directed at demonstrating criterion validity of these instruments and thus helping to establish construct validity. Further, by encouraging appropriate validity testing of all instruments, we can also learn about the varying importance of the different domains tested in distinguishing materials that are less able to teach patients from ones that have a very good ability.

Unfortunately, the systematic review was not helpful in identifying validated outcomes of patient education interventions to assess efficacy. Despite the lack of validated outcomes, there are some interesting observations from the review of these instruments. Based on the areas of the educational intervention that are chosen to be tested by these various instruments (tables 3a and 3b), it would seem that the domains of

content, graphics, design and the intervention's ability to engage or motivate the reader are the most widely used by researchers in the area of patient education. This suggests that there is likely some agreement in the patient education research community that an educational material's ability to be understood (relating to domains of content, graphics, and design) and engage the reader is important. Although the review did not reveal why these areas are chosen or that any instrument can reliably measure them, it would seem improving knowledge and impact on the reader (motivation/engagement) may be important outcomes for assessment of efficacy. However, are there others that are equally important? To answer this question, I then proceeded with a literature review of patient education intervention studies in all diseases and then subsequently only in cancer patients. I hoped that I would be able to discover a consensus within the literature as to what are thought to be ideal outcomes given that I had failed to find validated measures.

Literature Review of Patient Education Studies

The review of the literature in patient education intervention studies across both oncology and non-oncology populations revealed a myriad of "health outcomes" used without any consistency. Consistent with my own finding above, there were no common or endorsed methods to evaluate these interventions in terms of their efficacy, a critique that has previously been made of this body of literature by others (McPherson, Higginson, & Hearn, 2001; Ryhänen, Siekkinen, Rankinen, Korvenranta, & Leino-Kilpi, 2010). For example, a meta-analysis of all patient education intervention studies in chronic diseases conducted between 1960 and 1980 included 30 trials that had approximately 16 different outcomes reported (Mazzuca, 1982). The outcomes were

grouped into behavioural (including compliance with medication and preventative health behaviours), therapeutic (such as blood sugar, weight, cholesterol and blood pressure measures) and health measures (such as heart function, lung function and rate of hospitalization) (Mazzuca, 1982). No two trials used the same outcomes. More recently, a review of 35 meta-analyses including 598 studies using patient education in chronic diseases, such as diabetes, asthma, obesity and cancer, conducted between 1999 and 2009 showed that overall, there was a positive effect on patient outcomes through patient education interventions (Lagger, Pataky, & Golay, 2010). However there was considerable variation in outcomes reported including biochemical measurements (such as HbA1c) to hospital readmission rates to quality of life parameters (Lagger et al., 2010). Again no consistent outcome is reported, thus making it even more difficult to evaluate the relative efficacy of differing patient education interventions. In some disease sites there is more robust evidence that links disease knowledge and clinical outcomes. In diabetes, Persell et al (2004) surveyed 670 patients with a diabetes knowledge questionnaire and identified that there was a significant correlation between increased diabetes knowledge and improved compliance with dietary and lifestyle recommendations. In contrast, in the cardiology literature, a randomized computer based education intervention study on 154 patients measuring effect of knowledge about congestive heart failure failed to show any correlation between improved knowledge and the other outcomes measured: compliance with treatment, self-care or quality of life (Stromberg, Dahistrom, & Fridlund, 2006). Despite having consistent outcome measures (compliance and knowledge), it remained difficult to compare the effect of increased

knowledge between these studies, as there was no consistent method used to measure outcomes. That being said, one can argue that patient education interventions are disease-specific and that it would not be appropriate to compare an intervention used in diabetes with an intervention used in another disease site such as rheumatology or cardiology. As such, the literature specifically pertaining to oncology was reviewed.

Oncology Education Literature

The oncology patient education literature also, not surprisingly, identifies a wide range of intended outcomes. Some of these include the patient's own assessment of improved knowledge, patient satisfaction, lower anxiety scores, and various health outcomes or behaviours including decreased pain to improved cancer screening rates (Bennett, Bagnall, & Closs, 2009; Ling, Lui, & So, 2012; Lovell et al., 2014; McPherson et al., 2001; Ryhänen et al., 2010; Salonen, Ryhänen, & Leino-Kilpi, 2014; Whelan et al., 2003). For example, in Ream and Richardson's review of the literature about the role of information provision on patients' abilities to adapt to cancer treatment, patient education was associated with increased frequency of self-care behaviour which they proposed was linked to improved self-efficacy (Ream & Richardson, 1996). The review identified six educational intervention studies that assessed the impact of education about treatment, side effects and management of symptoms on cancer patients' abilities to provide self-care and impact on anxiety levels. Unfortunately, the individual studies used different outcome variables and measurement instruments, including various measurements of self-care behaviour, feelings of control, anxiety, and knowledge; as such it was difficult

to assess the relative efficacy of the interventions between studies (Ream & Richardson, 1996).

To further identify and explore the wide variety of outcomes used in education studies in cancer, four recent systematic reviews from the oncology literature that included 59 studies in cancer patients were reviewed.

The four systematic reviews chosen all looked at the impact of education on differing primary outcomes: knowledge, pain, fatigue and quality of life (Du et al., 2015; Gysels & Higginson, 2007; Husson, Mols, & Van de Poll-Franse, 2010; Marie, Luckett, Davidson, Lovell, & Lal, 2013). There was some overlap in the outcomes assessed in the individual studies included across these four reviews, mostly with use of patient satisfaction. Gysels and Higginson's (2007) review included 9 randomized trials looking at the efficacy of interactive technology based educational interventions; 3 studies using video tapes and 6 using computer programs, in cancer patients. The review demonstrated an overall trend to improved knowledge and satisfaction by incorporation of interactive technologies. In line with previous recommendations discussed, the authors also advocate for the need of standardized evaluation criteria to assess effectiveness between different educational interventions (Gysels & Higginson, 2007). Marie et al (2013) reviewed 15 randomized controlled studies investigating the effect of education and behavioural training on cancer related pain. Overall there was a significant effect on pain scores identified with education suggesting improved pain management skills, especially when behavioural training was added to standard education (Marie et al., 2013). Du et al (2015) reviewed 10 randomized studies that assessed the effect of patient education programs on

cancer related fatigue. They found the intervention studies to have a variable effect on measurements of cancer related fatigue; some studies showed an association between education and decreased fatigue levels, while others did not (Du et al., 2015). Husson et al (2010) reviewed 25 studies in cancer patients that evaluated the relationship between satisfaction with information provided to them and quality of life parameters, anxiety and depression. They included a mix of randomized, prospective cohort and cross-sectional studies. Educational interventions varied between studies and included provision of booklets, discussion with care providers, audiotapes, and CDROM (Husson et al., 2010). Eight of the studies were randomized and examined the effect of two different types of interventions on satisfaction with information, quality of life, anxiety and depression. They identified that increased levels of satisfaction with the information provided was associated with better health related quality of life parameters, less anxiety and depression (Husson et al., 2010). Given the lack of standardized outcomes for patient education interventions, it would have been helpful if studies referred to an underlying theory in support of the outcomes chosen and the rationale of their intervention. Unfortunately, only very few of the studies in the four systematic reviews used a theoretical framework in support of their work. The ones that did were related to directing behaviour change, mostly management of pain and fatigue (Dalton, 1987; Du et al., 2015; L. O'Brien, Loughnan, Purcell, & Haines, 2014; Purcell, Fleming, Burmeister, Bennett, & Haines, 2011; Ream, Richardson, & Alexander-Dann, 2006; Ward, Donovan, Owen, Grosen, & Serlin, 2000; Ward et al., 2009; Yates et al., 2005; Yates et al., 2004; Yun et al., 2012). The table below lists the outcomes measured and the frequency of their

use across the 59 studies. The most common outcomes measured were quality of life,

patient satisfaction with educational intervention, anxiety/depression, knowledge and

behavioural change.

Table 5: Frequency of Outcomes & Theory used in 4 Systematic Reviews

of Patient Education in Cancer

Outcomes	Number of studies n = 59	Theoretical Framework
Quality of Life	35 (59%)	None of the studies used a theoretical framework for these outcomes
Patient Satisfaction	33 (56%)	
Anxiety/Depression/Mood	22 (37%)	
Knowledge	16 (27%)	
Coping/Sense of Control/ Self-Efficacy	8 (14%)	
Decision Making	7 (12%)	
Recall	1 (2%)	
Behavioural change:	37 (63%)	
Pain Management	19	Adult learning theory (Dalton, 1987); Self-regulation theory (Ward et al., 2000), PRECEDE model (Yates et al., 2004), Common sense model and model of conceptual change (Ward et al., 2009)
Fatigue Management	16	Health belief model (L. O'Brien et al., 2014; Purcell et al., 2011), PRECEDE model (Yates et al., 2005), Trans-theoretical model of change (Yun et al., 2012), Psychobiological entropy model (Ream et al., 2006)
Compliance	2	None

What remains unclear is what the important outcomes of patient education programs in oncology are? Are there general outcomes that should be measured in all types of educational interventions? Do they differ at different time points in a patient's disease trajectory? Although provincial bodies, such as the BC Cancer agency and Cancer Care Ontario (BC Cancer, 2018; Cancer Care Ontario, 2018a) endorse education programs, there have been no defined outcomes for these interventions. A recent survey of cancer patients in Ontario regarding their educational needs uses patient satisfaction as the ultimate outcome in assessing the quality of patient education programs at different centers (Cancer Care Ontario, 2017). Although this is a very important component of assessment and used very frequently in the literature, should it be the only outcome? Clarifying goals of patient education interventions provided at cancer centres will help identify outcomes to measure in terms of evaluating effectiveness of both interventions and the education program as a whole.

Patient Education Theories

Without defined outcomes for patient education interventions we are unable to assess them properly and thus unable to evolve and make progress in the field. The first step in building a robust patient education program is to develop defined objectives through a systematic approach that reflects the needs of all stakeholders involved. In the field of medical education for example, great strides have been made in improving educational techniques, such as the incorporation of problem based learning into medical school curricula across the country (Neville, 2009), these would not have been possible if outcomes were not defined and a program of evaluation was not in place. Both the field

of medical education and patient education target an adult population of learners, and as such it is important to incorporate some of the principles of adult learning theory in the development of an assessment program for educational interventions in cancer care. The earliest principles of adult learning theory are based on Knowles' theory of Andragogy which stipulates that for effective learning to take place learners must view the topic as having immediate value to them and they need to understand why it is important to them (Kaufman, 2003; Knowles, 1973). As such in exploring what are identified as important outcomes for education in cancer, involvement of the target learner in the development and assessment of education programs is essential. Unfortunately, as Roter et al (2001) have critiqued of the body of literature, patients, who are the ultimate target, have not been incorporated in the process of assessing the merits and limitations of these education interventions.

