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Women's Stories of Breast Cancer: Sharing Information Through YouTube Video Blogs

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A thesis submitted in partial fulfillment of the requirements for the degree in Master of Science

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WOMEN'S STORIES OF BREAST CANCER: SHARING INFORMATION
THROUGH YOUTUBE VIDEO BLOGS

(Thesis format: Monograph)

by

Jenna Kressler

Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science

The School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

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Abstract

Breast cancer is one of the most prevalent chronic diseases among North American women. Individuals need accessible and reliable health information for self-care and self-health promotion. Increasingly, individuals are contributing to and accessing information about cancer, using interactive online resources such as YouTube. The purpose of this research was to investigate the personal YouTube video blogs of women with breast cancer and their portrayed messages. This study used a narrative inquiry to examine the video blogs of four women with breast cancer. The women talked about having cancer as a transformative experience. Information about breast cancer from healthcare providers was helpful but not always sufficient. The women sought and provided additional information on treatments, complementary and alternative methods, side effects, prosthetics, and changes to their identity. YouTube is growing in importance as a source of peer-to-peer health information sharing and support.

Keywords: breast cancer, women, social media, YouTube, blogging, health literacy, storytelling, narrative, peer-to-peer support, Health 2.0

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List of Abbreviations

ALLS	Adult Literacy and Lifeskills Survey
IALLS	International Adult Literacy and Life Skills Survey
NAAL	National Assessment of Adult Literacy
SNS	Social networking sites
URL	Uniform Resource Locator
U.S	United States

CHAPTER 1: INTRODUCTION

In Canada, cancer, cardiovascular disease, diabetes, and chronic respiratory disease are among the most prevalent and fatal chronic diseases (Harvey, Hook, Kozyniak, & Selvanathan, 2002). Surpassing diseases of the heart, almost 30% of deaths in 2009 were attributable to various cancers (Canadian Cancer Society, 2009). Breast cancer is the most prevalent cancer among women (26%) followed by lung (13%) and colorectal cancer (11%) (Canadian Cancer Statistics, 2013).

Based on the most recent breast cancer prevalence figures, an estimated 23,800 Canadian women and 200 Canadian men were diagnosed in 2013 (Canadian Cancer Statistics, 2013). The majority of women diagnosed with breast cancer (6,400 diagnoses) in 2013 were between the ages of 60-69 (Canadian Cancer Statistics, 2013). There were 5,900 breast cancer diagnoses among women aged 50-59 years and 3,300 between 40-49 years of age (Canadian Cancer Statistics, 2013). Individuals under the age of 40 years of age were the least likely to be diagnosed with only 1,055 diagnoses (Canadian Cancer Statistics, 2013).

Breast cancer is the second most common cause of cancer death in females (13.9% in 2013), however breast cancer mortality rates have steadily been declining since the 1980s at a rate of 2%, on average, per year (Canadian Cancer Statistics, 2013). In fact, Canada's decline in breast cancer related mortality has been attributed to increased mammography screening, early detection of disease, and advanced treatments (Canadian Cancer Statistics, 2013). The five-year relative survival rate refers to the probability that women diagnosed with breast cancer will live five years past their diagnosis; current estimates indicate 88% of women diagnosed with breast cancer between the ages of 40 and 79 years old will reach this benchmark (Canadian Breast Cancer Foundation, 2013; Canadian Cancer Statistics, 2013).

Currently breast cancer is perceived as a chronic disease given the need for continued management of breast cancer beyond the 5-year survival benchmark and the life long implications it has on quality of life, self-esteem, family roles, and every day functioning (Loh, Packer, Chinna, & Quek, 2013). Chronic diseases, as defined by the Centers for Disease Control, are "illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely" (Centers for Disease Control and

Prevention, 2012). As such, chronic diseases and illnesses require self-care management rather than a curative care paradigm that is reliant on client participation in self-health promotion and self-care (Kennedy, Rogers, & Bower, 2007). Individuals with chronic disease and illness contribute to self-care management through collaborative decision making and engaging in behaviours to assist their health condition, such as gathering disease-related information, following treatment protocols, and managing their emotional care (e.g., de-stressing by doing yoga) (Kennedy et al., 2007; Schulman-Green, Bradley, Knobf, Prigerson, & DiGiovanna, 2011). Reliable disease-related information, services, and support are important to self-care management (Griggs et al., 2007; Halkett et al., 2010).

The Internet is an important source of health information, services, and social support. Current evidence suggests that the majority of adult Internet users (55%) seek disease specific information and 43% are interested in information about medical treatments and procedures (Fox & Duggan, 2013; Underhill & McKeown, 2008). The functions and capabilities of the Internet continuously evolve enabling individuals to connect with each other and contribute information to websites, known as Web 2.0 technologies (further explained in Chapter 2) (Aghaei, Nematbakhsh, & Khosravi Farsani, 2012; Eysenbach, 2008; Fox, 2010). With increased access to the Internet and advancements of Web 2.0 technologies, individuals are taking advantage of Health 2.0 social media network applications for health information and support (Eysenbach, 2008; Fox, 2011; Jung Oh, Lauckner, Boehmer, Fewins-Bliss, & Li, 2013). Participation in Health 2.0 online communities and social networking sites, such as YouTube (video-sharing website), allows individuals to access and share health and disease-related information (Eysenbach, 2008).

For many, the Internet is a source of cancer-related information related to diagnoses, treatments, social support, and living and coping with cancer (Ziebland et al., 2004). Individuals who have access to the Internet and are living with a chronic disease, such as cancer, are also more likely to engage in online health communication regarding medical treatments and drugs and monitor another individual's health experience online compared to other online users without chronic disease (Fox & Duggan, 2013; Bundorf, Wagner, Singer & Baker, 2006; Ziebland et al., 2004). Over half of e-patients (individuals

who seek online health information) between the ages of 18 to 49 have viewed other individuals' reported-experiences or stories about health or medical issues within an online news group, website, or blog (Fox, 2009).

Storytelling has a long history within healthcare as a way for clinicians to engage with clients to diagnose illness and as a way for individuals to share and access disease related information by listening to illness stories (Chou, Hunt, Folkers, & Auguston, 2011; Kreuter et al., 2010; Shapiro, Bezzubova, & Koons, 2011). Arguably, individuals learn best through storytelling, as it provides the experience of another within a real-world context (Lieblich, Tuval-Mashiach, & Zilber, 1998; Shapiro et al., 2011). In fact, individuals managing chronic disease frequently use narratives as a method of healing and sense-making of their disease (Hawkins, 2007). Illness narratives provide a voice to personal experience and offer a nuanced understanding of disease management beyond that available by healthcare providers (Frank, 1995). Individuals with cancer have long told stories of their diagnosis, treatments, and life after cancer, as well as offer information and insights regarding their treatment and healing plan (Gualtieri & Akthar, 2013). The interactive nature of Health 2.0 applications have created an online avenue for communication and storytelling. In fact, public interest in disease related online blogs has steadily increased and several studies have examined the use and utility of cancer blogs as a source of cancer information (Chiu & Hsieh, 2012; Katz Ressler, Bradshaw, Gualtieri, Kenneth, & Chui, 2012; Keim-Malpass et al., 2013; Kim, 2009; Kim & Chung, 2007).

Of late, individuals are turning to video blogs and video sharing websites, such as YouTube, to disseminate personal experiences of illness and in particular breast cancer (Chou et al., 2011; Liu, Huh, Neogi, Inkpen, & Pratt, 2013). YouTube is a free online video-sharing social media website where individuals are able to watch, share, and upload videos (YouTube, 2014). Recent estimates indicate that over 1 billion users visit the YouTube webpage each month (YouTube, 2014). Despite the abundant health content on YouTube, very few studies have examined the nature of health information and health messages individuals are providing via YouTube (Fox, 2010; Fox & Duggan, 2013; YouTube, 2014). Thus, this research study will provide insight to the conveyed health messages distributed by women with breast cancer who post their journey on YouTube.

CHAPTER 2: LITERATURE REVIEW

This chapter will begin with a descriptive overview of breast cancer and the health information needs of individuals living with breast cancer. Literacy and health literacy will be defined and the importance of these concepts in relation to breast cancer care will be outlined followed by a discussion of online health information, focusing on social media and the interactive nature of Health 2.0 practices. This chapter will conclude with an explanation of online visual representations.

The following section includes the literature that is relevant to this study. The databases used in the literature review included the PubMed, Scopus, and ProQuest. Inclusion dates of literature ranged from 2003 to 2013. The following key search terms used included: “breast cancer”, “breast cancer and chronic disease”, “women and breast cancer”, “stages of breast cancer”, “information needs and breast cancer”, “breast cancer and diagnosis”, “breast cancer and treatment”, “breast cancer and survivorship”, “information and breast cancer”, “social media and cancer”, “YouTube and cancer”, “YouTube and breast cancer”, “YouTube and health”, “Facebook and breast cancer”, “health literacy”, “health literacy and cancer”, “cancer and blogs”, “video blogs”, “vlogs”, “video and qualitative research and YouTube”, “social networking sites and health”, “social networking sites and cancer”, “internet and chronic disease”, and “peer to peer support and health”. The key search terms were used individually, as well as in combination with one another.

Breast Cancer

Breast cancer is defined as a tumour or cancerous growth in the breast linked to issues of genetics, lifestyle, and environmental factors (Canadian Breast Cancer Foundation, 2013; National Cancer Institute, 2012). Breast cancer is the most prevalent diagnosed cancer among women with nearly 1.7 million women diagnosed worldwide in 2012 (World Cancer Research Fund International, 2014). In Canada alone, one in nine women will develop breast cancer over their lifetime and one in twenty-nine will die from it (Canadian Breast Cancer Foundation, 2013; Canadian Cancer Statistics, 2013). The majority of Canadian women diagnosed with breast cancer are older women 50+ (Canadian Cancer Statistics, 2013).

Individuals with breast cancer experience significant emotional effects, as well as substantial physical impacts (pain, hair loss, loss of one or both breasts, swelling) (Canadian Breast Cancer Foundation, 2013; Parrish & Adams, 2003; Turner, Kelly, Swanson, Allison, & Wetzig, 2005). The uncertainty of how and what information to disclose about one's diagnosis to family and friends and answering questions regarding potential death has emotional impacts on an individual, such as stress, sadness, and anxiety (Turner et al., 2005). The uncertainty surrounding life longevity, the loss of independence, the success of treatments, and the strength to endure the *unknowns* associated with breast cancer also creates substantial stress and influences one's quality of life (Parrish & Adams, 2003; Turner et al., 2005).

Newly diagnosed individuals experience initial shock and fear the potential threat to their health; experience anxiety and anger due to limited or inaccurate information about breast cancer treatment; can develop overall depression and are concerned about the possible impact on family, and doubt about future plans (e.g., career and relationships) (The Canadian Breast Cancer Foundation, 2011; Epping-Jordan et al., 1999; Hegel et al., 2006; National Cancer Institute, n.d.). Emotions experienced at the time of breast cancer treatment can include: psychological stress arising from treatment and its side effects, anxiety about the phases of treatment, fear that treatments will fail or that the cancer will return, guilt about the demands that the condition may impose on family and friends, the feeling that things will not get better, lack of motivation, and a sense of hopelessness or desire to withdraw from family and friends (National Cancer Institute, n.d.; The Canadian Breast Cancer Foundation, 2011).

Physical impacts of breast cancer can range from negative perception of body image (breast loss, weight gain, hair loss) to sickness and pain. Detrimental body image is both a physical and emotional concern that affects individuals with breast cancer (Turner et al., 2005). Losing a breast can be perceived as the loss of womanhood and femininity, and can instill fear and uncertainty regarding family members' (e.g., spouse or partner) perception of individuals with breast cancer (Turner et al., 2005). Weight loss and gain are common physical responses experienced by women with breast cancer, resulting from chemotherapy and hormonal treatments, as well as prescribed medication (Brunet, Sabiston, & Burke, 2013; Goodwin et al., 1999; Helms, O'Hea, & Corso, 2008; Irwin et

al., 2005). The fluctuation of weight can be life altering, stressful, and potentially depressing (Helms et al., 2008). Hair loss is another significant physical and emotional change that women experience, as a consequence of their treatment, and contributes to their stress levels, perception of body image, and femininity (Helms et al., 2008; Lemieux, Maunsell, & Provencher, 2008). Breast cancer patients experience a variety of other physical impacts on their body, such as lack of energy, loss of appetite, vomiting, nausea, hot flashes, dizziness, swelling, and a general feeling of illness from the treatment (Avis, Crawford, & Manuel, 2005; Pinto & de Azambuja, 2011; Turner et al., 2005).

Pain (e.g., chest, breast, arms, bone, and joint pain due to the compression of a tumour) is another treatment related physical consequence among individuals with breast cancer (Arathuzik, 1991; Canadian Breast Cancer Foundation Ontario Region & Princess Margaret Hospital, 2010; Collins, Nash, Round, & Newman, 2004; Jordan, Hayward, Blagojevic-Bucknall, & Croft, 2013; Peretti-Watel, Bendiane, Spica, & Rey, 2012). Surgical interventions can cause tenderness and shooting pains, whereas radiation can cause skin colour changes, tenderness, redness, edema, some pain on treated areas, and fibrosis (Canadian Breast Cancer Foundation Ontario Region & Princess Margaret Hospital, 2010; Hopwood et al., 2010; Sjövall, Strömbeck, Löfgren, Bendahl, & Gunnars, 2010). Individuals with breast cancers' pain can limit daily exercise and leisure activities, housework, and disrupt sleep; enduring pain can lead to quitting work or taking a leave of absence and becoming dependent on others (Arathuzik, 1991; Collins et al., 2004; Hirschman & Bourjolly, 2005; Turner et al., 2005). The significant physical and emotional influences of breast cancer can cause doubt in one's own ability to endure and survive this disease; thus, informational support is fundamental (Canadian Breast Cancer Foundation, 2011).

Health Information Needs of Individuals with Breast Cancer

Breast cancer patients access diverse information resources to support them through their journey from ill health to wellness (Hodgkinson et al., 2007; Leydon et al., 2000; Vogel, Bengel, & Helmes, 2008). Information needs change over the course of an individual's breast cancer experience and timely access to relevant information assists in preparing an individual to contribute to treatment decisions and reduce feelings of

vulnerability and confusion; as well increase an individual's health competence and sense of control over their choices (Griggs et al., 2007; Vogel et al., 2008). Information needs align with the different stages of one's breast cancer experience: diagnosis, pre-treatment and treatment, and survivorship (Avis et al., 2005; Halkett et al., 2007; Taylor, & Spry, 2010; Vogel et al., 2008).

At the time of diagnosis and within the first six months of being diagnosed with breast cancer, individuals seek information on diagnostic processes, prognosis, treatment options, support services, and the impact of the illness and treatment on their family and themselves (Hodgkinson et al., 2007; Vogel et al., 2008). Vogel et al. (2008) found that the intensity of participants' information needs shifted away from issues of medication, treatment side effects, and treatment options throughout the duration of their breast cancer trajectory; however, consistently inquired about information pertaining to examinations and medical tests at each stage of their breast cancer experience (Vogel et al., 2008).

Information needs at diagnosis.

Common information needs among individuals with breast cancer at the time of diagnosis include: healthcare services, tests and treatment options, medications, side-effects of medications and treatments, the post-likelihood of survival, and advancement of the disease (Liao, Chen, M., Chen, S., & Chen, P., 2007; Luker, Beaver, Leinster, & Owens, 1996; Mills & Sullivan, 1999; Sutherland, Hill, Morand, Pruden, & McLachlan, 2009). Whelan et al. (1997) study of newly diagnosed cancer patients (e.g., breast, lung, head and neck, colorectal, prostate carcinoma) found that 84% of the research participants wanted detailed information about treatment, requested disease-specific information, details of procedural issues, and resources for social and community support. Other information needs that are common at the time of diagnosis are related to hereditary implications of the disease and the impact it will have on family members, friends, work and social life, self-care, self-esteem, and confidence (Luker et al., 1996).

Women reported that they receive adequate information regarding treatment options and procedures, however more information on intrapersonal and interpersonal relationships (e.g., how breast cancer will influence relationships and how they will feel about themselves) was desired (Avis et al., 2005). Avis et al. (2005) argue that the better-prepared women are when dealing with breast cancer the better their overall quality of

life. Thus, information regarding the emotional, psychological, and social side effects of breast cancer diagnosis is needed (Avis et al., 2005).

While all women want practical and explicit information regarding their diagnosis, prognosis, side effects of treatments, and complications, researchers found that women under 40 years of age want information pertaining to fertility related issues and menopause (Posma, van Weert, Jansen, & Bensing, 2009; Thewes et al., & 2005). In contrast, researchers have suggested older women (over 65 years of age) prefer more specific (on a *need to know* basis) medical information pertaining to their prognosis and diagnosis, side effects of treatments, and complications; older women also want information regarding how to remain independent and how to improve their quality of life (Posma et al., 2009; Yoo, Levine, Aviv, Ewing, & Au, 2010). At the time of diagnosis, women tend to feel alone and need ongoing support (Landmark, Bohler, Loberg, & Wahl, 2008). Women diagnosed with breast cancer, in one study, felt the time between diagnosis and surgery was too short and that they were still trying to deal with the shock of their diagnosis (Landmark et al., 2008). These women explained that constant information and social support were needed from their family, friends, as well as health professionals at the time of diagnosis, between diagnosis and surgery, immediately after surgery, and beyond the post-surgical period (Landmark et al., 2008).

Information needs at treatment stage.

Graydon et al. (1997) examined 70 Canadian women with breast cancer (22 in the surgery group, 25 in the chemotherapy group, and 23 in the radiation therapy group) between the ages of 21 to 91 years of age to assess the information needs of women during their treatment for breast cancer. Graydon et al. (1997) concluded that regardless of the type of breast cancer treatment (chemotherapy, surgery, or radiation), women needed detailed information on the disease, tests, and treatments to help them cope and manage their illness.

Halkett et al. (2010) conducted a study that examined 34 Australian women, ages 18 to 75 years, with breast cancer who received radiotherapy treatment. Using a grounded theory approach, the researchers inquired about the adequacy of information and social support provided to women receiving the cancer treatments. There were four points of time where breast cancer patients needed information: (a) meeting with radiation

oncologist, (b) planning appointment, (c) first day of treatment, and (d) approaching the end of treatment to address strategies and information needs (Halkett et al., 2010).

Breast cancer patients' expressed information needs were highest during the initial and planning appointments. During their initial appointment with their radiation oncologist, the women wanted detailed information on treatment, such as, what the treatment would involve, the types of machines and technology used, the potential side effects, and how and why physicians planned their treatment in such a way; as well as the need for other medications and the availability of other health services (Halkett et al., 2010). The planning appointment(s) is where individuals stated that they wanted to know what to expect the first day of treatment; the length of treatment, the costs involved (if any) and how much is covered by health insurance, how much of the breast is treated, and they want to become acquainted with the staff (Halkett et al., 2010). Towards the end of treatment individuals want to know about any changes in their treatment plan, when and if treatment stops due to adverse side effects, if side effects do not stop when treatment is over, and whether it is possible to recognize (e.g., visually or feel internally) the treatment has eliminated the cancer (Halkett et al., 2010).

A qualitative descriptive research study conducted by Landmark et al. (2008) found that women 39 to 63 years of age who had undergone their first breast cancer treatment needed knowledge and psychosocial support related to physical (body changes), emotional (personal reactions), and social (relationships and social welfare, e.g., social welfare services and patient rights) aspects of everyday life (Landmark et al., 2008). Women expressed the need for information to understand: (a) the anticipated physical changes to their body, (b) their emotional reactions, (e.g., stress and anger), (c) the social impact of the disease on their relationships (e.g., women not wanting their husband to see them naked, feelings of shame), and (d) social welfare (e.g., feeling forced to return to work, no one cares about them) issues (Landmark et al., 2008). Overall, women need detailed information from health professionals (oncologists, nurses, physicians) to support their understanding of their treatment including: benefits of certain treatments, consequences and side effects, physical changes, and the transition post-surgery (Graydon, 1997; Halkett et al., 2010; Landmark et al., 2008).

