# Didactic or Narrative? Evaluating the Effectiveness of Video Style on Breast Cancer Patients' Knowledge and Communication about their Cancer in the Workplace

#### By Sarah Michelle Rouse Kehoe

A Thesis Submitted to Saint Mary's University, Halifax, Nova Scotia in Partial Fulfillment of the Requirements for the Degree of Master of Applied Health Services Research.

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#### **Abstract**

Currently there is little extant research on patient education comparing multiple media. This mixed design randomized experiment aimed to evaluate the effectiveness of knowledge translation video styles (didactic vs. narrative) for educating women diagnosed with breast cancer on communicating about cancer within the workplace. Participants completed two online surveys administered 30 days apart. Participants received one of four randomly assigned knowledge translation interventions: narrative video, didactic video, narrative infographic handout or none. Statistical analyses of the hypotheses were completed to test the direct impact of intervention type on knowledge, intentions, behaviours and transportation (i.e., feeling immersed). Due to the small sample size (N = 62), there was not sufficient power for the statistical models to detect significant effects of the experimental manipulation. However, effect sizes for knowledge and transportation were sufficiently large to warrant consideration of the potential role of cancer stage as a moderator for the effect of medium.

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#### List of abbreviations

ARCC Canadian Centre for Applied Research in Cancer Control

BCANS Breast Cancer Action Nova Scotia

CCS Canadian Cancer Society

CIHR Canadian Institutes of Health Research

DOCITA Department of Communications, Information Technology and the Arts

HWRBC Healthy Workplace Response to Breast Cancer

KT Knowledge Translation

MSSU Maritime SPOR SUPPORT Unit

NSHA Nova Scotia Health Authority

NSHRF Nova Scotia Health Research Foundation

PBC Perceived Behavioural Control

PIPEDA Personal Information Protection and Electronic Documents Act

REB Research Ethics Board

RTW Return to work

SMU Saint Mary's University

TPB Theory of Planned Behaviour

TRA Theory of Reasoned Action

WHO World Health Organization

#### Glossary

Attitudes An individual's beliefs, perceptions or positions.

Didactic Clearly presenting information to allow the user to efficiently gather

and process the facts presented (Wise et al., 2008).

Knowledge An individual's basic understanding and/or awareness of

information, not necessarily expressed through practice and

behaviours.

Narrative Using personal experiences or testimonials to share information of

lived experiences.

Perceived An individual's perception of their ability to perform a behaviour or

behavioural controls not (Ajzen, 1991).

Behaviour A person's actions (Fishbein & Ajzen, 1975).

Subjective norms Social pressures that influence an individual's behaviours (Ajzen,

1991).

Transportation How individuals are transported into the narrative created by the

storyteller and are affected or changed by the experience (Gerrig,

1993).

Didactic or Narrative? Evaluating the Effectiveness of Video Style on Breast Cancer

Patients' Knowledge and Communication about their Cancer in the Workplace

Education is an important part of a woman's cancer journey. Women who are diagnosed with breast cancer face the challenge of possibly educating themselves on a new and extensive subject matter. There are limited materials on certain topics concerning cancer, including work and cancer. Current patient educational information available for breast cancer is typically produced in an instructional, didactic format (Wise, Han, Shaw, McTavish & Gustafson, 2008) such as brochures, handouts, articles and papers. This approach to providing patient information goes against the research which shows videos are a more effective way to educate patients (Wise et al., 2008; American Academy of Ophthalmology, 2017; Krouse, 2001).

Video has become a popular medium in recent years with the rise of accessible content on video sharing websites such as YouTube, Vimeo and Dailymotion. Videos, by design, are created to be shared and are easily accessed on mobile devices and through social media channels. Within video design there are multiple styles including motion graphics, slideshows, personal experience/testimonials (narrative) and informational (didactic). Personal experience videos have been shown to be more effective than any other written or video educational resource in aiding decision making for patients (Bekker et al., 2013; Schapira, Meade & Nattinger, 1997; Kreuter et al., 2010). In a systematic review of effective teaching strategies and delivery methods for patient education, Friedman et al. found "audiotapes, videotapes, written materials, and lectures" (2011, p. 18) were more effective in increasing an individual's knowledge, decreasing

anxiety and increasing satisfaction, than in-person teachings and discussions. However the systematic review did not distinguish among video styles when reviewing the studies.

Video has become one of the most popular tools in healthcare for educating patients due to the popularity of this medium (Boydell, Gladstone, Volpe, Allemang & Stasiulis, 2012). This format of developing patient educational information is defined by the Canadian Institutes of Health Research (CIHR) as knowledge translation (KT), "a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system" (Canadian Institutes of Health Research [CIHR], 2015). The dissemination tools CIHR references include research-based content and materials developed to educate individuals. This may include tools such as websites, webinars, handouts and videos. This increase in video popularity may be due to eHealth, a contemporary approach to delivering patient education through online and interactive formats.

#### What is eHealth?

The term eHealth first appeared in a 1999 report by John Mitchell for the Federal Australian Department of Communications, Information Technology and the Arts (DOCITA). According to Mitchell's definition, eHealth is "the combined use of electronic communication and information technology in the health sector, comprising digital data—transmitted, stored and retrieved electronically" (Mitchell, 1999). eHealth interventions differ in design, medium, deliverance and content matter. Educational information may be customized based on the end user and their needs. The internet and eHealth have increased in popularity for patient education, specifically for health care

information websites (Diviani, van Den Putte, Meppelink & Van Weert, 2016; Atienza et al., 2007). Content on these websites often includes resources such as basic health information, links to social media channels and videos. eHealth allows patients to self-educate therefore participating more in their own care. The 24/7 accessibly of the internet allows for easy access to eHealth resources, such as video, for health care information. These elements allow for the greatest impact and reach on a targeted population.

#### eHealth Regulation

According to most recent Canadian Census data from the 2011 National Household Survey (NHS), the main content users currently accessing the internet and social media tend to be women (Statistics Canada, 2010c). In all, 79.7 per cent of females used the internet in 2009 (Statistics Canada, 2010a), which increased due to the rising popularity of mobile devices and the development of higher speed internet connections. More than 87 per cent of women between the age of 35 and 54 use the internet regularly (Statistics Canada, 2010b). The rise of research being developed into content for the general population (Tetroe et al., 2008; Straus, Graham & Mazmanian, 2006) has also helped increase eHealth popularity in Canada (Straus, Tetroe & Graham, 2009). Due to the lack of online regulation, anyone can produce and access content available on the internet. As pointed out in the research, the majority of health websites receive considerable hits (visitors) (Diviani, et al., 2016; Gustafson & Wyatt, 2004) whether the content is peer-reviewed research or not. Therefore individuals need to be cautious when looking for health information. According to Statistics Canada's most recently released data, 69.9 per cent of the population in 2009 were searching for medical or health related information (Statistics Canada, 2010a).

#### Impact of Breast Cancer in the Workplace

Currently there is insufficient educational content, video or otherwise when it comes to work and breast cancer. With survival rates on the rise the majority of survivors of working age will return to work after treatment or will continue to work throughout their treatment (Pryce, Munir & Haslam, 2007). Research shows breast cancer survivors face job discrimination, difficulty combining their treatment and work, and physical or mental limitations (de Boer, Taskila, Ojajärvi, van Dijk & Verbeek, 2009). However, the work environment may also be a place of healing and normalcy for women with cancer. Workplaces and colleagues provide psychosocial supports including personal identity—who you are as a person, as well as social support and fulfillment (Aaronson et al., 2014).

The evidence suggests interventions such as available benefits, accommodations, social support and control (over communications and resources) are associated with a positive workplace response to breast cancer (Aaronson et al., 2014; Pryce et al., 2007; de Boer et al., 2009). These positive responses include maintaining job status and returning or staying at work. Women who are diagnosed with breast cancer commonly take time off work during their cancer trajectory to seek treatment and for recovery. Treatment lengths vary for breast cancer depending on the stage and other factors. Time away from work may last anywhere from 4 months to more than 13 months (Drolet et al., 2005). Cancer affects both the employer and employee financially, including direct costs such as disability and indirect costs from missed work days due to sick time and lost productivity. Employment insurance may be an option for some employees, however benefits only last 15 weeks and only pay a portion of the original salary (Service Canada, 2016). Other financial implications of treatment are not always considered, including prescription costs

and alternative therapy costs, which increase the burden on the cancer patient and their family. Some provincial health plans and private health insurance may cover some costs but not everyone has private coverage, again adding to the financial burden.

#### Transportation and Narrative Communication

Interventions addressing breast cancer in the workplace need to be reflective of individuals. Scenarios representative of possible interactions allow for women to see what may happen or what they have experienced. Gerrig (1993) was first to introduce the concept of transportation in relation to novels and the ability they have to transport readers into the story being told. The concept of transportation relies on how individuals are transported into the narrative created by the storyteller and are affected or changed by the experience (Gerrig, 1993). Transportation increases an individual's likelihood of experiencing attitude and belief changes due to the narrative and their ability to be transported into the narrative (Green & Brock, 2000). This narrative persuasion is a good foundation to utilize when developing knowledge translation materials to reach their greatest impact (Appel & Richter, 2010). Narratives may be in the form of videos, plays, written content and may play a role in influencing an individual based on their own experiences through its persuasive means. Transportation does not happen for all individuals. However transportation does occur at a higher rate when sensitive or highly emotional narratives are used (Gerrig, 1993; Green & Brock, 2000; Green, Brock & Kaufman, 2004; Kreuter et al., 2007; Slater & Rouner, 2002), such as narratives relating to cancer.

#### Theory of Planned Behaviour

Currently there is no accepted standard theory for KT evaluations. Several researchers (e.g., Cane, O'Connor & Michie, 2012; Davies, Walker & Grimshaw, 2010) have called for the need to integrate some form of theory into implementation research, or KT research. The lack of KT theories shows a gap in the current body of understanding behavioural interventions and how individuals consume knowledge and act upon it. There is a need to engage existing theory-based frameworks for behavioural-related studies. Eccles et al. (2005) highlight that there is a strong need for a theory-based study design in KT studies. Eccles et al. also mentions the characteristics important to include in theoretical considerations and the relevance of each toward KT studies. Eccles et al. highlights feasibility and efficiency as two areas that need to be included in a KT study, specifically in relation to "method of delivery of an intervention (e.g., written materials, interactive DVD) and methods of delivery of the experiment (e.g., postal questionnaire survey, face-to-face interview)" (Eccles et al., 2005, p. 110).

The main theory chosen and modified for this research was the Theory of Planned Behaviour (TPB; Ajzen, 1985). TPB was adapted from the Theory of Reasoned Action (TRA; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975), which focuses on the links between beliefs, attitudes and intentions and how these all translate into behaviours. The TPB expands the concepts of the TRA to include perception and control in relation to an individual's behaviour. According to the TPB, behaviour is understood as a direct consequence of an individual's intentions, and those intentions are influenced by an individual's attitude, subjective norm and perceived behavioural control (PBC). Figure 1 presents a Theory of Planned Behaviour model.

TPB has been applied to many studies including in the areas of development and delivery of health education and knowledge translation (Lohan, Aventin, Oliffe, Han & Bottorff, 2015; O'Boyle, Henley & Larson, 2001). The TPB has also been the focus of systematic reviews and scoping reviews (Davies et al., 2010; Colquhoun, Letts, Law, MacDermid & Missiuna, 2010) specifically in relation to behavioural changes associated with KT. Both studies show reliable theories, such as the TPB, are necessary and may contribute to the overall impact of KT strategies; however further research is needed in this area (Colquhoun et al., 2010). Ajzen conducted a meta-analysis (Ajzen, 1991) in which he concluded the TPB is an effective theory that is able to measure current day questions which further the understanding of human behaviour.

The TPB has been used in multiple studies to understand individual behaviours in relation to online education. For example, McCaffery, Wardle and Waller (2003) used the TPB to study individuals' knowledge of colon cancer screening practice in order to understand participants' intentions to get screened. McCaffery's (2003) study highlights the adaptability of the chosen TPB model to measure knowledge, intentions and behaviour, including using TPB for evaluating health interventions. McCaffery et al. found that increasing knowledge may positively impact intentions and lead to behaviour changes. Others have also emphasized the importance of knowledge as a precursor to the other components of the TPB model. According to Polonsky, Renzaho, Ferdous & Mcquilten (2013), the TPB assumes knowledge is developed prior to intentions and overall decisions or behaviours; if individuals are not knowledgeable about a subject, they cannot make affective assessments surrounding behaviours. McCaffery et al. found that knowledge was a significant predictor of attitudes, specifically toward cancer.

Recently, although they acknowledge that other variables should also be included in the understanding of behaviour change, Guerin, Toland, Okun, Rojas-Guyler, & Bernard (2018) also consider knowledge as a necessary precursor to the TPB. According to McCaffery et al. knowledge is an important fact on health behaviour change that requires further study.

The TPB has been tested in many studies including in evaluations such as Gustafsson et al. (2013) who examined educational interventions for nurses. TPB has also been endorsed in documents authored by organizations such as the Alberta Health Services (2010) and the National Institutes of Health – National Cancer Institute (Glanz, 2005) to be key in focusing on multi-level strategies centred around policy and community health promotion interventions.

There have been a few vocal critics towards TPB, including McEachan, Conner, Taylor and Lawton (2011) and Sniehotta, Presseau and Araújo-Soares (2014). The two main criticisms of the TPB include its validity, specific to behaviours, and the timeliness of conducting intervention follow-up. In Ajzen et al. 2011 paper he responds to the critics, specifically toward McEachan et al. (2011) to clarify the "inaccuracies" in their interpretation of the theory.

Validity of the TPB is questioned mainly due to the lack of measures for behaviours in the theory. Some critics believe that attitudes, subjective norms and PBC are not specific enough in their measures to predict an individual's intentions or behaviours. Critics such as McEachan et al., 2011 and Sniehotta et al., 2014 have suggested adding variables such as social context to the theory in order to be more specific and improve validity in the theory's measures. Some researchers believe that the

TPB is too strictly focused on the cognitive aspects of the individual and is limited in understanding behaviour if it does not account for such things as beliefs, emotions, habits/past behaviours and motivation (McEachan et al., 2011; Sniehotta et al., 2014). Additional variables have been suggested by researchers as additions to the theory (Conner & Armitage, 1998). Ajzen has argued that the criticisms of the theory for being subjective for certain behaviours, such as emotion, are mistaken. Intentions, according to Ajzen et al. (2011), do include consideration of factors such as motivation, which may influence an individual's behaviour. Including these factors allows for greater understanding of behaviour. However capturing belief is not included due to the "inaccurate and incomplete" (p. 1116) nature of the variable as it can be based on false or incorrect information including fear or other emotions. This then creates inaccuracies in the data. In Armitage and Conner's (2001) meta-analysis of 185 studies, they found evidence to suggest there is strong validity in the TPB measures including in the areas of intention. In Browne and Chan's study (2012) they used the TPB to look at communication interventions in regards to the relationship between intention and behaviour when it comes to mammography. They found strong evidence that the TPB "has utility in predicting health-related and communication behaviour" (Browne & Chan, 2012, p. 667). Ajzen et al. (2011) also states that demographic information can be included in behaviour studies to allow for predictions of such factors as socio-economic status and beliefs for more accurate measures.