Many different theories have been used in the support of patient education. I will briefly review ones which have been used more prominently in the oncology patient education literature and then describe the qualitative study I undertook to identify what breast cancer patients, physicians and nurses feel are important outcomes of patient education.

The review of patient education literature in all disease sites revealed a variety of theories used in support of patient education programs. These included use of adult learning theory (andragogy, self-directed learning, and transformational learning) (Merriam, 2001; Rager, 2003), psychological and sociological theories of illness and behaviour (transactional model of stress and coping, theory of social support, and theory

of learned helplessness) (Aujoulat, d'Hoore, & Deccache, 2007; Gonzalez et al., 1990;

Holmström & Röing, 2010) and theories aimed at health behaviour change (theory of

self-efficacy, social learning theory, health belief model, and the trans-theoretical model

of change) (Bellamy, 2004; Eraker, Kirscht, & Becker, 1984; Gonzalez et al., 1990;

Graves, 2003; Prochaska & DiClemente, 1982; Prochaska, DiClemente, & Norcross,

1992; Syx, 2008). However, as previously discussed, theories have been rarely used in

the development of patient education programs in oncology. Review of all these theories

is beyond the scope of this paper; therefore I will highlight three theories that are

important in this qualitative study.

<u>Andragogy</u>

Knowles introduced Andragogy, often synonymous with adult learning theory, in

the late 1960s as a novel approach to helping adults learn (Merriam, 2001). He positioned

this as distinct and in contrast to pedagogy, which he associated as guides for learning in

children. The main tenets of andragogy identify the adult learner as one who "(1) has an

independent self-concept and who can direct his or her own learning, (2) has accumulated

a reservoir of life experiences that is a rich resource for learning, (3) has learning needs

closely related to changing social roles, (4) is problem-centred and interested in

immediate application of knowledge, and (5) is motivated to learn by internal rather than

external factors" (Merriam, 2001, p. 5). Since its introduction there has been much debate

about whether this truly represents an educational theory versus a model to guide

educational interventions. There has also been heavy debate about the validity of the

claim that this concept would only apply to adult learners. Over time the concept of

andragogy has become more closely related to the concept of learner-centred and student-directed learning, with less emphasis on the age of the learner (Merriam, 2001). However, this principle continues to be used in development of educational programs directed at adult learners (Syx, 2008) and concepts discussed support use of patients in the process of developing and evaluating patient education materials. The last two principles of andragogy discuss how learners (for example breast cancer patients) want education that is readily applicable to their situation and are motivated to learn by internal factors. Given these can be variable between individuals and may differ from views of the education providers, it is important to include patients in the process of developing evaluation programs for patient education interventions.

Transactional Model of Stress and Coping

Lazarus and Folkman proposed the transactional model of stress and coping in the 1980s (Bellamy, 2004). The model describes how individuals use different behavioural and cognitive strategies to cope with stressful situations (Bellamy, 2004). They define coping as "the person's constantly changing cognitive and behaviour efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resource" (Gonzalez et al., 1990, p. 136). This is accomplished through a primary appraisal, where the individual asks if the situation poses a threat to them, and a secondary appraisal where they ask themselves if they can impact or control the outcome. The efforts made by the individual in response to the above appraisal can be divided into two types of coping strategies, problem-focused and emotion-focused. Problem-focused strategies are ones aimed at how an individual can alter the situation to manage the stress.

This can include information seeking, confronting and taking action. Whereas, emotion-focused coping is aimed at managing or avoiding the stressful emotions associated with the situation. This can include avoidance and distancing or detachment (Van Der Molen, 1999). Other strategies identified to improve coping include: seeking social support, accepting responsibility and positive re-appraisal (Gonzalez et al., 1990). In the patient education literature, increasing knowledge to improve self-control such as self-management of symptoms or side effects of treatment is thought to also improve coping. In fact, Lazarus and Folkman identified information seeking as one of the major ways in which individuals cope with stressful events (Van Der Molen, 1999). Van der Molen (1999, p. 239) describes that in this scenario "information is conceptualized as a form of cognitive control as it allows the individual to actively participate in decision making." Other main categories of support used in the patient education literature include emotional support and instrumental support, such as being given materials or practical help (Van Der Molen, 1999).

Self-Efficacy Theory

Bandura proposed the theory of self-efficacy in the 1970s. The theory describes that an individuals' ability to cope with stress is dependent on their own self-efficacy (Bellamy, 2004), and that this sense of self-efficacy will impact behaviour (Bandura, 1977). In the oncology patient education literature this theory has been used to describe how education can lead to increased self-care behaviours (Ream & Richardson, 1996). Bandura describes an individual's self-efficacy as the belief "in their ability to influence events that affect their lives" (Bandura, 2010, p. 1). This was the core belief that he

proposed to serve "the foundation of human motivation, performance accomplishments and emotional well-being" (Bandura, 2010, p. 1). Self-efficacy is developed through four principle sources of information: (1) previous successful experiences, which is thought of having the strongest influence, (2) social modeling or vicarious experience, which relates to the notion that seeing peers succeed can motivate an individual in their own capabilities, (3) social persuasion or verbal persuasion, which can lead to increased sense of confidence if positive feedback and motivation are received from others, and (4) enhanced physiological and mood states or emotional arousal (Bandura, 1977, 2010). Self-efficacy will then have an impact on individuals through cognitive, motivational, affective and selection processes. In the cognitive process analytical thinking is required for individuals to visualize solutions to obstacles they are presented with in life. The higher the self-efficacy the more effective they are in devising successful plans. Motivational process describes how self-efficacy beliefs affect one's motivation to undertake certain tasks. Those with high self-efficacy are more likely to undertake challenging scenarios and remain motivated through the process. Affective process refers to the notion that beliefs about one's ability to cope with difficult scenarios will affect their ability to regulate emotional states. A sense of low self-efficacy would be associated with higher levels of anxiety and depression during or in anticipation of a difficult scenario. Lastly, self-efficacy impacts selection processes through influence on selection of activities or environments. Individuals avoid activities they feel less capable in accomplishing successfully (Bandura, 2010). Bandura (1977) proposed that the likelihood of an individual undergoing a behavioural change is a function of both their

self-efficacy expectations, the belief that they can perform the behaviour required for the desired outcome, and outcome expectations, the prediction that the behaviour change will lead to the desired outcome. This concept is popular in the health behaviour change literature and in the arthritis patient education literature programs created to promote self-efficacy have had a positive impact on rates of behaviour change (Gonzalez et al., 1990).

Summary

The theories reviewed above all incorporate, to varying degrees, the concept that increased knowledge impacts health and behaviour, thus supporting the process of patient education. Unfortunately, despite a thorough review of instruments developed to evaluate patient education interventions and a broad review of published patient education intervention studies, there does not seem to be any consistency in what outcomes are used, or generally preferred for assessment of efficacy of these interventions. Effect on knowledge and behaviour are prominent outcome measures but are the others described previously, such as coping, anxiety, improving recall and quality of life equally important? Would patients themselves identify these as important outcomes of their learning? Based on the lack of clarity and direction in the literature on the measurement of patient education outcomes, I decided to address these questions and identify valued outcomes of patient education in our breast cancer population by conducting focus groups of key stakeholders involved: breast cancer patients, medical oncologists and oncology nurses.   A generic qualitative research approach was used, specifically through interpretive description to identify common themes, which could be analyzed for

generation of outcomes of importance in evaluation of educational interventions.

METHODS

Methodological Framework

A generic qualitative approach, specifically through interpretive description was used in the conduct of this study. This approach was chosen over other common qualitative methodologies such as phenomenology or grounded theory because the aim of this study was to identify what healthcare providers and patients would identify as outcomes of patient education in breast cancer so that they could be used in practice. Given that my aim was not to describe the experience of patient education or develop novel theory, interpretive description was used as its framework (and especially its focus on relevance for practice) fit best with this study's goals.

Generic Qualitative Research and Interpretive Description

The philosophical underpinnings of this methodological framework will be reviewed first. In describing the philosophical framework of a research approach, ontology refers to what is believed about the nature of reality and epistemology refers to what is believed about the nature of knowledge. Generic qualitative research has a social constructivist epistemology and assumes that knowledge is constructed, specifically by people "as they engage with the world they are interpreting" (Merriam & Tisdell, 2016, p. 24). The purpose of studies with a constructivist philosophy is to describe, understand

and interpret a phenomenon with an ontological view that multiple realities exist and that these realities are context bound (Merriam & Tisdell, 2016). This is in opposition to the epistemological perspectives of quantitative research that have a positivist view. The purpose of studies under the positivist philosophy is generally to predict, control or generalize theories with an ontological view of reality as singular, objective and measurable (Merriam & Tisdell, 2016). All qualitative research methodologies "aim to understand how people make sense of their lives and experiences" (Merriam & Tisdell, 2016, p. 24) and each respective methodology adds an extra dimension to this aim. For example, phenomenology does this by describing the underlying structure of the lived experience, ethnography describes the interaction of individuals within the context of their society for that experience, and grounded theory aims to build a theory underlying the specific experience. Generic qualitative research methodology has been described as research that is not guided by the philosophical assumptions of other qualitative methodologies (Caelli, Ray, & Mill, 2003; Kahlke, 2014). Generic qualitative research aims to explore "(1) how people interpret their experiences, (2) how they construct their worlds, and (3) what meaning they attribute to their experiences" (Merriam & Tisdell, 2016, p. 24). There are two types of generic approaches described in the literature: descriptive research as proposed by Sandelowski and interpretive description as proposed by Thorne (Caelli et al., 2003). Descriptive qualitative research is one that aims to purely describe a phenomenon without any attempts at explaining or interpreting the data. Interpretive description on the other hand requires interpretation of the phenomenon

under study with the aim of developing an understanding that can be applied in practice (Kahlke, 2014; Thorne, Kirkham, & MacDonald-Emes, 1997).

