

**THE LIVED EXPERIENCES OF MIDDLE EASTERN IMMIGRANT WOMEN  
DURING THEIR CANCER SURVIVORSHIP JOURNEY:  
A PHENOMENOLOGICAL STUDY**

by

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## **ABSTRACT**

The number of Middle Eastern immigrant women (MEIW) living in Canada has significantly increased. However, this group of women are under-represented in health research, and there is a gap in knowledge of their cancer survivorship experiences in Canada. This phenomenological qualitative approach was employed to uncover the meaning of the lived experiences of MEIW during their cancer survivorship journey (CSJ). Data were collected through unstructured interviews and one written description from three MEIW. The participants' perspectives of cancer risk factors were believed to be the cause of their cancer and their CSJ was fear-inducing and anxiety-provoking. For the participants, social support, coping, language, information, and cancer care by professionals, as well as cultural beliefs, had significant impacts on this journey. Healthcare professionals need to identify immigrant women's unmet needs of support and psychosocial responses during their CSJ. Language-specific and culturally competent cancer-care intervention programs need development within the Canadian healthcare system.

## **DEDICATION**

To Khaldoun and Michal, your unconditional love and support allow me to chase my dreams.

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# **Chapter 1: Introduction**

## **Introduction**

Cancer is a heterogeneous disease with different types, stages, therapies, and outcomes (A. Surbone, Annunziata, Santoro, Tirelli, & Tralongo, 2013). Cancer represents one of the public health challenges in Canada because it is the leading cause of death (responsible for 30% of all deaths) and premature mortality. Cancer is a prevalent disease in this country. Fifty percent of Canadians are expected to develop cancer in their lifetime. Females between the age of 20 and 59 years are at a higher risk of developing cancer than males. This is due to the high incidence of breast and thyroid cancer among women (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017). However, cancer survival rates have significantly increased due to advanced biomedical technology in early diagnoses, and the use of effective therapies (Edwards et al., 2005). For example, the five-year age-standardized net survival rates for thyroid and breast cancers in Canadian females are 98% and 87%, respectively (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017).

The etiology of cancer is related to multiple, complex factors connected to biology (genetics), lifestyle (socio-behavioural), and environment (Vogel, Wilson, & Melvin, 2004). In fact, it has been estimated that only 2-10% of cancers are related to gene mutation or gene operation (Lee-Davis et al., 2007), indicating that cancer risks go beyond biological factors. This suggests that environmental factors, lifestyle, and the interaction between them play a significant role in cancer etiology. Furthermore, many socio-behavioural factors are firmly connected to the social determinants of health, such

as child development, employment, education, income and social status, social environment, and culture (Merletti, Galassi, & Spadea, 2011; Monfared et al., 2017).

Cancer survivorship care and cancer survivorship experiences are profoundly affected by the heterogeneity of cancer. This includes cancers that can be prevented, cured, and controlled rapidly or through long periods of treatment stages. Some cancers (e.g., advanced stages), however, are managed by palliative care to relieve pain or ease the symptoms of advanced cancer because they cannot be cured or controlled (Canadian Cancer Society, 2016). The diagnosis process requires different tests such as ultrasound, biopsy, hormone receptors, complete blood count, and blood chemistry tests. The medical decision for cancer treatment depends on factors that include type and cancer stage, overall health, the risk of recurrence of cancer cells, age, and biological factors (Taplin et al., 2012; Vogel et al., 2004). Therefore, healthcare providers will offer the cancer patient one or more of the standard cancer treatments such as surgery, chemotherapy, radiotherapy, hormonal therapy, immunotherapy, and targeted therapy (Taplin et al., 2012; Vogel et al., 2004). After the cancer treatment has finished, cancer patients begin follow-up care, which involves regular visits to family physicians or oncologists to monitor the treatment progress recovery (Giudice, Grunfeld, Harvey, Piliotis, & Verma, 2009; Miedema, Tatemichi, & MacDonald, 2004).

The cancer survivorship journey is very complicated and affects cancer patients physically, psychosocially, and emotionally due to associated feelings of fear, worry, sadness, distress, anxiety, and depression (K. T. Ashing-Giwa & Lim, 2011; Duffy & Aquino-Russell, 2007; F. Williams & Jeanetta, 2016; K. Williams, Jackson, Beeken, Steptoe, & Wardle, 2016). The cancer survivorship journey is influenced by various

factors, including ethnicity, race, cultural beliefs, socioeconomic status, education, lifestyle, and access to health services (K. T. Ashing-Giwa & Lim, 2009, 2011; Holst-Hansson, Idvall, Bolmsjö, & Wennick, 2018). For example, lower socioeconomic status and lower levels of education have been linked to diminished health outcomes in women diagnosed with cancer (K. T. Ashing-Giwa & Lim, 2011). Furthermore, women from ethnic minorities, who are cancer survivors, experience lower rates of emotional well-being, higher rates of fear of recurrence, and more symptoms of depression than non-minority women (K. T. Ashing-Giwa & Lim, 2011; S. Christensen et al., 2009).