This current study follows the approach of exploring the relationship of knowledge as a precursor to intentions and behaviour. Indirect effects of knowledge through attitudes, subjective norm and PBC were not examined for this particular

investigation because the potential direct impact of knowledge on intentions and behaviour was of focus. The current study looks at the influence an educational intervention has on determining behaviour based on knowledge. The online survey used to measure the impact of the experimental manipulation was constructed according to published TPB guidelines (Ajzen, 2013; Francis et al., 2004), however does not directly follow the TPB guidelines due to the specific needs and elements measured in this study. Elements excluded from the TPB model include attitudes, subjective norms and perceived behavioural controls (PBC). These elements were excluded as the study looked to focus on three main variables (knowledge, intentions, behaviours) as they were easily constructed from the interventions used in this study. These three utilized factors are important measurable outcomes that are potentially influenced by KT manipulation.

#### The Current Study

Currently research on patient education fails to evaluate video style or multiple mediums. Studies tend to focus on specific educational tools and minimize the need for understanding effective learning experiences, such as approach and style. Understanding how women communicate in the workplace while coping with cancer needs to be better studied in order to gain an understanding of what their needs are and how patient educational information plays a role. A search of the databases PubMed, PsycINFO, Science Direct and Google Scholar revealed 154 papers acknowledging videos as part of their dissemination efforts to educate patients and one paper using videos to educate individuals about psychosocial effects of illness and work (Robinson et al., 2015). Only one study was found that compared video styles (informational and narrative; Kreuter et al., 2010). Initial search results show there is a large gap in the research on video style

and patient health educational information. It has been demonstrated that internet users view web content for health information including educational health videos that they find on health charity websites, drug provider websites and even hospital websites, but little is known about how these videos are beneficial (Diviani et al., 2016).

There is also little understanding about what extent videos provide support or knowledge to the viewers, who they are, and who and when they are viewing them. Researchers are continually creating and recommending videos as the best format for educating individuals (Bouton et al., 2012; Chelf et al., 2001) but offer no evaluation of the video content and its outcomes. Results of the literature review found most studies tend to compare a video with another form of knowledge translated content, including infographics, PDF handouts and websites. By excluding multiple video styles, the deeper understanding of transportation and patient preference to video style is missed and assumes the presented style is the chosen or preferred style (Schapira, Meade & Nattinger, 1997). It is also unclear what the optimal length for patient educational videos is for retention of information. Recent research has been conducted about student engagement for massive open online courses (MOOC) (i.e., Coursera, edX) and they found 6 minute videos are ideal in engaging audiences (Brame, 2015; Guo, Kim & Robin, 2014). No studies were found that looked into patient education videos and ideal video lengths.

The effect of timing of when an intervention is shown is also a concept that needs further study. The effectiveness of patient education provided during a patient's cancer trajectory is unknown due to possible high levels of stress and anxiety which could

impede the desired effects of the intervention. In order to address this area of timing, cancer stage is included to examine any differences between participants.

The findings from the literature review show little research on comparisons of didactic and narrative content, with no research on didactic and narrative video comparisons. For this study, narrative is defined as using personal experiences or testimonials to share information of lived experiences. Didactic is defined as clearly presenting information to allow the user to efficiently gather and process the facts presented (Wise et al., 2008). Only one study was found that compared didactic and narrative/personal experience videos. Kreuter's study (2010) evaluated how two groups of women were educated on mammography using a narrative video and an informational video, without a separate comparator group (e.g. PDF handouts, websites). Including a comparator group is necessary in determining and measuring the cause of an outcome, rather than only presuming why the outcome occurred. No explanation was given by Kreuter (2010) why a non-video comparator was not used in the study.

Due to the lack of research evaluating video style it cannot be confirmed patient education videos are effective in educating individuals. Without evaluations it is unknown how videos affect or influence individuals' intentions and behaviours, or even if individuals prefer videos. The literature reviewed reveals, for the most part, when videos are evaluated they are only evaluated based on the number of hits they receive rather than based on content or effectiveness. According to Gustafson and Wyatt (2004) eHealth content should be evaluated by more than hits and testimonials, as it is a flawed and outdated perspective. The increase in internet use for patient health information

highlights the need for guidelines on the evaluation of health related content, which currently do not exist.

This research aims to evaluate the effectiveness of alternate versions of a knowledge translation video (didactic and narrative) for educating women diagnosed with breast cancer on the effects of communicating about cancer within the workplace. This research aims to 1) understand the effect of presenting different forms of health information (narrative video, didactic video, narrative infographic handout (electronic), none); 2) understand women's knowledge and intentions on communicating or not communicating about their cancer in the workplace. By presenting women with information while they are currently or have recently experienced breast cancer, this will help us understand if presenting information is useful in educating them. The choice to focus on knowledge and behaviours as outcomes were primarily due to they were areas targeted by the existing video. By including a measure for transportation we will also be able to understand key elements in the videos that women find relatable. The questionnaire will include measures to understand the influence the videos have on their knowledge, intentions and behaviours in the workplace and to observe changes over time (Wave 1 - Wave 2).

#### Hypotheses

The TPB framework was adapted in this research to allow for a greater understanding of the knowledge, intentions and behaviours of women recently diagnosed with breast cancer. Including the element of knowledge within the TPB model allows for a greater understanding of how changes in relation to knowledge may influence overall behaviour change. Knowledge was used as the main measure as it is a precursor to

attitudes, subjective norms and perceived behavioural controls. Knowledge was chosen as the measure of choice for this study due to the straightforwardness of measuring content shown in the interventions (narrative video, didactic video, narrative infographic handout (electronic)) and measuring the level of knowledge gained through each intervention. As in Ajzen et al., 2011, this study also looked at how knowledge influences intentions and behaviours. By testing participant's knowledge from content shown in the interventions it allowed for a measure in relation to intentions and behaviours. See Figure 3 for the KT framework for behaviour change graphic.

Based on the TPB framework and in light of the knowledge translation literature reviewed, the following hypotheses were proposed:

Hypothesis 1: Participants who view an intervention (narrative video, didactic video, narrative infographic handout (electronic)) will have increased knowledge relative to those who are not exposed to an intervention.

Hypothesis 2: Participants who view either the narrative or didactic video will have higher intentions and behaviours scores relative to those who view the narrative infographic handout (electronic).

Hypothesis 3: Participants who view a narrative intervention (narrative video, narrative infographic handout (electronic)) will report increased intentions and behaviours relative to the other three groups.

Hypothesis 4: Participants who view the narrative video intervention will have higher transportation scores relative to the didactic video group.

#### **Methods**

#### **Participants**

Participants were women aged 22 to 58 currently living in Canada diagnosed with breast cancer after 2011 and employed (including self-employed) at the time of diagnosis. In all, 69.35% women reported they were either married or living in common-law unions and 14.52% were divorced or separated, with the remainder indicating they were single. Approximately 66% of participants had children. The majority of participants (83.87%) had completed some form of higher education (i.e., diploma/certificate, undergraduate degree, master's degree or doctoral degree). The majority of participants lived in Nova Scotia, Ontario and Saskatchewan (67.74%). Most women were working full-time (77.27%) at the time of diagnosis, with 43.48% employed full-time during study participation, and 32.26% on medical leave from their employment. Of the 62 participants, n = 16 (25.81%) were diagnosed with Stage 1, n = 23 (37.1%) diagnosed with Stage 2, n = 15 (24.19%) diagnosed with Stage 3, n = 3 (4.84%) diagnosed with Stage 4 cancer; n = 5 (8.06%) were unsure or did not respond to the question. Demographic, health and work variables are presented as frequencies (percentage) in Tables 1 - 3.

#### Recruitment

Participants were recruited through online advertising methods, including the research team's research website (workwellness.ca), provincial and national organizations' websites (e.g. Canadian Breast Cancer Network; Young Adult Cancer Canada; Canadian Cancer Survivor Network), and social media and online community boards (e.g. Kijiji, Twitter, Facebook, LinkedIn). Recruitment posters were circulated and

posted on bulletin boards throughout the province of Nova Scotia. An article also appeared in the local newspaper The Chronicle Herald (McPhee, 2017), both print and online, which advertised the study. See Appendix E for a list of recruitment efforts and Appendix F for recruitment materials.

#### **Procedure**

Data for this online experiment were collected through online questionnaire software LimeSurvey Version 2.50+ (LimeSurvey GmbH, 2016). Interested recruits reviewed an informed consent form online, asking them whether or not they agreed to the terms. By clicking the "yes" button they provided their consent to participation.

Participants were informed their participation was entirely voluntary, and they could withdraw from the study at any time, or refrain from answering any question they wished. Participants were also screened as part of the demographic questions to ensure they meet the basic requirements of the study (i.e., females, currently living in Canada, diagnosed with breast cancer within the past 5 years, were employed at time of diagnosis). Ethics approval was sought from the Saint Mary's University Research Ethics Board (SMU REB) prior to recruitment and implementation of the questionnaires. Approval was received on May 23, 2017.

Participants completed two waves of the online survey administered 30 days apart (Figure 2). During Wave 1, participants were exposed to one of four randomly assigned KT intervention conditions: narrative video (n = 16), didactic video (n = 18), narrative infographic handout (electronic) (n = 17) or none (n = 11). These interventions were built directly into the online survey. The random assignment was constructed through the LimeSurvey software which automatically generated which intervention participants

would receive. Of the N=62 women who completed Wave 1, N=48 completed Wave 2, representing a 23% attrition rate. Further data collection is ongoing to achieve necessary sample size for the expected effects. G\*Power analysis for a mixed ANOVA with 4 groups and an effect size f (i.e.,  $\eta^2/1-\eta^2$ ) = .19 ANOVA would necessitate n=50 participants per cell. Recruitment of this particular population has been very slow, in spite concerted efforts on the part of the researcher and members of her research partnership.

#### Measures

Participants were asked a series of general demographic, health, and employment questions in addition to questions tapping the variables of interest. The reason participants were asked a variety of questions was for researchers to have as complete as possible a description of the sample, given the wide variety of occupational and health statuses represented in what may seem to be a homogeneous sample of women who have experienced the same illness. The questionnaire questions used in this study can be found in Appendix B. For the purpose of this master's thesis, only certain sections and measures were included from the questionnaire. The variables analysed or described in this paper are as follows:

**Demographic.** Participants were asked standard demographic questions including age, gender, education level, occupation, marital status and number of children. See Table 1 for a list of chosen demographic responses with frequencies and means.

*Health.* Participants were asked questions about their current state of health, stage of breast cancer, treatment plan ("Does your treatment plan include surgery?"; "Does your treatment plan include chemotherapy?") and symptoms ("Within the last month, how much have you felt the following symptoms? Rate the extent to which you agree or

disagree that you have experienced each of the following symptoms."). Scales used included Yes/No, open text response and 4-point Likert-type scale, ranging from "strongly agree" (1) to "strongly disagree" (4). See Table 2 for a data on selected health responses with frequencies and means.

Work. Participants were asked questions about their current employment status and their employment status when they were first diagnosed. Their communication at work was assessed by asking general employment questions ("What was your employment status when you were diagnosed with breast cancer?") and questions about their personal experiences of being employed while diagnosed with cancer ("Have you told your supervisor about your breast cancer diagnosis?"). Scales used included multiple answer responses, Yes/No, open text response and multiple 4-point Likert-type scales. See Table 3 for a list of selected work responses with frequencies and means.

Knowledge. Knowledge about breast cancer and work, including options for requesting assistance from co-workers and supervisors, were measured using a series of true/false questions developed specifically for the study. These questions were based on content appearing in the narrative video and narrative infographic handout (electronic). The information contained in the narrative video and PDF infographic were national statistics produced by the Canadian Cancer Society (2013) and the work of Robinson et al., 2015. The questions developed for the present study captured a portion of the knowledge disseminated by the videos, as a KT evaluation theory was not used in the development of the original KT video. Example items included "Breast cancer experiences vary" and "I can learn from the experiences of others". A total score was calculated, with higher scores denoting a greater number of correct answers.

These questions were included prior to the interventions and used to measure the retention of information from the narrative and didactic videos between waves. All content from the questions were included in both videos. Statements directly worded from the interventions (narrative video, didactic video, narrative infographic handout (electronic)) were used to create the questionnaire questions and correct answers were determined based on those. The correct responses from each were summed to create a knowledge accuracy score.

Intentions. The intentions of women asking for accommodations in the workplace were measured using disclosure factor measures (Lennon, Link, Marbach & Dohrenwend, 1989) with a measure of Yes/No ("I intend to talk to my boss about my experience with breast cancer."; "I intend to talk to my colleagues about my experience with breast cancer."; "I intend to ask my workplace for accommodations because of breast cancer-related challenges in doing my job."). All questions were then analysed using responses from Wave 1 and Wave 2 to look for changes. Intentions could only be recorded for participants who indicated that they had not communicated to their colleagues or bosses.

*Behaviour.* This section acts as a comparison to intentions to understand if women were speaking about their breast cancer in the workplace, particularly during Wave 2 after having seen an intervention (narrative video, didactic video, narrative infographic handout (electronic)). A measure of Yes/No was used to reveal if the women follow through with their intended behaviours between Wave 1 and Wave 2 responses (Lennon et al., 1989). ("I have talked to my boss about my experience with breast cancer."; "I have talked to my colleagues about my experience with breast cancer"). This

measure was compared with the intention questions ("I intend to talk to my boss about my experience with breast cancer."; "I intend to talk to my colleagues about my experience with breast cancer.") to show any behaviour changes from Wave 1 to Wave 2. Behaviour was also measured by inquiring about those who have not spoken about their breast cancer at work.

*Transportation.* Transportation was measured using questions from Green and Brock (2000) and edited to be representative of this study's use of video ("When I was watching the video, I could easily picture the events in it taking place."; "While I was watching the video, activity going on in the room around me was on my mind."; "I could picture myself in the events described in the video."; "After watching the video, it was easy to put it out of my mind."; "The video affected me emotionally."; "I found my mind wandering while watching the video."; The events in the video are relevant to my everyday life."; "While watching the video, I had a vivid image of myself."). These questions were only given to the participants who viewed the videos to allow for comparison between the narrative and didactic user groups. These transportation questions were measured on a scale of 1 ("Very much") to 7 ("Not at all"). Cronbach's Alpha for this scale was rather low ( $\alpha = .57$ ). With the deletion of one item (i.e., "When I was watching the video, I could easily picture the events in it taking place"), a more acceptable level of internal consistency was achieved ( $\alpha = .77$ ). This item was removed from the calculation of the mean transportation scores.

Knowledge Translation Intervention Preferences. General questions about education and KT were included to understand the participants' needs using questions developed by the researcher for this study ("How do you prefer to receive your health

information?"; multiple answer response question). A personal advocacy activity scale (Hawley et al., 2016) was used to include questions regarding patient education resources ("In the past month, how many times have you gotten new information about breast cancer or breast cancer resources?"; "In the past month, how many times have you used resources at work to get your breast cancer-related needs met?"). The responses for these questions were "Not at all", "1-4 times" and "5 or more times". These questions were given to all participants no matter their intervention.