Interpretive description was first described by Thorne in 1997 as a novel qualitative approach to address a gap in nursing research for qualitative designs whose research products could readily be applied in practice (Thorne et al., 1997). In this approach, research questions are drawn from clinical practice using the experiential knowledge of the investigator as the platform. The findings of the research can provide theoretical and methodologically sound evidence to guide practice (Hunt, 2009). The underlying epistemological belief in this approach is that the health and illness experience is socially constructed and that shared realities between individuals can exist (Hunt, 2009; Kahlke, 2014; Thorne et al., 1997). Its key philosophical underpinnings include: 1) multiple constructed realities of the phenomenon under study exist and are complex, contextualized and subjective, 2) the investigator and the object of study interact and influence each other, and 3) a priori theory cannot encompass the multiple realities likely to be encountered, as such discoveries must emerge or be grounded in the research data (Thorne, Kirkham, & O'Flynn-Magee, 2004). It advocates for research inquiry to be borne out of the foundation of existing knowledge of the phenomenon. This foundational knowledge can be in the form of existing theory or published work, or out of the investigator's own clinical experience. The products of this research approach should also have the potential for application in clinical practice and constitute what is described as a "tentative truth claim" about commonalities in a clinical experience (Thorne et al., 2004, p. 3). To reach this end, design strategies are borrowed from other qualitative disciplines,

such as grounded theory, ethnography and naturalistic inquiry (Kahlke, 2014; Thorne et al., 2004). Theoretical and purposeful sampling is encouraged so that the participants chosen are those most likely to describe variation in the realities they have constructed about the phenomenon under study, but whose accounts are also likely to reveal elements that are to some degree shared by others (Thorne et al., 2004). This approach encourages data collection through multiple sources. Concurrent and constant comparative methods are employed during data analysis in an iterative fashion with the aim of generating a broad understanding of the data (Hunt, 2009; Thorne et al., 1997; Thorne et al., 2004).

The approach outlined by interpretive description was an ideal framework for use in discovering the outcomes of patient education in breast cancer. The inquiry was borne out of the clinical experience of an oncologist with the aim of discovering outcomes of education interventions that were meaningful and important to all individuals involved in the process of patient education, and which could also be applied in practice.

I will review the methodology that I used based on Caelli's recommendations for reporting generic qualitative research (Caelli et al., 2003). I will address each of the following areas: my theoretical positioning, the congruence between the methodology chosen (interpretive description) and my methods, the strategies used to establish rigour and the analytical lens used to examine the data.

As discussed in the introduction, my motives for pursuing this study emerge from a clinical need to identify whether providing education to breast cancer patients referred to our centre prior to their first meeting with medical oncologist would be beneficial. I was not able to find standardized outcomes for this intent. As such, using the principles

of adult education, where the intended targets of the education must believe the outcomes

of the intervention to be meaningful; I instead pursued a project that would help identify

these important outcomes. I approached this with a social constructivist stance that

individuals involved in the process of patient education (physicians, nurses, and patients)

would likely have differing understandings and views of what would constitute outcomes

of importance. I also postulated that there would likely be some shared understandings

within the three groups of major stakeholders involved. Given the topic was familiar and

that my time line for the project was limited, I chose to pursue a focus group design. To

limit concerns of power differentials within groups that may have influenced responses I

chose to conduct focus groups of physicians, nurses and patients separately. My

assumptions coming into this work were that patient education was beneficial and

important. Given my goals for this study, for reasons given above, I chose to pursue an

interpretive description approach. In order to establish rigour in the findings of this study,

I intended to continue data collection until a saturation of emerging themes regarding

objectives of patient education was reached within each group. Also, patient groups were

recruited with the aim to have participants of varying ages and those at differing points

during treatment to ensure a broad reflection of the patient perspective. In congruence

with the interpretive description approach, data collection and analysis were completed in

a concurrent fashion with subsequent data collection occurring in an iterative fashion.

The belief that there were likely multiple understandings of how patient education

impacts our patients, the likelihood that there were shared understandings within groups,

and also the existence of some shared broad understandings between groups describe the

analytical lens through which this data was reviewed. In the next section, the study

protocol is described.

Study Protocol

Context

      Breast cancer patients are often advised of their diagnosis by their surgeon and

then referred to the cancer centre to be seen by a medical and/or radiation oncologist for

discussion of further treatment options. When patients arrive for their first visit, they are

provided with information booklets, which give a general overview of breast cancer, its

staging and treatment modalities. Drug information sheets with lists of common side

effects are often provided to patients during this visit. This could include information

about chemotherapy and/or anti-hormonal therapy. If patients are recommended to pursue

chemotherapy, they are also encouraged to attend a one-hour chemotherapy teaching

class. At the end of the first visit, patients are also often provided with a small informal

tour of the cancer centre, usually by the nurse, to orient them.

Research Question and Objectives:

      This study's objectives were to identify what breast cancer patients, physicians

and primary nursing identify as outcomes of importance in patient education

interventions. Education interventions were defined as any educational discussions,

materials or resources that were provided to patients during their encounters with the

cancer centre. Although I did not specify types of interventions, all groups during their

discussions only referred to the general education provided to new patients such as the

breast cancer booklet, drug sheets, chemotherapy teaching class and discussions with physicians and nurses.

Study Population

The study population included health care providers, specifically physicians and nurses, providing care to breast cancer patients at the Juravinski Cancer Centre, and breast cancer patients actively followed at the cancer centre.

Recruitment and Sampling

Between July and December 2017, four separate focus groups and one interview was conducted. The physician and nursing group participants were identified through email request to those who treat breast cancer. Recruitment methods for the patient focus group included information posters about the study in the waiting rooms of the cancer centre asking for volunteers (appendix A), and active recruitment by primary nursing and radiation therapists in clinics. In the first patient focus group, one patient brought a support person along with them. The support person sat in for the discussion but did not contribute to the discussion of what patients identified as outcomes of importance in patient education. Given this and the fact that the individual was not a cancer patient, this person was not included in the data collection or analysis.

Instruments

Focus groups and one interview (see appendix B for focus group guide)

Purposive sampling was employed. Homogenous focus group design (group by profession) was planned to avoid significant differences in power and status in the same

group. The physician and nursing groups allowed for identification of respective professional norms and shared understanding. The patient groups allowed for the exploration of the impact of their shared experience on their perspectives to the questions. Each group was limited to 5 participants.

One focus group was conducted with physicians and one with nurses. Attempts were made to organize a second set of focus groups for both physicians and nurses but this unfortunately was not possible to organize due to the busy clinical schedule of the participants and the time frame under which this research was being conducted. Two focus groups and one interview were conducted for the patient group. Due to the difficulty of organizing the schedules of multiple participants, two participants could not arrange to take part in the focus group. One of these participants served a unique viewpoint given young age and having had gone through treatment twice. As such an interview was conducted instead at a time the participant was available using the same prompts used for the second focus group discussion to capture her unique view point.

Data Collection

After obtaining informed consent, study participants participated in a 60-minute semi-structured focus group session with the investigator serving as the facilitator. These group discussions were held in conference rooms located in the Juravinski Cancer Centre. The sessions were audio-recorded and transcribed with permission. At the end of the session participants were asked to fill out a background characteristics form, which was anonymous (appendix C). Following each focus group, audio-recordings were transcribed and anonymized by the investigator. During the focus group field notes were taken by the

investigator to aid in the data analysis. Data collection was planned to continue until a

saturation of emerging themes occurred. For this study's purposes, saturation meant that

no further themes regarding outcomes of importance from patient education interventions

where identified. However due to time limitations of this study, I was not able to continue

to collect further data from the physician and nursing group as I had originally intended.

However, the themes identified in both groups were very similar suggesting that themes

from the healthcare provider perspective were close to reaching saturation.

Table 6: Timeline of Data Collection

Date	Instrument	Participant Group	Number of Participants
July 24, 2017	Focus Group	Nursing	5
July 26, 2017	Focus Group	Physician	4
July 27, 2017	Focus Group	Patient	4
October 27, 2017	Focus Group	Patient	3
November 1, 2017	Interview	Patient	1

Data Analysis

Data analysis followed an iterative design. The transcription and field note

following each focus group was analyzed by the investigator. A priori themes were not

used in the coding tree and were generated through the analysis of the data by the

investigator. The data was coded using the following strategies to identify themes

described by Ryan and Bernard: review of the transcript line by line to identify topics

frequently repeated, topics with similarities and differences, topics of interest identified

in field notes, and through cutting and sorting the data (Ryan & Bernard, 2003). The field

note, which had been used to record general observations and key discussion points

during the focus group, was reviewed first to orient myself in identifying broad general

emerging themes and codes. With this general overview of the focus group discussion in

mind, an initial review of the transcript was done line by line to identify areas of repeated

topics, areas of similarities and differences, and areas where there was congruence with

the codes that emerged during review of field notes. This process helped identify multiple

codes. For example review of the field notes from the first patient focus group identified

three general concepts: the need to decrease anxiety, the importance of orientation to the

cancer system and the need to improve breast cancer knowledge. As I read through the

transcript I coded for the above concepts and added new codes as new concepts emerged.

New concepts were identified using the observational techniques of repetition and

similarities and differences. The identification of concepts or codes when topics reappear

multiple times in a text, either by one participant or by multiple participants, is a simple

and widely used technique to identify themes in narrative material (Ryan & Bernard,

2003). Identifying novel concepts by examining the text for similarities and differences

of participant answers to focus group discussion points is another observational technique

used in this study to identify concepts or codes. This technique has also been referred to

as a constant comparative method and "involves searching for similarities and differences

by making systematic comparisons across units of data" (Ryan & Bernard, 2003, p. 91).