Immigrant women's cultural identity and values influence various aspects of their survivorship experiences. These include the perception of illness, relationship with healthcare providers, ability to communicate their illness symptoms, the preferred type of care and degree of compliance to the recommended care, ability to share their emotions, and their responses to life-threatening diseases (K. T. Ashing-Giwa et al., 2004; Holst-Hansson et al., 2018). A healthcare system comprised of health care professionals who are culturally sensitive is essential in Canada in order to improve health outcomes and quality of care. It can also contribute to the elimination of racial and ethnic health disparities to achieve health equity.

### **The Significance of the Problem**

In the last sixty years, the ethnic and cultural makeup of immigrants in Canada has changed dramatically, resulting in a significant impact on the composition of Canadian society (Statistics Canada, 2016). For example, within the last 15 years, the number of immigrant women from Asia and the Middle East has significantly increased to more than 50% of the total female immigrant population in Canada (Hudon, 2015).

Therefore, the frequency of healthcare providers to interact with immigrant women from the Middle East and Asia has increased and will continue to grow, along with the need for healthcare providers to have more knowledge about their cultures and experiences in order to provide culturally competent healthcare services.

Several Canadian studies have shown that immigrant women who are from South-Asia, new immigrants to Canada, and in the family and refugee classes have the lowest cancer screening rates leading to delays in cancer diagnosis and poor cancer survivorship outcomes (A. K. Lofters et al., 2019). Immigrant women from the middle east and Africa have higher breast cancer incident rates compared with counterpart immigrant women in Canada (Shuldiner, Liu, & Lofters, 2018). Although there are some research reports in the literature focusing on the experiences of South-Asian and East-Asian immigrant women during their cancer care in Canada (Gurm et al., 2008; J. Hulme et al., 2016; Hyman, 2007), there is little known about the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey in Canada.

Furthermore, immigrant women experience challenges in understanding the Canadian culture, communicating the English/French language, integrating into Canadian society, and finding employment (Esses & Medianu, 2012). This leads to immigrant women having challenges navigating the Canadian health care system and available programs for cancer patients, accessing culturally sensitive education programs and female healthcare professionals (Vahabi & Lofters, 2016), and finding cancer support groups for immigrant women who can communicate in the same language as them in order to understand their cultural needs. All of these challenges will have a significant impact on their cancer survivorship journey and its outcomes.

## **Research Objective and Question**

Since there is a dearth of knowledge about the lived experiences of Middle Eastern immigrant women during their cancer survivorship in Canada, the purpose of this phenomenological study is to understand the lived experiences of Middle Eastern immigrant women in Canada during their cancer survivorship journey. The results of this study will contribute to enhancing health care providers' understanding of Middle Eastern immigrant women's lived experiences, cultural beliefs, and attitudes towards health and illness during their cancer survivorship journey. The voices, perceptions, and meaning of the experience for these women will help healthcare professionals to provide this cultural group of women with culturally appropriate and patient-centered care. Therefore, to capture the lived experiences of these women, the research question for this study is: What are the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey? The findings will be viewed through the lens of the population health theory (Raphael, 2009).

## **The Significance of the Study**

Middle Eastern immigrant women in Canada are underrepresented in health research and very little is known about their cancer survivorship journey in Canada. Therefore, this study will help to reduce the knowledge gap in the literature. This study is foundational, and it can be used as a first step in the development of a research program where further action and interventional research can be built. These programs will give practical guidance to health care providers and policymakers to reform or promote culturally competent health services for this group of women. From a health services perspective, where the patients are partners in their care and where treatment

aims to empower persons, participatory non-patriarchal interventions that are based on knowledge emerging from cancer survivors will be more applicable to achieve this aim. Therefore, conducting this descriptive phenomenological study is significant because the cancer survivorship experience will be captured and understood from the participants who have lived the experience.

### **Researcher's Perspective**

I have not experienced living with cancer myself, however, I have had family members who have lived the experience outside of the Canadian context. From my lived experience, as a Middle Eastern immigrant woman in Canada, there are many factors related to the new culture and acculturation process that I believe may influence the health and well-being of immigrant women in Canada. I believe that when immigrant women are diagnosed with cancer in Canada, it would be a very distinct and distressing experience for them. As a Middle Eastern immigrant woman and an Applied Health Services Researcher, I questioned what Middle Eastern immigrant women were living and experiencing during their cancer diagnosis and treatment, and thus wanted to explore what might be the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey.

### **Definitions of Key Terms**

#### **Cancer Survivorship**

As defined by the National Comprehensive Cancer Network (NCCN) in the United States of America, a cancer survivor is an individual who experiences cancer from the time of diagnosis, through the balance of his or her life (Denlinger et al., 2014). This definition of a cancer survivor includes not only cancer patients, but also their

families, friends, and healthcare providers. Based on this definition, for cancer patients, cancer survivorship is an ongoing process that starts from diagnosis, passes through treatments and follow-up care until the individual gains stability in his/her life.

### **Middle Eastern Immigrant Women**

Middle Eastern immigrant women include a heterogeneous background of Arabs, North Africans (from Egypt), Armenians, Persians, Sephardic Jews, Kurds, and Turks ("Middle East," n.d.). They are grouped by common geographical location, genetic backgrounds, universal religions, languages, and lifestyles. It is important to note that the Middle Eastern population is not officially recognized as a distinct ethnicity and is included with the white [Caucasian] race (Nasseri, Mills, & Allan, 2007). In this study, Middle Eastern immigrant women cancer survivors will be defined as women who are: between 20 and 65 years of age, have been diagnosed with cancer within the past five years, immigrated to Canada from the Middle East, and presently live in Canada.