Information needs throughout survivorship.

Breast cancer survivor is a term that has several meanings depending on the individual who is affected by breast cancer and their place on the disease trajectory (e.g., post-diagnosis survivor, living with disease as a survivor, or survivor of living five years disease free) (Little, Sayera, Paul, & Jordens, 2002). Breast cancer survivors need information and readily available resources that differ from the needs of individuals recently diagnosed or are going through treatment. Most breast cancer survivors experience ongoing anxiety and require current, comprehensible, and accessible information on supportive care services 2-10 years post-diagnosis (Hodgkinson et al., 2007).

Hodgkinson et al. (2007) examined the supportive care needs, psychosocial distress, and quality of life of 117 women breast cancer survivors between 32 to 88 years of age and found there was an average of eight unmet information needs. These unmet needs included: up-to-date breast cancer information, clear and concise information regarding women's concerns about relapsing (having cancer again and going through treatment) their fear of disease reoccurrence, alternative therapy services or treatments, existential survivorship (becoming familiar with spiritual and personal beliefs once becoming a breast cancer survivor and throughout the duration of their life), dealing with expectations of a breast cancer survivor, and dealing with changes to their belief 'nothing bad will happen in my life' (Hodgkinson et al., 2007).

Educational interventions, such as informational support and symptom management provided by physicians, nurses, and other allied health care providers are valued by breast cancer survivors. In addition, the need for innovative approaches to providing information, for example on the Internet and in peer group sessions, was identified (Griggs et al., 2007). Yet, despite the significant information burden associated with chronic disease and breast cancer disease management, approximately half of North American adults lack the literacy and health literacy skills needed to maintain and manage their health (Canadian Council on Learning, 2007; Canadian Public Health Association, 2008; Statistics Canada, 2005).

Literacy

Literacy comprises the knowledge and skills needed to understand and use information from four areas: prose literacy (reading texts), document literacy (understanding visual formats, such as maps, charts, and diagrams), problem solving, and numeracy (National Center for Education Statistics, 2005). The Adult Literacy and Lifeskills Survey (ALLS) reports on five levels of Canadian adults' literacy skill; level 1 and 2 reflect limited skills; level 3 reflects the basic skills needed to function in Canadian society; levels 4 and 5 are the most advanced forms of literacy (Literacy Nova Scotia, 2003). The ALLS indicator measures literacy abilities for both English and French for Canadian adults over the age of 16 (Canadian Public Health Association, 2008). Level 1 indicates that an individual has difficulty reading any sort of material (e.g., the ability to pick out a single piece of information) and level 2 specifies a person to have the ability to understand basic information and material (e.g., able to locate information within text) (Statistics Canada & Organization for Economic Cooperation and Development, 2005). In 2003, 48% of Canadians scored below the level 3 literacy skill category (Statistics Canada & Organization for Economic Cooperation and Development, 2005).

Health Literacy

Health literacy is defined by the Canadian Public Health Association expert panel on health literacy as “the ability to access, understand, evaluate, and communicate information as a way to promote, maintain and improve health in a variety of settings across a life-course” (Canadian Public Health Association, 2008, p.11). Health literacy builds on one's literacy skill and constitutes an important determinant of health, which evolves and changes over one's lifetime (Nutbeam, 2000). In 2008, scholars from Canada, the United Kingdom, and the United States met to examine the issue of health literacy and further refine its meaning and purpose (Coleman et al., 2008). Adequate health literacy includes diverse skills, such as reading, writing, speaking, listening, numeracy, critical analysis, and application of information to improve the ability of individuals to act on information to live a healthier life (Coleman et al., 2008).

Improved health literacy skills contributes to better informed choices, reduced health risks, enhanced navigation throughout the health system, improved patient safety,

and fewer inequities in health (Coleman et al., 2008). Adequate health literacy skills also provides a foundation for equal and easy access to and delivery of health care and health care information (e.g., searching for and understanding online health related information) that can assist in producing equal power relationships among individuals, healthcare professionals, and the health system (Coleman et al., 2008; Nutbeam, 2000).

Nutbeam (2000) provides a health literacy framework, which includes three broad categories of: functional, interactive, and critical health literacy skills. Functional health literacy is reflected in individuals' skills of reading, writing, and listening that support the health of individuals in accessing health information and services (Nutbeam, 2000). For example, health literacy skill is required in order to understand the purpose and use of prescribed medications, to comprehend labels on prescriptions and over the counter medicines, and to coordinate health care appointments (Nutbeam, 2000). Functional health literacy skill supports individuals' information seeking skills from multiple sources including online information. Someone with adequate functional health literacy skill would have the ability to access information and services and are able to comprehend health pamphlets, magazines, and articles (Nutbeam, 2000).

Interactive health literacy reflects greater cognitive and social skills needed to comprehend health information and associate meaning from various forms of dialogue (Nutbeam, 2000). Interactive health literacy requires individuals to have the personal skills to act independently on knowledge and to have self-confidence and motivation to seek out information and to act upon information and advice received (Nutbeam, 2000), for example, the ability to participate in and retrieve information from an online support group. This is an important skill set to have as it permits individuals to gather information, and seek and access resources to develop and maintain positive health behaviours. Adequate communication and social skills are needed for interpersonal interaction with other individuals and healthcare professionals (Nutbeam, 2000).

Critical health literacy emphasizes cognitive skills, which reflect an individual's ability to critically analyze and utilize information to obtain more control over personal, community, and societal health situations. Critical health literacy reflects population based benefits by incorporating political and social change by addressing social, economic, and environmental determinants of health at the community and societal level

(Nutbeam, 2000). Adequate critical health literacy skill allows for greater autonomy and personal empowerment (Nutbeam, 2000). In juxtaposition to functional health literacy, it allows individuals to be more critical and analytical about health information and have the ability to give (confidently) advice, advocate, and facilitate health information to the community and leaders.

Despite the benefits associated with adequate health literacy, 60% of Canadian adults have limited health literacy; thus they are limited in their ability to access, understand, evaluate, and communicate information as a way to promote and maintain and improve health in a variety of settings across a life-course (Canadian Council on Learning, 2007; Canadian Public Health Association, 2008). Having low levels of literacy and health literacy adversely affects individuals' health ranging from being able to understand written and verbal health related communication regarding, various illnesses, treatment, symptoms, to disease prevention and health promotion (Porr, Drummond, & Richter, 2006). Low health literacy can contribute to uncertainty of side effects among individuals, not knowing how to describe symptoms or what to disclose to clinicians, misuse of medications, and frequent visits to health care provider (Williams, Davis, Parker, & Weiss, 2002; Wolf, Davis, Tilson, Bass III, & Parker, 2006). The use of medical language by health care providers is often a barrier to care among those with inadequate health literacy (Williams et al., 2002). Essentially the majority of Canadian adults do not have sufficient skills to read, write, communicate, and comprehend situations and information regarding health on a daily basis.

Similarly, a health literacy assessment was designed by the National Assessment of Adult Literacy (NAAL) to measure an American adult's ability to locate, obtain, process, and understand basic health related information and services in order to make adequate health based decisions (Kutner, Greenburg, Jin, & Paulsen, 2006). This assessment uses four performance levels ranging from below basic, basic, intermediate, to proficient (Kutner et al., 2006). The NAAL classifies individuals who score below basic have no more than the ability to understand the simplest words, documents, and numbers and having the simplest concrete literacy skills (e.g., the ability to locate breasts on a labelled diagram). Whereas, the basic level is the ability to perform simple skills during daily activities, such as reading short, easy documents, and basic writing skills (Kutner et

al., 2006). Intermediate indicates a performance of moderately challenging, day-to-day literacy activities (e.g., the ability to understand and summarize text and make inferences), compared to proficient performance, where an individual can perform more complex and challenging literacy skills (Kutner et al., 2006).

The U.S. report, *Health Literacy of American Adults: Results from the 2003 National Assessment of Adult Literacy*, revealed that 56 % of U.S. adults age 40-49 years and 38% of individuals aged 65+ had intermediate level health literacy skill (Kutner et al., 2006). Older adults (65 years +) were those most challenged in terms of their health literacy skill. The majority (59%) of older adults demonstrated below basic or basic health literacy compared to 28% of individuals aged 25-39 years (Kutner et al., 2006). In order to access and use health information and service resources in support of their health, individuals require adequate health literacy skills.

Evolution of the World Wide Web

The Internet has provided ease of access to health information, social support, advocacy, and activism within the online setting (Hackworth & Kunz, 2011). An estimated 74% of American and 79 % of Canadian adults access the Internet (Fox, 2010; Statistics Canada, 2011). Information sharing on the Internet has evolved from simple information retrieval of information (e.g., Web 1.0), to the ability to create and contribute information in multiple formats (e.g., text, video, image) to online sites, and interact with others (e.g., Web 2.0) (Aghaei et al., 2012). Most recently, Web 3.0 includes personalization of Internet information to an individual's needs (Aghaei et al., 2012; Harris, 2008). The function of Web 1.0 allows information seekers a read only view of the information, much like a brochure or advertisement, provided by the webpage creator (Aghaei et al., 2012). Individuals are not able to contribute to the website by providing feedback or leaving comments (Aghaei et al., 2012).

Web 2.0 technologies have shifted from the read-only capabilities of Web 1.0 to involve the development of online communities, the ability to interact with other online participants, connect with others with similar interests, and the ability to create online content (Aghaei et al., 2012; Murugesan, 2007). Online interactivity is reflected in the shift from lecture type information to include the ability of individuals to contribute to

online conversations (Aghaei et al., 2012). The interactivity of Web 2.0 allows users to modify and participate in expanding information of online content and applications, such as wikis, photo and video sharing, podcasts, social networking sites, and streaming media (Hackworth & Kunz, 2011). Web 2.0 also recreates new applications by reusing and combining various applications, data, and information on the Internet, a process referred to as mash-ups (Murusegan, 2007).

Currently, the third generation of the Internet, named Web 3.0 or the semantic web, allows the Internet to be readable by both machines and humans (Aghaei et al., 2012). Web 3.0 customizes services, news, advertisements, pictures, calendars, email, etc. to an individual's preferences. Web 3.0 shifts previous web capabilities (read-only websites, upload, share, contribute to sites) whereby the web remembers previous searches, what the individual is interested in, and is able to connect and share information pertaining to an individual (W3C Semantic Web, 2009). For example, iGoogle is a personalized homepage on the Google website containing information ranging from emails, news, movie theatre show times, calendars, weather, and a Google search box (Google, 2012). Information is integrated and personalized for users without users having to leave one site to go to another. For example, when shopping online at Chapters Indigo, the site provides suggested reading material or books to the individual based on past purchases.

Understanding Social Media

Social media is an interactive online tool for socialization and sharing thoughts and interests (Eckler, Worsowicz, & Rayburn, 2010). Social networking sites allow users to create, maintain, and update personal profiles, pictures, and links, and to post and comment on other user's profiles, like Facebook and MySpace (Eckler et al., 2010). Users of social media are able to access various social media sites (e.g., Facebook, Twitter) from any device (e.g., computer, smartphone) that supports an Internet connection (Facinelli, 2009). This allows quick, easy, and broad communication that connects millions of people together worldwide (Backman, et al., 2011). The use of social media has increased over the past five years and has evolved to include: blogs, micro-blogging, social networking sites, wikis, and photo, video, and file sharing sites (Eckler et al.,

2010). Blogs, such as Tumblr, are online journals that allow participants to express and share opinions, experiences, or events on a variety of topics, whereas microblogs applications (e.g., Twitter) are shorter blogs that only allow a maximum number of text characters (e.g., 140) and are updated more frequently (Eckler et al., 2010). Wikis, (Wikipedia) are a websites that provide information on various subjects, people, places, and things; they can be edited by anyone who has access (Aghaei et al., 2012). In addition, photo, video, file sharing sites, such as YouTube, Instagram, Pinterest, and Flickr, allow individuals to post, share, search and download images and videos (Eckler et al., 2010). In fact, many would argue that social media is transforming the way healthcare operates as it continues to engage individuals (Backman et al., 2011; Eysenbach, 2008; Fox & Jones, 2009).

Social Media and Health

As more individuals gain access to the Internet (about 75% of American adults and 95% of American teenagers have Internet access in 2010), more health issues and behaviours can be searched and discussed (Fox, 2010). In addition, individuals often go online to find others who have common health interests and to share knowledge (Fox, 2010). Over half of American adults (61%) go online to seek health related information, and 8.7 million Canadians went online to seek health information in 2005 (Underhill, & McKeown, 2008; Fox, 2009; Backman et al., 2011). These individuals go online to social media sites to: read; contribute to blogs, wikis, and social networks: to share videos and photos, and listen to podcasts (Backman et al., 2011). The use of social networking sites (SNS) has quadrupled since 2005 and it is anticipated that the use of SNS will continue to increase rapidly over the next few years (Jones & Fox, 2009).

Internet based social networks have provided social support and interconnectivity among individuals, and importantly information shared on the Internet and within social media sites tends to support a more patient-centered type of care (Ziebland et al., 2004). More individuals are turning to the Internet for health information because of the accessibility and availability of information (Ziebland et al., 2004). For some health issues, searching for information on the Internet is less embarrassing than face-to-face interactions (Ziebland et al., 2004). Fox and Jones (2009) reported that 39% of online health information seekers use social networking sites, such as Facebook and MySpace to

update, search for, and gather health information. Reportedly, individuals who used social media applications for health purposes acknowledged a positive impact on their health and how they cared for others, for example regarding decisions on treatment, changes in maintaining their health or another person's health, developing the confidence to ask physicians questions, help with stress management, and for support (Fox & Jones, 2009). Thus, social networks provide members with informational and emotional support and services (Bender, Jimenez-Marroquin, & Jadad, 2011).

Apart from individual users, healthcare organizations are increasingly using social media as a means of communicating and marketing their philosophy and the services they offer, and for purposes of health education (Backman et al., 2011; Eckler et al., 2010). Social media can improve doctor-patient communication by having online support groups, facilitating scheduling of appointments, and allowing feedback (Eckler et al., 2010). For instance, a health blog may be used to educate patients on flu prevention. Of the social media applications, Twitter is the predominant Health 2.0 tool used by hospitals in the United States, followed by Facebook, YouTube, and blogs (Eckler et al., 2010). Further, Eysenbach (2008) suggests consumers should be able to contribute to their personal health records and data (not just the ability to view and access it), much like the website PatientsLikeMe (<http://www.patientslikeme.com>), which will further develop and enable the concept of openness.

Medicine 2.0: collaborating, communicating, and sharing health information.

Medicine 2.0 refers to the use of applications, services, and tools through Web 2.0 technologies for health purposes. Eysenbach (2008) argues that the interactive technologies of Web 2.0 has created a shift away from traditional, hierarchal organizations of health care and medicine and have fundamentally changed the way people (health care professionals, consumers, patients, and researchers) seek information, and communicate (e.g., Facebook, wikis, blogs, YouTube) about health. Online SNS underpin the way in which people come together, form relationships, and collaborate (Eysenbach, 2008). The communicative processes enabled by SNS in Medicine 2.0 bring consumers and patients, health professionals, and researchers together (Eysenbach, 2008).

The Medicine 2.0 model of health care communication proposes a significant change in health information ownership and accessibility. Eysenbach (2008) suggests that

individuals, consumers, and patients are becoming important guides (apomediaries) to reliable and applicable information and resources. For example, within an online environment, a woman with breast cancer who recommends and directs others to breast cancer information resources is acting in the apomediator role. While not replacing the role of a healthcare provider, these individuals or apomediaries provide health information seekers an alternative to the traditional information gatekeeper model (Eysenbach, 2008).

Cancer and the use of social media. The Center for Studying Health System Change (2008) reported cancer patients are more likely to go online and use Internet resources to obtain preventative care, maintain a healthy diet and exercise, self-manage behaviours, and seek health information compared to those living with other chronic diseases. Similarly, a study by Ziebland et al. (2004) found that men and women diagnosed with either breast, testicular, prostate, cervical, or bowel cancer use the Internet throughout the disease trajectory; diagnosis, treatment, and both long term and short term follow up. Cancer patients gather information and understand disease etiology, treatments others have received, learn about living with cancer, and gain support from others through various sites and networks on the Internet (Ziebland et al., 2004). In fact, breast cancer patients are among the highest Internet users as there is an abundance of information and support services online (Ziebland et al., 2004).

Bender et al. (2011) in their study entitled *Seeking Support on Facebook: A Content Analysis of Breast Cancer Groups* examined breast cancer groups on Facebook inquiring about the creators of the Facebook groups, and the purpose and use of Facebook groups in relation to breast cancer. Study participants were English speaking and were involved with publically available Facebook based Breast Cancer support groups. Bender et al. (2011) examined participant conversations among breast cancer group participants and identified four types of breast cancer groups: fundraising, support, raising awareness, and promote-a-site groups. Interestingly only 7% (46 / 620) of the Facebook groups analyzed were dedicated to peer support, whereas 82.7% (513 / 620) of the groups were for purposes of fundraising and creating awareness (Bender et al., 2011). Of the Facebook support-related groups, none of the creators were healthcare professionals or associated with the health system (Bender et al., 2011).

While young adults, more so than older adults, tend to engage in online social support nearly half (49%) of the established online breast cancer groups were created to support anyone affected by breast cancer (Bender et al., 2011). Thirty-eight percent of online breast cancer groups were created to support a loved one affected by breast cancer or the creator (who had breast cancer), (Bender et al., 2011). Perhaps, because healthcare services are less attentive to post treatment physical and psychosocial needs of women affected by breast cancer, Facebook is becoming the fastest growing social network for health care concerns, including breast cancer (Bender et al., 2011).

Online blogging and cancer. Cancer blogs are online diaries that users can personalize with narrative text and pictures (Keim-Malpass et al., 2013). They are typically created to share personal experiences regarding cancer or illness, provide and share information, and form social networks (Keim-Malpass et al., 2013). Many individuals managing chronic disease and illness, more so individuals with cancer, are increasingly using online blogs as a means of support and to share stories (Chou et al., 2011; Katz Ressler et al., 2012). Individuals are motivated to create blogs pertaining to their chronic disease for three main reasons: (a) to reflect on their experience, (b) to communicate their experience (if they find it difficult to articulate their experience in person), and (c) to connect with others (with the same chronic disease or to connect with others for sharing purposes) (Katz Ressler et al., 2012; McBride, 2011). McBride (2011) further adds that online blogging provides emotional and informational support, as well as providing a forum for patients to vent about their illness experience.

Katz Ressler et al. (2012) study included 230 individuals ages 18 to 75 with a variety of chronic diseases, such as cancer (ovarian, breast, leukemia), Parkinson's disease, cerebral palsy, chronic pain conditions, bipolar disorder, and cystic fibrosis. Individuals in this study indicated that as a result of their blogging they: (a) gained a broader perspective on their illness (e.g., framed their illness differently and recognized other parts of their life), (b) were able to identify patterns of illness, (c) used blogging as an expressive outlet and received support from others, (d) developed a sense of accountability to one's self (commitment to blog) and to others, and, lastly, (e) blogging helped to cope with illness and disease (Katz Ressler et al., 2012). Katz Ressler et al. (2012) argue that writing illness blogs may have therapeutic potential.