For example, when reviewing the data for the first patient focus group, as I was coding
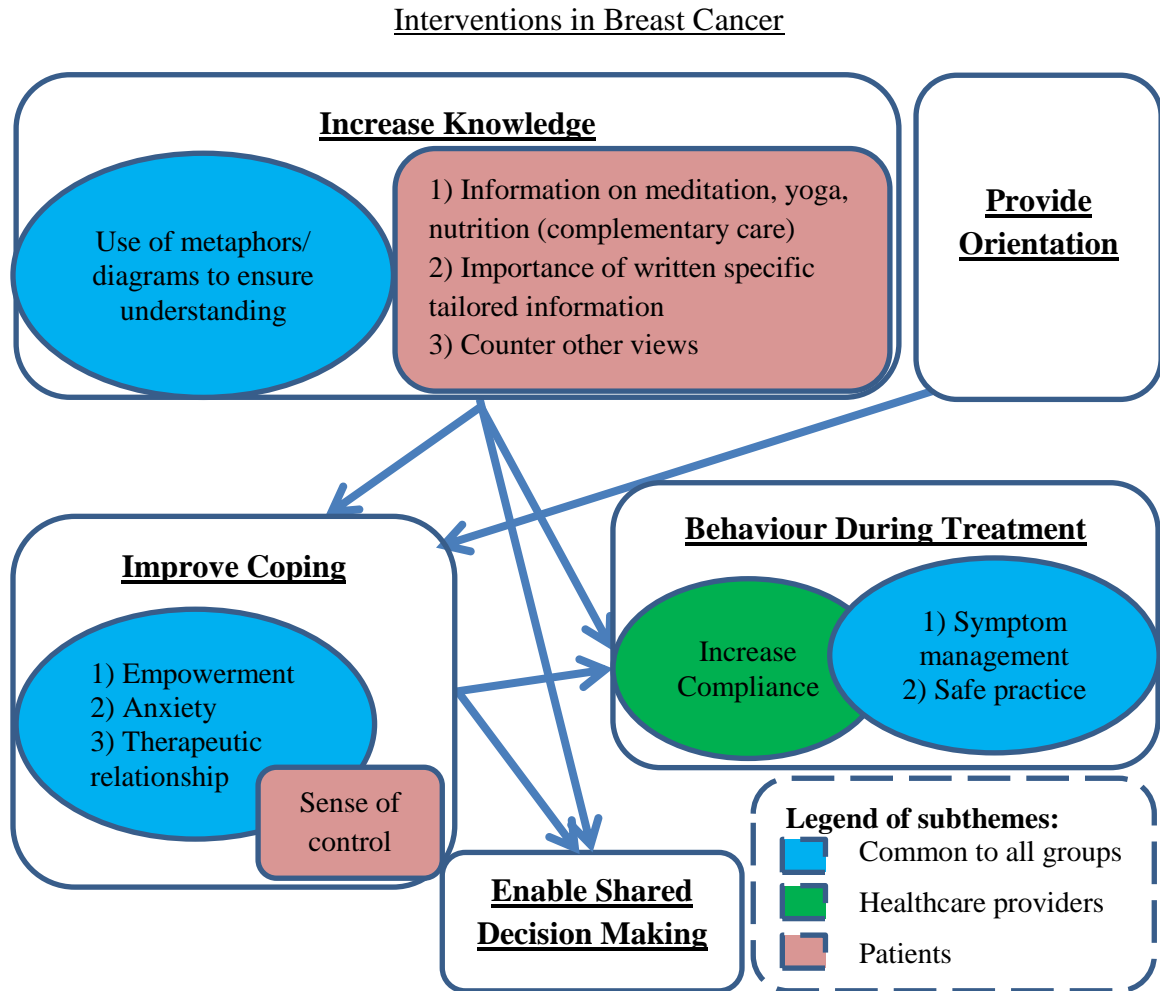
text for anxiety, I noticed that in some cases this was intimately connected to a sense of control and ability to cope. Moving forward, I started to code for both instances of anxiety, coping and control. After the initial review of the transcript using the above techniques a total of fifteen specific recurring concepts or codes were noted including the ones identified on review of the field note. Lastly, with the help of NVivo 11 software the coded sections of the transcript were then cut and sorted to see if any further codes or refinements to codes would be identified. The above methods were repeated for data from the physician and nursing focus groups and a set of themes of what each group defined as goals of patient education were identified.

The subsequent patient focus group was planned and discussion points modified based on the emerging themes from the previous analysis. This included asking the second set of patient participants about their thoughts on the themes that emerged from the physician and nursing groups. The above process was repeated on the data obtained from the second patient focus group and the one patient interview. The data was coded based on the previously discovered coding tree and new codes were added as necessary. All the transcripts were then re-read for a second time in totality using the final coding tree and then the process of cutting and sorting with the NVivo 11 software was repeated. With the help of a concept map, the categories identified were then further aggregated under common themes and subthemes that directly related to outcomes of importance for education interventions. For example the codes of improving breast cancer staging knowledge, increasing information about treatment options, and using diagrams or pictures to enhance understanding from all patient groups were combined and grouped

under the broader category of increasing knowledge of breast cancer and management options. Given that no new themes were identified through the second patient focus group or interview, no further data collection was planned for the patient group. A second reviewer was not used in the analysis of this study.

Themes that emerged from each of the stakeholder groups were also compared to each other for similarities and differences. Quotations from the coded sections of all groups were reviewed and similar codes were then aggregated under larger categories. In this tertiary review process the above categories where again aggregated under a final set of common themes and subthemes pertaining to outcomes of importance for patient education from all stakeholder groups with the help of a concept map (diagram 1) that outlined all broad themes and how they were related to one another.

Diagram 1: Concept Map of Outcomes of Patient Education

Interventions in Breast Cancer

Increase Knowledge

Use of metaphors/ diagrams to ensure understanding

1) Information on meditation, yoga, nutrition (complementary care)
2) Importance of written specific tailored information
3) Counter other views

Provide Orientation

Improve Coping

1) Empowerment
2) Anxiety
3) Therapeutic relationship

Sense of control

Behaviour During Treatment

Increase Compliance

1) Symptom management
2) Safe practice

Enable Shared Decision Making

Legend of subthemes:
Common to all groups
Healthcare providers
Patients

Ethical Considerations

This study was reviewed and approved by the Hamilton Integrated Research Ethics Board (HiREB). All participants signed consent (appendix D) to enter into the study and these consent forms were kept in a locked cabinet at the Juravinski Cancer Centre.

RESULTS

Participant Characteristics

I conducted one focus group with 4 physicians and a second one with 5 nurses. The characteristics of participants are outlined in table 7. Two focus groups with patients, 4 in the first group and 3 in the second, and 1 interview with a patient were conducted, including a total of 8 patients. The patient characteristics are outlined in table 8.

Table 7: Health Care Provider Characteristics

Nursing group, n=5	
Worked as a nurse in breast cancer with:	
Medical oncology	5
Radiation oncology	4
Previous involvement with education:	
Chemotherapy teaching class	2
One on one teaching	5
Developed printed patient education resource	3
Involvement with patient education conference	5
Practiced as breast cancer nurse for:	
5-10 years	2
>10 years	3
Physician group, n=4	
Currently working as:	
Medical oncologist	1
Radiation oncologist	1
General Practitioner in Oncology	1
Surgical Oncology Fellow	1
Previous involvement with education:	
Developed printed patient education resource	1
Involvement with patient education conference	2
Practiced as a breast cancer physician for:	
<5 years	2
5-10 years	0
>10 years	2

Table 8: Patient Characteristics

Patient group, n=8	
Age:	
<45	1
46-55	5
56-65	2
>65	0
Highest Educational Level:	
College/University degree	6
Professional degree/diploma	2
Breast Cancer Treatment:	
Recovering from breast cancer surgery	1
Currently undergoing treatment	2
Completed chemotherapy and radiation treatment	5
Primary Language:	
English	8
Self –Reported Ethnicity:	
Canadian	6
Italian	2
Occupations:	
Teacher, TV broadcaster, Banking, Journalist, Administration, Assistant controller, 2 Home makers	

Themes

In the design of this study I had postulated that the outcomes of importance in patient education identified by breast cancer patient groups might differ from those of the health care providers, however through the process of running each of these focus groups common themes to all groups emerged. There was only a minority of distinct views within some themes that differed amongst groups. The physician and nursing groups identified similar themes without major differences and will be often referred to as healthcare providers. Five themes in regards to objectives of patient education emerged that were common to all groups: (1) increasing knowledge, (2) improving coping, (3)

providing an orientation to the cancer system, (4) enabling shared decision making and
(5) impacting behaviour during cancer treatment. Some of these themes have multiple
subthemes. As indicated in the concept map depicted in diagram 1, the themes of
increased knowledge and providing orientation were independent outcomes, whereas the
other three themes identified were also related in some way to one another. For example
increasing knowledge and providing orientation both seemed to have an impact on the
ability for patients to cope, whereas discussion of impacting behaviour during treatment
seemed to also be related to the knowledge gained by patients and their coping ability.
Four subthemes emerged under the larger theme of increasing knowledge and three of
these reflect the divergent and distinct opinions that emerged within the patient group
alone. Under the theme of improving coping, three subthemes emerged, and one was only
identified in the patient group. Similarly within the theme of impacting behaviour, a
subtheme emerged which was only associated with the healthcare providers. Table 9
shows a summary of the themes and subthemes to be discussed.

Table 9: Summary of Themes & Subthemes

Common Themes and Subthemes	Distinct Subthemes	
	Healthcare Providers	Patients
1. Improving Knowledge of Breast Cancer		
• Subtheme A: Use of metaphors and diagrams to ensure understanding		• Subtheme B: Need for complementary care information • Subtheme C: Need for tailored and specific information • Subtheme D: Knowledge to counter popular misinformation
2. Improving Coping		
• Subtheme A: Empowerment • Subtheme B: Decreasing emotional distress		• Subtheme C: Gaining control
3. Providing Orientation		
4. Enabling Shared Decision Making		
5. Impacting Behaviour During Treatment		
	• Subtheme A: Improving compliance	

Five common themes related to outcomes of importance for patient education interventions emerged across all three groups of participants; as such I will present the data of the participants together grouped by theme. Subthemes will also be reviewed under the larger theme category. For example the first theme was that a major objective of patient education is to increase knowledge, however within the patient group there were unique subthemes related to the larger theme that emerged and were an important

distinction to highlight. The themes and subthemes will be reviewed in the context of each group.

Theme 1: Increasing knowledge about breast cancer and management options

Nurses, physicians and patients all discussed the importance of increasing knowledge about breast cancer and its treatment options as an outcome for education. All groups also acknowledged the important use of pictures and metaphors to ensure patient understanding. However, the healthcare provider groups, physicians and nurses, had a more homogenous view of what increased knowledge reflected, specifically increased knowledge was related to breast cancer diagnosis, treatment options and side effects of treatment. Whereas the patients' views on what breast cancer knowledge encompassed was more heterogeneous and included other content including information on complementary care during breast cancer treatment, and more tailored specific information about their type of cancer. Lastly, the patient group identified another important use of increased knowledge; use of it to counter some popular "false" messages in their social circles including recommendations from friends and on the internet.

A traditional concept of what is identified as patient education content at the cancer centre includes information on breast cancer diagnosis, treatment options and side effects of treatment. All groups identified increased knowledge in these areas as a very important component of care. Physician D described how educating patients is "helping them understand what is their disease, what it's about, just the basics of it and then [sic] but mostly their treatment." In some instances it was also pointed out as being a necessary component of care. Nurse C explains its necessity, "well it's based on informed

consent right? So how can you consent to something, if you don't know why or what you are doing? You don't understand why. And it also gives them personal empowerment, choices." Patients also agreed that the standard information provided was important. Patient H recounts her thoughts on the new breast cancer patient education package she received from the cancer centre, "I found it very useful. That big bag you get at the beginning when you first go, I read through that thing from start to finish once I got home and I referred to it often." One patient who had gone through a diagnosis of breast cancer twice recounts how her previous experience was helpful with her second in terms of knowledge acquisition.