### **Lived Experience**

Lived experiences are everyday experiences as described by individuals in terms of how they perceive, feel, judge, remember, make sense, and interact with the context of their experiences (Van Manen, 2016).

### **Social Determinants of Health**

The social determinants of health represent all of the economic and social factors that shape the health of communities, individuals, and jurisdictions (Raphael, 2009). Social determinates of health control the ability of an individual to have the physical, social, and personal resources to recognize and achieve personal ambition, satisfy requirements, and cope with the environment. The quality and quantity of various

resources that are available for communities and individuals are two essential features of social determinates of health. These social determinants of health are income and social status, education, childhood development, biology, health and social services, culture, employment and working conditions, gender, social support, social environment, and physical environment (Government of Canada, n.d.; Mikkonen & Raphael, 2010; Raphael, 2009).

### **Chapter Summary**

Chapter one provided an overview of the background and the rationale for this research on Middle Eastern immigrant women's lived experiences during their cancer survivorship journey. There has been considerably less health research done on Middle Eastern immigrant women and their experiences in Canada. With increasing the number of Middle Eastern immigrant women in Canada, the perspective of understanding their cancer survivorship journey can facilitate the building of a bridge between this group of women and Canadian healthcare providers. This study can help to initiate practical guidance for health care providers and policymakers in order to reform or promote culturally competent health services for this group of women

### **Organization of this Thesis**

Chapter 2 describes the literature review of cancer prevalence amongst Canadian and immigrant and ethnic minorities, cancer care within the health care system, and health disparities in cancer care and cancer survivorship outcomes and experiences. Further, it focuses on the impact of women's cultural identity and race on their cancer survivorship experiences, and the current gaps in research related to the experiences of Middle Eastern immigrant women in Canada. Chapter 3 describes the methodology and

method used in this study, including methodological rigour and ethical considerations.

Chapter 4 provides the results from this qualitative study using a phenomenological approach that is developed by Giorgi (1970). In Chapter 5, the findings of this study are discussed in detail from the population health lens. Finally, conclusions and implications are included in Chapters 5.

## **Chapter 2: Literature Review**

### **Introduction**

This chapter will address an overview of cancer prevalence amongst Canadian population and Canadian immigrants. Then, cancer care within the Canadian healthcare system, health disparities in cancer care, and the impact of the social determinants of health on cancer survivorship experiences as well as outcomes. An overview of cancer research related to survivorship experience and outcomes. This chapter reviews the literature of cancer research on Middle Eastern immigrant women in Canada.

### **Cancer Prevalence in Canada**

Cancer is one of the significant public health challenges in Canada, which causes health and economic burdens on the Canadian healthcare system (Poirier et al., 2019). Fifty percent (50%) of Canadians are expected to develop cancer in their lifetime, and twenty-five percent (25%) are expected to die from cancer in Canada (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017, 2019). Cancer is the leading cause of death and premature mortality in Canada and responsible for 30% of all deaths in Canada (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017, 2019). In addition to the health burden, the economic burden of cancer care has increased from 2.9 billion to 7.5 billion Canadian dollars per year between 2005 and 2012. This cost includes hospital care, physician care, and public and private pharma care (de Oliveira et al., 2018).

The most common cancer types in Canada are prostate, breast, lung, and colorectal cancer, which are responsible for over fifty percent (50%) of total cancers diagnosed in Canada. Cancer incident rates have variable trends across cancer types.

However, the cancer incidence rates are decreasing for men, and no longer increasing for women (CCS Advisory Committee, 2018; 2017, 2019). Between 1988 and 2017, the cancer mortality rate has decreased by 32% and 17% for men and women, respectively. It is important to point out that cancer incidence rates in eastern Canada are higher than that in western Canada (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2018; Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2019).

Breast cancer is the most common cancer among Canadian females, where one in eight women are expected to develop breast cancer in their lifetime. Canadian females between the ages of 20 and 59 are at higher risk of developing cancer than males due to the high incidence rates of breast and thyroid cancer among Canadian women (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017, 2019). Although the Aged Standardized Incidence Rates (ASIR) are not changing among Canadian women, the number of new cancer cases is going to increase by 80% by the 2030 (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2018).

With improving diagnosis and treatment technologies, cancer survival rates are increasing. The average age-standardized five-year net cancer survival rates were 60% and 63% between 2006-2008 and 2012-2014, respectively (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017, 2019). The number of female cancer survivors is higher than males, in which females have 13% lower risk of death than males (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017, 2019). The underlying reasons for differences in cancer survivorship outcomes between males and females are not yet well understood. The probability of surviving cancer is

affected by several factors including the stage of cancer at the diagnosis, the aggressiveness of the tumour, availability and quality of early detection, and diagnostic and treatment services (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017, 2019). Furthermore, cancer prevalence and survival are influenced by the social determinants of health (e.g., ethnicity, race, and socioeconomic status) (Halpern, McCabe, & Burg, 2016) and immigration (e.g., immigration status and immigrants origin) (McDermott et al., 2011).