Online video blogging and cancer. As an online video application, YouTube allows people to connect, interact, inspire, and inform a global audience (YouTube, 2014). Recent estimates indicate that over 1 billion users visit the YouTube webpage each month, and over 100 hours of video are uploaded each minute (YouTube, 2014). Video-based sources of online information are equally effective as text-based resources, but are better at engaging viewers (Bollinger & Kreuter, 2012).

A study conducted by Steinberg et al. (2010) looked at the quality of information of 51 prostate cancer videos (14 prostate-specific antigen videos, 5 radiotherapy videos, and 32 surgery videos) that were less than 10 minutes in length on YouTube. Two physicians rated each video based on the information provided related to testing, surgery, radiotherapy, as poor, fair, or excellent (Steinberg et al., 2010). The researchers concluded the majority of video postings (73%) had poor to fair information content and concluded that YouTube was an inadequate source of information for prostate cancer (Steinberg et al., 2010).

Chou et al. (2011) examined 35 online, personal YouTube narratives of English-speaking individuals with cancer. The authors used the search terms, “cancer survivor” and “cancer stories” (Chou et al., 2011). The selected 35 YouTube video stories focused on the individual’s construction of their cancer diagnosis experience. Common themes among the videos included: (a) the set up of the story as pre-diagnosis (life before cancer), (b) time and place (where and when diagnosis happened), (c) absence of control (why me? or this cannot be happening to me) and (d) depersonalization of the medical personnel (referring to health care providers as *they* or *the nurse* or *doctor* (Chou et al., 2011).

Cancer organizations are providing patient narratives as a communicative device on popular websites, such as, LiveStrong, The Mayo Clinic, and the American Cancer Society (Chou et al., 2011). These websites are supporting video stories of individuals affected by cancer and their caregivers to inspire, provide hope, support, and to educate individuals on a more personal level (Chou et al., 2011). Chou et al. (2011) argue that personal narratives have the ability to raise public awareness, provide information and support, and change behaviours for those living with cancer. The effectiveness of utilizing personal narratives from a cancer survivor’s perspective enhances source credibility and

meaningfulness of the information, as it is a personal, truthful, and reflective story (Chou et al., 2011). The authors suggest that personal online narratives are an efficient communication and education tool among those affected by breast cancer.

Kreuter et al. (2010) investigated the effectiveness of breast health promotion information videos and narrative videos among 429 low-income, never diagnosed, over the age of 40 African American women. After a three and six month follow up, the study concluded that the narrative videos were preferred and the women had greater recall of breast health information, and a better perception of the prevalence among breast cancer in African American women compared to the informational videos (Kreuter et al., 2010). Thus, personalized and visual information sources can be effective for those who are less educated and do not trust health information, however they may be less useful for those who do not have a personal connection or experience with breast cancer (Kreuter et al., 2010). Kreuter et al. (2010) argue that narrative videos are more effective because of the personalization of the stories and character, which engages audiences compared to factual information that can be more easily forgotten.

Research Literature Gaps in Breast Cancer and Video Blogs

In summary, previous research studies have suggested personal narrative videos are better understood compared to factual and informational videos. However, research is extremely limited regarding video blogs and cancer, despite the popularity of online videos over other social media sites and applications (Madden, 2009). As well, to date, no study has been published that investigates what information women are providing and how they are expressing their experience with breast cancer through the use of video blogs. An investigation of women's publically available breast cancer videos on YouTube could contribute to a greater understanding the information, service, and support needs of women managing breast cancer that surveys or questionnaires may not identify. Breast cancer video blogs on YouTube may also provide the *lived experience* alternative to traditional information sources for individuals with breast cancer accessible within their own home with unlimited and around the clock availability.

CHAPTER 3: RESEARCH METHODOLOGY AND METHODS

Within this chapter, the study's research purpose, methodological framework, and research methods are outlined. Ethical issues have been considered and are addressed followed by a description of the process of data collection; details and information pertaining to how participants were selected, how data were analyzed, and how analytic rigor was addressed are also included. Lastly, the use of field notes, reflexivity, and reflectivity are explained.

Methodology

Research Purpose

The purpose of this research was to investigate the personal YouTube video blogs of women with breast cancer and their portrayed messages. The following research questions guided data collection in this study:

1. What are the health messages the women are providing?
2. How are the women conveying their breast cancer journey?

Methodological Framework

This research is located in a constructivist / interpretivist paradigm (Chase, 2005). The constructivist / interpretive paradigm is based on the discovery of multiple realities constructed by the research participants and the aim is to bring to light the uniqueness of each human action and event rather than their common properties (Chase, 2005). Each video blog represented a distinct reality of the individual's experience; there is not one single reality (Chase, 2005). Narrative inquiry aligns with this position, as not everyone will have the same story or experience. I am the daughter of a breast cancer survivor. My location and personal experience with breast cancer was acknowledged in the co-construction of the women's stories.

Narrative inquiry

"Storytelling is a natural part of the human experience" (Nagy Hesse-Biber & Leavy, 2011, p.121). Individuals create and construct meaning, identity, and personality through oral, text, and non-verbal communication making narrative inquiry a method of understanding experience (Clandinin & Caine, 2008; Lieblich et al., 1998; Nagy Hesse-

Biber & Leavy, 2011). Leiblich et al. (1998) states that to understand and learn from an individual's experience it is best if told through personal stories. The telling of an event or experience can provide meaning and perspective of the experience and also provide insight into the storyteller's knowledge (Smith, 2000). Thus, this research study used a narrative inquiry to explore women's breast cancer experiences through online video blogs.

Narratives can be classified as one of three story types: (1) a short topical narrative regarding a particular event or specific individual, (2) an extended story concerning a point in one's life, or (3) an extended narrative of an individual's entire life (Chase, 2005). This study focused on the analysis of extended stories concerning a point in one's life. Specifically, this study explored individuals' videotaped stories about their breast cancer experience, which they posted on YouTube. Narratives are performed and designed for an audience with a particular aim (Riessman, 2008). Messages and stories are a type of discourse that are shared among others as a way of providing information and experiences, which creates meaning, develops and expands understanding and social knowledge; thus making narratives transactional and developmental (Mello, 2002). Narrative inquiry is also a way of understanding one's actions, situations, and life events (Chase, 2005). Chase (2005) states a storyteller entertains, informs, defends, complains, confirms, shapes and constructs experiences, and reality.

Illness narrative. Hawkins (2007) believes illness narratives, also known as pathographies, to be a method of creating meaning and sense-making of their illness. Hawkins (2007) stated, "People write about their experience of illness because they expect to find readers... This is a way of establishing connection with the larger human community" (p.125). Teucher (2007) also contends, "...patient-writers commonly attempt an identification of self that invite the audience, in turn, to identify with the writer, preparing the basis for a catharsis of pity and fear" (p.78). Individuals living with illness create illness narratives to find, explore, and find meaning to their new identity in hopes that other's will be able to relate to their stories (Teucher, 2007). Frank (1995) claimed that, "people tell stories not just to work out their own changing identities, but also to guide others who will follow them" (p.17). Illness story-telling gives voice to experience in which medication, treatment, and surgeries cannot (Frank, 1995).

Frank (1995) defined three types of illness narratives: (1) restitution plot, (2) chaos narrative, and (3) the quest narrative (Frank, 1995). A story of becoming healthy again is classified as a restitution plot. With this type of story, the storyteller discusses tests, their interpretation of the illness, treatments and alternative treatments, and the potential outcomes. It can be told prospectively, retrospectively, and institutionally. The chaos narrative is told as the storyteller experiences it and has no sequential order, hence the name *chaos narrative*. There is a sense of no control and the storyteller uses a lot of verbal crutches and repetitions, such as ‘and then’ and ‘and’. The quest narrative seeks to meet suffering “head on”, they accept their illness, and “seek to use it” (Frank, 1995, p. 115). Frank (1995) also suggests that, “illness is the occasion of a journey that becomes a quest” (p.115). When an ill individual realizes their sense of purpose, the idea of their illness as a journey emerges (Frank, 1995). The journey is taken in order to figure out what sort of passage has been taken (Frank, 1995). Frank’s (1995) idea of the word *journey* is used throughout this study to capture the women’s progression of their disease, from one stage to another. The quest narrative has three categories, (1) memoir, (2) manifesto, and (3) automythology. The memoir includes both an illness storyline while telling other stories of the individual’s life (Frank, 1995). Manifesto asserts that illness is a social issue and automythology uses metaphors as their predominant storyline (Frank, 1995).

Construction of narratives. While not all participants have the exact same experience or story, oral narratives are constructed by following five sociolinguistic features of oral narratives, (1) orientation, (2) complication, (3) evaluation, (4) resolution, and (5) coda (Labov & Waletzky, 1967). Narrative orientation provides an overview of the context of the story. It informs the listener(s) about actors, time, place, and situation. Complication is the action of the story. Evaluation refers to the point of the story, whereas the result of the action is characterized by the resolution. Lastly, the fifth feature coda brings the listener back to the present moment. See Appendix B for an example of sociolinguistics features of a story.

Research Methods

Ethical Considerations

Ethics approval for this study was sought from the University's Research Ethics Board. The ethics review board determined that a full review of the proposed research plan was not required given the public nature of the YouTube videos and the assumption that individuals who post publically available online videos have no reasonable expectation of privacy. YouTube's Terms of Services states, "As a YouTube account holder you may submit Content to the Service, including videos and user comments. You understand that YouTube does not guarantee any confidentiality with respect to any Content you submit" (YouTube, 2010). Ethics exemption notification for this research was obtained (see Appendix A). Eysenbach and Wyatt (2002) stated, "reviews of information posted by consumers on the Internet may help to identify health beliefs, common topics, motives, information, and emotional needs of patients, and point to areas where research is needed" (p.1). Although the collected data for this study were publically available, personal boundaries regarding ethical research practices arose. Participants' online videos blurred the lines of what constitutes *publically available* data from a researcher perspective. The public nature of the data contravenes traditional ethical research practices that protect the confidentiality of participants, the privacy of their data, and individual consent to participate in the research. Although the women knowingly posted their cancer experiences in the form of publically available online videos, it was unlikely they considered that their information would be used for research.

Discussions regarding how to represent participants' data to incorporate both the audio and visual components of the videos included integrating video clips, still images, and providing links to the video blogs within the research findings. Providing video clips of participant data as supportive evidence of research findings challenged personal ethical considerations, such as participant confidentiality and information privacy within an emotionally charged health care context. At the core is the outstanding issue of *publicly private* data versus *privately public* data (Eysenbach & Till, 2001). The YouTube video blogs collected for this research study were available to anyone. However, despite their public availability, the videos target specific audiences (by the wording in the title and category of the video), hence making it more private.

Eysenbach et.al. (2001) introduced the idea of passive analysis that looks at “information patterns on websites or interactions on discussion groups without the researchers actually involving themselves” (Eysenbach & Till, 2001, p.1103). This study used passive analysis in that no attempt was made to contact the women included in this study, nor were written interactions, such as contributions to the comments section on the YouTube blog page were made. Researchers who post on online social networking sites (SNS), such as YouTube, may be perceived as intruders and may damage the communities” (Eysenbach & Till, 2001, p.1103). Individuals participating in online groups or SNS do not become involved in such public communities to be included in a research study (Eysenbach & Till, 2001). Researchers can maintain privacy and confidentiality of participants by using existing standards of ethical research processes that include protecting confidentiality to avoid providing personal, intimate, and potentially damaging information (Moreno, Frost, & Christakis, 2008). Eliminating individuals’ names can enhance anonymity of the women’s information, however given the nature of the study and the video blogs being publically available the online usernames given by the women were reported in the findings.

Different from participant self-recorded videos, the video recording of individuals in research studies, such as ethnographies, use videotaping to record behaviours of individuals or communities to examine naturally occurring situations in which people produce them in (Dufon, 2002). This helps researchers capture visual images of the situations their participants are in, which audio recordings cannot recreate. Further, video recordings display more contextual data, and visual and non-verbal communication, which assists in analysis (Dufon, 2002; Henry & Fetters, 2012; McLafferty, 2004). Participant-generated video recordings are videos that are produced by individuals who control what is recorded and / or record the video themselves (Gibson, 2008). There is intention and purpose behind developing participant video recordings. The women in this study recorded their own video blogs regarding their breast cancer journey and posted it, publically, to YouTube for viewers to watch.

The women in this study stated their intention or motivation to video blog was to help others by sharing their story and experience of having and living with breast cancer. This creates an interesting tension related to the researcher’s responsibility to abide to

ethical research practices (e.g., obtaining consent to participate and collect data) and the responsibility for knowledge dissemination of the research implications for client care, clinical practice, and future research. The YouTube bloggers in this study and researcher shared the same motivations in respect to the intention of video blogging; both want to help others by sharing their stories. By examining different areas and topics, researchers assist in helping individuals, communities, various populations, and experts by disseminating their findings from their study.

As a researcher I wanted to support these women by sharing their stories. For logistical reasons and abiding by YouTube's policy and copyright legislations, video clips were excluded. Still images of the women were also omitted for the reason that still images do not capture the essence of video blogging (e.g., the tone of voice, non-verbal communication). However, the personal, YouTube channel of each woman has been included in Appendix D, for the purpose of sharing their stories, as their intention was to reach many viewers.

Participant Recruitment

Purposeful sampling. Qualitative research has no precise rules for the determination of sample size, but the study's sample size should involve a sufficient number of participants to achieve an adequate breadth of perspective and a complete and accurate picture of process or meanings individuals attribute to their experience (Elo & Kyngäs, 2007; Nagy Hesse-Biber & Leavy, 2011; Van Hulle Vincent, & Gaddy, 2009). Purposeful sampling involves selecting participants based on the particular research and resources available to the researcher (Nagy Hesse-Biber & Leavy, 2011). Sandelowski (1995) stated researchers who use purposeful sampling do so because they consider particular individuals as good sources of information and will assist them in achieving an analytical goal.

Purposeful sampling was used to recruit three to five participants and their video blogs as it allowed for an in-depth analysis related to the proposed research question to ensure data richness (detailed descriptions) (Sandelowski, 1995). "Determining an adequate sample size in qualitative research is ultimately a matter of judgment and experience in evaluating the quality of the information collected..." (Sandelowski, 1995, p.183). Qualitative research looks at the how, what, and why rather than numbers and

generalizations are not made (Sandelowski, 1995). Furthermore, narrative studies use smaller sample sizes because of the quantity of material given and the amount of hours to listen, transcribe, re-listen to text, and watch video; as well, sample size should be measured by depth of data and consist of participants that best represent the research topic (Lieblich et al., 1998; Morse et al., 2002).

Participants were sought until data saturation was achieved. *Saturation* is a commonly used term within qualitative research signifying that no new information was discovered (Morse, 1995). From a constructivist / interpretivist position, which acknowledges multiple realities, the concept of data saturation presents an analytical challenge. However, it is important to explain how saturation will be met and how it will be recognized (Caelli, Ray, & Mill, 2003). For this investigation, saturation was met through an iterative analytic process that included observing the video blogs, listening to the video blogs, and reviewing the transcribed videos. “It is more important for the researcher to ‘know it all,’ than to hear things over and over, forcing a false sense of saturation” (Morse, 1995, p.148). Data saturation can be met if sampling is more restrictive, “the tighter and more restrictive the sample and the narrower and more clearly delineated the domain, the faster saturation will be achieved” (Morse, 1995, p.148). The richness and quality of data is important rather than the quantity or frequency of data (Morse, 1995).

Inclusion and exclusion criteria. This study examined YouTube bloggers with breast cancer. Two search terms used to identify potential research participants were *breast cancer story* and *breast cancer journey*. The search terms were entered into YouTube’s search bar, *breast cancer story* resulted in 6,750 hits recorded on January 21, 2013 and *breast cancer story journey* resulted in 774 hits recorded on January 21, 2013. The women were selected for inclusion in the study using the following the inclusion / exclusion criteria (see Table 1). While the potential pool of research participants was broad, the selection of research participants was significantly reduced by excluding YouTube videos that constituted interviews for a news broadcast, advertising, or were sponsored by an organization, such as LiveStrong and the Mayo Clinic. The decision to focus on women was based on the predominance of breast cancer among women, affecting nearly 1.7 million women globally in 2012 (World Cancer Research Fund

International, 2014). Secondly, YouTube was chosen as the means of accessing women’s stories on breast cancer because of its increasing popularity and growth of over 1 billion users each month (YouTube, 2014). Data for this study included the personal, audio-video blogs, uploaded to YouTube of women’s self-reported experiences with breast cancer. Other studies have examined a singular YouTube video blog submitted by numerous users pertaining to cancer or other chronic diseases (Chou et al., 2011; Forsyth & Malone, 2010; Kelly, Fealy, & Watson, 2011; Steinberg et al., 2010). The women YouTube bloggers posted numerous videos or had at least 20 minutes of footage expressing their breast cancer experience on YouTube. This allowed for greater substance and understanding of the individuals’ breast cancer experience. If only one video submitted by various users was collected, understanding of the participants’ experiences could potentially be fragmented and information could be insufficient.

The women YouTube bloggers were purposefully selected to reflect a broad range of breast cancer stages, from the diagnosis stage to survivorship or disease-free. Because there is no visible demographic profile for YouTube users nor do users have to include that particular information in their story, there was no defined age range for the inclusion criteria in this study. Additional inclusion criteria required that the women’s YouTube videos had more than 50 views (public reviews) on their initial video blog as it indicates the video had been of interest and viewed by a number of people. A summary of the participant and video inclusion and exclusion criteria is provided in Table 1.

Table 1. YouTube Participant Video Inclusion and Exclusion Criteria

Criterion	Inclusion	Exclusion
Gender	Women	Men
Language	English	Non-English speaking
Location	North America	Outside of North America
Age	Any age	

Phase of Breast Cancer	At any point of the progression of their disease	
Length of video blogs	Must elapse to at least 20 minutes	Under than 20 minutes
Number of Views	The initial video blog must have more than 50 views	Less than 50 views
Time Period	Videos posted between February 2005* to January, 2013 <i>*February 2005 was the year YouTube was available for internet users</i>	Anything outside these dates
Types of Video Blogs	Non-scripted and free-flowing conversations of the woman's experience	Public service announcements, advertisements, interviews, videos sponsored by an organization and entertainment purposes

The title of the video, the video Uniform Resource Locator (URL), the length of the video, the number of viewers, and the stage of cancer experience of the included participants was documented and charted using Microsoft Excel.

Data Collection

Data were collected from the online, YouTube website. YouTube is an online video sharing website that allows individuals to upload, share, and watch originally created videos (YouTube, 2014). As an online social network site, the YouTube website allows people to connect and interact with a global audience (YouTube, 2014). Recent estimates indicate that over 1 billion viewers visit the YouTube webpage each month, and over 100 hours of video are uploaded each minute (YouTube, 2014). The number of people subscribing to YouTube has doubled since 2012 and the site is available to 56 countries across 61 languages (YouTube, 2014).

Traditionally, researchers conducting narrative research retrieve information by interviews or conversations, and initiate those dialogues by doing one of two things, (a)

listen to the storyteller and (b) live alongside the individual as they experience their stories (Clandinin & Caine, 2008). In this study, online video blogs were reviewed to understand the breast cancer narratives of women who documented their stories and made them publically available on YouTube. A benefit of using video recorded narratives is the ability to capture details and complexities of the verbal and non-verbal behaviours, which a single interview or observation can potentially neglect or miss (Gibson, 2008). Participant-generated YouTube video blogs of women who have personally recorded their breast cancer experience were purposefully selected for inclusion in this study.