> Patient J: "Way easier. Umm, the stage 4 was kind of hard, understanding the mechanics of it, so there was a lot of conversation around how did it happen. Like, where did it start? What was the path? And you know what the hell does this mean…that part was where you know gathering all the knowledge, all the same thing but I was way more confident. I just didn't care what I was asking, all my questions were answered."

Subtheme A: Use of metaphors and diagrams to ensure understanding

It was also interesting to note that all groups described the importance of ensuring understanding on the patient's part through use of various educational methods. Physicians, nurses and patients all described methods to enhance understanding of difficult concepts for patients in the context of enabling patients to improve their knowledge of disease. Use of pictures and metaphors was described as particularly helpful in this regard. Physician C highlights the importance of "…contextualizing it to

the patient's understanding. Some people understand the idea of seeds, some people understand the idea of you know this whole idea of micro-metastases right. So I am trying to figure out the language, obviously we are providing a lot, umm, of knowledge." Nurses felt that it was an important component of their role to ensure understanding on the part of patients.

> Nurse C: "when my patient can repeat back to me, not just verbatim, what I've just told them but in their own words that they understand what we are doing and why we are doing it and ask relevant questions, that makes me think ok, I think they get what I am trying to tell them … Sometimes we are just translating the doctor to them, admittedly."

In this regard, one patient described how she finally understood the concept of lymphedema, a complication she suffered following treatment of her cancer. Patient H: "…so simple, diagrams. So they held up spaghetti [in regards to explaining the concept of lymphedema and lymphatic system], you know, so maybe diagram how they are connected." Patient F describes of her surgeon, "she had a graphic board and showed where, you know there is [sic] three different grades of tumours, she showed me where mine was and what the treatment options are for that."

Subtheme B: Need for information on complementary care

However, despite all groups describing increased knowledge as an important outcome of education, the content of that required knowledge is also more heterogeneous in the minds of patients. Healthcare providers view topics of importance for review to include disease specific and treatment tailored information on treatments whereas patients

described that in addition there is a need for information on complementary care to support them during breast cancer treatment.

All patients who participated in this study commented on the importance and need for more information regarding complementary care while they were undergoing treatment for cancer. This information was heavily related to nutrition but also information about meditation and yoga was discussed. This was distinct from both healthcare provider group discussions where the focus of education was on the specifics of cancer and treatment. When patient J was asked to discuss how nutritional information would have changed her experience, she describes "I think nutritionally I would have known, I think it would have helped me with symptoms; it would have helped me with the side effects from treatment. I think it would have made me stronger. Like there are definite things I could have been doing differently." The need for nutritional information was also ultimately linked to allowing patients to gain a sense of control and empowerment, which is described in more detail below. Patient B describes "to me, again, I am a big control freak, to me, that gives me mentally a little bit of control over things. I know I am putting this in my body, I am reducing my sugar, I am not eating alcohol. You hear about like tofu and soy. Is that good is it not good? Like I want to know nutritionally, like what I can do." Information about yoga and meditation was identified as something that might have been helpful during treatment, mostly to help reduce anxiety. Like patient D who described: "well I wish someone had suggested, like, in my first year that I try meditation."

Subtheme C: Need for printed tailored and specific information about breast cancer

Patients also identified the need for printed tailored patient specific information about breast cancer to compliment the discussions during clinic with health care providers. Many patients noted that although detailed information about their diagnoses and management was discussed with their physicians and nurses, the take home informational booklets they received were too general. Patient J describes this frustration:

"it was so general; I didn't want to wade through all that info...so we get

the documentation on the medication we are about to get, those are

detailed side effects, but you don't get a sheet that says you have, you

know triple positive whatever, you don't get a sheet that you know, they

go and get all these pamphlets well why not get one that's specific for

what you have that's really specific."

This is especially important for patients given that the initial meetings with oncologists are very stressful and they are unlikely to remember much of what was discussed. Patient C describes how her "…brain stopped when they said you have breast cancer, right and I am pretty smart. I've been in newspapers for 35 years, I am used to asking questions, I am not intimidated by medical people, umm, but my brain shut down and my husband's brain shut down too. So, we were just sitting there going, oh."

It is interesting that although healthcare providers generally provide this detailed information in dialogue with patients, they did not identify the discrepancy with respect to degree of specificity in what is discussed and what is provided as take-home information. This could be important for patients.

Subtheme D: Increased knowledge to help counter popular misinformation

In addition to information about complementary care and tailored and specific take home breast cancer information, patients also identified another important distinction relating to how increased knowledge was also helpful. Some patients described how the knowledge also helped them combat popular misinformation about breast cancer, whereas healthcare provider groups did not comment on this perceived benefit.

Patients highlighted the importance of gathering accurate information and knowledge to help them counter some of the popular misinformation they would encounter in their daily lives, including from friends and through online sources. Patient F describes how this knowledge is especially important at the early stages of diagnosis: "I think at that point in the beginning, I think that it's maybe the most important component. Before you are a cancer patient you hear all these things." Patient D describes how she needed to navigate through an awkward scenario at the time of her diagnosis "…like I had a, the mother of a friend of one of my daughter's called me to tell me about coffee enemas as a way to cure cancer."

In summary physicians, nurses and patients all agree that an important goal of patient education is to improve knowledge and understanding. They all agree that incorporation of metaphors and diagrams in this regard is very helpful and all acknowledged that informational needs will differ at various points during a patient's care. However, patients and healthcare providers' discussions had differing emphasis on two issues: one is on the impact of this increased knowledge outside of cancer care, where patients feel it helps them combat popular misinformation. The second is that the

content of what patients feel is important to gain knowledge of is more heterogeneous than that of care providers. In addition to the standard educational discussion of disease and treatments, they want more information in regards to complementary care and specific information that they can have available at home in regards to their disease.

Theme 2: Improving Coping

Physicians, nurses and patients all described to different degrees the impact of education on improving a patient's ability to cope with diagnosis and treatment. This was described largely through gaining a sense of empowerment and education's ability to decrease emotional distress. A distinct subtheme for the patient group was the highlighted need for control of things other than cancer treatment to help them cope throughout the cancer experience which was not discussed by the nurses or physicians. Through these discussions however, important limits of education in helping patients achieve these states was also revealed.

Subtheme A: Empowerment

The physician and nursing group felt that by improving knowledge about breast cancer and process of treatments, patients would feel more empowered. Specifically, that they would be more engaged in their healthcare and feel that they have some control over their breast cancer management. Physician C describes how "…information sharing is the first step in empowerment too right so, basically you are trying to establish that you know, the individual should feel like they can … participate in care and ask questions right." The nurses also identified education as enabling empowerment and serving as a coping strategy for patients. Nurse D describes how she believes "…that once they know,

and so being educated, empowers them too, and so they kind of like have some kind of control because they understand what's coming to them right." Patients also described a process of trying to gain empowerment through education; Patient B describes:

> "That's why I educate myself …to try to get the best possible care that you can… [and identify whether there are] studies, are there treatments, that you know, that are not offered here. Like, you want to get the best care and you want to reduce your anxiety and fears."

As such, it seems empowerment through the process of education is an important aspect of how patients cope with their diagnosis and is felt to be an important outcome of education.

Subtheme B: Decreasing emotional distress

Healthcare providers and patients acknowledged the impact the process of patient education can have on the emotional toll of a diagnosis of cancer. Most discussions revolved around the idea that increasing knowledge of disease and management would alleviate anxiety to certain degrees. However the physicians and nurses also described how the process of education itself, regardless of the content of information being portrayed, was in and of itself a method of establishing rapport and building a therapeutic relationship. Physician C describes "I mean the first part is to use it to establish the relationship, and kind of, and that way you also kind of set the context and how the relationship is going to be managed because the other thing is that we all try to personalize what we do too."

Information and its effect on anxiety was a common discussion point across all groups. One of physician B's goals in providing education was to

"…alleviate patient anxiety. Umm, in that, even if its bad news conversations, I think that information can be helpful for patients to cope. The more they understand what's going on, umm, and the more you can take away the unknown aspect, I think, often patients can, umm or it may relieve patient anxiety."

The nurses were also in general agreement with this concept. Nurse D describes this rationale: "…I think it's natural for the human being right. You afraid of unknown, if I go someplace that I don't know, I will be uncomfortable right. So it's the same thing, if you know more, and you won't be too frightened." The patients also described the impact of education in relation to anxiety. Patient C describes how reviewing the pathology report with her surgeon and gaining understanding of the specifics of the report was reassuring and helped alleviate anxiety:

"…so the pathology report had insufficient margins, well that's cause the margin was here, it was right against the outside, and she said, you know if you ever read your pathology report don't get scared about that because this is what it means and she drew a picture and all that stuff. So she was great."

However, another patient describes the complexity of the relationship between information and anxiety.

Patient H: "I think the knowledge is key. I think it does help relieve the anxiety. Umm, sometimes the more you know, I don't know if it's good or bad, but sometimes the more you know, whether it's good or bad, I think it helps. I think it is important because you, regardless of what you know, you are still going through this and you are still in shock and until the very end."

All groups also noted the limits of information on relieving anxiety. The need to take into account variation in the amount of information patients want for individualized education was highlighted by physicians and nurses, as in some cases the increased knowledge may in fact worsen anxiety. This fact, also acknowledged by patients highlights, the struggle this can pose for healthcare providers at times in deciding what amount of information is necessary and appropriate.

Physician A: "I think individualizing how much education you are offering is critical. Like for some patients what relieves anxiety is knowing everything that they can about breast cancer…and there's this whole other bunch of patients that it's just too overwhelming, they don't really want to listen more and they are just looking at me like well you have two surgical options, what do you recommend, I am going to go with what you recommend and I don't really want to know the pros and cons, I just want somebody to tell me what to do."

Nurse B: "…We can all talk about a patient who did not want to know that information; that does not want to know a bad outcome"

Nurse D: "There are some patients like that"

Nurse C: "But that's a coping strategy"

Nurse D: "Yup"

Nurse E: "It is a coping strategy, so umm, so that presents a real difficult situation as far as education and it's a goal that we have [to educate patients about their disease and prognosis]."

Patient C: "I think for me not knowing creates more anxiety than knowing it, but for some people knowing causes the anxiety, that's the problem right."