### **Cancer Prevalence Among Immigrants in Canada**

Immigration has been a significant strength in shaping Canadian society. Immigrants represent 21.9% of the Canadian population who come from almost 200 countries (Statistics Canada, 2017). Canada has four immigration categories which are (1) economic immigrants such as skilled workers and business investors, (2) family immigrants who are sponsored by Canadian citizen family members, (3) refugee immigrants who are granted permanent resident status on the basis of a well-founded fear of returning to their home country, and (4) other immigrants who are granted a permanent residence for reasons that do not apply under the previous three categories (Statistics Canada, 2019).

There are national and international studies identifying the “healthy immigration effect” amongst recent immigrants, whereby recent immigrants are in better physical health upon arrival than host country-residents due to the selective immigration process (De Maio, 2010; Gushulak, Pottie, Roberts, Torres, & DesMeules, 2011). For example, research has shown that recent Canadian immigrants have lower mortality and morbidity rates of chronic diseases than those within the general Canadian population (Vang,

Sigouin, Flenon, & Gagnon, 2017). However, this healthy immigration effect is lost with time while living in the host country, suggesting that the social determinants of health have a significant impact on immigrants' health (De Maio, 2010). Cheung et al. (2017) suggested that immigrants may adopt the lifestyle of the host country over time, causing a decline in their health and well-being outcomes.

In general, there is limited administrative data and research on population-level cancer outcomes amongst immigrants that connect cancer prevalence and immigrant information such as immigration status, time living in Canada, ethnicity, and place of birth. However, there are a few Canadian studies that have tried to connect some immigrant information with cancer incidence rates, cancer screening (e.g. breast cancer), and cancer care outcomes (A. K. Lofters et al., 2019; McDonald, Farnworth, & Liu, 2017; Vahabi, Lofters, Kumar, & Glazier, 2016; Voruganti et al., 2016). These studies have shown that new immigrants in Canada have lower cancer incidence and mortality rates than Canadian-born population (Cheung et al., 2017; McDermott et al., 2011; McDonald et al., 2017; Shuldiner et al., 2018). Nevertheless, this healthy immigrant effect declines with length of time living in Canada (approximately ten years), and the possibility of being diagnosed with cancer may increase among specific immigrant groups. This has been primarily attributed to the environmental changes, stress, acculturation, low social support, unhealthy lifestyles, and unhealthy coping mechanisms such as smoking and drinking, as well as poor access to health services (Hyman, 2007; McDonald et al., 2017).

The geographical region from where immigrants come from also has a significant impact on cancer prevalence and type. McDonald et al. (2017) have declared that all immigrants who came to Canada from regions other than the US, UK, and

Ireland have lower cancer incidence rates than Canadian-born people. Shuldiner et al. (2018) found that immigrants from central-Asia and Europe have the highest risk of developing colorectal cancer, and immigrant women from North-Africa and Middle-East have the highest risk of developing breast cancer. On the other hand, immigrants from South-Asia have the lowest risk of developing these two types of cancer. McDermott et al. (2011) found that immigrants from South-East and North-East Asia have the highest risk of developing liver cancer compared with other immigrant groups in Canada. This had been attributed to the high prevalence of hepatitis B and C in these regions.

Immigration category also has an impact on cancer prevalence among immigrants in Canada. Refugee immigrants have higher cancer incidence rates than non-refugee immigrants (McDermott et al., 2011). For example, it has been found that refugee immigrant women have higher cervical cancer incidence rates than that of Canadian-born women and other immigrant groups (economic class and family class) (Beckett, 2016; McDermott et al., 2011). This has been accredited to the low cancer screening rates amongst refugee immigrant women in Canada (Beckett, 2016). Women from the family class are at higher risk of having breast cancer and being diagnosed at later stages than immigrant women from economic class (A. K. Lofters et al., 2019). These disparities in cancer prevalence and survival in Canada will likely have an impact on the cancer survivorship experiences.

### **Cancer Survivorship Journey**

The American Society of Clinical Oncology has indicated in its 2016 Annual Meeting that cancer survivorship journey is not the same for every cancer survivor (Halpern et al., 2016). This has raised the questions what makes cancer survivorship

journey different? Is it cancer care program? What are the factors affecting this journey? Since the number of cancer survivors is increasing, it is significant to understand their lived experiences during the survivorship period of their life. Focusing on the survivorship experiences and outcomes promote patient-centred care by providing cancer survivors with requisites for psychological and physiological needs, essential and recommended resources, preventative behaviours, and appropriate interventions (Hausman, Ganz, Sellers, & Rosenquist, 2011).

Numerous qualitative studies have focused on increasing the understanding of the psychosocial and treatment aspects of cancer survivorship (Duffy & Aquino-Russell, 2007; Holst-Hansson et al., 2018; F. Williams & Jeanetta, 2016). Other studies tried to enhance understanding of the factors leading to different cancer survivorship journeys (Halpern et al., 2016). The following is an overview of the literature of cancer survivorship experiences amongst women.

### **Articulating the Meaning of Cancer Survivorship**

Some cancer patients have the misconception of their identity as cancer survivors because they find it challenging to articulate the meaning of cancer survivorship (F. Williams & Jeanetta, 2016). The transition from cancer treatment stage to cancer follow-up care was very abrupt for them, which caused a dramatic decline in their perception of the kind of support that would be provided for them. Cancer survivors experienced changes (i.e., a decline) in the social support from their healthcare providers, family, and friends as soon as the treatment stage was done (Flórez et al., 2009; F. Williams & Jeanetta, 2016). This action made them feel confused about their identity (i.e., as a

cancer patient, or survivor, or warrior) because they believed that they still needed support from their social environment during the recovery stage.