Data Analysis

Data analysis in narrative inquiry. Leiblich et al. (1998) lists numerous strategies to analyze narrative materials, "...such as contents; structure; style of speech; affective characteristics; motives; attitudes, and beliefs of the narrator; or his or her cognitive level" (p.9). In this research, verbal information from the research participants' videos were transcribed, observations of the visual components of the video were recorded in (e.g., body language and non-verbal communication) researcher field notes and a self-reflective journal assisted in analysis and reflexivity (Nagy Hesse-Biber & Leavy, 2011).

Data gathering and analysis occurred concurrently. The following data analysis approach was taken. One YouTube blogger was examined at a time. Firstly, each video was transcribed verbatim in chronological order (from the first video to the last video post) and was documented using Microsoft Word. Video blogs were looked at separately for the reason that thoughts, feelings, emotions, setting, and context can change each time the YouTube Blogger posts a video of their experience.

Secondly, the construction of the participants' narratives was assessed and guided by Labov and Waletzky's (1967) five sociolinguistic features of orientation, complication, evaluation, resolution, and coda. These features gave structure to the women's narratives and highlighted the content and similarities and differences among the chosen individuals. Using Microsoft Word, a sociolinguistics chart was made to guide interpretations and understanding of the five features. These five features were used in analysis to assist in demonstrating the participants' stories by making reference to the characters involved, their feelings, their point of their video blog, as well it assisted the researcher by organizing the structure of the story and further understanding of it.

Thirdly, the visual and non-verbal communication of each video was analyzed by reviewing the video blogs again. These sightings and hearings were recorded by the use of field notes (described below). Non-verbal communication (behaviours that are not spoken or written, which can create meaning, such as body language, gestures, facial expressions, proximity, and eye contact), and the setting or context, which the individual recorded her experience in were analyzed. As well, sentences, words, context, tone of voice, and non-verbal communication can indicate important meanings, which were included in the field notes.

Next, reading through field notes and transcriptions further developed coding. Words, sentences, and phrases were developed into (interpretive) analytical codes, which "...rely[s] on the researcher's insights for drawing out interpretation or understanding of the participant narrative" (Nagy Hesse-Biber & Leavy, 2011, p.311). Codes assist in the analytical process by sorting text, generated analytical concepts, assigning words to segments of text, and condensed data (Nagy Hesse-Biber & Leavy, 2011). Each video blog was re-watched and any potential codes were written down. The codes that emerged from the video blogs assisted in the development of storylines by building clarity on concepts, highlighting similarities and differences, condensing data, and creating story threads (Nagy Hesse-Biber & Leavy, 2011).

Throughout the research I was conscious and considerate of my thoughts on each individual's cancer experience. I acknowledged how my thoughts and perspective as breast cancer survivor's daughter and researcher may alter and affect my data collection and analysis. My position before the research, during, and post-research is included in my journaling to show my journey and the transformation I experienced with this study. Together, field notes and journal writing, "...provide a reflective balance" of what the researcher and participant selects as interesting and uninteresting (Clandinin & Connelly, 2000, p.104).

Using these analytical practices allowed the voice of the woman YouTube blogger to be represented alongside the researcher's interpretations for greater understanding (Mello, 2002). Researchers must acknowledge the voice of the participant and original message as they must also acknowledge their own voice and constructed meaning out of messages (Fabian, 2008). I acknowledged and understood the voices of the chosen

individuals by listening, observing, and taking field notes of each video the YouTube Blogger shared and represented their voice appropriately, as it is my ethical responsibility as a researcher.

Quality of data analysis. Methods used to establish rigor, trustworthiness, and transferability in this study included verbatim transcriptions of participants' stories, the consistent application of sociolinguistic features to each of the women's video blogs, and keeping field notes and a reflexive journal. Reflexivity is thought to enhance the rigour of a study because it calls upon the researcher to examine his / her influence on the data. Transferability of research findings was addressed through detailed and rich descriptions of context and content of the YouTube videos permitting readers to judge for themselves whether the findings can inform their own context (Schwandt, Lincoln, & Guba, 2007). As well, the rigour applied to data collection and analysis enables transferability to similar research, topics, and context (Burchett, Mayhew, Lavis, & Dobrow, 2013). However, because of cultural norms and different healthcare systems, some information and findings may differ, but if other studies were conducted using this process, it would highlight commonalities and differences among women with breast cancer around the world.

Data collection and research findings were created by the researcher and then collaboratively discussed with the research advisory committee who provided input and feedback throughout data collection and analysis. Member-checking could not be conducted in this study; the women YouTube bloggers were not contacted nor communicated with. Field notes and reflexive-journaling, further explained below, were consulted to ensure a systematic approach to analysis and openness. Thus, the co-construction of the women's breast cancer stories were influenced by my constructivist / interpretivist lens, my personal experience with breast cancer and through consultation with my research advisory committee.

Field Notes and Reflexive vs. Reflective Journal

Researcher's notes were organized into two journals, a field note journal and a self-reflexive journal. Being reflexive is an on-going, continual practice (conscious self-awareness) (Finlay, 2002; Nagy Hesse-Biber & Leavy, 2011). Field notes were written to capture what I heard, saw, experienced, and thought throughout data collection and

analysis (Morse & Field, 1995). Morse and Field (1995) recommend detailed and extensive field notes that record description of events and reconstruction of interactions. However, Mulhall (2003) stated field notes can be written in as little or as much detail as the researcher prefers; sometimes too much detail neglects deeper meaning and intrinsic experience during observation as the research can become too focused on recording field notes than observing and listening to the participant.

During the initial viewing of the video and throughout the data analysis process, field notes were taken to provide an outline of events and capture detailed emotions of each woman. Non-verbal communication and the setting or context in which the individual recorded their experience were documented in field notes and analyzed. Detailed emotions of the women were important to document in the field notes as interpretations of the women YouTube blogger's emotions can alter each time the video was watched. Non-verbal communication expressed by the women were documented; as well, a time stamp of the elapsed video was recorded of memorable events or happenings for the purpose of easing further analysis and to note quality data (Derry et al., 2010; Morse & Field, 1995).

A self-reflexive journal exposes self-awareness and can show influences on the research process, as well as inform new insights, and deeper understanding of breast cancer, the participants, and research process (Holloway, 2005; Lichtman, 2010). This journal helped organize and include my personal thoughts, feelings, and emotions after watching each video blog and throughout the research process. It also assisted in comparing (reoccurring) themes to initial assumptions (Holloway, 2005). A self-reflexive journal supports exploration of my positionality as a researcher (thoughts, feelings, emotions, understandings) and my experience (Clandinin & Connelly, 2000). Narrative inquiry researchers need to explore their experiences pre, during, and post-study as narrative is a reflective and reflexive methodology (Clandinin & Caine, 2008). Conscious self-awareness constitutes reflexive analysis and requires continual evaluation of personal responses, intersubjective dynamics, and the research process (Finlay, 2002). Because of my personal experience with breast cancer, a self-reflexive journal was important to have to continually reflect on the research process and personal feelings.

CHAPTER 4: FINDINGS: THE WOMEN'S STORIES

This chapter presents results of the narrative analysis from the four women, Cancerlady78, Coralee, Krista, and Alicia, who were purposefully selected for this study. The findings of this investigation are reported in two parts: (a) participant profiles and (b) the emergent storylines. The storylines that emerged from the data analysis include: Battling Cancer, Blurring Identities, Becoming Breast Cancer Experts, and Finding / Receiving Support. The first storyline illustrates how the women YouTube bloggers depicted their cancer experience as a battle. The second storyline describes their evolving identities in relation to their cancer experience. The third storyline highlights the development of their breast cancer knowledge. The fourth storyline discusses the different types of support they sought and received. Direct quotations from the women are included in italics to support the four storylines.

Profile of the Women YouTube Bloggers

The following section provides a descriptive profile of the participants. Descriptive information was limited to what the women disclosed about themselves within their online videos. In this study, all YouTube bloggers were American; two were African-American and two were Caucasian. Their reported ages at the time of the video blogs ranged from 32 to mid 40s. Only three of the four women indicated employment: one as a teacher, another woman stated she was a minister with her own business, and a third woman mentioned she was a marketing specialist. See Appendix C for a comparison among the women.

Cancerylady78

Cancerlady78 is an African American woman from a “*hurricane prone area*” of the United States. She is married with a husband and has three young children (two daughters and a son). She was 32-years-old and a recent Master’s graduate student when she found a lump in her breast while in the shower. Cancerlady78 was diagnosed with Stage 3B breast cancer. Her first video blog was posted 3 months after her diagnosis. It was not the first time she had encountered a breast cancer scare, “*given my history I figured it was best if I’d go ahead and get in there*” she explained when talking about the

discovery of a lump in her breast. Cancerlady78 had 13 videos with over 1 hour and 45 minutes of video footage and a total of 2,298 views by others (as of December 2013). The video blog, *My Cancer Story - The Diagnosis* was the most watched video with 1,016 views and *A Bumpy Road to Recovery* had the least amount of views, 35. Throughout the video blogs, Cancerlady78 expressed and shared her struggles with the financial stress of her illness. She also informed viewers of the types of treatments and surgeries she received for her type of breast cancer. She spoke of using traditional methods of healing, which included chemotherapy and radiation, and indicated that she had a single mastectomy as recommended by her physician.

Coralee

Coralee is a Caucasian woman from the state of Massachusetts. She did not provide any detail regarding her age, marital and employment status, and family circumstance. Coralee found a “lemon” sized lump in her breast while “feeling around” when she was on a beach. She was diagnosed with Stage 4 breast cancer. Coralee shared a three-part video blog with all three blogs posted on the same day with a total time of 21 minutes and 45 seconds. In this series of video blogs, she reflected back on her first four months of having Stage 4 breast cancer. Coralee had a total of 17,267 (as of December 2013) views with *Part 1 of 3* having the highest views, 8,809. *Part 2 of 3* had the least number of views at 3,851. At the time of her video blogs, Coralee stated she was on hormonal therapy, Arimidex, and had Zometa treatments, which is used to reduce and delay bone complications due to high blood levels of calcium caused by cancer. She had a single mastectomy.

Krista

Krista is a Caucasian woman from the state of Michigan. Throughout her breast cancer journey, she was in the process of getting a divorce, which was not revealed until the last couple of video blogs. She has two young children, a boy and a girl, who are physically present in two out of 18 of her videos. Krista worked from home as a marketing specialist. She is over the age of 35 as she mentioned, “...my mom actually had breast cancer when she was 34 and so I have been getting mammograms since I was 35...” Krista posted 18 videos that collectively amounted to a time of 77 minutes and 55 seconds with a total number of 51,883 views (as of December 2013). *Waking up from*

mastectomy surgery had the greatest number of views reaching 32,789 and *thank you – breast cancer update 3* had the least number of views at 312. Krista initiated video blogging of her breast cancer journey the day after being diagnosed. She initially stated her diagnosis as Stage 1 Grade 3 Invasive Ductal Carcinoma breast cancer, then a month later referred to her breast cancer as aggressive cancer. Krista tested positive for the Breast Cancer Gene (BRCA gene) and she had Human Epidermal Growth Factor Receptor 2 (HER2 negative) also known as triple negative breast cancer. Throughout her video blogs she was strongly opposed to traditional methods of breast cancer treatments (e.g., chemotherapy). Despite this, she had two chemotherapy sessions, but indicated she decided to stop due to her low white blood cell count. Krista altered her diet to include more fruits and vegetables and juicing on a daily basis. She initially had a single mastectomy and decided later to have the other breast removed, followed by breast reconstruction surgery.

Alicia

Alicia is an African American woman who lives in Maryland. She does not have any children and does not mention being in a relationship. She had her own business, identified herself as a minister, and as a martial artist. At the age of 41, she was diagnosed with Stage 3 breast cancer, after finding the lump herself. Alicia does not give any details on how she found the lump in her breast. Her video blogging began two days after her diagnosis. Alicia had a total of 45 videos with over 3.5 hours of footage. She had a total of 9,115 views (as of December 2013), with *Endometrial Biopsy.....The Results Are In!* having the greatest number of views, 1,232, and *You, Courageous? How to Know That You Are Courageous!* with only 49 views. Throughout her breast cancer journey, Alicia used a mixture of allopathic and naturopathic care strategies. She had chemotherapy, radiation, and chiropractor treatments, practiced meditation, and received acupuncture and massage therapy. Alicia made the decision to have a double mastectomy.

Presenting the Women's Stories

Table 2 provides a summary of the women's storylines and story threads. Storylines, in this study, refer to major plot lines that were consistent among all four women. Story threads refer to sub-plots, which support and connect to plot lines.

Table 2. Storylines and Story Threads

Storyline	Story Threads
Battling Breast Cancer	<ul style="list-style-type: none"> • Financial struggle • Cancer as an enemy
Blurring Identities	<ul style="list-style-type: none"> • Pre-cancer identity • Physical changes • Responding to changes
Becoming Breast Cancer Experts	<ul style="list-style-type: none"> • Healthcare providers as sources of information • Personal information seeking • Information quality
Finding / Receiving Support	<ul style="list-style-type: none"> • Offline self-directed support: prayer and spirituality • Offline support: individuals and groups • Online support - Social media: YouTube and Facebook

Storyline 1: Battling Breast Cancer

All of the women referred to some part of their journey with breast cancer as a battle, whether it was financially or emotionally, referring to the cancer as an enemy or intruder.

Financial struggle. Costs of treatments, tests, surgeries and loss of work can contribute to financial burdens. Cancerlady78 was transparent about her struggles with being able to afford treatments, surgeries, and tests for herself and to maintain the costs of living for herself and her family. Although she had health insurance, she indicated that it was still a significant problem to afford treatments and tests. When she talked about this in her video, her eyes were partly closed perhaps due to fatigue and her body remained still as she talked about her struggles with money. She spoke quietly:

“You know this has been a strain on my family’s finances, y’know trying to pay for a lot of these tests that I’ve had to take. You know try to maintain my- monthly bills, while you know my kids needs things, me and my husband needs things. Y’know I’ve had to buy a lot of pain medication because over the last couple of months...and I had to buy some sleeping pills as well...my insurance still does help but I’m still paying out of pocket...So you know it’s been a really struggle”.

Not only did she struggle to afford treatments for her breast cancer, but also to provide for her family. The following excerpt highlights the stress of her financial situation:

“...I shoulda had this [test] a few weeks ago but they discovered that I didn’t have this BRCA analysis to see if ...I had the gene...for breast cancer. Funny thing is even after doing the test I still don’t know because as simple as the test was and it’s gunna cost like \$3500 for the lab to test it and get the results and who has that kind of money just laying around? You would think seeing how I am paying almost 600 a month for insurance they’d cover most of that cost but nooo”.

This statement illustrated that this was a major concern for Cancerlady78, and her non-verbal communication confirmed this was a burden. She let out a loud sigh, her shoulders came up towards her ears and as she exhaled, slowly, they came back down. She pursed her lips and released them. The sigh and exhale showed the tension and stress she was enduring and releasing from her body, momentarily, and the video clearly illustrated that this was a major concern for her.

Krista also described the healthcare policies of her insurance company as a barrier to covering costs related to her general healthcare. Here she talked about Flonase, a prescription nasal spray she used, *“Um but of course that’s \$90 a month for the drug and my insurance doesn’t cover that. And so I can’t afford it and also I- I don’t want to take those drugs anymore if I don’t have to”.* Krista made the decision to discontinue the use of that particular medication, as it was a financial burden.

While Alicia did not speak directly about having health insurance or not being able to afford treatments, surgeries, medication, or tests, both she and Cancerlady78 solicited financial support from their You Tube viewers. Cancerlady78 began asking for donations within her first few video blogs, whereas Alicia did not request financial support until after her double mastectomy (32nd video blog). Alicia invited viewers to support her financially, *“um if you’d like to offer support, financially, you can do that”* and provided instructions on how to do so. This quotation and procedure also reflected Cancerlady78’s way of asking viewers for financial support by visiting her website.

Cancer as an enemy. The women referred to their cancer as a foreign object and an enemy invading their body. This put the women in a position of wanting to take action to eliminate, *“kill”* or *“nuke”* the enemy. The women talked about fighting for their life and fighting to stay alive for their children. With any battle or fight, anticipated

consequences might include pain, wounds, markings, and scars. The four women in this study discussed and sometimes showed their battle wounds (scars, markings, swelling, redness) from their battle (e.g., surgeries and treatments) to rid themselves of the cancer enemy.

Cancerlady78 talked about “killing” the cancer while at her chemotherapy treatment facility. She turned the video camera to the bag of chemotherapy medication (e.g., Taxol), and pointed out in a quieter voice, “*You see that big bag of medicine? That’s the one*”; then turned the camera back on herself and continued to say, “*That’s the one that’s gunna kill my cancer*”. Cancerlady78 talked about fighting for her life, but in the context of her family and kids, “*That truly was the hardest thing I had ever had to do... Tell my kids that their mom was sick and that that they could possibly lose her*”. She stopped to wipe the tears from her eyes with a tissue and continued to say, “*but at that moment I also knew that I had to fight for my life and that’s exactly what I was going to do*”. Her initial reaction to the news of being diagnosed with breast cancer was that she was going to die and she vowed to fight the disease after seeing her children upset and crying, knowing their mother could potentially die.

The battle against cancer was not without pain. During one of her chemotherapy treatments, Cancerlady78 described the pain from a “shot” in the arm that would help her blood count stay ‘normal’, “*That shot was a stinger... They did that right here in my arm...and it hurt...they said it would cause bone pain and it did*”. She also explained the pain she sustained after the first few sessions of chemotherapy: “*...I just feel this overwhelming rush of pain from my neck...to my shoulder, my chest, my back, my hips, and my thigh area. I mean... pain to where...I couldn’t do anything I just had to lay there and rest*”. Cancerlady78 took pain medication, “*...which helped but the pain did kind of linger over the next couple of days...*”

Cancerlady78 had scars and markings from chemotherapy and radiation. She also was the only one who commented on other side effects of the treatment aside from hair loss and the loss of her breasts. In the excerpt below she describes her markings as unattractive and referred to her radiation tattoos as “*markers*” and a “*map*”:

“Uh the only thing I don’t like is that that it has really has caused my skin to get dark...all of my uh hair follicles are starting to show. Not attractive at all. And here I

don't know if you can see this. This is one of my markers kinda like my map as they call it where they need to focus in on the treatment. I have a few of these on my chest".

Coralee used more literal terms to describe how she dealt with her breast cancer. She exclaimed, *"So, hopefully the radiation is gunna basically NUKE that area and get rid of those cancer cells"*. She emphasized the word "nuke" by raising her voice, her eyes widened, and she raised her eyebrows; her hand circled over the right side of her chest where her breast once was and where the radiation would take place. Coralee also commented on her radical mastectomy and demonstrated the change in mobility in the arm affected by the mastectomy. She noted, *"But now when I stretch and as you can see I can move my arms pretty well it feels sort of like a tight muscle and it doesn't really hurt at all"*. She did not talk about the pain experienced immediately after her surgery, but informed viewers of her physical capabilities four months post-surgery.

Krista also commented on killing the cancer, but not as aggressively as some of the other women, *"So I need to make sure that, if it's somewhere in my body that's not detected right now through testing whatever, that it gets killed"*. She too commented on fighting the cancer, *"I just want it gone so I can sleep a little easier at night to know um that I'm doing something about it and I'm fighting it"*.