Subtheme C: Control

Control was a common theme in the discussions with patients, specifically using education as a strategy to gain control in a situation where most felt vulnerable and powerless. This theme was very evident and consistent in all the discussions with patients; however it was not noted in the discussions with physicians or nurses who only referred to the importance of control with respect to patients' involvement in care decisions. Interestingly, all patients pointed to the need to gain more knowledge of complementary aspects of treatment to enhance a sense of control, as they felt control over conventional treatments was limited. This points to a limit of patient education in this regard, regardless of the amount of information provided about cancer and their

treatment; patients feel powerless about the process and have a general sense of a lack of control. The following discussion highlights this well:

> Patient C: "I'd like to know what I can do for myself. At home, nutrition, sleep and all of that, is it exercise, all that, again it's a little bit of control over your own…"
>
> Patient B: "We are partners right, it's my body, you are doing the medical part of it that we don't have control but what can we…"
>
> Patient D: "What can I do spiritually or emotionally or physically that may not, may not be a medical procedure."

The need to find anything to be able to have control over during treatment is highlighted by the following patient's experience.

> Patient C: "…talking about control, for three days after chemo I only ate white food because if I barfed I didn't want it to be colourful… *laughter*…now how dumb, like when I think about it now, I think you're smart why did you think that? But it was, it was in my head"
>
> Patient B: "It was your way to cope"
>
> Patient C: "I could control the colour of my puke"

In summary physicians, nurses and patients all describe how information can help alleviate some of the emotional toll of diagnosis and help patients feel empowered thus improving coping. The patients highlight the need to have a sense of control; however education does have limits in helping patients achieve this.

Theme 3: Providing Orientation

Healthcare providers identified that a large proportion of the patient education provided at initial visits was aimed at orienting patients to the cancer system so that they would be aware of what to expect and identify resources available to them. In the discussions with patients, multiple participants also identified the importance of system navigation and orientation, however, it was mostly in the context of how it could have been improved or been more encompassing.

Physician C describes the intent of the initial meeting and education session with patients as "…a bit of an orientation session, like not only to the cancer, but to sort of the room that we are in, and how this place works and all of that, right, because it's sort of a complicated, different … so giving a bit of orientation." Nurse A describes the importance of this orientation during the initial visit, "well I think a lot of confusion, and not with just breast but probably other disease sites, is that [patients] don't really know how the treatments are going to play out. Like the order of treatments, why they see certain people before others … so they really come to us and they have either little to none information or they have a bit more depending. Everybody is starting at a different start point." Multiple patients also highlighted this need. The reason why understanding the cancer system, normal time frames and sequence of events are important is highlighted by patient A's experience:

> Patient D: "Even something like [patient A] not knowing that 3 weeks
> before you heard from them (the cancer centre for an appointment) didn't
> mean you were dying next week"

Patient A: "Exactly, like, like I was convinced, you know what how could

they take three weeks?"

Patient D: "…they've given up on me"

Patient A: "Yeah there's nothing they can do, and nobody has, the nerve to

pick up the phone and call me"

In summary, it seems that an important outcome of patient education for initial

visits at the cancer centre is to provide patients with appropriate orientation to the centre,

the sequence of treatments and timing of events. This again highlights that the content of

patient education is not limited to the standard discussion of disease and treatment

options.

Theme 4: Enabling Shared Decision Making

All groups identified education as a facilitator in the process of shared decision-

making. However, limitations of this were noted by the patient group, specifically in

regards to surgical decision-making.

Physician C described how the process of education, communication and decision

making are intertwined in practice: "you want, strong communication to make sure that

you're making value-based decisions and that the ultimate care plan reflects what the

patient's goals are along the disease trajectory. That's not really patient education and yet

education comes into that equation, so I would say values based decision making is a

goal."

Nurse E described her experience in a clinical trial with breast cancer patients

using an educational instruments as part of the study to help patients make treatment

decisions "…that was really interesting, umm, the way people, the way some of the patients actually looked on that and reflected on that [to make decisions]."

Some patients also identified shared decision making as a goal of the education process they experienced and found it generally helpful in that regard. Specifically, when meeting with the medical oncologist, patient J felt "…that was very much, very, very participatory, collaborative, I would say, the whole time it was. And but here are your options: you could do nothing, which I do not recommend, and then you know here's the other options and we would just talk about it and weight it out together." She also felt that having been provided with resources that increased her knowledge of the disease and benefits/harms of treatment helped her participate in the above discussion.

However, patients also discussed the limitation of education in the process of shared decision-making as well. Specifically, the need for time to help process and integrate the information received before they could fully engage in the process of collaborative care. This was especially felt in surgical decision-making where the pressure felt for making timely decisions was high. Multiple participants discussed a similar experience that patient J describes:

> "I would say the initial and I don't know if this is the same but my initial appointment was with a surgeon really urgently… I saw her resident and the first thing he said to me when he came in was so do you know what you have? …so he explained it and then he said you have an option a mastectomy or lumpectomy do you know which one you want? We are

like, no we do not, like within 5 minutes can you please make this

decision…"

In summary, all participants described how increased knowledge can help with

the process of shared decision making and that it would be an appropriate outcome of

patient education. Limitations of this were however described by patients, especially

highlighting the need to allow for time for patients to integrate and process the new

information learned before they can engage in decision making.

Theme 5: Impact on Behaviour during Cancer Treatment

Physicians, nurses and patients identified instances where the education provided

could impact patient behaviour that affects the trajectory of their disease management.

Healthcare providers discussed the importance of providing patients with education so

that they can anticipate and react to expected side effects of treatment in order to promote

safe practice and complete the recommended course of treatment without complications.

Patients were also in agreement with this and recounted how they used information

provided to them to help guide behaviour in different scenarios. However, a unique

theme to the healthcare providers was that increased knowledge could also help improve

compliance with treatment; this was not something that patients identified or discussed.

Education was generally thought to help patients with symptom self-management

and promote safe practices. For example, Physician B describes how educating patients

"to try to anticipate problems that may arise to avoid crises" is important, specifically

reviewing action plans pre-emptively such as "…talking about side effects of

chemotherapy for example and what would you do if you had a fever? What would you do if you had severe diarrhea?" Along the same tone, physician D describes:

> "…the hope is that patient education can contribute to avoiding crises, for example, allowing us to utilize RESCU (an ambulatory clinic created to see sick cancer patients urgently) appropriately, and hopefully to intervene before someone becomes very sick. As opposed someone running into crisis in [the emergency department]. I mean obviously there are going to be circumstances where people are going to get sick and there is nothing we can do about it but certainly there are circumstances where we could have intervened if there had been perhaps better understanding on the patient's side."

Patients also described how they used the knowledge provided to them to guide their responses to side effects or symptoms. For example patient H discussed "…if I had a side effect from something, I'd look it up and you know, is this normal, is this not normal, when are you supposed to call the hospital or when is it ok not to call the hospital." Patient F also provided a similar example of the usefulness of the take home information booklets:

> "For me it was, it's still on my bed side table. I kept it …*laugh...* All of those things right there, as soon as something happened I would be looking and searching. You know I did get a fever one night, so I woke up my husband and I said oh my god I got a fever and we'll have to see how

high it goes cause at a certain point you got to go right. It didn't get there

thank goodness though."

Although all groups described how the information provided to patients can impact their actions in differing scenarios, only physicians and nurses also associated the process of education with patients' acceptability of treatment recommendations.

Subtheme A: Improving compliance

Healthcare providers described how understanding of disease and treatment can be associated with a patient's acceptance of the treatment plan and could ultimately lead to improved compliance. Physician D described, "so if they understand why they are taking a particular drug and maybe how it works, like when I go into tamoxifen, …it's like a light bulb goes off right…and they go oh wow, no one's explained it to me like that and they understand it and I always thought that if they understand things that they are compliant with it better right." Similarly Nurse C comments about the process of ensuring patient's knowledge of disease and treatment is "…to make sure they know what the plan is and why we are doing it. Cause if they understand the why then they'll carry out the plan for the most part and they'll be more comfortable about what we are doing."

In summary, physicians, nurses and patients agree that increased knowledge and education about treatment and its side effects can have effects on patients' course of management and their behaviour responses. Interestingly, patients identify this behaviour as only related to symptom management whereas the healthcare providers also associate it with compliance.

Conclusion

In conclusion, despite the noted differences between groups on certain topics, the underlying major themes identified in this study were similar across all groups. This is reassuring and helps clarify what the major stakeholders in the process of patient education find to be outcomes of importance in education interventions for breast cancer. These outcomes revolved around the following common themes: (1) increasing knowledge, (2) improving coping, (3) providing an orientation to the cancer system, (4) enabling shared decision making and (5) impacting behaviour during cancer treatment.

DISCUSSION

The diagnosis of cancer is a very stressful and frightening time for patients. It is also a time where patients are often expected to participate in complex care planning decisions with healthcare providers. To enable this, healthcare providers need to make attempts to ensure patients understand their diagnosis and management options. Thus, patient education has become an important part of care at cancer centres. However, there still remains considerable debate about the nature and amount of resources that should be dedicated to the process of patient education, and about the effects, merits and limitations of patient education. To address the benefits of education in newly diagnosed breast cancer patients referred to our cancer centre, I initially intended to conduct an intervention study. However, through the process of this inquiry I identified a lack of consensus in the field of patient education about what would constitute a good quality

intervention and a lack of agreement about what outcomes should be used in assessing efficacy. The early part of my thesis research involved demonstrating this lack of consensus about measurement of quality in interventions, and lack of consensus in outcomes: I undertook a systematic review of patient education assessment instruments to identify whether validated measures to assess quality of interventions existed and a literature review of patient education intervention studies to identify whether there was consensus in the field as to what would constitute important outcomes. Unfortunately both these reviews failed to show consistency within the field in regards to what would constitute as a good quality patient education intervention or what was considered as important outcomes to measure.

To properly assess the merits of patient education and advance the field to benefit our patients, there is a need for an evidence-based and a methodologically sound approach for identification of outcomes of importance. Given this knowledge gap that I surprisingly found, I pursued a qualitative study to identify what patients, physicians and nurses would identify as important outcomes for patient education in breast cancer. Once I accomplished this, I could pursue interventional studies in the future.

There are three key findings from my thesis research on patient education. Firstly, through a systematic review of the literature I found a general lack of psychometrically sound instruments developed to assess the quality and outcomes of patient education interventions. In addition, there was no consistent outcome measure used to assess efficacy and a lack of consensus as to what aspects of an educational intervention are important to gauge its quality. The PEMAT was the only one of eighteen

instruments identified that showed evidence of methodological rigour in its development. It showed good evidence of face validity, reliability, and convergent validity but was limited in its criterion validity due to discrepant results in its assessment of quality of asthma patient education material versus colonoscopy patient education materials (Shoemaker et al., 2014). There were no validated instruments identified which had been used in cancer patient education materials. There needs to be an increased emphasis on establishing criterion and construct validity for instruments in the field of patient education. Without agreement on standardized outcome measures and how to best assess the quality of educational interventions there will continue to be large variability in their assessments impeding advancements in patient educational techniques.