### **Managing Fear**

Cancer survivors face plenty of fear and concerns during their cancer survivorship journey. Therefore, managing this fear is essential to control their health and well-being. The findings from previous studies indicated that cancer survivors had fear and concerns about: facing the diagnosis, managing treatment-related worries, trying to gain control after treatment, their appearance (i.e., body-image), their social life, sexual relationships, and waiting for recurrence (K. T. Ashing-Giwa et al., 2004; Holst-Hansson et al., 2018; F. Williams & Jeanetta, 2016). Learning how to manage all these fears and concerns is considered to be a part of what it means to be a survivor (F. Williams & Jeanetta, 2016).

### **The Power of Knowledge and Information**

Many cancer survivors value the importance of information and knowledge of cancer risk, cancer care processes, and outcomes because their understanding influenced their decision-making process throughout their cancer survivorship journey (Duffy & Aquino-Russell, 2007; F. Williams & Jeanetta, 2016). Knowledge and information can empower them to make the best decisions concerning their health in order to have the best health and well-being outcomes, thus gaining a sense of control over their situation, reducing anxiety, and formulating a plan for the future (Halkett, Arbon, Scutter, & Borg, 2005). Individualized knowledge about their bodies is essential in order to notice changes and seek immediate professional help from primary healthcare providers (F. Williams & Jeanetta, 2016).

## **Social Support**

Different studies have indicated the importance of social support during the cancer survivorship journey (Hodges & Winstanley, 2012; Kornblith et al., 2001). Cancer survivors find consultation, social and psychological support from health services providers, friends, family, coworkers, and other cancer survivors were helpful during their survivorship journey (Doumit, Huijjer, Kelley, El Saghir, & Nassar, 2010; Duffy & Aquino-Russell, 2007; F. Williams & Jeanetta, 2016). This support for individuals provided them with the strength to fight cancer, hope, and the ability to accept their conditions (F. Williams & Jeanetta, 2016).

## **Physical Changes in Appearance**

Changes in physical appearance (e.g., losing hair) during the treatment stage was a significant factor that negatively affected cancer survivors' ability to cope during the treatment stage (Doumit et al., 2010; F. Williams & Jeanetta, 2016). Changes in physical health and appearance caused anxiety, isolation, and emotional distress for many female breast cancer survivors (Alhusban, 2019; Joulaee, Joolae, Kadivar, & Hajibabae, 2012). Further, women's social role and relationship with the spouse have been affected by the multitude of changes in body-image (Joulaee et al., 2012).

## **Receiving Timely, Affordable, and Quality Care**

The quality and types of healthcare services that are provided for cancer patients are essential as they affect the survivorship journey (Halpern et al., 2016). Cancer patients' satisfaction with health services is influenced by different factors such as the wait time, cost, and the rate at which the patients shared their feelings with their healthcare providers (Saito, Suda, Sasai, & Jagsi, 2016). Provided health care services

affect cancer patients physically, psychologically, socially, and emotionally (Landmark & Wahl, 2002). Poor access to cancer quality care is associated with adverse health outcomes and higher risks of recurrence (de Moor et al., 2016).

### **Cancer Care within the Canadian Healthcare System**

Canada has a universal healthcare system in which equity in healthcare delivery is a fundamental principle, and the healthcare system is a shared responsibility between federal/provincial/territorial governments. In this system, the provincial and territorial governments are responsible for healthcare delivery (Marchildon, 2013). Cancer care services are part of the provincial/territorial acute care delivery, where dedicated cancer care programs are available to diagnose, treat, and support cancer patients (Sutcliffe, 2011). In general, cancer care programs are very complicated because of the involvement of various health care providers, various health services, and multiple settings. Therefore, the cancer control outcomes at the provincial and territorial level are monitored by the Canadian Partnership Against Cancer Corporation, which is a non-governmental organization that is a federally funded, population-based cancer control program and accountable through the federal/provincial/territorial relationships. This organization works on enhancing the cancer control outcomes and the quality of cancer care at the provincial and territorial levels (Sutcliffe, 2011).

Various Canadian resources have shown that Canadian experience health inequity and poor health outcomes due to long wait-times for health services, geographical barriers, lack of culturally sensitive care, language barriers, and inadequate health coverages (Clarke, 2016). Canadian statistics have shown that women, aboriginal people, immigrants, and socioeconomically disadvantaged communities (e.g., vulnerable

person) experience difficulties in accessing health services (Clarke, 2016). Literature has also shown that there are cancer care disparities at various cancer care levels including the primary care and secondary prevention, diagnosis, treatment, end of cancer care (e.g., palliative care), and cancer research (Ahmed & Shahid, 2012; Maddison, Asada, & Urquhart, 2011). Further, those vulnerable groups experience disparities in cancer care. Therefore, guaranteeing equitable access to cancer care is essential due to time sensitivity in cancer care, and its significant impact on the cancer survivorship journey and reduce health disparities (Maddison et al., 2011).