Toward the end of Alicia's video blogs, she framed her journey with breast cancer as a fight for her life. In an excerpt from one of her video blogs she stated, *"...I am, in fact, in somewhat of a battle. But I understand now without that sort of mentality, I don't think I would have made it. I had to be willing to fight for my life and allow my life to fight for my body. And I'm still here"*. Alicia acknowledged that she had to prepare herself mentally to be prepared to fight, defeat, and take on the cancer in her body. Alicia received a Neulasta shot during a chemotherapy treatment, which caused her pain, *"But I'm y'know super, super tired and um a whole lot of pain and it feels like I'm in a ring with this hundreds and hundreds of pound animal fighting me..."*

Alicia talked about her scars more metaphorically compared to the other women. She related her "markings" (radiation tattoos) to a physical battle and as part of her initiation for battle (radiation). She stood topless in front of a mirror, holding a small video camera in her right hand in front of her face. You can see a couple of scars on the

right side of her upper chest and black markings on the left side of her neck, down towards where her breast was, and back up to her shoulder:

“You know when you are about to go into battle, if you are a warrior, usually there is some kind of markings you put on your face...like under the eye. Um... with different tribes around the world all sorts of....demarcations are put on the body. Some of them even scarification like what you see here for me... So what you are looking at here are the marks, the latest marks that I’ve received from the radiologist...This is the next part of my initiation...the next part of my battle, however you choose to see it”.

She decided to see her markings, her tattoos, as something positive and as part of her cancer identity.

All four women storied their breast cancer journey as a battle. They identified their breast cancer as the enemy by referring to it as an “intruder”, the need to “kill” it, and “fight” it off. Because of undergoing treatments and surgeries, the women endured pain, markings and scars, and swelling. They also indicated it was a battle financially due to insurance companies not being “cooperative”, thus not leaving them with enough money to support their families and their cancer needs and treatments. When fighting for one’s life, one’s identity may shift, change, or blur over time to help guide the individual through the battle and assist in defeating the enemy.

Storyline 2: Blurring Identities: Pre-cancer, Cancer, and Post-treatment Identities

The women storied transformations of their identity throughout their breast cancer journey. They reflected back to their life and physical appearance before their diagnosis of breast cancer and communicated to viewers how their identities have altered. Faced with the uncertainty of their battle with cancer and how to cope with having the disease, the women expressed concern with trying to negotiate being a cancer patient with their other roles of mother, career woman, partner or wife, daughter, etc., while attempting to maintain ‘feeling like themselves’.

Pre-cancer identity. The women struggled with their new identity of being a woman with breast cancer while trying to hold on to their pre-cancer identity and having a sense of normality. They reflected back on their life and their identity prior to having breast cancer as busy, physically active, career women, mothers, and wives.

Cancerlady78 described her pre-cancer identity as healthy, youthful, and busy. She exclaimed, *“I’m young. I’m vibrant. I stay on the go you know between my job and*

my family". However, during her cancer identity she became more lethargic and emotionally weak. Within the first few weeks of her diagnosis, Cancerlady78 recalled crying and feeling overwhelmed with sadness, *"I just remember...me and my husband went to the doctor's office and I'm filling out the paper work of course and I just start crying I mean just uncontrollably crying... I really wanted to stop crying but I just couldn't"*.

Before her chemotherapy treatments began, she described being scared and knew chemotherapy would be difficult on her emotionally and physically, *"But the first four would be the roughest on me and so leading into that first treatment I was very scared"*. Even after a couple of chemotherapy sessions she was still scared, *"and so my first few sessions dreaded, dreaded, dreaded... still scared because after the first session a week of being just down, uh feeling sick and not being able to do anything I just couldn't do that again"*. Cancerlady78 was not used to having others look after her and her family, as she was the primary caregiver. It was difficult for her to let go of the caregiver role and be the 'patient'.

Cancerlady78 stopped video blogging after her last chemotherapy treatment, because she considered her journey with breast cancer over. In this excerpt, she discussed her post-treatment lifestyle, as it will include taking preventative measures; as "tears of joy" ran down her face she explained, *"I will be taking daily medication to help prevent the cancer from returning. Still have imaging, blood tests, uh doctor visits that I have to go to and I still have another surgery... this is not the end...but for now all I can say it's over"*. She moved her shoulders and head back and forth as she talked, and looked down at the floor frequently; however, she stared at the camera direction when she said *"...all I can say it's over"* with a sense of relief. Cancerlady78 acknowledged that there are other treatments and potential surgeries to deal with in the future related to her breast cancer; thus she stated, *"it is not the end"*, but framed her next phase as prevention.

Coralee had the most advanced stage of breast cancer, Stage 4; however, she reported that she felt, and acted the same as she did before being diagnosed with breast cancer, *"So, with stage 4 I actually feel fine and in fact I feel like I've always felt so in some ways it's kind of hard to believe this is happening except that I seem to be in doctors' offices - every couple of minutes"*. Coralee did not frequently express her

emotions regarding her cancer identity, but mentioned she was fearful prior to having her mastectomy, *“but, I must say that before being wheeled into the operating room”*, she nodded her head in a positive motion, raised her eyebrows and confirmed, *“I WAS terrified”*.

Coralee mentioned feelings of anxiety, akin to Krista, with her breast cancer journey, *“They’re feelings you know when you’ve been a little stiff or you’ve, y’know... muscles a little sore or something like that, it’s all feelings like that so it’s very difficult to know if you’re feeling cancer or if you’re just being silly”*. Both women expressed anxiety and a lack of control of their physical well-being, which they attributed to their breast cancer. Coralee implied that she was not like that before her diagnosis of cancer.

Coralee’s treatment plan was palliative for Stage 4 breast cancer. Wrapped only in a scarf around her neck and chest, she concluded a video blog with, *“So now what I’m planning to do is to spend the next couple of months being as emotionally cancer free as possible”*. She did not explain exactly what she meant by *“emotionally cancer free”*, however it could be perceived that she was in the process of accepting her disease and is continuing living life as if she were disease-free.

For Krista, a major turning point from her pre-cancer self to cancer-self was becoming aware of how diet and nutrition affected her health and well-being. She reflected back to her lifestyle habits before being diagnosed with breast cancer:

“And um that’s the one thing that bugs me the most about the whole entire thing because for the past ten years, at least since [child] was born.... I have been, I’m so disappointed in myself in the way that I eat. A lot of people might have thought that I ate pretty healthy but I had the problem of eating too many treats”.

She referred to her pre-cancer self as not being as healthy as she could have been. In part, Krista inferred a sense of personal accountability for developing breast cancer because of her eating habits. Her cancer experience influenced her to be more conscious of her nutrition and health, the benefits of eating more fruits and vegetables, cutting out sugars, and juicing. She noticed a difference physically, mentally, and emotionally with her altered diet, *“we seem to all have more energy and we’re more um have a clear mind and we’re more even keeled...”*. Krista’s cancer-self had a difficult time adjusting to being a ‘patient’ and dependent on others after her treatment and surgeries began, *“So I know it’s really hard to be the patient and let people do that for you. It’s a hard thing to adjust to”*.

A year and a half after her second and last chemotherapy session (only did two), Krista posted a video blog called *Breast cancer update – 2 years* to provide information and insight on her life after breast cancer treatments and surgeries, her post-treatment self:

“... I haven’t seen any kind of specialist or anything. I’ve just been maintaining my health with juicing, which I do. Uh it’s just my way of feeling like I’m trying to prevent cancer, so I buy as many organic vegetables as I can get my hands on and juice about four to six cups every single day. I have been doing it for about a year and a half, so it’s a really part of my daily habit now...”

She seems to be “*more even keeled*” with her emotions and has found more energy since switching her diet.

Alicia reminisced on her pre-cancer self and how she had changed since being on her breast cancer journey, “*Oh my gosh. Was I ever a workaholic*”. The realization of being a “*workaholic*” occurred when Alicia’s acupuncturist informed her of the importance of taking time for yourself each day. She decided to include this in her daily routine; she even proceeded to advocate to viewers to incorporate ‘down time’ in their lives to reenergize their body. Unlike her pre-cancer self, she had to balance work with resting to ensure she did not become even sicker. Alicia experienced fatigue related to her chemotherapy treatment, comparable to Cancerlady78, “*Um I’m tired a lot I mean sometimes I take three naps a day, two naps a day um and- and it’s hard to be productive when-when you’re exhausted in the middle of the work day*”. Before she was diagnosed with breast cancer, Alicia used to take more natural remedies for her health, “*You know that I am – have not been one to take medicine before this whole breast cancer journey has started. If I had a headache I took a nap. That’s how I was. I wasn’t even really taking Advil or Aleve and all that good stuff*”, whereas her cancer-self took prescriptions, over-the-counter medications, and natural remedies to help cope and heal.

Although Alicia had a more positive outlook on her life with breast cancer, she did have moments where she displayed vulnerability. She broke down sobbing twice throughout her video blogs when two of her friends passed away, one with brain cancer and the other because of breast cancer. Alicia talked about an online friend who passed away as a result of breast cancer, “*...she passed away this morning...and I have to be very honest and tell you all that I am afraid. I feel afraid*”. She began to cry. “*I feel afraid for myself*”. Her eyebrows rose, as she was surprised with what she has said. She took a

moment to pause and collect her thoughts. The clock ticked loudly in the background. She looked up to the right corner of her eyes as more tears run down her face. “ *Um. And that’s just the reality*”, she said as she wiped her left side of her wet face. Though she participated in self-care and in all of the recommended treatments, she knew that these actions would not guarantee that she would defeat the cancer.

Physical changes experienced. In the video blogs, the women described physical changes that occurred throughout their breast cancer journey, such as weight changes, hair loss, and the loss of one or both breasts. This affected the women emotionally and they struggled with their identity of being a woman.

Throughout chemotherapy, Cancerlady78 experienced numerous changes, such as hair loss, weight gain, and exhaustion, to name a few, to the point where she did not recognize her pre-cancer self anymore. In one of her videos, Cancerlady78 was wearing a baseball hat over her baldhead and no make-up, but when she went to work or out in public she acknowledged she dressed up in a *costume of normality*, appearing to mimic her pre-cancer self. She tried to *perform* her pre-cancer identity by masking the ‘signs’ of having cancer:

“People don’t know on my way to work sometimes I cry and it’s not because I don’t want to go to work. ... I enjoy being at work. It’s because it’s a lot of times it’s a struggle to get myself up and mentally ready to go to work because I’m looking in the mirror I -I don’t see my old self. I struggle to put on my clothes because I’ve gained all this weight. My wig doesn’t look right ‘cause it’s not my hair. I try to draw in my eyebrows... so I don’t look funny”.

In Cancerlady78’s video blogs, she always wore a baseball hat, no make-up, and baggy clothing. It was evident that she felt comfortable being her cancer-self at home and showing viewers this new aspect of her identity. Ironically, her video blogs are on a public website for anyone to watch. However, she obviously felt comfortable in her own home and in her videos to reveal herself during her battle against breast cancer. One could argue that her video blogs, though public, are more private and customized to those who have breast cancer or wanting to understand what it is like to have breast cancer; thus, making her video blogs seemingly more private and restricted.

Three of the women (Cancerlady78, Coralee, and Alicia) described the changes in their weight both positively and negatively. Cancerlady78 initially associated cancer

patients with “...hospital beds and wheelchairs looking really sick...pale, frail, unable to move too much, uh spending half their day hanging over a toilet”, which differed from Coralee’s preconceived notions of cancer as a ‘weight loss aid’, “About the third thought that I had after I was told I probably have cancer was “oh good, I won’t have to diet this winter”. To their surprise, they both gained weight, 10 and 15 pounds respectively. Coralee’s lifestyle and physical appearance (no hair loss, slight weight gain) did not drastically change compared to the other women; thus she did not have a significant experience with the physical aspects of transitioning identities. Although Cancerlady78 originally feared she would appear brittle and sick-like, she described being satisfied with her weight gain. Alicia was the only YouTube blogger who vocalized losing weight. She experienced significant weight loss after a chemotherapy treatment session, “I ended up losing half my body weight in blood I had- let’s see I was given 3 units of blood”. She stayed in the hospital for a few days where she felt “tired and a little weak”.

Two of the video bloggers had double mastectomies and two had a single mastectomy. The women described a range of emotions when deciding on the type of mastectomy surgery and expressed a sense of losing a part of themselves through the process. Alicia expressed conflicting emotions when trying to decide between a mastectomy and a double mastectomy:

“...I’m leaning towards, believe it or not, a double mastectomy and I never thought that would ever, ever cross my mind let alone my mouth, But it’s an option and at least I feel like I want to give it the respect of at least thinking about it and looking at it as a possibility before I rule it out so- so I’ve been sitting on that and it’s brought up a lot of grief. It’s brought up a lot of um sadness. It’s brought up um you know what I – I don’t know just a lot of different thoughts”.

Krista expressed sadness before having her mastectomy, “I’m sad that my breast is going to be gone. Say goodbye to my lady here. She’s going to be gone tomorrow...”. Losing her breast was saddening because it would be obviously and visibly absent. Krista changed her opinion about losing her breast post mastectomy. “Um so this is what it looks like to have one boob and honestly cause I had small breasts anyways it’s not that big of a deal...I have a coat on...and you can’t even hardly tell. So it’s not that big of a deal”.

Alicia expressed sadness after deciding on a double mastectomy, but decided to look at her decision as being able to live, “I am gunna admit I felt sad but ... the bottom

line is I have a contract to live". Coralee, Krista, and Alicia eventually expressed acceptance of their mastectomy and embraced their breast-less chest. Statements from all three women included, *"I haven't missed that breast at all"* to *"I had small breasts anyways"*. These women expressed how they were 'coming to terms' with having a single mastectomy or double mastectomy.

Responding to changes. The women demonstrated and articulated feeling out of control at the time of their cancer diagnosis and treatment and talked about how they regained control throughout their breast cancer experience. This story thread exemplifies how the women responded, both negatively and positively, to the changes experienced due to having breast cancer.

Alicia made the decision to cut off her hair before it fell out, whereas Cancerlady78 felt a lack of control due to her hair loss and not being able to have a particular hairstyle. Cancerlady78, Krista, and Alicia experienced hair loss because of chemotherapy, however Krista refrained from talking about her hair loss. Cancerlady78 stated, *"I combed out a huge chunk of my hair and so, you know, that week was a little rough"*. However, she attempted to control her appearance by wearing a wig and drawing on eyebrows. While altering her 'cancer-identity' in this manner may have 'fooled' others, costuming herself did not make her truly feel nor appear like her 'old' self, *"I just don't even look the same"*, she said sadly.

Krista took control of her body by deciding to have her other breast removed a couple months after her initial mastectomy. She then had full reconstruction surgery and was pleased with her results, which she shared in a video blog:

"So I had ...the full mastectomy and then I did full reconstruction after that a couple months after that and... I had just had them do everything in one procedure for the reconstruction, which is really nice cause I only had to have one surgery. And it - it turned out pretty good. I'm- I'm fairly happy with it".

Alicia showed she was in control and defiant of her breast cancer by not wearing a wig during her video blogs nor did she try to cover up her baldness. She embraced her situation and showed viewers that she was going to defy breast cancer and took the initiative to cut her hair before it started to fall out:

“So, uh rather than me uh sit and wait for big ol’ clumps or patches of hair to come out. I just said you know what I’m gunna take the uh take the bull by the horn here and uh went ahead and had it cut uh myself so... that actually feels really good, I actually feel really light about that”.

When her hair started growing back, she videotaped her excitement, *“can you see my hair growin’ back? Cute little pixie cut goin’ on here”* she squealed with delight. Not only did embracing baldness take courage and strength in light of North American normative standards for beauty, it also revealed how Alicia viewed herself as a woman. She did not wear breast prosthetics nor did she wear wigs on video camera. This perhaps illustrates a sense of being comfortable with herself and her body. She confirmed this by saying, *“Well...I’m telling myself today that I... love myself. I approve of myself. I appreciate myself and that everything is ok”*. Alicia chose to have a double mastectomy. She commented on her breasts being smaller and being athletic, so she was more accepting of having no breasts at all, knowing she would be *different* and going against North American society’s stereotype of the *ideal* woman.

Alicia followed her doctor’s treatment plan of chemotherapy and radiotherapy, but she also took the path of healing into her own hands: *“Instead what I’ve decided is to allow my life energy, my life to fight for my body and I’m doing that with a combination of naturopathic, homeopathic, and allopathic remedies”*. The more naturopathic treatments she used included acupuncture, chiropractic, massage, yoga, reflexology, physical therapy, breath work, and meditation, along with allopathic methods to defeat the cancer.

In response to the side effects of chemotherapy, Alicia responded by taking control of her chemotherapy treatments by creating a calendar to chart physical and emotional reactions to her treatment. In this way she could anticipate her reaction to treatments and be prepared for what was to come, and try to prevent severe sickness:

“So I started actually keeping a record of what’s happening in my body what things I could do to be preempted in my self-care. S...o I have my-my calendar here, so this is my day at a glance, and this is my month at a glance... I know exactly when the low point is supposed to be with my white blood...cell production which means y’know my immune system is at its absolute lowest. It’s most loving during those days for me to stay home and not be around a lot of people um to protect myself from other people you...So, I kept track of that last time. So, because I did that I knew Tuesday and Wednesday was when

it'd hit me really hard so I was ahead of time um taking...my nausea medicine and when I felt sleepy I was jus' laying down just rest...All those different things".

She learned through the experience of having chemotherapy the days where she needed to rest, when to expect nausea, and when to take certain medications. This suggests Alicia worked with breast cancer treatment rather than fighting against it; as well this assisted her with her self-care.

All four women storied some sort of change to their identity whether it was a lifestyle change, changes in their physical appearance, or internal change. However, the women indicated struggle with change and trying to remain *normal*. They also explained how they responded to changes. Some of the women were more proactive in response to their change, for example cutting their hair off before it started to fall out and having a double mastectomy to prevent cancer from reoccurring. With lifestyle and physical appearance changes, the women storied becoming a breast cancer expert by receiving informational support from healthcare providers, and by conducting their own research and information gathering to better help and prepare them for their breast cancer journey.

Storyline 3: Becoming Breast Cancer Experts

As part of their breast cancer journey, the women storied themselves as breast cancer experts. They received informational support provided by healthcare professionals and they took the initiative to become knowledge experts on breast cancer through personal experience and by doing their own research and information gathering. They did not tell viewers *this is what you have to do* regarding treatments or surgeries nor did they say that the information they were providing was 100 percent accurate. The women appeared to hold an expectation that the information they obtained (especially from healthcare providers) would be accurate and helpful; however, they found that not all of the information they received was sufficient.

Healthcare providers as sources of information. The women discussed the information they obtained from healthcare providers, such as their family physicians, nurses, surgeons, oncologists, and radiologists. They obtained information about the process of their surgeries, the type of breast cancer they had, and the treatments they were going to receive. The women demonstrated understanding of information obtained from healthcare professionals by explaining their diagnoses or treatments to viewers.

Cancerlady78 met with her oncologist, who provided specific details about the type of breast cancer she had:

“...The doctor calls me in and he basically tells me about my cancer. He tells me what type of cancer I have, uh it is invasive... and of course that’s something else you really don’t want to hear because that really means it’s likely to spread, in fact mine had already spread to one of my lymph nodes under the arm. (sigh). So you know he tells me that depending on the stage of my breast cancer... it could be curable”.

Cancerlady78’s doctors informed her to expect hair loss by “day 13” because of her chemotherapy treatment. She exclaimed, *“...I had no hair because that was about day 13 and they said my hair would start to fall out and sure enough that very day, day 13, I combed out a huge chunk of my hair...”*.

Coralee was also given information concerning her breast cancer diagnosis. She talked about her “therapy”, quality of life, and prolonging her life as much as possible:

“Like I said I was diagnosed stage 4 and what that means is that it not only was my tumour very big at 8.2cm and I had 13 malignant lymph nodes, but it’s also spread to my bones... and that means that I won’t be cured and it means that right now my therapy is - is quality of life and so I take one thing, one treatment and when my body no longer reacts to that then I’ll take another one and sort of walk through everything that’s available”.