Emotions. The Differential Emotions Scale (Izard, Dougheny, Bloxom, & Kotsch, 1974) was used to measure twelve fundamental emotions (anger, contempt, disgust, fear, guilt, hostility, interest, joy, sadness, shame, shyness, surprise) in relation to the narrative video, didactic video and the narrative infographic handout (electronic). See Table 4 for a list of selected KT responses with frequencies and means. Another question developed for this study was ("I am glad to see this content at this point in my breast cancer journey."; Likert scale, 1 ("Strongly agree") to 4 ("Strongly disagree")), which was given to only to the participants who viewed an intervention (narrative video, didactic video and the narrative infographic handout (electronic)).

Open-Ended Additional Comments. Participants were also given an opportunity to add additional comments with the final question that included an open text box response ("Do you have any further comments you would like to add?").

#### **Knowledge Translation Interventions**

Participants were randomly assigned through the online questionnaire software, LimeSurvey, to one of three knowledge translation intervention conditions or a no intervention control group upon completion of the demographic, work, behaviour,

intentions, and knowledge portions of the survey. Upon viewing the intervention, they completed the knowledge translation evaluation questions.

Videos. A narrative video existed on the topic of breast cancer and work (Robinson et al., 2015). The narrative video, "I Wanted You to Know", was created during Phase One of research conducted by the Breast Cancer Survivors' Work Wellness project, led by Dr. Lucie Kocum, of Saint Mary's University, Halifax, Nova Scotia. The video contains voiceover statements of researchers and survivors depicting the words of the women with breast cancer whom they interviewed during the research study. The video is approximately five minutes in length and is intended to educate women diagnosed with breast cancer, and their employers and co-workers, about the challenges of discussing breast cancer in the workplace and how the workplace plays a role in the needs of women with breast cancer. One main reason the video was created in a narrative style was to help women diagnosed with breast cancer relate to the women portrayed in the video and understand their experience is not uncommon.

For this research the existing video was adapted as the original video file did not exist and therefore creating a didactic adaptation could not be easily duplicated. All efforts were made to duplicate the original video to maintain the authenticity of the research and its creators. The original creators and researchers gave input on the development of and changes to the new video, as well as thesis committee approval before development. In order to duplicate the video, a storyboard document was created to ensure the video's content is represented both equally and accurately (Appendix C). All content remained the same for both newly created videos (narrative and didactic) including pictures, music and timing. One exclusion to this was the text appearing on the

slides. The text in both videos was modified to best reflect the same line length and word count in order to maintain continuity. The didactic video shows non-narrative text in place of the personal experience narrative from the existing video (e.g. *Narrative* - "I asked them not to tell..."; *Didactic* – "Some women ask others not to tell..."). Voiceover was not included in either newly created video, which is a change from the original, as it was considered a narrative element which could influence participant responses. Only written content from the videos were evaluated. Both videos were created using the video production company, TECHNA Institute for the Advancement of Technology for Health, which is a part of the University Health Network (UHN), which specializes in developing healthcare specific KT. Both videos are only available in English.

The "I Wanted You to Know" video was based on the themes found from a study conducting interviews with working women (NSHRF: 1329; Robinson, Kocum & Loughlin, 2014). The video is structured into 7 sections including credits (Appendix C). Within these sections are slides detailing the women's thoughts and experiences with their colleagues and workplaces. The below descriptions are from the updated video but both the narrative and didactic videos maintain the integrity and originality as best as possible to the original. The videos begin by introducing the statistics ("Breast cancer will affect almost 17,000 working women this year in Canada") and include the reasoning for the videos creation (slides 2-4). The videos then transitions into the women's stories and concerns (slides 5-7) including calling in sick a lot and discussing their diagnosis with an employer. The videos then transition to the needs and preferences of the women with breast cancer in the workplace (slides 8-15). This includes conversations with employers and colleagues (Narrative video - "I asked them not to tell"; Didactic video -

"Some women ask others not to tell"), emotions they faced (Narrative video - "I didn't want to cry..."; Didactic video - "Some don't want to cry..."), and their intentions for discussing their diagnosis (Narrative video - "I wanted other women to learn from me"; Didactic video - "Some women want other women to learn from them"). The videos next section includes describing what helped them, specifically expressing concern and letting the woman know throughout the course of her treatment that others at work were thinking about her (slides 16-23). The content included in this section included offerings of help (Narrative video - "Do you want me to call anybody?"; Didactic video - "Offering to call people") and showing of concern by employers to the women with cancer (Narrative video - "They emailed just to say, I'm thinking about you"; Didactic video - "Sending an email just to say, thinking about you"). The next section shows the contrast of the previous section to highlight the things that others did that hurt them (slides 24-28). This included how employers and employees communicated (Narrative video - "Not once did my boss call..."; Didactic video - "Employers not calling...") and how others felt uncomfortable (Narrative video - "My boss was uncomfortable"; Didactic video -"Employers may be uncomfortable"). The final descriptive section of the videos is a summary and outlook (Narrative and Didactic video - "Most women recover and continue at their jobs") (slides 29-31). The narrative and didactic videos both conclude with credits and an explanation of content included: "Original comments have been paraphrased for this project. No images of participants were used" (slides 32-34).

Narrative Infographic Handout (Electronic). The narrative infographic handout (electronic) was used to compare the knowledge, attitudes and behaviour responses of participants against the video groups as an alternative intervention format style. This aids

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in understanding what patient education format is preferred and the effectiveness each have on educating participants. The narrative infographic handout (electronic) was developed specifically for this study and was based on the narrative video which includes images and text taken from the narrative video (e.g. "Most women with breast cancer recover and continue at their jobs"). The narrative infographic handout (electronic) document is only available in English (Appendix D).

#### **Results**

#### Assumptions and Manipulation Check

Listwise deletion was used to remove 17 cases from Wave 1 who did not complete Wave 2; more sophisticated options for imputation of repeated-measures missing data, such as full information maximum likelihood, were not used, given they are not readily available in SPSS. Outcome variables were checked for univariate outliers, separately for each condition in Wave 1 and for Waves 1 and 2 separately using  $\pm 3.29$  as the cut off criteria; none were found. The data were also checked for by group for normality, homogeneity of variance, and homogeneity of slopes for Wave 2 regressed onto Wave 1 among the four conditions. These assumptions were met satisfactorily. The manipulation check question, asking participants to respond to a completely arbitrary request to follow a specific instruction, was reviewed for accuracy. All responses were retained but data were checked further for incorrect responses to ensure there were no irregularities or abnormalities due to inattention, such as response sets. This step was taken as participants may have been distracted due to their current health state. The last verification was a test to see if random assignment worked to equalize the groups with regards to their pre-test levels of knowledge and transportation. There were no significant differences among group means for either knowledge, F(3, 37) = 1.59, p = .208,  $\eta^2 = .11$ or transportation, F(3, 37) = 0.11, p = .742,  $\eta^2 = .01$ . However, given the medium to large effect size for knowledge of 11% (and low statistical power of .38 to detect a significant difference), further descriptive follow-up was warranted for knowledge. Indeed, Figure 4 shows that knowledge seems to be higher for the didactic group at the outset of the experiment, before the manipulation is introduced. As a result, analyses of covariance

models were used to test the impact of knowledge translation intervention on Wave 2 knowledge, adjusting means for differences in knowledge at Wave 1.

#### **Analyses**

The four proposed hypotheses were tested with SPSS Version 24.0 (IBM Corp., 2016) using two sets of analyses. The first set was a series of two 4 (Knowledge Translation Type) x 3 (Cancer Stage) ANCOVA models with Time 1 Knowledge as the covariates; there was not sufficient power to include age, income, and education as additional covariates, though once data collection goals are met, those covariates would be important to include. Specifically tested was the impact of Knowledge Translation Type (narrative video, didactic video, narrative infographic electronic handout, none) on knowledge and transportation over two time periods, spaced 30 days apart (Table 5). Stage of cancer was included as a possible moderating factor, specifically Stages 1, 2, and 3/4 combined (as there were not enough respondents at stage 4 to test that group individually). Cohen's (1988) effect size classification was used to understand the potential meaningfulness of effect sizes for non-significant effects (i.e.,  $\eta 2$ = .01 small, .06 medium, and large .14 effects).

The second set of models planned were logistic regression models with a similar set-up to the ANCOVA models, but with binary outcomes: intentions to disclose or disclosure to boss and colleagues (yes or no). Due to the low frequency of changes in disclosure intentions and behaviours over the course of the month (i.e., 1 additional disclosure for each of the intervention groups; no increase in the no treatment control group), these models could not be tested (see Table 6). Instead, a review of the reported

frequencies and written responses to these questions was conducted to elucidate intentions and behaviours qualitatively.

**Knowledge.** A 4 (Knowledge Translation Type) x 3 (Cancer Stage) analysis of covariance model was tested on knowledge scores, controlling for pre-test knowledge. As could be expected given the low statistical power, only the effect of the covariate was significant, F(1, 21) = 11.49, p = .003, partial  $\eta^2 = .35$ . The effects of Knowledge Translation Type, F(3, 21) = 0.39, p = .76, partial  $\eta^2 = .05$  and stage, F(2, 21) = 1.62, p = .22, partial  $\eta^2 = .13$ , were not significant, though the latter effect size of 13% was between medium and large, suggesting a meaningful difference among the stages of cancer might be observable with a larger sample size. Figure 5 compares average knowledge for the different stages of cancer. Knowledge appeared highest among women with Stage 2 breast cancer.

The Knowledge Translation Type x Stage interaction was again not significant, but potentially very meaningful, given the large effect size of 30%, F(6, 21) = 1.50, p = .23, partial  $\eta^2 = .30$ . This interaction is displayed in Figure 6. It appears that the narrative condition may have had the largest impact on knowledge for women at Stage 2 breast cancer. The infographic may have had the next highest impact, which is understandable, given it was based on narrative information. Videos appeared to be less effective at Stage 3, when the infographic or even no information seemed to yield higher knowledge scores than either video. Follow-up comparisons were not powerful enough to detect any differences, and are not reported.

*Transportation.* A Knowledge Translation 2 (Video Type) x 3 (Cancer Stage) factorial ANOVA model was applied to transportation scores (Table 8). Note that

because this variable was only measured for participants in the video conditions, it was even more severely underpowered. It is not surprising, then, that none of the effects was significant (see Table 7). Only Stage emerged as a potentially meaningful effect with its large effect size, F(2, 8) = 0.68, p = .53,  $\eta^2 = .15$ . See Figure 7 for a plot of the transportation means. As with knowledge, transportation was observed to be highest among women with Stage 2 breast cancer.

Intentions and Behaviours. Responses to several qualitative questions were reviewed to gain further insight from participants about participants' opinions and thoughts that were not fully captured through the quantitatively analyzed questions. A total of N = 20 participants provided written responses to questions asking them if they discussed their diagnosis with their boss and/or colleagues, and to provide any other comments they wished at the end of the survey. Of these participants n = 5 were in the narrative video condition, n = 6 in the didactic video condition, n = 5 in the narrative infographic handout condition and n = 4 participants did not receive any intervention.

Written comments were read and re-read by the researcher to find any commonalities or "theme-like" connections. The researcher grouped the written responses under three headings: education, support, comments about the study and interventions. Although this is not a formal thematic analysis, the quotations elucidate some of the considerations and struggles of women with breast cancer *in their own words*, as well as their impressions of the knowledge translation materials presented to them. Given this study is a unique and new endeavour in this population, it was important to collect as much data as possible, and capture the women's voices as they shared their experiences.

Education. Participants were asked about why they decided to talk to their boss about their experience with breast cancer. One woman wrote, "I feel that if survivors share their experiences with breast cancer, it will help others if they are diagnosed as well as educate people about the impact breast cancer has on one's life (physical, emotional, mental)."

When asked about talking to their colleagues about their experience with breast cancer and the things they considered, one woman wrote, "If I share my experience, it helps me accept what has happened as well as educate others about this disease and experience." Participants also tried to explain the importance and the need to educate others on the important elements and topics of a breast cancer journey. One woman wrote:

I really just want to say that I feel passionately about his topic. My breast cancer experience has left me feeling strongly about how we talk about serious illness in the workplace. I am a Bank Manager with [Bank name] and have had an overwhelmingly good experience, however; there is still opportunities for education. Throughout my journey, I was saddened by some of the stories that other women told me, especially those working in small business.

Another woman encouraged the narrative of the individual as cancer is not the full story but rather a chapter in life.

Breast cancer is a disease that you are living with, like any other cancer or chronic illness it takes work and perseverance. However, it is not 'who' you are. It is important at work to set in place what you need to work effectively, and have a healthy, supportive environment. Once this is accomplished get on with your work, and if you don't enjoy your work, change your job. But that has nothing to

do with your cancer diagnosis. Illness has become part of your life story, but don't make it your whole story.

**Support.** Some women did not share their diagnosis with the workplace. Most responses from the participants who did not communicate were due to the lack of support and understanding by their employer or colleagues. Responses included:

While I did advise my supervisor, I did not really sit down with any co-workers to discuss my cancer. Obviously, as it became clear that I was not well, most people would ask my husband, or my supervisor. People are not comfortable discussing cancer, it is to [sic] common and no one wants it, so they don't look directly at it.

Also, I find that the advertising for breast cancer makes it look like a walk in the park. Many times have I heard, "at least you got the easy one." Shocking, really.

One participant also stated: "Only female working and the men don't understand or know how to react".

One participant shared at the end of the survey the comment about her experiences about returning to work after cancer, "I think the hardest thing about returning to work is people see me and think I'm 'fine' only I'm not always fine. I'm still dealing with side effects from it all. I will never be the same again."

Showing support and compassion is an important element in a woman's cancer trajectory.

One participant shared her experience of fellow colleague's experiences in comparison to her own.

When two of my colleagues were diagnosed with cancer, I threw fundraisers and raised over \$10,000 for each of them. When I was diagnosed, I didn't even receive a card from anyone at work. When I returned to work, my new manager was very

nice, I have another new manager now and I'm feeling like a hot potatoe [sic].

Genuine and long term concern is important. Authentic compassion is also important, Many women may return to their jobs but many feel differently and are seeking greater purpose and meaning in life after cancer.

Comments about the Study and Interventions. Only two participants commented on the actual interventions themselves. One participant commented on the narrative video as she would like to see it be more relatable:

The video was a little slow and lengthy and you may want to capture that people's diagnosis can change quite soon after their original. It may be helpful to have some questions to clarify that situation if it is helpful info.

One participant who viewed the didactic video stated, "great video. maybe put the fact that the actual people were not shown in the video up front as alot [sic] of those people looked like models and not that realistic."

There were no comments from participants who viewed the narrative infographic handout (electronic) on the intervention. There were no comments from participants who received no intervention stating they wished to receive an intervention.