### **Health Disparities in Cancer Survivorship Journey**

Several international and national studies have indicated that there are health disparities in cancer survivorship outcomes (Kumachev, Trudeau, & Chan, 2016; McDaniel, Nuhu, Ruiz, & Alorbi, 2017). The cancer survivorship journey is influenced by various factors including ethnicity, race, cultural beliefs, socioeconomic status, education, lifestyle, access to health services, and many other social factors (Halpern et al., 2016; Monfared et al., 2017; Antonella Surbone & Halpern, 2016). Unfortunately, there is little evidence regarding the best strategies and policies needed to address this health disparities in cancer survivorship care. In this section, I will provide an overview of the impact of social determinants of health, such as culture, education, income, and social status, access to health services on women's survivorship outcomes and experiences.

#### **Education**

Education is one of the most critical determinants of health that has an impact on individuals, communities, and public health. Education reflects an individual's ability to

access health information and health services, personal health behaviour, and total health outcomes (Zimmerman, Woolf, & Haley, 2014). Several studies have investigated the relationship between education and cancer in women. It has been reported that education is linked to cancer's types, incidence rates, survival rates, and the survivor's physical and psychosocial health outcomes (McDaniel et al., 2017).

Lower education is associated with a high risk of stomach, liver, and cervical cancer in women, whereas a higher level of education is associated with a high risk of breast and ovarian cancer (Merletti et al., 2011). McDaniel et al. (2017) showed that women in developing countries with low levels of education often have lower survival rates (low survival rates indicate a higher ratio of mortality to incidence rates) than women in developed countries with higher education levels. The same trend also exists in developed countries where less-educated women have lower survival rates than educated women (Albano et al., 2007). For example, the mortality rate of breast cancer is 1.39 times higher in patients with an education level lower than high school compared to women with university education level (Albano et al., 2007; Sprague et al., 2011).

Furthermore, women survivors with lower education level experience poor mental and physical health, reduced quality of life, less perceived social support, and uncertainty during their cancer survivorship (K. T. Ashing-Giwa & Lim, 2009, 2011; Sammarco & Konecny, 2010). Women with lower education levels (grade 6 to 12) who also have poor English proficiency experience low emotional well-being levels, more fear of reoccurrence, and higher depression rates (K. T. Ashing-Giwa & Lim, 2009, 2011).

In contrast to lower educated women, women with higher levels of education engage in disease prevention and health promotion where they show up for the regular screening of breast and cervical cancer more frequently which results in earlier detection of cancer (Monfared et al., 2017; Shields & Wilkins, 2009). For example, Canadian statistics have shown that women with low education levels are less likely to go for mammogram screening (Shields & Wilkins, 2009). Unfortunately, women with lower education levels have less awareness and information about cancer screening programs, their cancer symptoms, available treatment, and health policies (McDonald et al., 2017; Voruganti et al., 2016). In other words, less educated women with low health literacy experience delayed diagnosis, which is associated with advanced stages of cancer, leading to lower survival rates.

### **Socioeconomic Status**

Income and social status have a significant impact on the individual's lifestyle as they shape housing, food security, education, health, personal behaviour and coping mechanisms, child development, and social life (Marmot, Friel, Bell, Houweling, & Taylor, 2008). Numerous studies have given tremendous attention to the impact of income and social status on cancer outcomes, which revealed a secure connection between socioeconomic status and survival rates, and physical and mental health of cancer survivors (Kumachev et al., 2016; Merletti et al., 2011; Shields & Wilkins, 2009).

Lower socioeconomic status is associated with higher cancer mortality rates and developed cancer stage diagnosis (Kumachev et al., 2016; Merletti et al., 2011). The same findings have also been reported in Canada (Kumachev et al., 2016; Shields & Wilkins,

2009), where the healthcare system is universal, and about 93% of people in Canada have access to primary healthcare services (Canadian Institute for Health Information [CIHI], 2017). For example, women who belong to the high-income group have 4.5% higher breast cancer survival rates than low-income women (The Pan-Canadian System Performance Steering Committee, 2012). However, the incidence rates of breast cancer are higher among women who belong to higher income groups. Women cancer survivors who belong to the low income and low social status group experience lower quality of life (Sammarco & Konecny, 2010), lower mental and physical health (K. T. Ashing-Giwa & Lim, 2011), and more depression symptoms (S. Christensen et al., 2009) than those who live in higher socioeconomic status.

There have been different hypotheses to explain the lower cancer survival outcomes among women with low socioeconomic status. Low socioeconomic status is associated with unhealthy behaviours such as smoking, drinking, and unhealthy eating, which are linked to cancer. Patients with lower socioeconomic status experience inadequate access to health services and postponed action to seek help leading to delayed diagnosis. Different treatments are also offered to patients from different socioeconomic status levels. Environmental factors, low educational levels, and living in rural areas that are far from cancer care facilities have also been reported as significant barriers (Kumachev et al., 2016; Merletti et al., 2011; Sprague et al., 2011).