She understood that no matter what treatment or medication she was on, it would not cure her of cancer. In order to remain comfortable and try to control the cancer, she would try one treatment or medication, which was Arimidex (hormonal therapy), until it was no longer effective, then would switch to a new treatment or medication.

Krista talked about meeting with her plastic surgeon in preparation for her surgery:

“So last week I went to see the plastic surgeon and talked a little bit more to what to expect out of the surgery that’s coming up on Friday and basically what he said was um after they remove the breast he is going to put an expander in and there will be some drains hanging down and something like that to drain any lymph fluid and that I shouldn’t do much for about a week as far as driving or vacuuming or cleaning and that kind of thing...”

Krista is the only participant who acknowledged that a friend gave her factual information and statistics regarding breast cancer. Her friend informed her that breast cancer is quite common in women, *“Um my friend Nicky said one out of every four women has breast*

cancer, so I'm sure that you probably know someone that has it". Krista's sister and mother also helped with finding different studies and information to assist her in making a decision regarding treatment that was best for her.

Personal information seeking. To expand their knowledge on their breast cancer, Coralee, Krista, and Alicia sought information on multiple options for treatments and surgeries and how to cope with having breast cancer. Coralee read several books, so she would know what to expect going into her mastectomy surgery. *"I read every book that I could get my hands and I thought I was completely prepared"*; however, Coralee was scared the moment she entered the operating room, as it became a reality.

Krista discussed her research findings in her video blogs, *"I've been reading this book. It's so good. It's called 'Anti Cancer A New Way of Life' and um this –this studies in here about the effects of eating fruits and vegetables on this disease is just amazing"*. Krista learned that it was beneficial to incorporate more fruits and vegetables in her diet as it can fight off the recurrence of breast cancer:

"Um this one study shows that from the University of Montreal, the doctor studied women like me who have the BRCA gene and uh I have like an 80% risk of getting breast cancer cause I have that – that gene. But it says that uh they studied some people did a study and they found that uh the risk of cancer development diminished sharply for some women who carry this gene and the main discovery was the more fruits and vegetables these genetically at-risk women ate, the lower the risk of developing cancer. Women who consumed up to 27 different fruits and vegetables a week and variety does seem to be important here saw the risk diminish by fully 73%. That's a lot".

Krista further explained in Anti Cancer A New Way of Life, *"...it's a good read but it also talked about American diet and he gives you an anti cancer diet. Uh a whole section here about what kind foods you should eat and things like that"*. Once Krista gathered her own information from studies and books and received information from family, friends, and her healthcare providers, she was able to make her own health decisions regarding her treatment for breast cancer. In the excerpt below, Krista discussed her struggles with the doctor's treatment plan of chemotherapy:

"...I feel I was being bullied into doing this chemotherapy because I don't have any other statistics. I don't have any other science to go and um so I mean yea the chemotherapy drugs have been shown, you put them in your body and they kill the cancer cells which is great but...they're not just killing the cancer cells. They're killing all the

good cells that grow back. My ovaries, it's going to kill my ovaries. So uh it's really frustrating...".

Krista decided:

"... [T]hat if I ate a healthy diet and live a healthy lifestyle that it can reduce my risk of recurrence just as much as I could if I do chemotherapy. I really believe that and I, my instincts are telling me, I know I could be wrong, but if I listen to my gut, you know we all have those feelings that my cancer is gone, they got it. And if I do these things and change the environment so that it can't grow back and I'm changing the environment of my body and my environment out here as much as I can, that I'll be fine".

Information quality. Coralee and Krista's video blogs highlighted their struggles with receiving adequate and quality information. They described the information received as biased, inadequate, or insensitive. Coralee prepared herself for her mastectomy, in part, by reading a book on breast cancer; however, the book did not prepare her for the experience she encountered:

"I read Susan Love's breast book cover to cover and I read a lot of other things too. Occasionally there was a mention of how you might swell up underneath your mastectomy... under the - the incision and it might have to be drained. The impression I got from these books was even once was unusual. Well, my incision swelled up for 5 weeks. I had to get it drained five times".

After her surgery, she had a winged scapula (shoulder blade protrudes from a person's back in an abnormal position), another experience she felt misinformed about from the books she read. Displeased, sarcastic, and annoyed she said:

"All along the way the things the books say you'll never get, I have gotten. In fact the first day after I got home from the surgery which was actually the day after I got home from the surgery I got something that the books talk about... in a very... brief, sort of dismissive kind of a way, I got a wing scapula".

Though she had prepared herself for her mastectomy, she felt misinformed or misguided by the information provided.

Post-surgery she asked a surgeon a question, for which she received an inadequate and insensitive response:

"As I was about to leave the hospital after my mastectomy, I asked someone how I went about getting something to stuff in my bra, was there anything available for people right after the surgery. A surgeon told me I could probably stop by the gift shop on my way out

of the hospital. That scared me. I live in Boston. These are world-class hospitals here. I didn't think that was very reasonable advice".

For Coralee, the response from the surgeon did not meet her expectations, given the reputation of the healthcare facility she was in, which was concerning to her. She struggled for months trying to find a prosthetic. *"I went without any kind of prosthesis for uh about 3 months. Largely 'cause I couldn't find one..."* She also did not receive important information regarding lymph node removal and information regarding post-surgical care. From her perspective, the physicians neglected to tell her not to get blood drawn or needles in the arm that you had lymph nodes removed from:

"... by the way anybody that's had any lymph nodes removed you can never again have any blood-blood drawn, blood pressure taken, or anything else, any other sort of medical procedure or regular routine thing on that arm. Another little thing they forgot to tell me in the hospital. And boy have I ever had a lot of blood drawn since".

Krista discussed the lack of detailed answers she received from her doctor:

"...My family physician just went to a breast cancer symposium and he offered us some information from there and what it said regarding triple negative, which is me, says that some people do well with therapy and some people do well without therapy and that we don't really know for sure much about it. So to me it's just a crapshoot".

She continued to explain:

"And um they don't present any other information at all. This is like chemotherapy and that's it. And the only way I would even get information about the fact that diet and what you need to do to change the environment that this cancer started in the first place is to seek that information out myself. And the fact they don't present the whole clear picture really just turns me off from it".

Krista expressed she was not getting the quality of answers to her questions or adequate information regarding treatment. She struggled with the fact that her doctors did not present other treatment options and felt they were regimented to do treatments a certain way.

The women in this study storied their experience with breast cancer as becoming a breast cancer expert with the assistance of information from healthcare providers and by conducting their own research and knowledge gathering. They indicated they needed and wanted to know more about the potential side effects due to surgeries and treatments, as well as other treatment options, which a couple of women professed were inadequately

communicated by their healthcare providers and books they read. The women received additional informational and other support (through various resources) regarding their breast cancer as revealed in the following storyline.

Storyline 4: Finding / Receiving Support

Throughout the women's video blogs, they discussed different types of support they found helpful, such as prayer and spirituality as support, emotional and tangible support from family, cancer support groups, healthcare providers, and social media such as YouTube and Facebook.

Offline self-directed support: prayer and spirituality. Three of the women talked about praying or taking a spiritual path throughout their journey with breast cancer. In Cancerlady78's last video blog she said, "*But it was my prayers, the prayers of my loved ones, my friends, my family [sniff], and it was those doctors that got me through this day right here*". She used prayer as a means to cope and to help her heal during her fight with breast cancer. Krista sought out prayer when deciding on chemotherapy treatment or another route, "*I prayed so hard on this and I thought so much about this. It's not an easy decision. It's very difficult to walk away from what these doctors are telling me*". She used prayer to help her determine what path to choose. Alicia used prayer to help her cope with her breast cancer. She videotaped herself in the prayer room in her house. She explained, "*Um I have a prayer room up in my attic uh where I spend a lot of time and um I'm up here today – I always come up here and pray for myself...*". Alicia also practiced meditation and yoga:

"... I...had a mindful meditation followed by...Yoga Nidra class...Um we were meditating but we were sleeping, scanning our bodies, and all that and just being more aware. Um what I understand it deals with the immune system and physiology and really having uh the ability to have your body rest really, really deeply".

Cancerlady78, Coralee, Krista, and Alicia noted various types of support throughout their breast cancer journey ranging from in-person, social and tangible support provided by family members and cancer support groups to online support from social media sites Facebook and YouTube, and by using prayer and spirituality. All women used more than one method of support to assist and encourage them through their journey.

Offline support: Individuals and groups. Social support came from family, cancer support groups, and healthcare providers. Throughout the women's video blogs

they acknowledged important social and tangible supports they received.

Cancerlady78 described her mother-in-law as providing a very unique form of emotional support that was different from any other: *“My mother-in-law who was also dealing with cancer – not the same type as I am, but you know she was able to help me, prayed with me, talked to me, and ensure me I’d be ok”*. Cancerlady78 found this unique relationship helpful, mentally and emotionally.

Cancerlady78 identified her family members as significant emotional and tangible supports (caring for her children) for her breast cancer journey. In the video blog, *My Cancer Story – After the Surgery (Again)* she thanked her family for their help:

“...and really have to put a heart felt thank you to my parents and sister for coming down to help me and my family while I was going through this. Uh my sister helped me with the kids getting them out the door and to school so that my husband could be with me as much as necessary. Um her and my parents uh coming back to my house make sure someone was here to meet my kids and they were taken care of again so my husband could take some time with me before I’d go to sleep again, uh while I was still in the hospital. Uh just making sure that we had everything we needed uh and-and that type of help is...priceless”.

Coralee participated in a cancer support group, which she framed as important in establishing a sense of normality. She was able to relate to other cancer patients who expressed panic, worry, and stress regarding doctor appointments. She stated, *“Well I belong to a support group and I see that others do the same thing just before their three month check-ups”*. This gave her a sense of relief that she was *normal* in feeling apprehensive about routine check-ups.

Krista had a difficult time accepting help around the house from her family, but still appreciated it:

“Um my mom came over here yesterday and worked like a dog to help me get my house cleaned up for the holidays and I actually had to leave cause I knew that I would not be able to sit here and watch her do all that stuff. Cause it makes me feel horrible. I mean it’s so nice and overwhelmed with all the kind wishes and little gifts people are sending me as well wishes to me and it’s overwhelming a little bit...but I do appreciate all the support and all the really nice things that people are doing so um so thank you all for that”.

Alicia had support from “midwives” (as she called them) that came to her house to assist her:

“I have a lot of midwives here helping me through it I had to do the heavy lifting of course. Some of them just came to give me a kiss on the forehead and tell me they loved me some of them were here all day all night and um ... uh I just want to say thank you. Definitely no I’m not doing this alone I could NOT do this alone...”

The midwives made sure she was comfortable, physically well, and helped around the house.

Alicia also described her first support group experience: *“Uh so I went to my uh first breast cancer support group. Uh I had gone to one before. Uh walked in to the building and that was as far as I could get myself to go. It was just far too emotional, um so I turned around and walked out the first time”*. Alicia smiled, making her seem a little bashful and embarrassed by this. She did go back almost two months later after she *“did some work”* on herself:

“[I] g[a]ve it a shot this past Monday. And I went in, sat in the room, introduced myself and uh listened to the other women’s stories and encouragement and support and that was really good. So just being present, um just showing up and saying a little bit was uh was good and that was enough – not to judge if it was good or bad. It just felt supportive and useful for me”.

Online support – Social media: YouTube and Facebook. The women reported that social media was as an important communicative avenue for them. They primarily used online support from the social media sites YouTube and Facebook. The four women uploaded their video blogs to YouTube to assist other individuals going through a similar experience and to help them cope with having breast cancer. Alicia was the only YouTube blogger to acknowledge using Facebook as a method of online group support.

Coralee created her video blogs to provide answers to those individuals going through a similar breast cancer experience, *“...Before I forget all the things that I would’ve liked someone to answer for me, I thought I’d make a tape of those answers for you, if you’re going through the same thing”*. Krista and Alicia indicated that their intention to video blog was to spread awareness and help others. Both indicated that they found video blogging to be personally “therapeutic”. The excerpt from Krista is illustrative of this:

“And um just the whole reason why I’m doing this is because is mostly for awareness and to help someone else that might get diagnosed or maybe you know someone. And um for me it’s kinda like I wish I knew more about what to expect. It’s like I have no idea what to

expect from all this. And um so you know maybe it would help somebody else or whatnot or anyways it's kinda therapeutic for me to do it. I've been journaling since I was in third grade and um this has kinda taken that to a whole other level I guess... I just feel compelled to do this for some reason. I don't know why. I can't explain it. I feel like I need to do this, good or bad, right or wrong".

Cancerlady78, Krista, and Alicia thanked viewers and supporters during one or more of their video blogs for their encouragement, support, kind words, and for taking an interest in their journey. Cancerlady78 said, *"I want to thank you guys for your many words of encouragement, your support..."* which reflected Krista and Alicia's *thank you* statements. Alicia further expressed her gratitude and said; *"I know that I could not have made it as far as I made it...without you [viewer]"*.

Alicia is the only woman who mentioned using additional social media outlets, such as Facebook, as a form of support. She was a member of a support group for individuals with cancer (she did not specify if it was for breast cancer or not) that was hosted on Facebook. Alicia attended a cancer benefit for a woman with brain cancer while grieving a loss of another friend who passed away from cancer. She attended the 'benefit', in part, as a way to manage her fear regarding her own mortality:

"...And I've decided to go because it would be much easier for me to sit here and uh to um marinate in fear um around myself, around my situation...um but I also think there's a reason I came across this information about this woman that is really in-in a battle for her life, uh dealing with brain cancer. And so, I can do something productive and I can do something positive and I can do something um that you know helps life carry on".

Alicia acknowledged that using Facebook as a vehicle for support was beneficial in helping her cope with breast cancer by meeting and talking to other people who are dealing with cancer.

The women in this study shared commonalities with their breast cancer journey. They storied their breast cancer journey as battling breast cancer, changing identities, becoming a breast cancer expert, and finding and receiving various types of support, online and offline. The next chapter will discuss these findings with further interpretations and coinciding literature, and future implications for both research and clinical practice.

CHAPTER 5: DISCUSSION

The purpose of this study was to gain an understanding of women's experience with breast cancer as narrated using online video blogging. Narrative inquiry was used to understand women's breast cancer experiences through an examination of the information they provided, and how they expressed their stories through the production and publishing of YouTube videos. The findings of this study resonate with Frank's (1995) restitution and quest illness narratives for the reason that three of the women tell stories of becoming healthy again, and one woman who had terminal breast cancer accepts her illness and uses it as a way to help others cope with having breast cancer.

Included in this study were four purposefully chosen female bloggers, Cancerlady78, Coralee, Krista, and Alicia, who publicized their breast cancer experience using YouTube. These women indicated they lived in the United States; two of the women were African American and two were Caucasian. The analysis of video data resulted in four storylines titled: Blurring Identities, Battling Breast Cancer, Becoming a Breast Cancer Expert, and Finding / Receiving Support.

The theme of Blurring Identities reflects an overarching storyline for the women and speaks to their pre-cancer, cancer, and post-treatment identities as a core theme, which was important to their understanding and sense-making of their disease. The term *blurring* was chosen to capture the intersecting identities and to demonstrate that the women have several identities that overlap and blend. The women in this study were not *solely* women with breast cancer; their identity was much *more* than that. The four storylines are included in the overarching theme of Blurring Identities. The women reflected on their feminine identity (storyline blurring identities) as a result of having breast cancer (e.g., loss of hair, mastectomy), they adopted a warrior identity (storyline battling breast cancer) because they were battling breast cancer, and they became breast cancer *experts* (storylines becoming a breast cancer expert and finding / receiving support) because they wanted and needed the knowledge and information pertaining to their breast cancer disease. The women negotiated these various identities in addition to holding on various dimensions of their pre-cancer identity. Thus, Blurring Identities is highlighted as a way to understand how the women expressed their breast cancer journey and the information they provided.

Blurring Identities

In this study and in previous research, identity has emerged as an important aspect of an individual's experiences with breast cancer. For example, Little et al. (2002) examined seven women and six men between the ages of 13 – 89 years of age who were cancer survivors (individuals living free of cancer at any time after treatment) to understand how cancer survivors narrate their survivor experience and how they perceive their *cancer-free* identity. They found that the extreme experiences associated with surviving cancer changes one's personal identity and produces discontinuities to an individual's identity, such as discontinuity of memory (e.g., looking at the past and future), discontinuity of embodiment (e.g., physical changes to the body), and existential disruption (e.g., what do I do now?) (Little et al., 2002).

Individuals in this study demonstrated similar discontinuities and how they coped with these changes by using: anchor points (e.g., values – health, family and social networks, and beliefs – religion), resumption (e.g., resuming a version of their former lives within the context of their changed embodiment and new perceptions), incorporation (e.g., enhancing cancer experience by helping others affected by cancer) and imbuing their experience with meaning (sense-making of disease) (Little et al., 2002).

Krista used health and diet as an anchor point to understand her breast cancer experience by attributing juicing and good nutrition to restoring her health, whereas Cancerlady78 and Alicia used religion and prayer to help cope with their breast cancer; Krista and Cancerlady78 incorporated the concept of resumption through their attempts to maintain their primary caregiver role while undergoing chemotherapy treatment, whereas Alicia decided to embody herself as a warrior. All of the women used *incorporation* as a coping strategy as demonstrated by their willingness to help others by posting their own personal experience of having breast cancer on YouTube; all four women demonstrated sense-making of their disease by sharing their experience and understanding their disease by seeking and retrieving breast cancer related information (Little et al., 2002).

An individual's cancer experience may result in a new identity and perhaps can even become permanent because of newly acquired values and ideals that are associated with roles and identity as a cancer survivor (Park, Zlateva & Blank, 2009; Zebrack, 2000). Identities and roles differ from one another; roles entail behavioural expectations

of an individual dependent on their social status or position, as well as actions and qualities that assist in making an identity. Identity is defined as an individual having conscious awareness of who one is (e.g., mothers are expected prepare meals, bathe, and ensure safety of newborns in addition to be caring and nurturing) (Ebaugh, 1988; “Role”, n.d.; Graham, Sorell, & Montgomery, 2004). The women in this study described how having breast cancer impacts on how they could take up and perform roles by restricting certain behaviours and actions. In turn, these role restrictions could present challenges to maintaining an acceptable sense of identity, such as a mother or employee, and required the women to re-negotiate their identities.

Using a narrative interpretation of online video blogs illustrated how the women’s identities transformed throughout their experience with breast cancer and how various identities (e.g., being a mother, an employee, martial artist, fitness enthusiast) intertwined with one another as they took on and made sense of the identity of being a woman with breast cancer. Harwood and Sparks’ (2003) understanding of identity as constructed via social identities and through the perception of others can be drawn upon to interpret the identity transformation expressed in the video blogs of the women in this study. These authors proposed that, “people orient to one another in terms of not only individuals but also group identifications. This occurs in terms of individuals of their own group (social identities), and their perceptions of other’s group memberships (e.g., stereotypes)” (Harwood & Sparks, 2003, p.145). Blurring identities highlights how the women’s expressions of identity were socially influenced and the multiple identities they discovered throughout their journeys with breast cancer. Throughout one’s life the process of negotiating and constructing identities takes place in conjunction with various roles associated with identity and relationships (Saayman & Crafford, 2011). Cancerlady78, Krista, and Alicia expressed their struggle in negotiating their multiple identities of career woman, breast cancer patient, and mother.