*Emotions*. The Differential Emotions Scale (Izard et al., 1974) measure was not properly included in the study so we could not measure the results as per the scale, however a percentage for each response was calculated based on the responses. Women who responded to the question, "How did viewing the content make you feel?" reported feeling multiple emotions after viewing an intervention (19 experienced negative emotions; 15 experienced positive emotions). The most common response for this question was "Interest" (33.33%) after seeing an intervention (narrative video, didactic

video, narrative infographic handout (electronic)). Women also reported feeling sadness (30.56%) and fear (8.33%). This shows that even though the information could be beneficial, negative emotions, such as sadness and fear, need to be better understood when developing educational materials, especially during vulnerable times such as having cancer.

Some research has shown that pamphlets are not effective in educating, nor very well targeted towards the correct audience (Wise et al., 2008; Gatherer et al., 1979). In the current sample, the PDF infographic appeared more beneficial to women diagnosed with cancer at Stage 2 or beyond. It is possible that the PDF infographic used in this study bolstered knowledge because it was actually in narrative format.

#### Discussion

It is expected in 2017, a total of 26,300 Canadian women will be diagnosed with breast cancer (Canadian Cancer Society's [CCS] Advisory Committee on Cancer Statistics, 2017). The Canadian Cancer Society predicts breast cancer cases in Canada will increase 55.4 per cent by the year 2032 (CCS Advisory Committee on Cancer Statistics, 2015). Despite the increase in cancer rates, cancer survivorship is on the rise (CCS Advisory Committee on Cancer Statistics, 2015). This improvement in the prognosis of individuals diagnosed with cancer is due in part to the increase in health promotion and education, specifically towards early detection of cancer as well as increasing the general public's awareness of cancer and its risk factors. The purpose of this research was to understand the influence of video style for educating women with breast cancer about communicating with their workplace about their needs. Three interventions were developed to test the proposed hypothesis that a narrative intervention would yield the strongest effects, increasing knowledge and evoking the strongest relatability among participants. The results were unable to reveal definitive support for the hypotheses due to the small sample size. More data would allow for a more powerful analysis and stronger conclusions. However, due to the substantial size of the effects, some potentially meaningful conjectures can be explored.

## Knowledge May be a Matter of Timing

Education plays an important role in increasing knowledge. Although this study was underpowered, and thus we cannot draw conclusion based on the data, the effects seem to suggest that disease course and the medium by which information is delivered might be important in bolstering knowledge. Women diagnosed with Stage 2 breast cancer seemed to have more knowledge than women diagnosed with breast cancer at

other stages. Cancer and work-related knowledge among women seemed to increase for those diagnosed with Stage 2 breast cancer who were shown the narrative video as opposed to the didactic video, PDF infographic, or no information at all.

The current study found that only 19 women (42.22%) at Wave 1 reported having the knowledge they feel they need about breast cancer. This result is supported by the response that women are educating others about their experiences (73.33%) at Wave 1. Also an important consideration is that knowledge appeared lowest among women diagnosed with Stage 3 or higher who were shown videos. The increase in knowledge in women who viewed the narrative video who were diagnosed with Stage 2 is an interesting finding. To understand this result a subject matter expert was consulted who has worked in the cancer sector for over 10 years and is also a breast cancer survivor. Her initial thoughts were people take Stage 2 "more seriously than Stage 1." She explained their diagnosis tends to be "scarier" but "still manageable in terms of recovery". Stage 1 is still a scary prospect, however "it can be seen as 'lucky' - lucky that it was found early; lucky that it was small; lucky that the cure rates are so high." Stage 2 can also mean the cancer has grown and therefore is more unknown. Stage 3 she states was "too scary to think about and therefore people tend to hide themselves from too much information." And Stage 4 is "too close and they feel the cancer is aggressive and more dangerous." This may result in women with Stages 3 and 4 not allowing themselves to be transported into content. If women do not see themselves in the narrative they therefore cannot be transported. Same goes for Stage 1, if women do not feel the content is relevant to them they may not be as involved in it as much as those with Stage 2. Both of these audiences may require another more tailored piece of KT to meet their needs. Another consideration may be that the content is not relevant to them, as we can see in this sample, that sometimes no information could be better than information presented in the wrong medium. Again, we cannot draw definitive conclusions beyond chance factors, given the small sample size. It is possible that with more data or by including other variables (i.e., beliefs, attitudes) these results could appear different then what was found in this study. More research is needed around this finding.

## Intentions and Behaviour

Given that knowledge is seen to be a major influence in intention and behaviour changes (McCaffery, Wardle & Waller, 2003; Occa & Suggs, 2016), it would be important to know that knowledge might be bolstered among women at a particular stage of their disease. The behaviour change targeted by the knowledge translation content was intention to talk to one's workplace about one's cancer, and the actual behaviour of doing so. In fact, most women had disclosed their diagnosis before their participation in this study. Furthermore, because of the small sample size, we were unable to detect sufficient changes statistically. Although we can observe a slight increase in frequency of disclosure in the three knowledge translation conditions as compared to no increase in the no information control condition, it would be an invalid to suggest that this change suggests the possibility of anything above chance levels.

## Transportation and Audience

It is worthy of discussion how cancer stage may determine how immersed women may become based on the medium used. It is possible that video is not the best medium for educating women at early stages of cancer (Stage 1), or at later stages (i.e., Stage 3 and beyond). However it cannot be dismissed, women at Stage 2 reported having been

transported by the experience of the videos, able to fully concentrate on the information presented and could picture themselves in the information presented. Zhang & Siminoff (2003) have found that the higher the stage of cancer the more difficult communication becomes. This could be due to the impact that the more serious the stage the more vulnerable a person could become. Factors that contend with an emotional response include the psychological changes from the treatment as well as the emotional response of being diagnosed with cancer (van der Molen, 2000). These factors also vary in their timing therefore the need for support and information changes throughout the cancer trajectory.

The narrative video (Robinson et al., 2014) was created with the intent of educating both employers and women, who have been diagnosed with breast cancer, with information about working and having cancer specifically about communicating to colleagues. In their interviews with breast cancer survivors, Robinson et al. (2015) found that survivors had a more positive experience when they had control over workplace communications about their cancer throughout the trajectory, from diagnosis onward. Interviews with managers revealed more positive experiences when they reported having more control through adequate resources to offer their employee (Robinson et al., 2015). Women find comfort in talking about their experiences, as found in this study and the "I Wanted You to Know" video creation study (NSHRF: 1329). It is possible that women diagnosed with Stage 2 breast cancer want to or enjoy listening to other women's experiences with cancer, but that women diagnosed with breast cancer at other stages do not. More research is needed to probe the possible negative and positive effects of exposure to narratives as providing this information could cause possible harm.

## **Experiences of Cancer**

The research shows that being diagnosed with cancer is a traumatic event (Taylor, 2000). Taylor found a diagnosis of cancer can change and often harm a woman's outlook. In order to reconstruct the view's on life after a cancer diagnosis a woman needs to go through multiple steps. These steps include: "deep introspection or reflection, prayer, talking with others about this experience, attending religious services or support groups, reading pertinent materials, and keeping company with family" (p. 784). Therefore it is believed that women need to be at a particular point in their breast cancer journey in order to understand and comprehend what cancer is, what is going to happen or what has already happened to them. Taylor (2000) interviewed 24 recently diagnosed women and found that once they have gone through this process of understanding they then are able to re-establish their sense of purpose, which is often the desire to help other women with breast cancer. By assigning meaning to their cancer diagnosis this allows women to begin the process of healing by talking to others and telling their story.

As found in many studies, women are interested in sharing their experiences (Robinson et al., 2015; Taylor, 2000; Kreuter et al., 2010), however there are very few studies where women have expressed desire to hear a possibly distressing story about cancer while currently going through cancer, or even after cancer. Cancer removes or destroys this previously conceived notion of identity (Taylor, 2000). Cancer is directly attacking and changing a women's identity. They therefore have to reshape their identity and purpose (van der Molen, 2000). In order to do this, some women prefer to share their experiences and talk to others about what they are going through. The comments included in the questionnaire show how important it is to foster a work environment built on

communication. Some women may not feel comfortable communicating for a number of reasons, however engaging a conversation before illness could allow for more open dialogue when needed. By talking about their experiences, this allows women to use this method to help them recover and move forward from their cancer diagnosis.

In the original narrative video (Robinson et al., 2014) the women interviewed stated they wanted others to "hear women's stories" and "I wanted other women to learn from me". Robinson et al. (2015) did not report any women wanting to hear about the possibilities of what could happen or wanting to hear about other women's experiences. It is possible that at certain stages of cancer, women want to hear other women's stories; at other stages, they may not. Also one major missing piece of this is that the audience is never specified. It is unknown as to whom women wish to tell their stories. This leaves a gap in the knowledge for researchers who develop educational content. Even though we heard in this study and Robinson et al. (2015) that women with breast cancer want to tell their stories, the audience to whom they tell these stories is never specified by the female participants. This leads to ambiguity in developing patient education information. By creating videos about women's experiences this runs the risk of imposing a specific story on a woman, which may not be correct or meaningful to the woman as shown in this research. By showing women with breast cancer a video about others' experiences in attempt to make women feel they are not alone in their journey, it is possible viewing the videos made them feel less special or unique. Women with breast cancer want to share their stories with other women with breast cancer, to let them know they're not alone in their experience, but perhaps women in the midst of the struggle possibly don't see value in others stories. It is also interesting to point out that women who did not want to tell

their story at work were still interested in sharing their story for this research study.

Consideration needs to be made when creating KT materials by first understanding the factors, such as stage, that may influence a woman's ability to process the information presented.

## KT Evaluation Framework

Educating individuals on a particular topic does not always lead to behaviour change. As seen in this study more questions were raised about how KT influences and impacts women with breast cancer. In order to properly evaluate the "I Wanted You to Know" video (Robinson et al., 2014), the video would have had to be developed with intended outcomes. Ideally each section of the video would have had specific objectives and measures attached to each section and each slide to fully understand the effect the video has on its audience. The video would have also been measured using multiple audiences (e.g. employers and women with breast cancer) as intended in the development stage. An evaluation on the procedure and lessons learned in creating the video would also be useful in understanding how to create a KT video. A framework specifically for evaluating KT materials would be a useful tool for understanding participant outcomes and the long-term roles and impact of developed KT materials. For this research the TPB was used as a framework for understanding the influence of knowledge and intentions have on behaviour.

Using the TPB allowed for a measure of behaviour and intentions and the impact KT interventions may have on a sample. This study adds to what we know about both the strengths and the weaknesses in the TPB. By using a broad construct of TPB it allowed for alternate measures (e.g. transportation) that better reflect the purpose of the study. The

TPB framework does not capture all influences on behaviour, however including the TPB allowed for structure around knowledge and intentions. This research shows the weakness in the components relating to intentions and behaviours. It is important for researchers to understand and include all elements so they can develop future interventions that specifically focus on areas that have been found to modify or change behaviours.

The narrative video was used to test if an emotional response to patient experience would have a greater impact on outcomes than a factual and instructional didactic style video. Narrative media tend to influence individuals because of the video's ability to transport viewers who rely "heavily on what they see, hear and read rather than on what they experience directly" (Bandura, 2004, p. 78). Bandura believes the individual identifies with and is motivated by narrative mediums as the stories are easier to identify with. These very preliminary results found that showing participants the experiences of others with cancer through the interventions increased their awareness of the negative and positive effects of managing expectations in the workplace, but possibly only if they were diagnosed with Stage 2 breast cancer. At other stages, this information may have no effect or possibly a detrimental effect.

## **Limitations and Future Research**

The primary limitation to this study was the small sample size. The target sample size was established using a combination of statistical and practical considerations. Using G\*Power, it was determined that at least double the sample size would be required to achieve significance at a power of 80%, should the large effects observed in this sample hold upon continued data collection (Faul, Erdfelder, Lang & Buchner, 2007). However

just because there is no significant findings it does not mean there is no effect. This research revealed several possible meaningful patterns, given their large effects. It also revealed a gap in the knowledge around audience and cancer stage therefore more research is necessary to advance the research in knowledge translation resources.

A consideration of the low participation rate at Wave 2 needs to be considered for an attrition bias. However an analysis was performed on the cross-sectional links of participants and variables and found no difference between the groups. It is not possible to say the reason why people did not complete the questionnaire, however a review of the demographics was completed and nothing emerged. A possibility for the low response rate could be due in fact to the length of the overall questionnaire and the timing required to complete. Repeated testing may also lead to bias in responses. Participants may remember their previous responses and answer accordingly. Missing data was an important element of the analysis and all efforts were taken to balance out the effect, however again the low response rate played a role in the data. We cannot assume as to why some participants partially completed the surveys (Wave 1 and Wave 2) or did not respond at all to Wave 2. It does need to be taken into consideration that the women responding are going through a difficult time and may not be focused on learning which may explain the results. The questionnaire was chosen as the measure of choice for this study because of the ease of collecting data during this difficult time in the participant's life. Due to a small sample size, it is recommended the larger study include more participants and explore in greater detail the connection between intended audience and interventions, specifically the videos.

The measure used for knowledge may include attitudes, beliefs and sub-knowledge. However in using an existing video, knowledge can only be abstracted with that of which is presented. With future study and better KT development knowledge should be measured based on subjective methods as some items did not have a right or wrong answers.

A strength of this research was the demographic representation of the population. This study (N = 62) was able to recruit from the majority of the Canadian provinces, with the exception of Prince Edward Island, Northwest Territories, Yukon and Nunavut yet. The sample was not proportionate to ethnic and racial subgroups. For example 56 participants (90.32%; N=62) self-identified as white, which is not representative of the Canadian population. The sample size also had high responses for individuals with Stage 2 breast cancer, so a broader response would be recommended to get more accurate results. This study would benefit from seeking input from other audiences (e.g. employers, individuals offering support to a woman with breast cancer).

Another limitation in regards to demographics was the age of participants considering the majority of cases in Canada occur over the age of 40 (CCS Advisory Committee on Cancer Statistics, 2017). There was a good reach of ages however the oldest participant was  $56 \ (N = 62)$ . Considering the age of retirement is 65 in Canada, including more individuals 55 and older would have made this study more representative of the population.

This research is important for highlighting the gap in the literature on the role of evaluations of KT based patient education. This research is expected to provide useful insights for future evaluations of eHealth videos, including building evidence for future

video development and determining the styles used in dissemination strategies. Aside from the employment effects, this research has the potential to allow researchers to better understand how female patients learn and understand patient educational information during stressful times such as dealing with a cancer diagnosis. The current results provide preliminary data for the larger study and for future studies. Future research should also include a larger population sample taking into consideration socioeconomic and cultural differences. It would be recommended that further research be conducted with women who've experienced breast cancer to inquire more around what information they need, what resources they used, how they processed the information and when they sought and processed the information.

## Conclusion

In conclusion, evidence to confirm that video is an influential KT tool to educate women with breast cancer is inconclusive. The findings of this study highlight the need for more research in the area of KT and communication about cancer. This study highlights the importance of tailoring patient education for specific audiences. The small sample size for this study was a factor in having statistically relevant data. However, this result clearly illustrates the need for further research to understand the impacts on the future of KT development. This research provides assistance in the larger study to examine the relationship between intentions of seeking assistance at work and general knowledge about breast cancer and possibly a broader assessment of audience. It is recommended that the prospective study consider further testing of this video including an evaluation using alternate audiences. This research will add to the knowledge base surrounding women diagnosed with breast cancer's communication in the workplace.