Secondly, the review of patient education intervention studies in both the field of chronic diseases and more specifically in the field of oncology also identified a general lack of consensus on the intended effects of educational interventions. Outcomes such as patient satisfaction, improved knowledge, quality of life, recall, coping ability and various symptoms are used without consistency and in variable combinations between studies. This makes it very difficult to assess the relative efficacy of each intervention and as a result also impedes potential progress for educational techniques in the field. There is no clear message from this body of research as to which of the outcomes constitute important ones that should be measured consistently in all studies.

As such, in both areas of assessment of quality and efficacy of patient educational interventions there are no validated measures or general consensus to guide practice. It is unclear as to why this is the case. This finding led to the third and major component of

this paper, a qualitative study aimed to identify outcomes of importance in breast cancer patient education. The themes reported from this study reflect perspectives on general educational interventions offered by healthcare providers in context of routine interactions with patients at the cancer centre (and not about specific educational interventions with defined objectives such as lymphedema teaching class). Reassuringly, despite minor differences, there was consensus amongst the key stakeholders on the important outcomes for these types of patient education interventions. The findings from this study constitute the first step in developing validated outcome measures for patient education interventions in cancer.

In addition to identifying key areas of agreement between patients, physicians and nurses regarding important outcomes of breast cancer education, the qualitative study also shed some light as to why there may be some inconsistency and variability in the discussions about patient education between care providers and patients. When patients think of and describe educational interventions, their needs and goals for education are very heterogeneous and dynamic. They describe the need for education that recognizes that breast cancer and its treatments affect their lives as a whole and not just the aspect of disease treatment itself. On the other hand, healthcare providers who are the most common developers of patient education materials have a much more homogenous view of education. They describe education that is mostly limited to understanding the mechanics of the disease itself and side effects of treatment. Although when they provide education in person they have the ability to be more dynamic and tailor information to the needs of patients. This dynamic and patient-specific aspect is lost when education

interventions rely heavily on pamphlets and brochures, which by intention are generic and applicable to a broad population. It may be prudent to incorporate educational mediums for patients than can provide more heterogeneous and dynamic educational support, such as a web based programs where patients could direct the amount and specificity of information received according to their own needs.

Key common educational outcomes of importance amongst patients, physicians and nurses include patients' knowledge, coping ability, shared decision making ability, directing treatment related behaviour and orientation to the cancer system. Some of these findings are in keeping with the described theories used to promote patient education. For example, the finding that improvements in knowledge are at times related to coping ability in my study are congruent with the transactional model of stress and coping described by Lazarus and Folkman, where information seeking is identified as an important way to support a problem focused coping strategy (Van Der Molen, 1999). Likewise, the finding that education and coping can affect treatment related behaviours in patients is also in keeping with the self-efficacy theory described by Bandura (Bandura, 1977, 2010). In this theory Bandura proposed that a person's self-efficacy is a key factor in the likelihood of them undertaking behaviour change and that self-efficacy can be informed by a person's emotional state and previous experience of success. Patient education in cancer in some instances has the ability to decrease anxiety, increase empowerment and improve coping ability. In keeping with both the theory and the findings of this study, these features of patient education can positively impact a person's self-efficacy expectations, the belief that they can accomplish a required task for a

desired outcome, and as such can increase the likelihood of a desired behaviour response in treatment related stress inducing scenarios, such as seeking medical attention if they develop a fever while on chemotherapy. Improving patient self-efficacy in managing treatment related side effects is integral to safe practice and avoidance of potential serious complications during treatment.

The common themes identified as important outcomes of patient education were also in keeping with some of the published literature on breast cancer patients' views on education. Rager's work with the experiences of self-directed learning in a group of breast cancer patients in Kansas revealed similar themes to ones identified here (Rager, 2003). Rager described how the process of self-directed learning impacted these patients through improving knowledge, increasing decision making ability, decreasing emotional distress and improving self-confidence. The concept of education as an important aspect of the process of shared decision-making was also identified by another study exploring breast cancer patients' perceptions of their treatment decision making (M. O'Brien et al., 2008). In the healthcare specific patient empowerment literature, patient education is described as a mechanism used in the process of empowerment, and as such it is through this process of empowerment that other outcomes associated with education such as change in health behaviours is observed (Aujoulat et al., 2007). In my study, the concept of gaining control and learning to cope through educational processes such as use of internet, peer support and information received from health care providers is in support of this concept. Healthcare providers in this study also described similar process whereby

safe practice through education would only be possible if patients felt empowered and were engaged in the management of their own health.

A notable finding in my study was the importance of peer support for patients during their cancer treatment. Although identifying sources of education beyond the cancer centre was not the goal of this study, a very prominent discussion point amongst all patients was the phenomenon of using peers as both source of support and source of knowledge during the diagnosis and treatment of cancer. Patients described repeatedly how they learned from other's experiences and how this helped them know what to expect and allay fears. The use of peers to improve coping with other aspects of their lives including identifying resources for child care, and managing the impact of diagnosis and treatment on personal relationships were also common discussion points. This finding is in keeping with the theory of social support proposed by Cassel in the 1970s. The theory proposes that social supports, which can be provided as emotional, informative, and practical support or through feedback, can positively impact health outcomes (Cassel, 1976; Gonzalez et al., 1990). It would be interesting in the future to explore and assess the effect of existing or newly developed peer mentoring programs at cancer centres for newly diagnosed patients. Other possibilities include exploring the impact of peer support through use of local web based forums for active cancer patients.

Limitations of the Research

Although I had aimed for purposive sampling to get the viewpoints of multiple patients at different points during treatment as well as a good distribution in age and background, most of the patients who volunteered for focus groups were ones that had

already completed treatment, were very well educated and spoke English as their primary language. As such these results may not reflect the opinions of patients that are from differing cultural backgrounds, ones early in their disease trajectory and older patients. Another limitation was the small sample size of my study. Unfortunately, due to the time constraints of focus group discussions, some patients who were actively undergoing chemotherapy or radiation showed interest but felt too fatigued to come and participate. It was also difficult for some patients to come into the cancer centre for the specific purposes of the focus group given that these were conducted during work hours. As such, it would be important to incorporate these limitations, the amount of time required to participate and the location and timing of focus groups, into plans of future studies involving cancer patients. This could be addressed by either including within the design the option for short interviews on days of treatment or open ended surveys that can be filled out while patients are sitting in waiting rooms. Interpretive description was an ideal approach for the purposes of this study but to ensure generalizability of my findings, future studies may need to consider mixed methods methodologies. Lastly, to add further rigour to the findings of this study another triangulation technique (in addition to the ones used: holding multiple focus groups and having multiple data sources), such as involving a second reviewer for development of the coding matrix and theme generation during analysis of data, could have been used. Despite the fact that I was not able to confirm saturation of themes with groups of physicians and nurses as I had originally intended, the fact that the themes identified by both the nurses and physicians were congruent with

the themes identified by patients and the fact that they also aligned with key themes in the literature lends confidence to the findings presented here.

Implications for Practice

Future studies assessing the acceptability of these themes as outcomes of importance should be pursued using a broader range of participants to clarify these proposed outcomes further. This could be done through surveys of physicians and nurses treating breast cancer across cancer centres in Ontario. Similarly, a short survey asking patients if they agree with these outcomes, and if they believe any important outcomes are missing, could be filled out while waiting for appointments. This would add further validity, and surveys are also more likely to allow for the viewpoints of breast cancer patients who were not able to participate in time consuming focus groups or interviews, such as those undergoing chemotherapy, to be heard. Despite the small size of this study, practical information was gleaned as to what could be used as outcome measures of importance in the assessment of patient education interventions. These include the impact of an intervention on the recipients' knowledge, anxiety, treatment related decision-making and relevant impact on behaviour if appropriate. In addition to the need to confirm whether these results apply to a broader population, another important question that remains is whether increased knowledge does in fact have a positive impact on the other outcomes described such as empowerment, coping, decision making and behaviour during treatment, or is there something else during the process of education that enables these independent of the knowledge gained by patients. There were suggestions in the focus group discussions that healthcare providers used the process of patient education to

build rapport and a therapeutic relationship with patients, maybe it is this aspect of the education process that lends to some of these described outcomes as opposed to improvements in knowledge. Lastly, future studies on patient education interventions should identify how and why certain outcomes are used and aim to use standardized measures of outcomes to allow for comparisons between studies.

CONCLUSION

This was the first study with the specific intent to describe outcomes of importance in the process of breast cancer patient education based on the viewpoints of key stakeholders: patients, physicians and nurses. Despite the variability and inconsistency of outcomes described in the field of patient education research, my qualitative study showed general agreement between patients and care providers that important outcomes of patient education in breast cancer include: improving knowledge, improving patients' ability to cope, providing an orientation to the system, enhancing decision making and positively impacting treatment related behaviour. It is reassuring that the results of my research align with theories used in the patient education literature. Some of the themes identified can be readily translated into practice as measurable outcomes, for example use of knowledge tests for impact on knowledge acquisition, and measurements of anxiety through validated instruments already in use such as the ESAS (Edmonton Symptom Assessment System) instrument (Cancer Care Ontario, 2018b). Some important questions which arose from my findings that warrant further research

include the need to explore incorporation of patient education interventions that are

dynamic and responsive to patient's individual needs, such as use of web based

applications, to explore methods of incorporating peer support early during diagnosis of

cancer and study the effect of increased knowledge on the other outcomes described.

However before this can be accomplished, it is important to continue the process of

developing validated outcome measures for patient education interventions, including

confirmation of whether these proposed outcomes apply to a broader population of

physicians, nurses and patients in oncology. Only after validated outcomes measures are

identified can we aim to assess the true merits of educational interventions and their

impact on our patients.

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APPENDICES

APPENDIX A – RECRUITMENT POSTER

PARTICIPANTS NEEDED

for a study exploring:

"What are the Goals of Patient Education

in Breast Cancer?"

*Have you had a diagnosis of breast
cancer?*

*Are you interested in sharing your thoughts
about patient education at the cancer centre?*

*Purpose: To understand our patients' opinions about benefits of patient
education*

If you would like to participate in a small group discussion or
hear more about this please contact:
Dr. Ghazaleh Kazemi at ghazaleh.kazemi@medportal.ca

APPENDIX B – FOCUS GROUP INTERVIEW GUIDE

"Outcomes of Patient Education in Breast Cancer"

I) INTRODUCTION AND INSTRUCTIONS:

"Hello, my name is Dr. Ghazaleh Kazemi.   Thank you for agreeing to participate in this focus group meeting. Just to remind everyone, I'm looking at opinions about patient education"

[POINT OUT REFRESHMENTS if available, NAME TAGS if used – people should use their first name or pseudonym only].