Cancer patients may identify changes to their identity after diagnosis noting discrepancies between their pre-cancer self and lives and their cancer self and lives, such as change to their daily routines (Mathieson & Stam, 1995). One of the predominant challenges to the identities storied by the women was their ability to enact their role as primary caregiver in their family, and in turn, the women had to re-negotiate their identity

as they became increasingly dependent on others. Caregiving is stereotypically characterized as a female trait that is biologically, psychologically, and sociologically engrained and developed in early childhood for women (Cancian & Oliner, 2000). Cancerlady78 (married) and Krista (divorced) had younger children and inferred they were the primary caregivers for their families. Both women demonstrated a notion of upholding this identity for as long as possible by continuing life as if they were their pre-cancer selves. They persisted in doing chores around the house, taking care of their families, and attending their children's extra-curricular activities; however, other research has indicated that mothers dealing with illness try to maintain normality in their lives for their children's sake and to keep them safe and happy (Helseth & Ulfset, 2005).

The women in this study noted it was challenging altering their roles and letting others take on tasks they had previously performed as the primary caregiver in their families. Cancerlady78, Krista, and Alicia described situations where their family and *midwives* gave tangible support by assisting in chores around the house, providing meals, caring for them and their children, and other tasks. Hirschman and Bourjolly's (2005) study found 97% of the women with breast cancer received tangible support (self-care, caregiving for the family, household responsibilities) from their immediate family members (parents, in-laws, partners, and siblings). This type of support aligns with several other research studies that examined caregiving and cancer (Cristine, Crooks, Grunfeld, Stonebridge, & Christie, 2003; Deshields et al., 2012; Stamataki et al., 2014). Although the women in this study expressed gratitude for such tangible support, it also appeared that it could be a threat or challenge to maintaining an acceptable image of oneself as a primary caregiver. For example, Krista expressed her struggle with receiving help and noted she had to leave the house when her mother came over to provide assistance. This finding coincides with Woods-Giscombé (2010) study in which the women expressed they preferred the *leader* role (independent or leader of the relationship) and acknowledged they had difficulty letting go of leadership. Another study found women with breast cancer were frustrated because they were unable to perform caregiving tasks for others and did not want to burden their family members by seeking and receiving their help (Hirschman & Bourjolly, 2005).

Blurring Identity: Femininity

Women, relative to men, typically experience significant pressure to conform to the cultural ideal of beauty, experiencing shame and self-reproach when this cannot be achieved (McKinley, 1998; Ucock, 2005). The women in this study experienced changes to their appearance and their identity as a woman after undergoing treatment for their breast cancer. Similar to the findings of others, the women expressed concerns about their perceived lack of attractiveness, were insecure with their *deformed* appearance, and felt they had lost a part of themselves in regard to their breast(s) (Batchelor, 2001; Freedman, 1994; Helms et al., 2008). Coralee inferred she felt deformed as a result of mastectomy surgery and even more that it was *fitting* that her mastectomy surgery was scheduled at the time of Halloween. Having breast cancer and losing a breast is a significant transformation for women and the physical changes resulting from a mastectomy move women further away from the cultural ideal of female beauty (Manderson & Stirling, 2007; Przedziecki et al., 2013; Spector, Mayer, Knafl, & Pusic 2011).

Mastectomy, for many women, results in the loss of confidence, self-esteem, and self-satisfaction and women may experience changes regarding their perceived quality of life, sexuality, and identity (Helms et al., 2008). Consistent with other findings (Helms et al., 2008), the women in this study expressed concerns about having a mastectomy and losing their womanhood and femininity. Cancerlady78 and Coralee wore a breast prosthetic, which may have been an attempt to conform to the body image cultural norm and used as a *disguise* to re-create their pre-cancer self as a *normal* woman in society. In fact, Wendell (1996) states that wearing a prosthetic post mastectomy can be indicative of an awareness of the rejected body, meaning that they are conforming to the physical ideals of society or culture noting they are *abnormal* or different from other women. Furthermore, there is some evidence that wearing prosthetics can go beyond the need to appear *normal*; it can be perceived as an avoidance of stigmatization, act of restoration, and displaying one's own physical comfort (Thomas-MacLean, 2005). Both women acknowledged they felt *womanly* again after being fitted for a prosthetic and were pleased when they were shown feminine, pretty, and specially designed bras.

In contrast, Krista and Alicia did not wear breast prosthetics as they both acknowledged having smaller breasts and were comfortable with having no breasts.

However, post mastectomy surgery Krista underwent reconstructive surgery noting she wanted the cancer *gone* (e.g., reconstructive surgery can help women believe that the cancer is gone) (Spector et al., 2011). Breast reconstruction can give women breasts that look and feel natural in addition to improving their quality of life, physically and psychologically (Spector et al., 2011). Krista noted they looked and felt natural, but did not speak to how and if her quality of life improved as a result of having the surgery.

Another change some of the women experienced was hair loss. Hair (e.g., appearance, style, colour) may also be viewed as an indicator of one's sexuality, attractiveness, and even femininity (Borsellino & Young, 2011). Some women associate hair loss with a loss of sexuality, attractiveness, and individuality (Batchelor, 2001; Freedman 1994). Yet there is a diverse reaction to cancer related hair loss; some women associate their baldness with pride and courage while others experience trauma and loss of identity (Boehmke & Dickerson, 2005). In her videos, Cancerlady78 wore a baseball cap to cover her head (to keep her head warm and cover up her baldness) and puts on a *costume of normality* - make-up, a wig, and breast prosthesis when she goes out in public to potentially hide or conceal her cancer identity. Wearing a wig could also hide the feeling of shame and fear of the disease, as baldness on a woman can be viewed as being sick or dying (Freedman, 1994; Frith, Harcourt, & Fussell, 2007; Gallagher, 1997).

In contrast, Alicia decided to cut off all of her hair before it started falling out due to chemotherapy treatment. Women who make the decision to cut their hair or shave it off may experience a greater sense of control, specifically regarding their emotional reactions to the cancer treatment process (Frith et al., 2007). By cutting her hair, Alicia felt that the action allowed her take back some control over her life that was lost as a consequence of having breast cancer. In fact, women who are accepting of their hair loss sometimes use it as a way to re-invent their image and identity (Frith et al., 2007). Alicia viewed herself as a warrior against her cancer and perhaps used her baldness as part of her warrior persona, which allowed her to be comfortable with her baldness.

The YouTube video narratives revealed a process of identity negotiation and demonstrated the coping strategies used by the women with breast cancer as they struggled to align their pre-cancer identity of an active and caring mother, a working woman, a partner or wife, with having breast cancer. Actively negotiating identities may

be done by openly communicating about cancer (Mathieson & Stam, 1995). Høybye, Johansen, and Tøjrnhøj-Thomsen's (2005) study used storytelling to investigate the motivations of 15 Scandinavian women, between the ages of 28-49, who chose the Internet (using the Scandinavian Breast Cancer Mailing List hosted by the Association of Cancer On-line Resources, a self-help group) to counteract the social isolation after having breast cancer. The authors concluded "passing on stories about support and care was seen not only as reaching out to others but also a way of dealing with one's own experience and making it meaningful..." (Høybye et al., 2005, p.216). The women in this study narrated the renegotiation of their identities and were able to make meaning of their experience by communicating their breast cancer journey through video blogging on YouTube.

The underlying foundation used by three of the women to make meaning of their breast cancer experience and renegotiate their identity was a particular type of illness narrative, restitution (Frank, 1995). Restitution narratives are stories that are told by individuals who want to be healthy again; they also uphold an expectation that other people want to hear stories of defeating illness (Frank, 1995). The restitution plots constructed by the women in this study included details and experiences regarding treatments, tests, interpretations of their illness, and how they journeyed through their disease experience. The women discussed their disease as they experienced it; they discussed becoming healthy again and their acceptance of the disease; and they used their breast cancer experience to communicate with and assist others. The women in this study noted they had to *kill* and fight the *cancer* so they could be healthy again. This type of narrative gives the women hope by thinking about the future and affirming determination to defeat breast cancer; it also assists in providing support as a way of coping and managing their breast cancer (Frank, 1995). Thus, restitution plot narratives assist individuals in communicating and sense-making of their disease, renegotiating their identity as a woman with breast cancer, and informing others, as well as it may be therapeutic.

Blurring Identity: The warrior

The *war* on cancer has been present in American media since 1971 when President Nixon declared *war* against cancer by signing the National Cancer Act (1971), which legislated financial aid to the National Cancer Institute to conduct cancer research needed to find a cure (“National Cancer Act 1971”, n.d.; National Cancer Institute, 1997; Skott, 2002; Sporn, 1996). Though researchers have not *won* the battle against (breast) cancer (no cure has been found), mortality rates have been decreasing (Haber, Gray, & Baselga, 2011). In particular, breast cancer mortality rates have steadily decreased with the assistance of preventative measures and more effective treatment and therapies (e.g., mammography screening and therapies post-breast surgery) (Canadian Cancer Statistics, 2013; Haber et al., 2011). Similarly, in this research all of the women expressed the idea that cancer was a battle. The term *battle* was chosen to highlight and describe the physical, emotional, and financial challenges the women experienced as a result of having breast cancer.

In the battle storyline, the women expressed and positioned their breast cancer as an enemy or intruder. The image of cancer as an intruder explains why cancer patients use metaphors, such as battle, or race to explain the treatment process (Teucher, 2003). The women in this study used language, such as *battle*, *kill*, *fight*, *nuke* and *get rid of*, to describe their battle against breast cancer. Individuals who apply metaphors, such as enemy, to their illness use it as a way to cope, and connect and give meaning to the disease (Lipowski, 1970; Penson, Schapira, Daniels, Chabner, & Lynch, 2004; Skott, 2002).

An enemy metaphor has been commonly used to express combat and struggle for individuals with cancer, however some studies have found negative connotations and stigma associated with it (Penson et al., 2004; Skott, 2002). Cancerlady78 and Krista acknowledged their cancer as an enemy that had invaded their body and expressed the need to fight and survive breast cancer for their children. Similarly in Degner, Hack, O’Neil, and Kristjanson’s (2003) study, women who viewed breast cancer as an enemy initially felt invaded, but eventually perceived it as something to fight in order to survive. Individuals battling cancer as the enemy may actively fight back by seeking *allies* in the form of healthcare providers, caregivers, treatments, and surgeries (Skott, 2002).

In order to battle and defeat the cancer, the women discussed the surgeries and various treatments they received to combat cancer, such as chemotherapy, radiation, and mastectomy and lumpectomy surgeries. Comparable to war, soldiers may lose a limb or a part of themselves during battle, Krista was saddened by the need to have a mastectomy and the thought of losing her breast, but reassured herself that mastectomy surgery was needed and she had to fight for her life. It is not uncommon for women to experience pain from their cancer treatments and surgeries and it is part of their healing and their fight with the disease (Peretti-Watel et al., 2012). When actively fighting against an enemy, pain, battle marks, and scars are anticipated outcomes.

Individuals with breast cancer can experience acute or chronic pain that can be caused by tumour invasion and tumour compression on bone(s) and nerves (Arathurzik, 1991). Cancer pain can be experienced at any point in breast cancer treatment; however, pain is more dependent on the type of the tumour present, and the location of the metastases, and less frequently caused by cancer treatment (Peretti-Watel et al., 2012). Physical pain was an important aspect of the women's stories and was viewed as a consequence of their battle with cancer. Peretti-Watel et al. (2012) reported in their study on women breast cancer survivors that the women experienced chronic pain related to post-operative complications, such as scar pain, arm lymphedema, and hormonal therapy side effects (e.g., musculoskeletal pain). Cancerlady78, Coralee, Krista, and Alicia endured physical pain narratively making sense of it by positioning it as part of the process to defeat and eliminate cancerous tumours.

Taking on the identity of warriors against breast cancer, Cancerlady78, Coralee, and Alicia revealed to YouTube viewers their battle scars - radiation tattoos, redness, and swelling - as a result of radiation therapy. Body markings and painting have been used to mask an individual's normal appearance and are commonly used in preparation for rituals and ceremonies, such as initiations, hunts, and battles (DeMello, 2007; Sherrow, 2001). In particular, Alicia storied her fight with breast cancer metaphorically and viewed herself as a warrior against cancer; her martial arts background may have been a contributing factor in viewing herself this way. She chose to see her radiation tattoos as markings as part of her initiation into battle. The ways the women framed their narratives as a battle with cancer, acceptance of pain and motivation to kill the cancer, is in accordance with current

literature on breast cancer and pain (Arathurzik, 1991; Peretti-Watel et al., 2012).

In their narratives, the women recognized health insurance companies as both friend and foe during their battle with breast cancer. Health insurance provided needed resource support to Coralee; her breast prosthesis and compression sleeve (garment worn that applies pressure to the area that helps reduce swelling and pain) were covered by insurance because of State law. Yet a predominant concern for many cancer patients is the loss of income (reduced pay, leave of absences at work) and the need to financially support themselves and their families (e.g., monthly payments, mortgages) (Amir, Wilson, Hennings, & Young, 2012). It is not uncommon to have financial difficulties as a consequence of having cancer; patients in a United States hospital oncology unit were surveyed and researchers found that 25% of patients indicated difficulties with being able to afford the cost of their cancer care and 14% reported financial hardships (hardships were not defined) as a result of having cancer (Bullock Hofstatter, Yushak, & Buss, 2012). Consistent with other research regarding women with breast cancer and work (Bradley, Bednarek, & Neumark, 2002) the battle against breast cancer storyline of Cancerlady78 and Alicia included a leave of absence from work or a form of job accommodation because of the physical and emotional toll taken by their fight against cancer. Both Cancerlady78 and Alicia sought financial support through video blogs; Cancerlady78 invited viewers to donate money to support her fight against breast cancer through her website.

In their battles against breast cancer, the women spoke of their many *combat allies*. The women in the current study acknowledged that they received social, emotional and spiritual support from their *allies* (e.g., family, social media, and healthcare providers). These types of supports are common methods that individuals with breast cancer seek and receive throughout their journey (Arora et al., 2007; Bender et al., 2011; Swinton, Bain, Ingram, & Heys, 2011). The women in this study were thankful to their *allies* (family, healthcare providers, and viewers) who supported them throughout their battle against the enemy. It is interesting that the women, except for Krista, neglected to acknowledge friends as *allies*, as friends are typically significant support systems (Arora et al., 2007; Moulton et al., 2013).

Blurring Identity: Breast Cancer Expert

Becoming a Breast Cancer Expert constitutes another identity transformation for the women video bloggers. Importantly, disease-related information provides knowledge pertaining to disease, treatment, and self-care management, and can also facilitate coping mechanisms and social support (Mayer et al., 2007). The women talked about their search for information regarding their breast cancer and offered information, advice and support to their viewers. Cox, Bowmer, and Ring (2011) emphasize health literacy skills as essential to understanding and acting upon disease and treatment information related to cancer. The women in this study demonstrated effective health literacy skills defined as “the ability to access, understand, evaluate, and communicate information as a way to promote, maintain and improve health in a variety of settings across a life-course” (Rootman & Gordon-El-Bihbety, 2008, p.11). They demonstrated an ability to find information (e.g., Coralee found information pertaining to lymphoma), review the research literature (e.g., Krista found research studies relating to nutrition, diet and cancer), assess the benefit of health services (e.g., massage therapy, prosthetics, support groups), and make informed decisions regarding breast cancer related treatments, surgeries, and other methods of healing (e.g., change in diet instead of traditional methods of treating breast cancer, have a double mastectomy and reconstruction surgery).

Adequate health literacy skills support individuals’ information seeking from multiple sources (Nutbeam, 2000). A previous study conducted by Bennett, Cameron, Whitehead, and Porter (2009) found younger cancer survivors were more likely to seek information from the Internet and books compared to older adult cancer survivors who relied primarily on information from family, friends, and books. In this current study, the women showed significant expertise in accessing information from health care providers, books, and research studies, and by participating in online and offline support groups.

Women with breast cancer want detailed information regarding various treatment options and procedures during the time of diagnosis and the treatment phase (Avis et al., 2005; Halkett et al.’s, 2010). Landmark et al. (2008) study revealed that women wanted information to understand and anticipate potential physical changes to their body due to the cancer and treatment. Coralee, Krista, and Alicia independently searched for breast cancer information and services through research studies, books, and Facebook. Thus, the

women's need to understand treatment options and potential side effects aligns with previous research regarding cancer patient information needs. In the study by Mok, Martinson, and Wong (2004), they found the 12 cancer patient-participants (breast cancer, colon cancer, nasopharyngeal carcinoma) were well-prepared (by healthcare providers and by personally seeking information) for treatments and better able to manage the side effects they experienced because of their knowledge about their disease.

Similar to the women in this study, researchers have found that women with breast cancer do not rely *only* on their medical care specialists for information regarding their treatments and surgeries (Robinson & Tian, 2009; Salzer et al., 2010; Sillence, 2013). The women in this study acknowledged and appreciated the information their healthcare providers gave to them; however, they also expressed to their viewers where their healthcare providers failed to provide them with information regarding side effects of treatments and surgeries, alternative treatments, and prosthetic resources.

Specifically, the women expressed a lack of information about breast prosthetics and the difficulty finding them after having a mastectomy. This finding is consistent with others who report that women want more information pertaining to the different types of prosthetics, the life span of a prosthetic, financial support, and written information on prostheses (Livingston et al., 2005). Krista was also dissatisfied with her physicians as they lacked details regarding treating triple negative breast cancer with Endomycin and chemotherapy. She also indicated that her doctors did not provide other options to her. This led her to find her own information on other alternative treatments for her type of breast cancer.

As well as seeking information regarding their breast cancer, the women in this study shared their breast cancer expertise through their video blogs and referred their viewers to breast cancer information resources. In doing so these women have taken on the role of information guide or an apomediator role as described in Eysenbach's (2008) Medicine 2.0 communication framework. Access to online social networks has allowed information seekers to rely less on traditional experts and authorities as information gatekeepers, and obtain guidance from others who have filtered information of interest (Eysenbach, 2008). For example, Krista referred viewers of her video blogs to several books and studies she found very useful.

In fact, all of the women provided information to viewers regarding their allopathic and natural treatments, prosthetics, wigs, and so on. Complementary and alternative medicine practices and products (acupuncture, homeopathic treatments, naturopathy, meditation, yoga) are not generally considered part of conventional or Western medicine and are commonly self-selected and self-prescribed (Barnes, Powell-Griner, McFann, & Nahin, 2004; Kremser et al., 2008; National Center for Complementary and Alternative Medicine, 2013). For many, the Internet, especially the interactive online social networking approaches (Facebook, wikis, blogs, YouTube, support groups, forums, etc.) have enhanced and diversified access to health information (Eysenbach, 2008). Not only did the women in this study provide information to viewers regarding treatments, surgeries, and other breast cancer related information, they also sought information through peer support. Beyond the predominantly specialized disease-based information offered by healthcare providers, peer support is especially beneficial for individuals who want detailed information on the lived experience, physical and lifestyle changes, and emotions associated with managing breast cancer (Avis et al., 2005; Landmark et al., 2008; Luker et al., 1996; Yoo et al., 2010). Peer support is based on mutual information sharing, often between individuals who share a common bond (e.g., cancer) (Moulton et al., 2013; Tilkeridis, O'Connor, Pignalosa, Bramwell, & Jefford, 2005).

Face-to-face support groups are often used during a cancer patient's first treatment session or upon completion of their treatment for social and emotional support (Gustafson et al., 1999; Campbell, Phaneuf, & Deane, 2004). Those who participate in breast cancer support groups have often experienced an improved quality of life, socially, physically, and psychologically (Michalec, 2006). Coralee and Alicia were the only women to acknowledge participation in face-to-face cancer support groups throughout their diagnosis and treatment stage. They both expressed personal benefit from their participation. A study that interviewed women with gynecological cancer and peer-to-peer support concluded that peer support reduced participants' fear and anxiety, provided hope for women going through cancer, and mitigated feelings of isolation and a lack of understanding from those who have not experienced cancer (Campbell et al., 2004; Moulton et al., 2013).