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Table 1
Participant Demographic Characteristics

Variable group	WAVE 1 $(N = 62)$		
	Frequency	Mean*	
Age range			
18-39	14	22.58	
40-49	22	35.48	
50-59	26	41.94	
	Frequency	Percentage*	
<u>Province</u>			
Alberta	5	8.06	
British Columbia	3	4.84	
Manitoba	2	3.23	
New Brunswick	3	4.84	
Newfoundland and	1	1.61	
Labrador			
Northwest Territories	0	0	
Nova Scotia	16	25.81	
Nunavut	0	0	
Ontario	15	24.19	
Prince Edward Island	0	0	
Quebec	5	8.06	
Saskatchewan	11	17.74	
Yukon	0	0	
Other	1	1.61	
Race			
Aboriginal/First Nations	2	3.23	
African-American/Black	0	0	
Asian-American/Asian	0	0	
Caucasian/White	56	90.32	
Hispanic/Latino	0	0	
Other	3	4.84	
No response	1	1.61	
_			
Marital Status			
Divorced	6	9.68	
Living with significant	10	16.13	
other			
Married	33	53.23	
Single	9	14.52	
Other	4	6.45	

<sup>\*</sup>Note: percentages may not equal 100 due to rounding.

Table 2
Participant Health Characteristics

Variable group	WAVE 1 $(N = 62)$	
	Frequency	Percentage*
Cancer stage		
Stage I	16	25.81
Stage II	23	37.1
Stage III	15	24.19
Stage IV	3	4.84
Unknown	3	4.84
No response	2	3.23
Variable group	WAVE 1 (r	n = 45)
Variable group	WAVE 1 (r Frequency	n = 45) Percentage*
Years since diagnosis	Frequency	Percentage*
	Frequency 8	,
Years since diagnosis	Frequency	Percentage*
Years since diagnosis Within the last year	Frequency 8	Percentage* 17.78
Years since diagnosis Within the last year 2 years	Frequency  8 18	Percentage* 17.78 40
Years since diagnosis Within the last year 2 years 3 years	Frequency  8 18 8	Percentage*  17.78 40 14.78

<sup>\*</sup>Note: percentages may not equal 100 due to rounding.

Table 3
Participant Work Characteristics

Variable group	WAVE 1 $(N = 62)$		
	Frequency	Percentage*	
Employment status at diagnosis			
Worked full-time	51	77.27	
Worked part-time	3	4.55	
Contract/Casual	0	0	
Self-employed	4	6.06	
Unemployed	1	1.52	
Other	1	1.52	
No response	6	9.09	
Current employment status			
Worked full-time	30	43.48	
Worked part-time	7	10.14	
Contract/Casual	1	1.45	
Self-employed	3	4.35	
Unemployed	5	7.25	
Other	17	24.64	
No response	6	8.70	
Industry			
Service	6	9.68	
Education	6	9.68	
Manufacturing	1	1.61	
Health Care	8	12.9	
Public Service	8	12.9	
Other	9	14.52	
No response	24	38.71	
Are you currently on medical leave			
from your job?			
Yes	20	32.26	
No	33	53.23	
Currently unemployed	0	0	
Other	3	4.84	
No response	6	9.68	
Do you plan on returning to your			
job?			
Yes	15	24.19	
No	2	3.23	
Unsure	1	1.61	
I have already returned	1	1.61	

I started a new job	1	1.61
No response	42	67.74

<sup>\*</sup>Note: percentages may not equal 100 due to rounding.

Table 4
Participant Knowledge Translation Characteristics

Variable group	WAVE 1 ( $N = 62$ )		
	Frequency	Percentage*	
How do you prefer to receive			
your health information?			
Select all that apply.			
Books	19	30.65	
Brochures or handouts	20	32.26	
Discussion with health	39	62.90	
professionals			
Friends/family	9	14.52	
I don't need/look for	2	3.23	
information.			
Podcasts	4	6.45	
Research papers	18	29.03	
Videos	6	9.68	
Websites	31	50.00	
Other	6	9.68	
No response	15	24.19	
1			
Variable arroun	WAVE 1 (n = 36)**		
Variable group	WAVE I (I	1 –30) · ·	
variable group		Percentage*	
How did viewing the content			
How did viewing the content			
How did viewing the content make you feel? Select all that			
How did viewing the content make you feel? Select all that apply.	Frequency	Percentage*	
How did viewing the content make you feel? Select all that apply.  Anger	Frequency 2	Percentage* 5.56	
How did viewing the content make you feel? Select all that apply.  Anger Contempt	Frequency 2 0	Percentage*  5.56 0	
How did viewing the content make you feel? Select all that apply.  Anger Contempt Disgust	Frequency  2 0 0	Percentage*  5.56 0 0	
How did viewing the content make you feel? Select all that apply.  Anger Contempt Disgust Fear	Frequency  2 0 0 3	5.56 0 0 8.33	
How did viewing the content make you feel? Select all that apply. Anger Contempt Disgust Fear Guilt	Frequency  2 0 0 3 1	5.56 0 0 8.33 2.78	
How did viewing the content make you feel? Select all that apply.  Anger Contempt Disgust Fear Guilt Hostility Interest	Frequency  2 0 0 3 1 2	5.56 0 0 8.33 2.78 5.56 33.33	
How did viewing the content make you feel? Select all that apply. Anger Contempt Disgust Fear Guilt Hostility	Frequency  2 0 0 3 1 2 12	5.56 0 0 8.33 2.78 5.56	
How did viewing the content make you feel? Select all that apply. Anger Contempt Disgust Fear Guilt Hostility Interest Joy	2 0 0 3 1 2 12 2	5.56 0 0 8.33 2.78 5.56 33.33 5.56	
How did viewing the content make you feel? Select all that apply. Anger Contempt Disgust Fear Guilt Hostility Interest Joy Sadness	Frequency  2 0 0 3 1 2 12 2 11	5.56 0 0 8.33 2.78 5.56 33.33 5.56 30.56	
How did viewing the content make you feel? Select all that apply.  Anger Contempt Disgust Fear Guilt Hostility Interest Joy Sadness Shame Shyness	Frequency  2 0 0 3 1 2 12 2 11 0	5.56 0 0 8.33 2.78 5.56 33.33 5.56 30.56	
How did viewing the content make you feel? Select all that apply.  Anger Contempt Disgust Fear Guilt Hostility Interest Joy Sadness Shame	Frequency  2 0 0 3 1 2 12 2 11 0 0	5.56 0 0 8.33 2.78 5.56 33.33 5.56 30.56 0	

<sup>\*</sup>Note: percentages may not equal 100 due to rounding.

<sup>\*\*</sup>The no-content group did not receive this question as they did not view an intervention.

Table 5
Descriptive Statistics of each Condition for Wave 1 and Wave 2

Variable group	WAVE 1 (n = 45)		
	Frequency	Mean*	Std. Deviation
General Knowledge			
Narrative Video	9	2.33	1.00
Didactic Video	12	3.08	1.24
Narrative Infographic	8	2.25	1.39
Handout (Electronic)			
No Content	8	2.25	0.71
	WAVE 2 (n	1 = 45	
	Frequency	Mean*	Std. Deviation
General Knowledge			
Narrative Video	9	2.11	0.92
Didactic Video	12	2.42	0.79
Narrative Infographic	8	2.00	1.41
Handout (Electronic)			
No Content	8	1.88	0.64
	WAVE 1 (n	1 = 45	
	Frequency	Mean*	Std. Deviation
Video Knowledge			
Narrative Video	7	9.86	1.46
Didactic Video	12	9.75	1.36
Narrative Infographic	6	9.83	0.75
Handout (Electronic)			
No Content	8	10.13	1.13
	WAVE 2 (n = 45)		
	Frequency	Mean*	Std. Deviation
Video Knowledge			
Narrative Video	7	9.71	1.11
Didactic Video	12	9.92	1.31
Narrative Infographic	6	9.67	1.21
Handout (Electronic)			
No Content	8	10.13	0.99

Table 6
Frequencies for Intentions and Behaviours for Wave 1 and Wave 2

Narrative Video Group (n = 12)	WAVE 1 (N	N = 45)	
	Frequency		
	Yes	No	No Response/Excluded
Told boss about breast cancer diagnosis	3	1	8
Told colleagues about breast cancer diagnosis	4	0	8
Intend to tell boss about breast cancer diagnosis	0	1	11
Intend to tell colleagues about breast cancer diagnosis	0	0	12
Narrative Video Group (n = 12)	WAVE 2 (N	(I = 45)	
	Frequency		
	Yes	No	No Response/Excluded
Told boss about breast cancer diagnosis	4	0	8
Told colleagues about breast cancer diagnosis	4	0	8
Intend to tell boss about breast cancer diagnosis	0	0	12
Intend to tell colleagues about breast cancer diagnosis	0	0	12
Didectic Video Crown (n. 14)	WANE 1 (N	J 45)	
Didactic Video Group (n = 14)	WAVE 1 (N) Frequency	N – 43)	
	Yes	No	No Response/Excluded
			•
Told boss about breast cancer diagnosis	6	1	7
Told colleagues about breast cancer diagnosis	7	0	7
Intend to tell boss about breast cancer diagnosis	0	1	13
Intend to tell colleagues about breast cancer diagnosis	0	0	14

Didactic Video Group (n = 14)	WAVE 2 (N	N = 45	
	Frequency		
	Yes	No	No Response/Excluded
Told boss about breast cancer diagnosis	7	0	7
Told colleagues about breast cancer diagnosis	7	0	7
Intend to tell boss about breast cancer diagnosis	0	0	14
Intend to tell colleagues about breast cancer diagnosis	0	0	14
Narrative Infographic Handout (electronic) Group (n = 10)	WAVE 1 (N	V = 45)	
	Frequency		
	Yes	No	No Response/Excluded
Told boss about breast cancer diagnosis	6	2	2
Told colleagues about breast cancer diagnosis	7	1	2
Intend to tell boss about breast cancer diagnosis	0	2	8
Intend to tell colleagues about breast cancer diagnosis	0	1	9
Narrative Infographic Handout (electronic) Group (n = 10)	WAVE 2 (N	N = 45)	
	Frequency		
	Yes	No	No Response/Excluded
Told boss about breast cancer diagnosis	6	2	2
Told colleagues about breast cancer diagnosis	8	0	0
Intend to tell boss about breast cancer diagnosis	0	2	8
Intend to tell colleagues about breast cancer diagnosis	0	0	8

No Intervention Group $(n = 9)$	WAVE 1 (N	N = 45)	
	Frequency		
	Yes	No	No Response/Excluded
Told boss about breast cancer diagnosis	5	0	4
Told colleagues about breast cancer diagnosis	5	0	4
Intend to tell boss about breast cancer diagnosis	0	0	9
Intend to tell colleagues about breast cancer diagnosis	0	0	9
No Intervention Group $(n = 9)$	WAVE 2 (N	N = 45	
	Frequency		
	Yes	No	No Response/Excluded
Told boss about breast cancer diagnosis	5	0	4
T-1.11114 14			
Told colleagues about breast cancer diagnosis	5	0	4
<del>_</del>	5	0	9

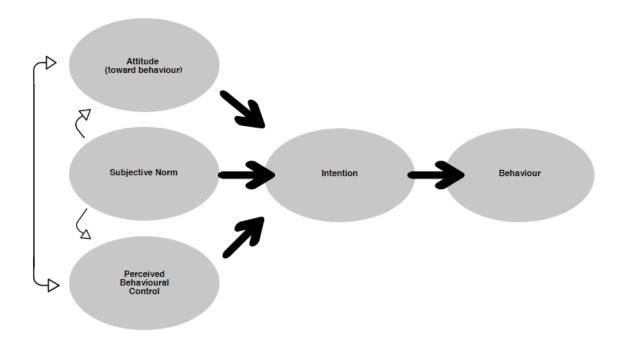
Table 7
Descriptive Statistics of Transportation for Wave 1

Variable group	WAVE $1 (n = 45)$		
	Frequency	Mean*	Std.
			Deviation
Transportation			
Narrative Video	4	2.91	0.31
Didactic Video	11	2.97	0.78

Table 8. Source Table for Two-Way Analysis of Covariance on Transportation Scores

Source	SS	df	MS	F	p	Partial $\eta^2$
	(	Covariates				
Video Type	0.002	1	0.002	0.002	.970	.00
Stage of Cancer	2.08	2	1.038	0.679	.534	.15
Video x Stage	0.002	1	4.937	0.002	.970	.00
Error	12.24	8	1.53			
Total	14.95	12				

Figure 1. Theory of Planned Behaviour Model



Source: From intentions to actions: A theory of planned behavior (Ajzen, 1985)

Figure 2. Study Design for Intervention and Control Groups for Wave 1 and Wave 2

#### Wave 1

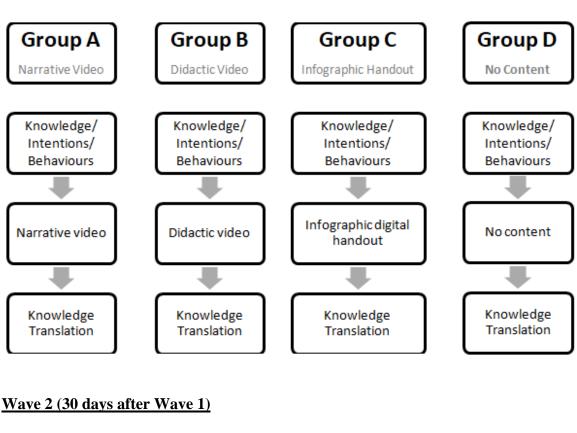




Figure 3. KT Framework for Behaviour Change Developed for this Study

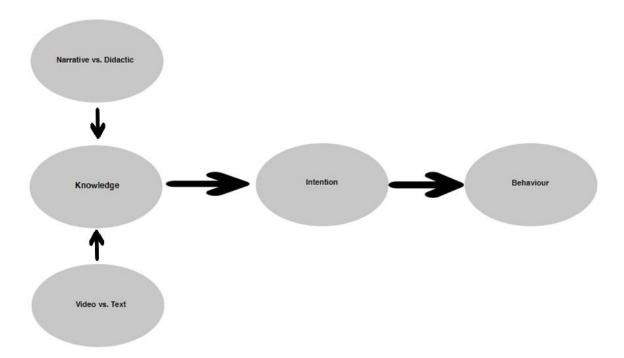


Figure 4. Knowledge Scores at Wave 1 Showing Observed Differences in Means Across Conditions (N = 45)

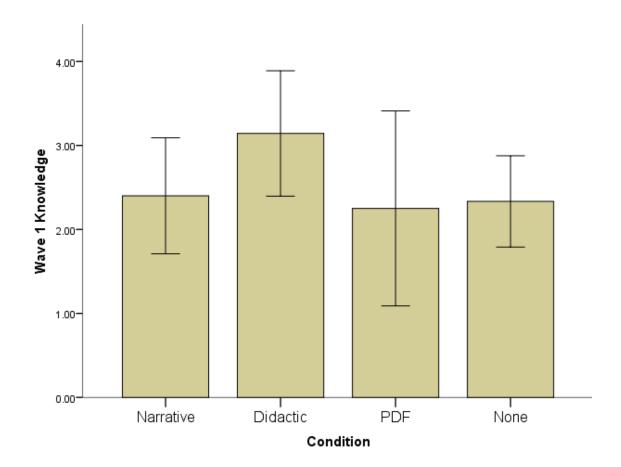


Figure 5. Mean Knowledge at Different Stages of Breast Cancer (Adjusted for Wave 1 Knowledge M = 2.53)