## **Culture**

The epidemiology, diagnosis, treatment, and cancer survival outcomes have been studied and compared across multi-ethnic and racial groups of women to understand the similarities and differences between these groups of women to create public health

intervention programs that are culturally competent. Women's ethnicity and race have a significant impact on cancer incidence rates, survivorship experiences, survival rates, and survival outcomes. Holst-Hansson et al. (2018) suggested that women's perception of illness, relationship with healthcare providers and family, ability to communicate their disease symptoms, the preferred type of care and degree of compliance to the recommended care, and ability to share their emotions with others are the significant reasons for having different survivorship experiences among women with diverse ethnic and cultural backgrounds.

In the US, Caucasian American women have higher breast cancer survival rates than Hispanic, Asian, Native, and African American women (Smith-Bindman et al., 2006). Black African women, however, are more likely to have advanced stages, positive tumours, and the highest cancer mortality rates compared with other ethnic groups (Schultz, Stava, Beck, & Vassilopoulou-Sellin, 2004; Smith-Bindman et al., 2006). Although black women have higher mortality rates, studies in Canada, UK, and the USA have shown that white women have higher breast cancer incidence rates than black women (Beckett, 2016; Jack, Davies, & Moller, 2009; V. B. Sheppard et al., 2010).

Cancer survival outcomes have also been studied and compared across multi-ethnic and racial groups of women in Canada. It has been found that First Nations women have higher cancer incidence rates (five times higher) and mortality rates than non-indigenous women. This is purported to likely be due to unhealthy lifestyle choices, obesity, cultural beliefs about illness, delayed cancer diagnosis, low awareness of early symptoms, tardiness in seeking medical advice, stigma, and a lack of culturally appropriate screening and cancer care programs (A. J. Sheppard et al., 2010; Withrow,

Pole, Nishri, Tjepkema, & Marrett, 2017). Further, Canadian-born visible minority women have lower cancer incidence rates than white women (McDonald et al., 2017).

Ethnic minority immigrant women in Canada are more likely to be diagnosed with cancer at later stages than non-immigrant and white women. This has been attributed to different cultural beliefs, lack of knowledge about health prevention and promotion programs, lack of knowledge about the Canadian healthcare system, low education levels, poor English/French proficiency, low income and social status, poor access to the healthcare system, age, and health illiteracy (Beckett, 2016; Vahabi & Lofters, 2016; Zanchetta et al., 2017). It has been noted that late breast and cervical cancer stages are very common in South Asian immigrant women in Canada (Voruganti et al., 2016).

A study in Ontario indicated that Muslim immigrant women from South Asia, the Middle East, and Africa have the lowest cancer screening rates compared with immigrants women from Central Asia and Eastern Europe (A. Lofters, Hwang, Moineddin, & Glazier, 2010; Vahabi, Lofters, Kumar, & Glazier, 2015; Vahabi et al., 2016). This has been attributed to the systemic barriers, mentioned earlier, as well as limited access to sexual health information, inadequate open discussion about sexuality within their communities, religious and cultural teachings, specific regulation regarding modesty, and premarital virginity and sexual behaviour (A. Lofters et al., 2010; Vahabi & Lofters, 2016). Moreover, many immigrants in Canada prefer female family physicians who have the same culture and speak the same language as they do (Vahabi & Lofters, 2016). However, it has been reported that Canadian medical graduate physicians are more likely to screen eligible immigrant patients for breast, cervical, and colorectal cancer than the international medically trained physicians (A. Lofters, Ng, &

Lobb, 2015). This suggests that the patient's and physician's cultural beliefs have a significant effect on health practices.

Ethnic minorities who are cancer survivors experience lower rates of emotional well-being, higher rates of fear of recurrence, low quality of life, and more symptoms of depression than non-minority women (K. T. Ashing-Giwa & Lim, 2011; S. Christensen et al., 2009; Sammarco & Konecny, 2010). This is likely due to their cultural health beliefs that cancer is a death sentence, lower social support, reluctant to share their diagnosis and feelings with their family, children, and friends (Holst-Hansson et al., 2018; Sammarco & Konecny, 2010; Vahabi & Lofters, 2016). Another study indicated that women breast cancer survivors from ethnic minorities experience shorter sleep durations than Caucasian women causing more fatigue, depression, pain, and sleep onset latency (SOL) (Note: SOL is defined as the time that is required to achieve the transition from full wakefulness to sleep) (Budhrani, Lengacher, Kip, Tofthagen, & Jim, 2014).

Multi-ethnic cancer studies with Latino, Hispanic, Caucasian, African, and Asian women have shown that based on their cultural beliefs, women from different ethnic groups have different strategies to survive and to face worry, sadness, fear of reoccurrence, and uncertainty. Some women believe that their cancer diagnosis is God's will and that God controls illness outcomes regardless of their actions. In this case, these women believe that spirituality, prayers, and turning to God will help them to maintain control. Other ethnic groups and more accultured women, however, try to understand the reasons (e.g., lifestyle, family history, and breastfeeding) behind their cancer diagnosis (K. T. Ashing-Giwa et al., 2004; Holst-Hansson et al., 2018).

Different ethnic groups use different coping mechanisms during their survivorship journey. Caucasian, Latino, and accultured women try to stay positive and

show more active involvement in healthcare, adopt a healthy diet, exercise, and perseverance to do whatever they can to survive. Less acculturated women, however, prefer doctors to make decisions, and they feel vulnerable to illness due to unhealthy habits (K. T. Ashing-Giwa et al., 2004; Holst-Hansson et al., 2018).