Women with breast cancer sometimes receive the most social support from peers when they use both online and face-to-face support groups simultaneously (Setoyama, Yamazaki, & Nakayama's, 2011). Online cancer support groups also offer informational and emotional support (Alexander, Peterson, & Hollingshead, 2003). Blank, Schmidt, Vangsness, Monterio, and Santagata's (2010) study revealed that online support groups offered more emotional support compared to other types of support (tangible, informational) for women with breast cancer. Alicia was the only woman in the study to vocalize that she was an active member of an online Facebook cancer support group. She indicated she made a couple of online friends who assisted in her emotional and social support; as well, Alicia was able to be productive by attending cancer benefits (invited through Facebook) and helpful to others (on Facebook) by communicating about cancer.

The women video bloggers in this study narrated their cancer experiences and spoke of the issues, concerns, struggles of greatest significance to them and the number of views the women received on their video blog postings provide some indication of what YouTube viewers were interested in. The next section discusses the use of YouTube as a source of breast cancer information.

YouTube and Health Information

This section provides a brief account of how YouTube can be an important and useful resource for women with breast cancer, the types of videos individuals were interested in and how the women shared information to viewers. YouTube is a relatively new and innovative resource for health information (Backinger et al., 2010; Chou et al., 2011; Snelson, Rice, & Wyzard, 2012). Watching online videos is more prevalent than other social media site use, such as using non-video sharing social networking sites, downloading podcasts, and updating Twitter and sharing updates (Madden, 2009).

Audience Engagement

Existing evidence suggests that women want practical and explicit information and ongoing support throughout the trajectory of their breast cancer (Landmark et al., 2008; Posma et al., 2009). The video bloggers in this study had a growing audience, as demonstrated by the number of viewers calculated for each video. Relative to the other videos posted by the women in the study, (if the number of views or hits is assumed to

reflect level of interest), YouTube viewers were particularly interested in information pertaining to the diagnosis of breast cancer (how they were diagnosed and how the breast cancer was detected), as each of the four women had over 1,000 views related to this *announcement*. Viewers of the video blogs were also interested in the videos that described the women's mastectomy post-operative experience; for example, out of all of Krista's video blogs, Waking up from mastectomy surgery had the highest number of viewers, as well Alicia's video blog, Endometrial Biopsy.....The Results Are In!, had the highest number of viewers indicating test results were of interest too.

Video bloggers can potentially offer and guide viewers to information and resources not provided by their healthcare provider. Individuals may feel overwhelmed, scared, or pressured to participate in or attend face-to-face support groups, whereas video blogs are more convenient by accessing them from the comfort of their own home and they are available 24/7. Information-preparedness increases an individual's perception of control, reduces feelings of anxiety and threat, and improves perceived quality of life (Davies, Kinman, Thomas, & Bailey, 2008).

Information Dissemination

Women with breast cancer in Halkett et al's (2010) study indicated a preference for treatment-related information, such as what the treatment involves, the types of machines and technology used, and potential side effects, to name a few. In their breast cancer expert role, Cancerlady78, Krista, and Alicia took their viewers on a *site visit* by videotaping their chemotherapy treatment facility and the operating room, for their viewers. Cancerlady78 videotaped her chemotherapy treatment. She filmed herself walking into the facility, she commented she had to sign in first, then filmed herself sitting in the chair, and then showed the chemotherapy treatment, Taxol, which was intravenously connected to her. Using YouTube technology viewers were able to see the setup of the room (e.g., big, comfy chairs lined up in a row) and became familiar with how chemotherapy treatments work. Cancerlady78 also showed pictures of the radiation machine, the mold that she lays on during radiation, which is *for comfort*, and a picture of her lying in the mold on top of a table with her arms bent above her head, awaiting the radiation treatment to be commence.

Alicia videotaped herself prior to her mastectomy surgery. Lying on a hospital bed, she wore a hospital gown and surgical cap as she discussed her thoughts on her surgery. Krista videotaped herself after her mastectomy surgery, while she recovered in the hospital, explaining the surgery and side effects she was experiencing (pain, swelling, tired). In the video, she wore a hospital gown, but her left shoulder was exposed and you could see a bandage wrapped around her chest. This can be helpful for viewers who have been diagnosed with breast cancer and for those awaiting treatments or surgeries by preparing and familiarizing them for what to expect. Using informational videos for preparing for treatment and surgery has been helpful in educating individuals and reducing stress and anxiety, as well as giving individuals affected by breast cancer an overall feeling of being more prepared (Krouse, 2001; Walker & Podbilewicz-Schuller, 2005).

Personal Reflections

I know breast cancer is an important topic that affects many women, families, and friends. I also knew that because I have a personal connection with breast cancer, emotions would be stirred and memories would resurface. Though it has been 10 years since my mother had her last chemotherapy treatment, I was not quite sure how exactly I would be affected by watching personal video blogs of women journeying through their breast cancer story. I was mostly affected by Alicia's story, as it was similar to my mother's experience with breast cancer. She resembled my mother by exuding similar strength and courage that radiated through every video blog. However, it was not until Alicia posted two video blogs concerning the death of a friend with breast cancer that emotions hit me hard. This woman demonstrated enthusiasm, positivity, optimism, strength and courage in video after video until her two video blog tributes to *fallen warriors*; she let go of this *warrior* persona and cried, and cried, and cried, acknowledging that it could be her reality too. This resonated with me. When my mother was sick, I tried to put on a brave face and stay strong for her, but every now and then when I was alone I cried, and cried, and cried, knowing she could die too. I had to stop the video, wipe the tears from my eyes, and walk away for a few minutes to collect myself. I knew I needed to acknowledge and reflect on my emotions and memories as a

way to understand other women's stories. Fortunately, there was a pause button. After listening to the video blog, I came to realize how powerful and moving YouTube video blogs can be.

The women in this study shared their personal stories about their breast cancer experiences, their personal concerns and struggles. These stories made me have a greater appreciation and respect for these women sharing their stories for anyone in the world to watch and listen to. After watching all of the women's YouTube video blogs, I realized how incredible this method of sharing stories was by its ease of access, availability, and communicating with women around the world who are going through a similar experience, as well as sharing information. I could only imagine how other women with breast cancer might feel and react to watching these video blogs.

Limitations

With all research there are limitations. The women included in this study were all American, and thus the study does not reflect the narratives or experiences of others with varying cultural norms, body image perspective, religion or spirituality, and access to health care and insurance. However, having all women from the same country provided consistency with respect to their illness experience within a U.S. healthcare system.

Secondly, the age range for participant inclusion was open as not all YouTube bloggers disclosed personal information regarding basic demographics details. Breast cancer narratives from women over 65 years of age and under 35 years of age may be quite different as research has indicated that younger women (40 and under) have different cancer information needs (e.g., fertility and menopause) compared to women over 65 years of age (e.g., maintaining independence and quality of life) (Thewes et al., 2005; Yoo et al., 2010). The women in this study (known ages 32 to mid 40's) are not in the prevalent age group of American women with breast cancer, as the leading age group from 2006-2010 was between the ages of 55-63 (25% of women with breast cancer) and only 9% of women with breast cancer were between the ages of 35-44 (Howlander et al., 2013). However, the ages of the women in this study align with the age group of individuals that are prevalent users of YouTube; individuals between the ages of 30-49 are the most predominant group to watch YouTube videos (67%) (Madden, 2009).

Furthermore, individuals under the age of 50 years use social media more than older adults, which could explain why the women in this study are under the age of 45 (Duggan, 2008; Kutner et al., 2006).

Thirdly, four women were included in this study. With a larger sample size different storylines may have been represented; however, there were rich and consistent data reflected in the four women's storylines, which allowed for an in-depth and detailed interpretation. Also men were excluded from this study. Though the experience of breast cancer in men (0.2% of men have breast cancer) is equally important, the majority of breast cancer cases are with women (26.1%) (Canadian Cancer Statistics, 2013).

A fourth limitation was the criterion for length or time of the YouTube videos. To be included in the study, YouTube bloggers' collection of videos had to be at least 20 minutes in length to allow for greater substance of narrative material. This eliminated the inclusion of women YouTube bloggers who posted fewer and shorter videos about their breast cancer experience.

Lastly, the ethical guidelines associated with the use of online data created a situation where direct contact with the women participants was prohibited. This precluded the opportunity for probing with additional questions, requesting additional explanation or detail, clarification, and the inability to conduct member-checking. Also, by holding a constructivist / interpretivist position, I must acknowledge that there are multiple realities and interpretations. Readers of this thesis have the opportunity for further interpretations of the findings.

Implications for Research

Further research of women's use of YouTube and their breast cancer journey could include exploring video bloggers of an older age, with specific ethnic and cultural diversity because different cultures and backgrounds experience and cope with illness differently (Doumit, Huijer, Kelley, El Saghir, & Nassar, 2010; Henderson, Gore, Davis, & Condon, 2003; Li, 2007). It would also be informative to focus on women who are at specific stages of their disease trajectory for a better understanding of their information, services, and support needs. Another interesting adaptation of this study would be to analyze the number of views of each video blog over a given amount of time to see how

the number of views fluctuates. This could reveal what viewers are interested in watching and wanting to know about depending on the tags used, descriptive keywords to help viewers find your video (e.g., health, cancer, disease, support), and words in the title (e.g., my breast cancer diagnosis). The number of views on a video blog can also contribute to previous literature pertaining to information needs of individuals with breast cancer, and as well inform healthcare providers of what individuals with breast cancer are discussing outside of their appointments. This study did not include an investigation of male narratives, and it would be important to investigate how men use YouTube and to understand their cancer experiences.

Researchers could also examine and analyze viewers' comments that are posted below the video blog to determine the nature of the comments, interactions, and the motivation or sense-making of the information viewed. Additional research might look at different countries and compare healthcare experiences, given those contextual factors, such as the availability of health insurance.

The women in this study provided information and resources to viewers to help support other women with breast cancer. However, it is unknown if the information is credible, reliable, and accurate; thus researchers and clinicians have the opportunity to examine the quality and accuracy of information women are providing. This would assist clinicians in providing accurate, credible, and informative video blogs to patients. Lastly, research investigating the demographic (e.g., ages, races, gender, education, income) details of video bloggers could characterize who is providing health information via online blog networks. This would assist in further understanding how breast cancer affects certain ethnicities, ages, and women who are advantaged and disadvantaged.

Implications for Clinical Practice

Healthcare providers may find value in these video blogs to better understand the experience of women with breast cancer; their struggles, their fears, and their concerns. Narrative inquiry was used to explore video blogs of women with breast cancer as a way to hear their illness stories; furthermore, the use of video blogs allowed for visual representation and communication of how the women expressed their stories. Stories of illness also provide different aspects of the disease and treatments from diagnosis through

life as a survivor (Gualtieri & Akhtar, 2013). Previous research has found videos of women breast cancer survivors more memorable and useful compared to informational or factual videos (Kreuter et al., 2010). Thus, personally created video blogs pertaining to an individual's breast cancer journey may provide an effective communicative method for support and information sharing. However, one individual's journey will not necessarily cover all treatments, surgeries, or side effects an individual can experience.

Health literacy skills are important for clients and providers in order to communicate, understand, and navigate through health information and services. Greater awareness related to the importance of health literacy skills as well as the multiple channels and formats of health care information are needed among all health care providers. In keeping with the tenets of client-centred care, health care providers are obligated to provide written information at a level the individual understands; as well, they should be able to communicate through multiple channels to ensure patient comprehension. Health communication and health literacy educational opportunities include attendance at workshops or online seminars.

Clinicians can offer *prescribed* online information and supportive services for individuals with cancer and have this information readily available for individuals. Cancer websites, Google, and other social media websites could even have a tab or link to direct consumers to trustworthy video blogs on breast cancer and other chronic diseases. Potential strategies in this regard might include: (a) establishing a library room with health-related information and computers for patients to access at the physician's office or health care clinic; and (b) healthcare professionals could provide links on their websites to valuable video blogs that address health information needs of their clients.

Healthcare providers may include health education focused on developing patients' skill in navigating and evaluating the Internet and participating in social media applications for information and emotional support. For example, health care providers who can provide their clients with an information criterion checklist could assist individuals in seeking credible online health information. This list could include questions and tips, such as providing websites they deem as credible and reliable for certain information (e.g., alternative treatments, personal health related stories), who is / are the author(s), is it a well known organization, do other studies suggest the same findings, how

long ago was the information posted or updated? Questions and tips on how to find credible information would be an asset for individuals to have, especially those with lower health literacy abilities, when searching for online health information.

Understanding and supporting client's information seeking within our contemporary technology enhanced health care climate is also educational importance.

Implications for Education

Healthcare providers could benefit from instruction related to online health information, service, and support resources for individuals dealing with breast cancer. It is important for health professional programs within universities or colleges to consider course content related to health literacy, Health 2.0 applications, and social media sites. Courses content could include: evaluation of social media and health 2.0 sites that are being used for sharing health related information, the creation and development of websites and programs that allows for credible and reliable health information, and how to improve health literacy in clinical settings. Healthcare professionals could also attend workshops related to Health 2.0 practices, that creates awareness and evaluation of popular social media websites being used for health information sharing, what information is being shared, how they can help their patients or clients use the Internet for health related information, and why the Internet and social media is important to include when disseminating information and support.

The women video bloggers shared their personal experience with breast cancer including information regarding diagnostic tests, treatments, surgeries, alternative medicines and healing, information resources, and breast prosthetic resources. The processes the women used to access breast cancer related information and the resources recommended by the women dealing with breast cancer can be a significant source of information, services, and support for other women and their families who are managing breast cancer. In addition, the posted video blogs enable viewers to *tour* treatment facilities helping viewers to visualize the treatment setting and procedures. Although this study did not look at the quality of information the women were providing in their videos, the diversity of information (i.e., complimentary treatments) on breast cancer and

practical information (i.e., breast prosthetic resources) within the videos extend beyond the medical information typically provided by health care professionals.

These video blogs are also educational as a way of sharing one's experience with breast cancer. These specific videos would be beneficial for those at the diagnosis stage, waiting for treatment, and the in-treatment stage, as they are a method of disseminating information, providing insight into treatments and surgeries related to breast cancer, and can emotionally support women. Family members and friends would also find value in these videos as a way to anticipate the breast cancer care processes and understand what it is like living with breast cancer.

Conclusion

This research study used narrative inquiry to understand the portrayed messages of women with breast cancer who posted YouTube video blogs. Illness narratives can be an important source of information and support as they showcase others' intimate experience with disease. Using YouTube to disseminate their stories, the four women narrated identity transformations while journeying through breast cancer. While the women perceived their cancer as an enemy and a battle, they used this analogy as motivation to enhance their well-being and become cancer-free.

The women in this study video blogged: at their home, in the car, at the hospital, and treatment facility. We can see their emotions, we can see their body language, and we can hear what they are saying and how they are saying it. YouTube may enhance storytelling by including both visual and audio components, non-verbal communication (body language), emotions, and intonation of voice. YouTube is an important source of peer-to-peer health information sharing as it provides a more intimate experience of listening and watching oral narratives, and can provide information that healthcare providers may not be able to offer individuals.

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Appendices

APPENDIX A

Exemption From Ethics Email

Hi there,

My name is Jenna Kressler and I'm in my MSC in the HRS program in Health Promotion.

I am hoping I'm contacting the right person to help me out.

My research study is going to look at YouTube videos (publically available) on women with breast cancer. I am wondering if I need to fill out an ethics form for this research since it is available online and analyzing messages conveyed by them.

If you need more information please email me back with what you need.

Thanks in advance,

Jenna Kressler

Hi Jenna,

As per TCPS guidelines on research exempt from REB review, research that relies exclusively on publicly available information does not require REB review, as long as the information is accessed legally and there is no reasonable expectation of privacy.

See TCPS Article 2.2 below:

<http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter2-chapitre2/#toc02-1a>

From what you have described, I see no reason for REB review. Feel free to contact me if you have any further questions.

My committee wanted me to get in touch with you again with regards to my research study on women with breast cancer who post their experience on YouTube.

As per the message below, you said it would be exempted.

However, my committee members question if it is ethical to:

- 1) provide a link of the YouTube video in my thesis,
- 2) show a clip of the video in my defense
- 3) provide still images of the YouTube video in my thesis and defense

I understand it is publicly available, but what they have a hard time with is that these women didn't put their story on YouTube to be a research study, however again, it is publicly available.

Thank you in advance,

Jenna Kressler

Hi Jenna,

Thank you for your email.
If it is publicly available you can do with it as you wish.

Unless it is on a protected area of YouTube or there is some expectancy of privacy then if someone puts something on a public channel it is public for anyone to use.

I hope this helps

APPENDIX B

Example of Sociolinguistics of a Story

Orientation	Actors: anorexic girl, classmates, doctors Time: at recess Place: at school Situation: a girl was called fat at school by classmates
Complication	Began to starve herself and workout excessively to lose weight
Evaluation	The girl became sick and hospitalized because of name calling and thinking she was fat
Resolution	The girl became fatigued, experienced hair loss, sleeping problems, and her eye sight worsened, so she had to go to a rehabilitation center to get help
Coda	The girl discusses the complications anorexia can have on an individual and how she is currently handling her eating disorder

APPENDIX C

Comparison of the Women YouTube Bloggers

Name	Cancerlady78	Coralee	Krista	Alicia
Age	32	Unknown	35+	41
Location	Hurricane prone area	Massachusetts	Michigan	Maryland
# of Videos	13	3	18	45
Total # of views	1,720	16,834	44,372	7,958
Most viewed video	My Cancer Story – The Diagnosis <ul style="list-style-type: none"> • 1016 views 	Part 1 of 3 <ul style="list-style-type: none"> • 8,809 views (diagnosis, surgeries, complications with side effects) 	Waking up mastectomy surgery <ul style="list-style-type: none"> • 32,789 views 	Endometrial Biopsy.....The Results Are In! <ul style="list-style-type: none"> • 1232 views
Least viewed video	My Cancer Story – The Bumpy Road to Recovery <ul style="list-style-type: none"> • 35 views 	Part 2 of 3 <ul style="list-style-type: none"> • 3,851 views (hormonal therapy, prosthesis, rare side effects) 	Breast cancer update 3 <ul style="list-style-type: none"> • 312 views 	You, Courageous? How to Know That You Are Courageous! <ul style="list-style-type: none"> • 49 views
Family	<ul style="list-style-type: none"> • 3 children • Married with husband 	<ul style="list-style-type: none"> • Unknown 	<ul style="list-style-type: none"> • 2 children • Divorcing 	<ul style="list-style-type: none"> • No children
Detection of lump	Self	Self	Not stated	Self
Stage of Breast Cancer	3B	4	Triple negative	3
Treatments	<ul style="list-style-type: none"> • Chemotherapy • Radiation 	<ul style="list-style-type: none"> • Radiation • Zometa • Arimidex 	<ul style="list-style-type: none"> • Chemotherapy (2 sessions) • Juicing and dieting • Exercise 	<ul style="list-style-type: none"> • Radiation • Chemotherapy • Neulasta • Herceptin • Chiropractor • Meditation • Reflexology & Acupuncture • Physical therapy • Exercise • Breath work

APPENDIX D

The YouTube channel link to each of the women; so their stories are heard.

Cancerlady78 - <https://www.youtube.com/channel/UC8Lbo-57yStYyIHLAT6zP9Q>

Coralee - <https://www.youtube.com/channel/UCfa8478BtHwb6XuBuTi6HjQ>

Krista - <https://www.youtube.com/channel/UCDV0uqVur8tcIbb7anPrFMg>

Alicia - https://www.youtube.com/channel/UCP68Jsc3k1hn_zRYPRm0LCQ

Curriculum Vitae

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Degrees:** University of Waterloo
Waterloo, ON, Canada
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