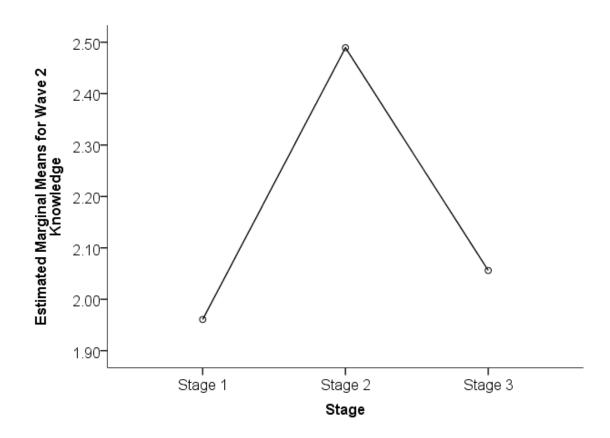


Figure 6. Mean Knowledge for the Four Different Knowledge Translation Types by Stage of Cancer (Adjusted for Wave 1 Knowledge M = 2.53)

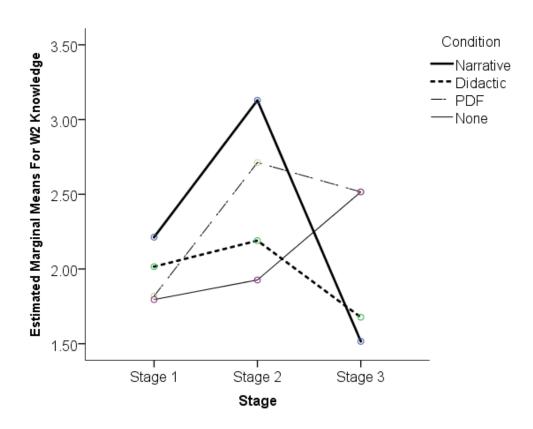
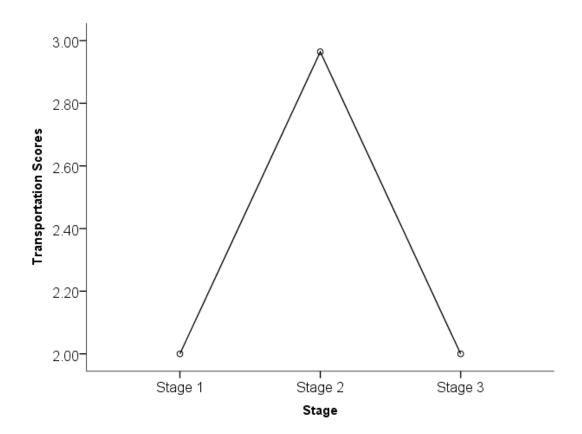


Figure 7. Mean Transportation Scores at Different Stages of Breast Cancer



### Appendix A

Breast Cancer and Work Questionnaire Informed Consent

#### **Breast Cancer and Work: Survey 1&2**

**Faculty Principal Investigator:** Dr. Lucie Kocum, Dept. of Psychology, Saint Mary's University, Halifax, NS B3H 3C3

**Student Co-Investigator:** Sarah Kehoe, Master of Applied Health Services Research, Saint Mary's University, Halifax, NS B3H 3C3

Study Contact telephone numbers: (902) 491-8628 OR (902) 491-6356 Study Contact emails: <a href="www.wellness@smu.ca">workWellness@smu.ca</a>; <a href="mailto:Lucie.Kocum@smu.ca">Lucie.Kocum@smu.ca</a>

SMU REB File # 17-303

#### INTRODUCTION AND PURPOSE OF THIS RESEARCH

Thank you for agreeing to participate in this survey on understanding newly diagnosed breast cancer patients' experiences on the barriers and effects of cancer and the workplace. This survey should take 20 minutes and all responses will remain anonymous. By completing this survey, you are agreeing to participate in this research. If you have any questions about this study or would like more information, please contact the Student Co-Investigator, Sarah Kehoe (WorkWellness@smu.ca).

#### WHO IS ELIGIBLE TO PARTICIPATE IN THIS STUDY?

To be eligible to participate in this study, you must be a woman, 18 years of age or older who has received a breast cancer diagnosis within the last five years. You must have been employed at the time of diagnosis and be living in Canada. We aim to recruit 362 participants for this study.

#### WHAT DOES PARTICIPATING MEAN?

In all, the study is made up of 5 surveys, which will each take about 20 minutes to complete, over the course of a year. The surveys are self-administered online surveys about your breast cancer and work experience. You will not be asked to disclose any personal information about your co-workers or employer and you have the option to skip any questions you do not feel comfortable answering. Personal health information will be included in the survey including specifics such as: date of breast cancer diagnosis, stage of breast cancer, treatment plan, symptoms, other major illnesses participant have been diagnosed with. All responses will remain anonymous and be saved on a secure Saint Mary's University server. The survey will not ask for your name, or any other identifying information, aside from your email address. We are collecting your email address so we can contact you for the follow up surveys.

The follow-up surveys will be sent to you by our research team:

Survey 2: in 30 days from today Survey 3: in 3 months from today Survey 4: in 6 months from today Survey 5: in 1 year from today

#### WHAT ARE THE POTENTIAL BENEFITS OF THIS RESEARCH?

The findings of this study will provide women with breast cancer, employers, and other workers with helpful information on how they can define and contribute to a psychologically healthy workplace response to breast cancer. With an increased understanding of accommodation among all stakeholders the workplace may allow women who have experienced breast cancer to derive maximal—and healing—benefit from positive engagement in their valued social role as a member of staff. Findings from this project will also have broader implications for individuals who are experiencing other serious illnesses, and want to maintain their work roles.

#### WHAT ARE THE POTENTIAL RISKS FOR PARTICIPANTS?

There is no danger of physical or social risk to you as a consequence of your participation in this study. Some aspects of the study may cause you some discomfort or stress, including feelings of emotion as you will be asked to think about your experiences regarding cancer. Dr. Kocum has been exploring these issues for 10 years and has studied over 250 women with no one ever having expressed any consequences; however it is a possibility in which we take very seriously. You will be provided with information of a free counselling service you can consult if you have any discomfort or stress due to this study. We also ask that you notify us at (902) 491-6356 or by email at <a href="mailto:Lucie.Kocum@smu.ca">Lucie.Kocum@smu.ca</a> if you experience any discomfort during or after the survey so we can ensure this is addressed and necessary action taken to prevent any further issues.

#### HOW CAN I WITHDRAW FROM THIS STUDY?

Your participation in this research is voluntary. You may withdraw your consent at any time and discontinue participation without penalty prior to the end of the questionnaire. You do not have to answer questions you do not want to answer and are welcome to stop the survey at any time if you no longer wish to participate. To leave the survey you can close your browser. Incomplete information may be included in the analysis of the responses.

### WHAT WILL BE DONE WITH MY INFORMATION?

All information you provide will be stored on a password-protected computer on campus at Saint Mary's University. The computer transferred data will be retained for a minimum of 5 years after publication. Individual information will not be shared outside the research team and results will be reported in aggregate (group level) form only. The information you provide will be used to understand how women experience work during and after their breast cancer diagnosis and treatment, as well as, to help formulate future research ideas and directions.

Information provided will be collected anonymously, which means no responses will be connected directly to you. Only the researchers listed below will have access to the survey results. All research disseminated will exclude any personal identifiers to you or your workplace, as only grouped data will be reported. The general findings will be

presented in a master's thesis (Ms. Sarah Kehoe, Saint Mary's University) and will be presented at conferences or in scientific journals. It is expected the research will help us understand how women are affected by cancer and the role of the workplace during a diagnosis of cancer. Moreover, it is anticipated that the findings of the research mentioned above will be presented to the scientific community through conferences, scientific papers, newsletters, brochures and workshops.

#### HOW CAN I FIND OUT MORE ABOUT THIS STUDY?

We know some people may have questions about this research project, and we would be happy to talk about this with you. Please don't hesitate to reach out if you should have further questions about this study. Please contact our research team by phoning (902) 491-8628 or email us at <a href="WorkWellness@smu.ca">WorkWellness@smu.ca</a>. We will aim to respond within 72 hour time frame, if not before. If you would like to be informed of the results of this study, please contact us at <a href="Lucie.Kocum@smu.ca">Lucie.Kocum@smu.ca</a> in August 2018.

For psychological or emotional support it is advised you talk to your physicians and care team. If you are facing direct distress as a result of your participation please contact Dr. Lynne Robinson at the contact information below:

Lynne Robinson Registered Psychologist Tel: (902) 464-1157 Lynne.Robinson@dal.ca

#### **CONSENT**

I understand what this study is about and appreciate the risks and benefits. I have had adequate time to think about this and have had the opportunity to ask questions. I understand that my participation is voluntary and that I can end my participation at any time prior to the end of the survey. I have read the above statements and freely consent to participate in this research:\*

Please choose <b>only one</b> of the following:
O Yes
O No
Would you like to be notified of the findings of the study?
Please choose <b>only one</b> of the following:
O Yes
O No

### Appendix B

Breast Cancer and Work Questionnaire Questions (only questions used in this study)

### **DEMOGRAPHIC**

The following questions pertain to your background, health, and work information. Please answer as many questions as you are comfortable with, keeping in mind that the more information you provide, the more valid our results will be.

1. Age (years): *(mandatory) Please write your answer here: [open text box]
2. Email address: *(mandatory) Please write your answer here: [open text box]
3. Gender:* (mandatory) Please choose <b>only one</b> of the following:  O Female  O Male  O Other [open text box]
<ul> <li>4. Which best describes your relationship status?</li> <li>Please choose only one of the following:</li> <li>Divorced, more than a year</li> <li>Divorced, within the last year</li> <li>Living with significant other</li> <li>Married</li> <li>Single</li> <li>Widowed</li> <li>Other [open text box]</li> </ul>
<ul><li>5. Do you have children?</li><li>Please choose only one of the following:</li><li>Yes</li><li>No</li></ul>
6. In which province do you currently live? Please choose <b>only one</b> of the following: Alberta British Columbia Manitoba New Brunswick Newfoundland and Labrador Northwest Territories Nova Scotia Nunavut

0000	Ontario Prince Edward Island Quebec Saskatchewan Yukon Other [open text box]
7.	In which city or town do you currently?
Ple	ease write your answer(s) here:
•	Live: [open text box]
•	Work: [open text box]
8.	What is the highest level of education you have completed?
Ple	ease choose <b>only one</b> of the following:
0	Elementary school
0	Junior high school
0	High school
Ō	Diploma/Certificate
Ō	Undergraduate degree
-	Master's degree
0	Doctoral degree
9.	What is your ethnicity?
	ease choose all that apply:
	Aboriginal/First Nations
	African-American/Black
	Asian-American/Asian
	Caucasian/White
	Hispanic/Latino
	Other: [open text box]
10.	. What is the total yearly income (estimated) for all of the members who contribute to
	your household income?
Ple	ease choose <b>only one</b> of the following:
-	Less than \$15,000
0	\$15,000 - \$25,000
$\circ$	\$25,000 - \$35,000
$\circ$	\$35,000 - \$45,000
$\circ$	\$45,000 - \$55,000
$\circ$	\$55,000 - \$65,000
0	\$65,000 - \$75,000
0	\$75,000 - \$85,000
0	\$85,000 - \$95,000
0	\$95,000 - \$105,000
0	\$105,000 - \$115,000
0	\$115,000 or more

### HEALTH

Wave 2 Question only
Has your treatment plan changed in the last 30 days?**
O Yes
O No
**A "Yes" response will skip the next 18 questions and sub-questions.
11. When were you diagnosed? If you do not recall exactly, please provide your best guess
Please enter a date: [open text box]
12. What was your stage of breast cancer when you were diagnosed?  Please choose <b>only one</b> of the following:  O Stage I
O Stage II O Stage III
O Stage IV
O Do not know
13. Does your treatment plan include surgery? Please choose <b>only one</b> of the following:  Yes No
14. When is/was the date of surgery?  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '13 [H12]' (Does your treatment plan include surgery?)  Please enter a date: [open text box]
15. Does your treatment plan include chemotherapy? Please choose <b>only one</b> of the following:  O Yes O No
16. When does/did the treatment start?  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '15 [H13]' (Does your treatment plan include chemotherapy?)  Please enter a date: [open text box]
17. What is/was the duration in weeks?  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '15 [H13]' (Does your treatment plan include chemotherapy?)  Please write your answer here: [open text box]

18. Does your treatment plan include radiation therapy? Please choose <b>only one</b> of the following:  O Yes O No
19. When does/did the treatment start?  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '18 [H14]' (Does your treatment plan include radiation therapy?)  Please enter a date: [open text box]
20. What is/was the duration in weeks?  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '18 [H14]' (Does your treatment plan include radiation therapy?)  Please write your answer here: [open text box]
21. Does your treatment plan include hormone therapy? Please choose <b>only one</b> of the following:  O Yes O No
22. When does/did the treatment start?  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '21 [H15]' (Does your treatment plan include hormone therapy?)  Please enter a date: [open text box]
23. What is/was the duration in weeks?  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '21 [H15]' (Does your treatment plan include hormone therapy?)  Please write your answer here: [open text box]
24. Does your treatment plan include any other therapy? Please choose <b>only one</b> of the following:  O Yes O No
25. What is it?  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '24 [H16]' (Does your treatment plan include any other therapy?)  Please write your answer here: [open text box]

26. When does/did the treatment start?
Only answer this question if the following conditions are met:
Answer was 'Yes' at question '24 [H16]' (Does your treatment plan include any other
therapy?)
Please enter a date: [open text box]
27. What is/was the duration in weeks?
Only answer this question if the following conditions are met:
Answer was 'Yes' at question '24 [H16]' (Does your treatment plan include any other
therapy?)
Please write your answer here: [open text box]
WORK
Wave 2 Question only
Has your employment status changed in the last 30 days?**
O Yes
O No
**A "Yes" response will skip the next 3 questions and sub-questions.
11 Tes Tesponse with stup the new e questions and stub questions.
28. What was your employment status when you were diagnosed with breast cancer? *
Please choose all that apply:
Worked full-time
Worked part-time
Contract/Casual employee
Unemployed
☐ Other: [open text box]
29. What is your current employment status?
Please choose all that apply:
☐ Work full-time
☐ Work part-time
Contract/Casual employee
☐ Self-employed
Unemployed
Other: [open text box]
30. In which industry do you work?
Only answer this question if the following conditions are met:
Answer was 'Self-employed' or 'Contract/Casual employee' or 'Work part-time' or 'Work
full-time' at question '33 [W2]' (What is your current employment status?)
Please choose all that apply:
Service
Education
☐ Manufacturing

Health Care
☐ Public Service
Other: [open text box]
31. Are you currently on medical leave from your job?  Please choose all that apply:  Yes  No  Currently unemployed  Other: [open text box]
32. Do you plan on returning to your job?  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '35 [W4]' (Are you currently on medical leave from your job?)
Please choose <b>all</b> that apply:  Yes No
☐ Unsure ☐ I have already returned ☐ I started a new job
33. Have you told your supervisor about your breast cancer diagnosis?  Please choose <b>only one</b> of the following:  Yes  No
34. Why did you decide to tell your supervisor about your breast cancer diagnosis? <b>Only answer this question if the following conditions are met:</b> Answer was 'Yes' at question '37 [W6]' (Have you told your supervisor about your breas cancer diagnosis?) Please write your answer here: [open text box]
35. Why did you decide not tell your supervisor about your breast cancer diagnosis? <b>Only answer this question if the following conditions are met:</b> Answer was 'No' at question '37 [W6]' (Have you told your supervisor about your breast cancer diagnosis?) Please write your answer here: [open text box]
36. How many hours do you normally work per week in your job? Please write your answer here: [open text box]
37. How many hours overtime do you work in your job in an average week? Please write your answer here: [open text box]
38. How many times a week do you change shifts?