"In a minute, we will all introduce ourselves – first names only. But first, I would like to walk you through the consent form that is in front of you."

[FOR FACILITATOR: REVIEW INFORMED CONSENT FORM AND ANSWER ANY QUESTIONS ABOUT IT. COLLECT SIGNED CONSENT FORMS AND ENSURE THAT PARTICIPANTS HAVE A COPY OF THE LETTER OF INFORMATION TO TAKE WITH THEM (IF APPROPRIATE FOR THE TOPIC AND GROUP).

Confidentiality: *[READ ALOUD]* Before we begin our discussion of patient education, I want to spend a few moments **talking about confidentiality** and to go over some basic ground rules for our focus group discussion today:

- Everyone's views are welcomed and important.
- The information, which we will collect today, will be attributable *(connected or associated)* to you <u>as a group</u>.
- We will not identify quotes or ideas *any one person* of this group. Because of the nature of small communities or groups, it is possible that people could link participants in this room to quotes in the report. This is why we need to talk about confidentiality.
- We *are* assuming that when we learn about one another's views, they remain confidential. In a small community (group) like this, people are identifiable to some degree by their views and opinions.
- Having said this, and having made these requests, you know that we cannot guarantee that everyone in the room will honour the request.
- Anything heard in the room should stay in the room.
- All voices are to be heard, so I will step in if too many people are speaking at once or to make sure that everyone has a chance to speak.
- I may also step in if I feel the conversation is straying off topic.

- *A*fter the discussion, I will invite you to fill in an anonymous "post-workgroup information sheet" to us help generally describe the kind of people who were part of the group today.
- You can expect this discussion group to last about 60 minutes.

Use of Recorder

- As you will recall, this focus/discussion group will be recorded to increase accuracy and to reduce the chance of misinterpreting what anyone says.
- All audio files and transcripts will be kept under lock and key by the researcher.
- Names will be removed from transcripts. Participants will have coded numbers attached to their name, which only I will know.
- Only the study investigators will have access to transcripts (with personal names removed) of this focus group.
- I will also take notes and write down key points during the focus group.
- We may also use sticky notes and idea boards to help facilitate the discussion today.

[AT THIS POINT, GROUP MEMBERS CAN QUICKLY INTRODUCE THEMSELVES – remind them that it is 'first names only'.]

[HAND OUT ANY MATERIALS (IF APPLICABLE) THAT THE PARTICIPANTS WILL NEED DURING THE FOCUS GROUP INCLUDING PENS OR SCRAP PAPER. GIVE THEM A FEW MINUTES TO READ OVER ANY WRITTEN MATERIAL NOTING THAT THEY CAN MAKE NOTES IN THE MARGINS BEFORE THE DISCUSSION BEGINS.]

II. INTERVIEW

- Focus group discussion begins with the facilitator asking the first question.
- *Open up discussion for general responses of participants to each question.*
- Advise the group: *for the purposes of this discussion "patient education" will be defined as any education offered by health professionals to patients at the cancer center about cancer, treatment options, side effects and survivorship. This could be in the form of a booklet/video, a teaching class, reference to a website or a one on one discussion.*
- **Interview questions**:
  - For the **patient group:**
    - How has patient education affected you?
    - What do you want out of patient education?
    - What do you think the goals of patient education are? What do you think they should be?

- *Prompts: is it to increased knowledge? Decrease anxiety? To help make decisions?*
  - For the **nursing group and physician group**:
    - When you provide patient education, what are your goals?
    - Why do you believe these are important goals?
    - How do you know if your goals are being met?
    - How do you think patient education interventions could or should be evaluated for efficacy?
  - For the <u>patient group</u> after asking the question about goals of patient education:
    - Ask everyone to write down each idea on a sticky note and stick it onto the idea board
    - At 15min ask group to stop and review/discuss all the ideas on the board
- Ask if there is anything we forgot or something important that we should know about patient education *(give 10 min for this)*
- Facilitator will take a picture of the final idea board (patient group)

Wrap-up:

- Introduce the anonymous "background information sheet" now.
- Remind participants "what is said in the room should stay in the room".
- Thank the participants.

APPENDIX C – PARTICIPANT BACKGROUND SHEETS

"The Objectives of Patient Education in Breast Cancer"
Patient focus group background information sheet

> **DO NOT**
> **Put your name**
> **on this sheet.**

INSTRUCTIONS: please fill out the following questions. This will help us identify some basic background information about you.

1. **I am** (please check one):
    [   ] between the ages of 18-35
    [   ] between the ages of 36-45
    [   ] between the ages of 46-55
    [   ] between the ages of 56-65
    [   ] between the ages of 66-75
    [   ] age of 76 or older

2. **Educational background: I have** (please check one):
    [   ] attended high school
    [   ] completed high school diploma
    [   ] completed college/university degree
    [   ] completed professional degree/diploma
    [   ] completed post-graduate degree

3. **Breast cancer treatment:** (please check one):
    [   ] I am recovering from breast cancer surgery
    [   ] I am in the process of making a decision about treatment
    [   ] I am currently undergoing chemotherapy
    [   ] I am currently undergoing radiation therapy +/- hormonal therapy
    [   ] I am currently undergoing hormonal therapy
    [   ] I have completed treatment and being actively followed at the Cancer Centre

4. **In what language(s) are you comfortable reading and speaking?**
    [   ] English
    [   ] French
    [   ] Other: _____

5. **Please identify your ethnicity:**
    _____

6. **Please identify your occupation:**
    _____

"The Objectives of Patient Education in Breast Cancer"
Physician focus group background information sheet

> **DO NOT**
> **Put your name**
> **on this sheet.**

INSTRUCTIONS: please fill out the following questions. This will help us identify some basic background information about you.

1. **I am a** (please check one):
   [ ] medical oncologist
   [ ] radiation oncologist
   [ ] medical oncology fellow
   [ ] radiation oncology fellow

2. **I have been treating breast cancer for** (please check one):
   [ ] less than 5 years
   [ ] 5 – 10 years
   [ ] greater than 10 years

"The Objectives of Patient Education in Breast Cancer"
Nursing focus group background information sheet

> **DO NOT**
> **Put your name**
> **on this sheet.**

INSTRUCTIONS: please fill out the following questions. This will help us identify some basic background information about you.

1. **I am/have worked as a nurse in breast cancer under** (please check one):
    [   ] medical oncology
    [   ] radiation oncology

2. **My previous involvement with patient education includes:** (please check all that apply)
    [   ] Chemo class teaching
    [   ] Out of the shadows presenter
    [   ] Life after breast cancer committee member
    [   ] One on one patient teaching in clinic
    [   ] Developed patient education resource

3. **I have practiced as a nurse for the care of breast cancer patients for:** (please check one)
    [   ] less than 5 years
    [   ] 5-10 years
    [   ] greater than 10 years

<u>**APPENDIX D – CONSENT FORM**</u>

LETTER OF INFORMATION / CONSENT

Study Title: "The Objectives of Patient Education in Breast Cancer"

Investigators: Drs. Ghazaleh Kazemi, Harold Reiter, Mark Levine & Christina Sinding

Local Principal Investigator:
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Purpose of the Study

This study is part of a thesis project for Dr. Ghazaleh Kazemi. You are invited to take part in this focus group because you are a breast cancer patient, or a breast cancer health care provider and we are very interested in your opinion. The purpose of this study is to understand what patients, physicians and nurses believe the benefits of patient education to be so that specific outcomes can be identified to help evaluate our current patient education resources. The information learned in these focus groups will be used to design a set of outcomes to be assessed when introducing new patient education materials/resources for our breast cancer patients.

What will happen during the study?

If you decide to participate, you will be invited to a group discussion "focus group" (a 60 min discussion with 4-5 other cancer patients, breast cancer physicians or nurses). The focus groups of cancer patients, physicians and nurses will be conducted separately. During the focus group you will be asked to share your views about patient education resources at the cancer centre. You may also be asked to write down your ideas and stick it on an idea board. With your permission the discussion will be audio recorded and handwritten notes will be taken. We will also ask you for some background information like your age and education. Your identity, as well as all information gathered, will be treated with the utmost confidentiality. You are free to refuse to participate or to withdraw from the study at any point. This decision will not affect any service you are or will be receiving.

There are no right or wrong answers to the focus group questions. We want to hear many different viewpoints and would like to hear from everyone. We hope you can be honest even when your response may not be in agreement with the rest of the group. In respect for each other,

we ask that only one individual speak at a time in the group and that responses made by all participants be kept confidential.

Are there risks to doing this study?

The risks involved in participating in this study are minimal. You may feel uncomfortable with sharing your ideas in a group. The topic of patient education may bring up memories of a stressful time.

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You can stop to take a break or withdraw (stop taking part) at any time. We describe below the steps we are taking to protect your privacy.

Are there any benefits to doing this study?

Although this research may not benefit you directly, your experience and opinions as a cancer patient, physician or nurse are very important to us and to this study. By participating you have an opportunity to help provide input in identifying important outcomes for our patient education program in breast cancer. This information will be important in creating a method to properly evaluate our patient education resources and in the future benefit our breast cancer patients.

How will you keep my information private?

We will undertake to safeguard the confidentiality of the discussion. We ask the other members of the focus group to keep what you say confidential, but we cannot guarantee that they will do so. We ask that only first names to be used during the discussion. Reports from this discussion will not use any names and results will be attributed to the group as a whole.

The information/data you provide will be kept in a locked cabinet where only the investigators of this study will have access to it. Some information will also be kept on a computer and will be protected by a password. Once the study has been completed, the data will be destroyed.

What if I change my mind about being in the study?

Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. Information provided up to the point where you withdraw will be kept unless you request that it be removed.

Information about the Study Results

The study is expected to be completed by June 2018. The results will be presented to the breast cancer multidisciplinary group and the patient education committee at the Juravinski Cancer Centre.

Questions about the Study

If you have questions or need more information about the study itself, please contact Dr. Ghazaleh Kazemi, at ghazaleh.kazemi@medportal.ca.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT

I have read the information presented in the information letter about the study "The objectives of patient education in breast cancer" being conducted by Drs. Ghazaleh Kazemi, Harold Reiter, Mark Levine and Christina Sinding, of McMaster University.
I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
I understand that if I agree to participate in this study, I may withdraw from the study at any time.
I have been given a signed copy of this form. I agree to participate in the study.

_____   _____   _____
Name of Participant (Printed)   Signature   Date

Consent form explained in person by:

_____   _____   _____
Name and Role (Printed)   Signature   Date