☐ 2 times ☐ More than ☐ On call ☐ Standby ☐ Non-stand ☐ Other: [op 39. How man job)	don't change 2 times  lard work we ben text box]  by hours per v	ek	k any other job? ( oox]	Please mark "0"	if no other
	WOME	N WITH BREA	AST CANCER A	ND WORK	
	e the appropr	o which you agre iate response for	ee with the follow each item:	ing statement:	Tr.
	To a very large extent	To a large extent	Somewhat	To a small extent	To a very small extent
I feel I have the knowledge					
I need about breast cancer and work.	0	0	0	0	0
or false:			lease indicate who	ether you believe	it to be true
Please Choose	e the appropr	iate response for True	each item:	False	
Breast cancer experiences vary.		0		0	
I can learn from the experiences of others.	f	0		0	
Employer support can b helpful during		0		0	

	True	False
breast cancer.		
Employer support can be harmful during breast cancer.	0	0
How the woman with breast cancer stays in touch with her workplace during their treatment and recovery should be her decision.	0	0
You should always tell your boss you've been diagnosed with breast cancer.	0	0
Most women recover from breast cancer and return to their jobs.	0	0
Women with breast cancer will have different needs and preferences at work.	0	0
The workplace	0	0

	True	False
should always leave the woman with breast cancer to deal with her illness, treatment, and recovery on her own.		
You should always ask the woman with breast cancer how you can help.	0	0
I feel I have more information on how to talk about breast cancer at work.	0	0
It is uncomfortable for some bosses to talk about breast cancer.	0	0
Some colleagues won't know what to do to help.	0	0

### TALKING ABOUT YOUR BREAST CANCER AT WORK

42. I have talked to my boss about my experience with breast cancer. Please choose **only one** of the following:

O Yes O No
<ul> <li>43. Why did you decide to talk to your boss about your experience with breast cancer? What things did you consider?</li> <li>Only answer this question if the following conditions are met: Answer was 'Yes' at question '56 [PI1]' (I have talked to my boss about my experience with breast cancer.) Please write your answer here: [open text box]</li> </ul>
44. I intend to talk to my boss about my experience with breast cancer.  Only answer this question if the following conditions are met:  Answer was 'No' at question '56 [PI1]' (I have talked to my boss about my experience with breast cancer.)  Please choose only one of the following:  O Yes O No
<ul><li>45. Why have you decided to talk to your boss about your experience with breast cancer' What things did you consider?</li><li>Only answer this question if the following conditions are met:</li><li>Answer was 'Yes' at question '58 [PI1b]' (I intend to talk to my boss about my experience)</li></ul>
with breast cancer.) Please write your answer here: [open text box]
<ul> <li>46. Why have you decided not to talk to your boss about your experience with breast cancer? What things did you consider?</li> <li>Only answer this question if the following conditions are met: Answer was 'No' at question '58 [PI1b]' (I intend to talk to my boss about my experience with breast cancer.) Please write your answer here: [open text box]</li> </ul>
47. I have talked to my colleagues about my experience with breast cancer. Please choose <b>only one</b> of the following:  O Yes  No
<ul> <li>48. Why did you decide to talk to your colleagues about your experience with breast cancer? What things did you consider?</li> <li>Only answer this question if the following conditions are met: Answer was 'Yes' at question '61 [PI2]' (I have talked to my colleagues about my experience with breast cancer.) Please write your answer here: [open text box]</li> </ul>

49. I intend to talk to my colleagues about my experience with breast cancer.  Only answer this question if the following conditions are met:  Answer was 'No' at question '61 [PI2]' (I have talked to my colleagues about my experience with breast cancer.)  Please choose only one of the following:  O Yes O No
<ul> <li>50. Why have you decided to talk to your colleagues about your experience with breast cancer? What things did you consider?</li> <li>Only answer this question if the following conditions are met:</li> <li>Answer was 'Yes' at question '63 [PI2b]' (I intend to talk to my colleagues about my experience with breast cancer.)</li> <li>Please write your answer here: [open text box]</li> </ul>
<ul> <li>51. Why have you decided not to talk to your colleagues about your experience with breast cancer? What things did you consider?</li> <li>Only answer this question if the following conditions are met: Answer was 'No' at question '63 [PI2b]' (I intend to talk to my colleagues about my experience with breast cancer.) Please write your answer here: [open text box]</li> </ul>
<ul> <li>52. I have asked my workplace for accommodation because of breast cancer-related challenges in doing my job.</li> <li>Please choose only one of the following:</li> <li>Yes</li> <li>No</li> </ul>
53. What accommodation(s) have you asked for?  Only answer this question if the following conditions are met:  Answer was 'Yes' at question '66 [PI3]' (I have asked my workplace for accommodation because of breast cancer-related challenges in doing my job.)  Please write your answer here: [open text box]
<ul> <li>54. I intend to ask my workplace for accommodation because of breast cancer-related challenges in doing my job.</li> <li>Only answer this question if the following conditions are met: Answer was 'No' at question '66 [PI3]' (I have asked my workplace for accommodation because of breast cancer-related challenges in doing my job.) </li> <li>Please choose only one of the following: <ul> <li>Yes</li> <li>No</li> </ul> </li> </ul>

55.	. What	accommod	lation(s)	will	you	ask for	?
_	_		_				

#### Only answer this question if the following conditions are met:

Answer was 'Yes' at question '68 [PI3b]' (I intend to ask my workplace for accommodation because of breast cancer-related challenges in doing my job.) Please write your answer here: [open text box]

56. Why have you not requested accommodations?

### Only answer this question if the following conditions are met:

Answer was 'No' at question '68 [PI3b]' (I intend to ask my workplace for doing my job.)

answer was the an december of [1166] (1 moone to assume the
accommodation because of breast cancer-related challenges in
Please choose <b>all</b> that apply:
☐ I do not require accommodations.
Other: [open text box]
57. I have found myself educating others about the experience. Please choose <b>only one</b> of the following: Strongly agree Somewhat agree
O Strongly disagree

#### INTERVENTION

### (random 1 – Narrative video/random 2 – didactic video/random 3 – PDF/random 4 no intervention)

Below is a 5-minute video on the experiences of women with breast cancer at work. Please watch the video and, once you are done, provide us with your opinions about it.

Only answer this question if the following conditions are met:

```
((random == 1)) ((random == 2))
```

Below is some information on the experiences of women with breast cancer at work. Please read it and, once you are done, provide us with your opinions about it.

Only answer this question if the following conditions are met:

((random == 3))

[Nothing]

Only answer this question if the following conditions are met:

((random == 4))

58. How much of the video did you watch?

Only answer this question if the following conditions are met:

((random == 1)) ((random == 2))

Please choose **only one** of the following:

None About 25% About 50% About 75% 100%	ó						
59. How much	h of the pa	mphlet o	did you read?				
Only answer ((random ==	_	tion if th	ne following con	ditions a	re met:		
Please choose	only one	of the fo	ollowing:				
O None O About 25% O About 50% O About 75% O 100%	ó						
and follov additional	the instruction.	actions in Regardle	at we know how this survey. For ess of your true a type the words "	this reas	son, we are as the question	sking th below,	is
Comment onl	y when yo	u choose	e an answer.				
Please choose  Strongly a  Agree: [op  Disagree:    Other: [op	gree: [ope en text bo [open text	n text bo x] box]	provide a commo x]	ent:			
	INI	ORMA	TION ABOUT	BREAS	Γ CANCER		
			nions about the e ch you agree or d			ancer at	work.
Only answer ((random ==	_	tion if th	ne following con	ditions a	re met:		
Please choose	the appro	priate re	sponse for each i	tem:			
	1 - Very much	2	3 - Moderately	4	5 - Slightly	6	7 - Not at all
When I was watching the video, I could easily	0	0	0	0	0	0	0

picture the events in it taking place.	1 - Very much	2	3 - Moderately	4	5 - Slightly	6	7 - Not at all
While I was watching the video, activity going on in the room around me was on my mind.	0	0	0	0	0	0	0
I could picture myself in the events described in the video.	0	0	0	0	0	0	0
After watching the video, it was easy to put it out of my mind.	0	0	0	0	0	0	0
The video affected me emotionally.	0	0	0	0	0	0	0
I found my mind wandering while watching the video.	0	0	0	0	0	0	0

	1 - Very much	2	3 - Moderately	4	5 - Slightly	6	7 - Not at all
The events in the video are relevant to my everyday life.	0	0	0	0	0	0	0
While watching the video, I had a vivid image of myself.	0	0	0	0	0	0	0
Please choose  Books  Brochures  Discussion Friends/fa	or handound with heal mily ed/look for papers	pply: ats th profe		ormation	? Select all th	at apply	<b>y.</b>
	O		t make you feel?		11.		
			ne following cond 2)) ((random ==		ire met:		
Please choose	e <b>all</b> that a <sub>l</sub>	pply:					
☐ Anger ☐ Contempt ☐ Disgust ☐ Fear ☐ Guilt ☐ Hostility							

☐ Interes ☐ Joy ☐ Sadnes ☐ Shame ☐ Shynes ☐ Surpris ☐ None o	SS : :SS			
	ollowing is about the	ne experience of breast sagree:	cancer at work. Plea	se rate the extent
-	_	if the following condit == 2)) ((random == 3		
Please cho	oose the appropriat	e response for each iter	n:	
	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree
I am glad to see this content at this point in my breast cancer journey.	0	0	0	0
65. Breast	cancer will affect	how many Canadian w	omen of working-ag	ge this year?
Please cho	oose <b>only one</b> of th	e following:		
_				
66. Please	check the box that	t best corresponds to yo	our answer for each o	question below.
In the pas	t month			
Please cho	oose the appropriat	e response for each iter	m:	
How man	y times	Not at all	1-4 times	5 or more times

have you gotten new information about breast cancer or breast cancer resources?	Not at all	1-4 times	5 or more times
How many times have you used resources at work to get your breast cancer-related needs met?	0	0	0

#### **ADDITIONAL COMMENTS**

67. Do you have any further comments you would like to add? Please write your answer here: [open text box]

#### **FINAL PAGE**

Thank you for participating in this survey.

If you have any questions about this study or would like more information, please contact the Student Co-Investigator, Sarah Kehoe by phone (902) 491-8628 or email at WorkWellness@smu.ca.

If you are experiencing any discomfort or stress due to this study you can reach out to our counsellor Dr. Lynne Robinson, Registered Psychologist, Tel: (902) 464-1157, Lynne.Robinson@dal.ca.

You may now close the window.

Submit your survey.

Thank you for completing this survey.

# Appendix C

Video Content Storyboards (Narrative & Didactic versions)

SLIDE IMAGES		VIDEO #1	VIDEO #2
		NARRATIVE TEXT (past tense)	DIDACTIC TEXT (present tense)
1)	I Wanted You to Know  Making it easier to talk about breast cancer in the workplace	I Wanted You to Know  Making it easier to talk about breast cancer in the workplace	[unchanged wording from narrative version]
2)	Breast cancer will affect almost 17,000 working women this year in Canada.  Canada.	Breast cancer will affect almost 17,000 working women this year in Canada.	[unchanged wording from narrative version]
3)	To better understand that experience, researchers Lucie Kocum, Catherine Loughlin and Lyne Robinson interviewed 19 working women.	To better understand that  experience, researchers Lucie  Kocum, Catherine Loughlin and  Lynne Robinson interviewed 19  working women.	[unchanged wording from narrative version]

	the workplace.	the workplace.
	They thought it was important	They thought it was important
	that others hear women's	that others hear women's
	stories so this experience could	concerns so this experience could
	be easier for everyone.	be easier for everyone.
5)	I'm calling in	Calling in
	sick a lot	sick a lot
	something's really wrong	something could be really wrong

6)	I knew I	I knew I	Sometimes one
	had to tell I just didn't know how	had to tell	has to tell
		I just didn't	Sometimes one doesn't
		know how	know how
7)	My mastectomy was scheduled.	My mastectomy was scheduled.	A mastectomy may be scheduled.
8)		We wanted others in	Researchers wanted
	We wanted others in the workplace to understand what these women were experiencing so all of us can be more comfortable taking about breast cancer and supporting women in the workplace.  Each woman we taiked to had different needs and preferences.  This is what they said:	the workplace to understand what these women	others in the workplace to understand what women were
		were experiencing so all of us can	experiencing so everyone can
		be more comfortable talking about	be more comfortable talking about
		breast cancer and supporting	breast cancer and supporting
		women in the workplace.	women in the workplace.
		Each woman we talked to had	Each woman has different needs and
		different needs and preferences.	preferences. This is what

	This is what they said:	researchers found:
9)	I was told I was going to lose my hair	Some are told they are going to lose their hair
10)	I asked them not to tell.	Some women ask others not to tell.
11)	I'm a private person.	Some individuals are private people.

12)	I didn't want to cry	Some don't want to cry
13)	I'm not a private person.  I told total strangers	Some women are not private people and tell total strangers
14)  Finance value	I wanted other women to learn from me.	Some women want other women to learn from them.
15) I won't is talking to you.	I won't be talking to you.	Some don't want to talk.

1.0		***	***
16)	Women told us many stories about	Women told us many	Women informed the
	what helped them. One thing was always helpful: expressing concern and letting the woman know	stories about	researchers about
	throughout the course of her treatment that others at work were thinking about her.	what helped them.	what helped them.
	Paying attention to a given woman's needs and meeting those needs, as much as possible, was always helpful.	One thing was	One thing women
		always helpful:	report as always
		expressing concern	helpful: people
		and letting the woman know	expressing concern and letting the woman know
		throughout the course of her	throughout the course of her
		treatment that others at work were thinking about her.	treatment that others at work were
		400000000000000000000000000000000000000	thinking about her.
		Paying attention to a	
		given woman's needs	Paying attention to a
		and meeting those	given woman's
		needs, as	8
		,	needs and meeting
		much as possible, was	those needs, as
		always helpful.	much as possible, is
			always helpful.
17		Whatayar	Having
17)	Whatever works for	Whatever	Having
	you works for us	works for	a
		you works	flexible
		for us	workplace
			I

18)		What helped?	What helps?
19)		"I'm so sorry."	Saying I'm sorry.
20)	Do you wanting to distribute t	"Do you want me to call anybody?"	Offering to call people
21)	Theyword constantly there for me.	They were constantly there for me.	Being there.

22)		They	Sending
	They emiliad just to say / m thinking about you.	emailed	an
		just to	email
		say, I'm	just to
		thinking	say, thinking
		about	about
		you.	you.
23)	insuranea forms	insurance forms	[unchanged wording]
	contects Sick feat/s	contacts	
		sick leave	
24)	Women also told us about things that others did that hurt them.  It was clear that some people in the workplace didn't know what to do to help or may have felt uncomfortable.	Women also told us about things that others did that hurt them.	Women reported on experiences with others that hurt them.
		It was clear that some people in the workplace didn't know what to do to help or may have felt uncomfortable.	It was clear that some people in the workplace didn't know what to do to help or may have felt uncomfortable.

25)		Some things hurt.	Actions can hurt.
		A lot.	A lot.
26)	A STATE OF THE PARTY OF THE PAR	Not once did	Employers not
		my boss call	calling
27)	Eprefer e-mail. Foodd control my sinctons more.	I prefer e-mail.	Some prefer email.
		I could control	Emotions can be
		my emotions	more easily
		more.	controlled.
28)		My boss was	Employers may be
	My bogs was uncombristly.	uncomfortable.	uncomfortable.

29)	Everyone welcomes an expression of concern but, beyond that, if you are the person in the workplace who a woman well well belief well the belief well have been share that information with the people she wants to know	Everyone welcomes an expression of concern but, beyond that, if you are the person in the workplace who a woman turns to for help, ask her what would help HER and then share that information with the people she wants to know.	[unchanged wording from narrative version]
30)		Most women recover and continue at their jobs.	[unchanged wording from narrative version]
31)		Thank you for hearing our voices.	Thank you for listening to women's experiences.

	ginal comments have been paraphrased for this project.  No images of our participants were used.  Less and images are from both survivors and community volunteers.	Original comments have been paraphrased for this project. No images of participants were used.  [not formatted]	[unchanged wording from narrative version]
Vide Lisa Fisher.	Researchers  Ide Room, Catherine Logdin, Lyree Roberson  Kanviledge Translation  an Matthew, Modul Things Research Institute  Production, Asia and Mill Tough Processing Stream Bodd  Volum  Volum  Samb Cary, Lyree Ong, Debroch Kicenick, Lucie Korum, evers Soutscale N. A. Lack Sory, Kern Wilson  Phonography  Lyre Ong, Samb Cary, Chryl MacCondid, Journel Roberton  Appeare Roberton, Lyree Roberton	Researchers - Lucie Kocum, Catherine Loughlin, Lynne Robinson, Sarah Kehoe. Knowledge Translation – Jan Matthews, Mindful Things Research Institute & Sarah Kehoe. Video Production, Audio and Still Image Processing – TECHNA Institute for the Advancement of Technology for Health. Photography – Lynn Gray, Sarah Gray, Cheryl MacDonald, Jeanne Robichaud, Lynne Robinson, Sarah Kehoe, Shutterstock, Pixel and Pixabay.  [not formatted]	[unchanged wording from narrative version]

34)	Audio Recording Video and Audio Production Services. CLT.	Music – "Photo [unchanged wording		
	Dalhousie University  Musslc		Theme," Antony	from narrative
	"Photo Theme," Antony Raijekov, Creative Commons  Funding  Nova Scotia Health Research Foundation	Raijekov, Creative	version]	
	Figure 1 to 1		Commons. Funding –	
	Special Thanks to Breast Cancer Action Nova Scotia, Ariel Watson		Nova Scotia Health	
			Research Foundation,	
			Maritime SPOR	
			SUPPORT Unit, The	
			Canadian Centre for	
			Applied Research in	
			Cancer Control.	
		Breast Car	Special Thanks to –	
			Breast Cancer Action	
			Nova Scotia, Ariel	
			Watson. 2017.	
			[not formatted]	

## Appendix D

Narrative Infographic Handout (Electronic)

# I Wanted You to Know: Making it easier to talk about breast cancer in the workplace

Breast cancer will affect almost 17,000 working women this year in Canada.



I knew I had to tell...

I just didn't know how...



Women told us many stories about what helped them. One thing was always helpful: expressing concern and letting the woman know throughout the course of her treatment that others at work were thinking about her. Paying attention to a given woman's needs and meeting those needs, as much as possible, was always helpful.

What helped?

"I'm so sorry."

They were constantly there for me.

They emailed just to say, I'm thinking about you.





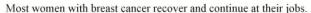
Some things hurt. A lot.

Not once did my boss call...

I prefer e-mail. I could control my emotions more.

My boss was uncomfortable.

Everyone welcomes an expression of concern but, beyond that, if you are the person in the workplace who a woman turns to for help, ask her what would help HER and then share that information with the people she wants to know.





Reference: Robinson, L., Kocum, L., Loughlin, C., Bryson, L. & Dimoff, J. (2015). I wanted you to know: Breast cancer survivors' control of work-place communication about cancer. Journal of Occupational Health Psychology, 20(4), 446-456. doi: 10.1037/a0039142

# Appendix E

# Participant Recruitment Efforts

Barb Thompson – HWRBC partner & former BCANS	Asked organizer of breast cancer retreat taking place in September to post about it. Email sent to a Mount Pearl, NF breast cancer group facilitator.
employee	
Bosom Buddies of Nova Scotia	No response
Breast Cancer Action Nova Scotia (BCANS)	No response
Breast Cancer Action Quebec	Article in August 2017 newsletter
Breast Cancer Society of Canada	No response
Canadian Breast	Blog post (https://www.cbcn.ca/en/blog/our-
Cancer Network	stories/work_and_breastcancer), Twitter (@CBCN),
(CBCN)	Facebook
Canadian Cancer Action Network	Twitter (@canceractionnet), Facebook
Canadian Cancer Survivor Network	Posted on website: http://survivornet.ca/act/surveys-research-studies-drug-reviews/seeking-participants-survey-breast-cancer-work
Canadian Partnership Against Cancer (CPAC)	No response
Cancer Care Nova	Email sent to contacts including: the Cancer Patient Family
Scotia (Meg	Network (a virtual network of 400 cancer patients/families
McCallum)	who signed up to be involved in cancer system
	improvement), Breast Cancer Action Nova Scotia (BCANS),
	Canadian Cancer Society, the Cancer Care Program
	Facebook and Twitter feeds and people from Bosom Buddies

Cancerandwork.ca	No response
Dr. Christine Maheu (McGill University) (Co-creator of Cancerandwork.ca)	No response
Chronicle Herald	Article – August 31, 2017 (http://thechronicleherald.ca/novascotia/1499526-wanted-working-women-with-cancer)
CURE Foundation	Twitter (@FoundationCURE), Facebook
Danielle Mercer's LinkedIn	Post
Dr. Kocum's Twitter	Multiple regular posts/re-tweets (@WorkScientist)
Handouts at booth for Occupational Health Psychology Summer Institute 2017 conference	July 17-20, 2017
Handouts at HWRBC Workshop 3	June 23, 2017
HWRBC Newsletter	Piece in newsletter (June 10, 2017)
IWK – Sunshine Room	No response
Kijiji	Over 100 ads Canada-wide – including regular re-posts with over 4000 hits.
Meeting with Maritime SPOR SUPPORT Unit (MSSU)	Sarah Kehoe met with Brian Condran (MSSU Patient Engagement Coordinator)
Metastatic Breast Cancer Advocacy Canada	Twitter (@MBC_Advocacy_CA), Facebook

Posters around Nova Scotia	75 posters
ReThink Breast Cancer	No response
Saint Mary's University Website	Link to questionnaire (http://www.smu.ca/searchresults.html?q=Breast+cancer+stu dy&sa=Search)
Sarah Kehoe's LinkedIn	Post (June 13, 2017)
Sarah Kehoe's Twitter	Multiple regular posts/re-tweets (@Sarah_Kehoe_)
The Coast Classifieds	Post (July 26, 2017)
Today@Dal website	Posts (July 4, 2017/August 4, 2017/August 14, 2017/August 21, 2017; https://www.dal.ca/news.html)
WorkWellness	Including paying to boost posts
Facebook	(https://www.facebook.com/WorkWellnessLab)
WorkWellness Twitter	Multiple regular posts/re-tweets (@WorkWellnessLab)
WorkWellness	Posts on website (http://workwellnesslab.com;
website	http://workwellnesslab.com/current-research-studies/)
Young Adult Cancer Canada (YACC)	Posted on website (http://www.youngadultcancer.ca/seeking-participants-for-survey-on-breast-cancer-work)

#### Appendix F

## Participant Recruitment Materials

General Email Content:

Hello,

This is a request for assistance with a research study being conducting in Dr. Lucie Kocum's Work Wellness Lab with the Department of Psychology at Saint Mary's University in Halifax, NS. The purpose of this study is to explore the barriers and psychosocial effects women face when returning to work with breast cancer. It is our intention to connect with women who have been diagnosed with breast cancer within the past 5 years and were employed at that time, to invite them to participate in this research. We are currently looking for volunteers to participate in our online questionnaires. Participation in this study includes completing 5 questionnaires over the course of a year. Each questionnaire will take approximately 20 minutes to complete. Participation is completely voluntary.

If you could please distribute this information at your discretion it would be appreciated. I have included the link to the questionnaire below, as well as attached a recruitment poster and a document with messaging about the study for your communications.

Study link: http://bit.ly/2t31c8C

If you have any questions regarding this study or would like additional information, please feel free to contact me. Contact information for myself and my advisor are in this email as well as on the recruitment flyer.

#### Yours sincerely,

#### Sarah Kehoe

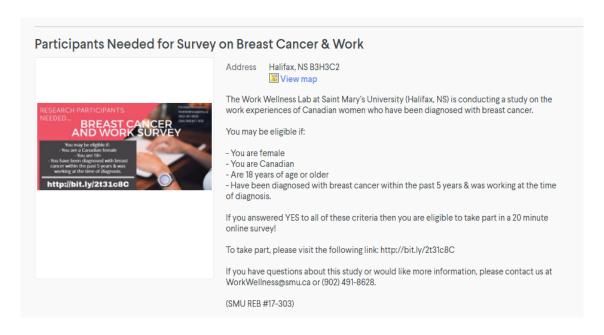
MAHSR Candidate - Saint Mary's University
Research Assistant - Work Wellness Lab, Department of Psychology (SMU)
Sarah.Kehoe@smu.ca

#### Dr. Lucie Kocum

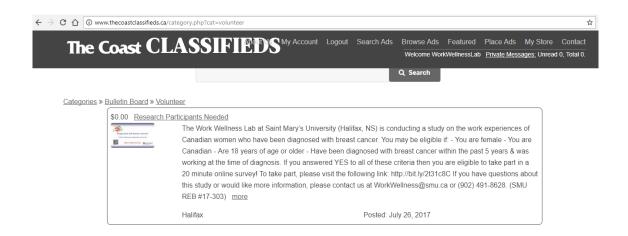
Associate Professor
Department of Psychology
Saint Mary's University
Lucie.Kocum@smu.ca

Connect with Us!
WorkWellnessLab.com
@WorkWellnessLab

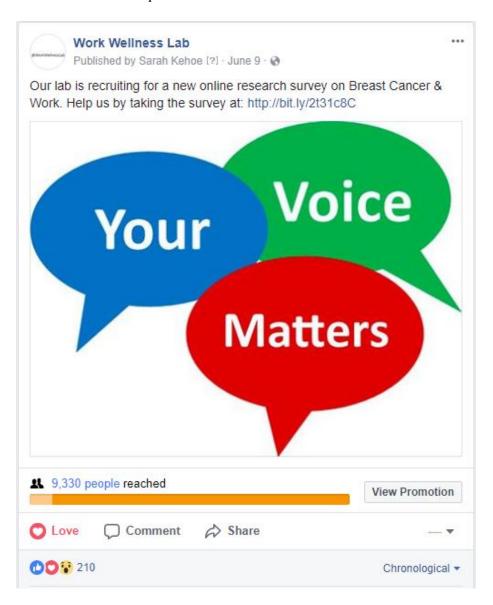
## Online Ad Example 1:



### Online Ad Example 2:



## Facebook Post Example:



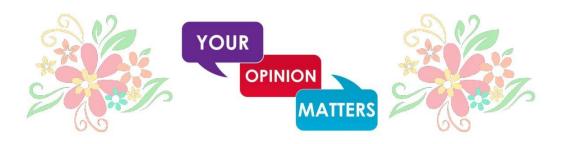
## Twitter Post Examples:





Poster Example 1:

# RESEARCH PARTICIPANTS NEEDED



# **BREAST CANCER AND WORK SURVEY**

Have you been diagnosed with breast cancer in the past 5 years?

Are you between the ages of 18-65 and employed when diagnosed?

<u>Are you interested in helping researchers</u> learn more about women's experiences with breast cancer in the workplace?

If you answered **YES** to all of these questions then you are eligible to take part in our survey study!

(5 surveys over the course of a year, 15-20 minutes each).



To take part, please visit the following link:

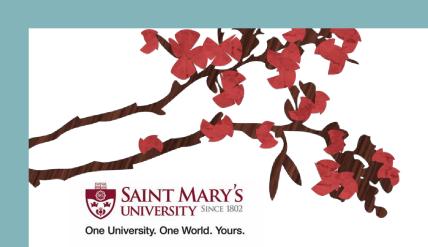
http://bit.ly/2t31c8C



If you have questions about this study or would like more information, please contact us at: WorkWellness@smu.ca (SMU REB# 17-303).

BREAST CANCER & WORK SURVEY http://bit.ly/2131c8C  BREAST CANCER & WORK SURVEY http://bit.ly/2131c8C	BREAST CANCER & WORK SURVEY http://bit.ly/2t31c8C	BREAST CANCER & WORK SURVEY http://bit.ly/2t31c8C	BREAST CANCER & WORK SURVEY http://bit.ly/2t31c8C	BREAST CANCER & WORK SURVEY http://bit.ly/2t31c8C	BREAST CANCER & WORK SURVEY http://bit.ly/2t31c8C	BREAST CANCER & WORK SURVEY http://bit.ly/2t31c8C
δο	20	Qo.	Qo	₽•	Qο	20

## Poster Example 2:



# RESEARCH PARTICIPANTS NEEDED

### **BREAST CANCER AND WORK SURVEY**

Have you been <u>diagnosed with breast cancer in the past 5 years</u>?

Are you <u>between the ages of 18-65</u> and employed when diagnosed?

Are you interested in helping researchers learn more about women's experiences with breast cancer in the workplace?

If you answered **YES** to all of these questions then you are eligible to take part in a 20 minute online survey!

To take part, please visit the following link:

http://bit.ly/2t31c8C



If you have questions about this study or would like more information, please contact Sarah Kehoe: **WorkWellness@smu.ca** 

SMU REB # 17-303