### **Social Support**

Women from different ethnic groups find that social support from healthcare providers, family, friends, and support groups help maintain control during their survivorship journeys (K. T. Ashing-Giwa et al., 2004; Duffy & Aquino-Russell, 2007; Holst-Hansson et al., 2018; F. Williams & Jeanetta, 2016). However, cancer survivorship has an impact on the patient's relationships with family, friends, and healthcare providers. Astonishingly, changes in family relationships amongst different ethnic/racial groups have been reported by Schultz et al. (2004). For example, Hispanic American cancer survivors are more likely to have improved their family relationships compared with families of African American and Caucasian American survivors. Cultural beliefs about the family role, women's roles, and perception of spousal support affect Asian American and Caucasian women cancer survivors. Asian immigrants believe that obligation and duty to their family increase their stress and makes them work harder to stay healthy (K. T. Ashing-Giwa et al., 2004; Ashing, Padilla, Tejero, & Kagawa-Singer, 2003).

### **Access to Health Services**

Access to health care services, health promotion, and health prevention programs have a significant impact on cancer survivorship outcomes among women from different ethnic minorities. Access to health services is one of the significant challenges that face

many immigrant women in Canada and the USA during their cancer care (K. T. Ashing-Giwa et al., 2004; Beckett, 2016; Booth, Li, Zhang-Salomons, & Mackillop, 2010). Low socioeconomic status, low levels of education, and language are the main reasons that complicate immigrant women's ability to access health services. The availability of an interpreter is also considered to be a barrier to access to health services (K. T. Ashing-Giwa et al., 2004). Despite the presence of the universal healthcare system in Canada, access to health services is still a challenge for many immigrant women due to long wait times, lack of family physicians, and geographical barriers (i.e., patients who live in rural areas) (Booth et al., 2010; Vahabi et al., 2016). Furthermore, other obstacles such as sociocultural practice, socio-demographic characteristics, unemployment, and unfavourable social conditions may influence the overall accessibility to healthcare services (Donnelly et al., 2015; Hwang et al., 2017; Vahabi et al., 2016).

Weerasinghe and Mitchell (2007) found that immigrant women in Atlantic Canada experience culturally insensitive and unresponsive healthcare. For example, healthcare providers sometimes misunderstand the connection these immigrant women make between their bodies, minds, and social health. This issue occurs not only in Canada but also in the US, where ethnic minorities experience unmet informational, emotional, practical, and spiritual support from healthcare providers during their cancer care (Moadel, Morgan, & Dutcher, 2007). Consequently, many ethnic minority women prefer female healthcare providers or healthcare providers who have the same ethnic and cultural beliefs as them (Redwood-Campbell, Fowler, Laryea, Howard, & Kaczorowski, 2011; Vahabi & Lofters, 2016). Patient-physician ethnic and linguistic semblance can

improve patient's health outcomes, health services satisfaction, improve quality of care, and continues care (Shah et al., 2015).

Unfortunately, many immigrant women mistrust the healthcare system and are afraid of health research (Beckett, 2016). Others do not access health prevention programs because they are afraid of the stigma, shame, and any other negative social consequences. Fear of cancer diagnosis, diagnosis technology, and treatment methods (e.g., chemotherapy and radiotherapy) has also been reported (Beckett, 2016; J. Hulme et al., 2016; Redwood-Campbell et al., 2011). Therefore, physicians and nurses must play an essential role in educating these women about different health prevention and promotion programs, symptoms, available screening and treatment methods, and other healthcare services (e.g., sexual health information). Healthcare professionals also need to be knowledgeable about how to provide culturally competent care.

### **Cancer Prevalence and Survivorship Amongst Middle Eastern Immigrant Women**

Several international studies have shown that cancer incidence rates in the Middle East are lower than those in North America (Bray et al., 2018; World Health Organization, 2018). However, cancer screening rates (e.g., mammogram) are low in the Middle East (Donnelly et al., 2015; Othman, Ahram, Al-Tarawneh, & Shahrouri, 2015). Similar findings have also been reported for first-generation Middle Eastern immigrant women in Canada, USA, Australia, and Sweden (Nasseri et al., 2007; Shuldiner et al., 2018; Vahabi et al., 2016; Yavari et al., 2006). Consequently, this group of women have lower cancer incidence rates than Canadian-born women. They are also diagnosed with later stages of breast cancer compared with Canadian-born and non-Hispanic White American women, but they have higher survival rates (Ziadeh, Ziogas, Jiang, & Anton-

Culver, 2018). The high survival rates have been attributed to the high social support that they receive and their adherence to the Mediterranean diet (Ziadeh et al., 2018).

When Middle Eastern immigrant women have been compared with other immigrant groups in Canada, it has been found that immigrant women from the Middle East and North Africa have the highest risk of developing breast cancer (Shuldiner et al., 2018). However, they have a cancer incidence standardized incidence ratio (Cancer SIR = 0.25) lower than the average SIR of all immigrant women groups in Canada (Cancer SIR = 0.29) (McDermott et al., 2011). Nasser et al. (2007) have shown that Middle Eastern women have lower cancer incidence rates than non-Hispanic white and African American women, but they have higher incidence rates than Hispanic and Asian women.

Research investigating cancer survivorship amongst Arab and Iranian women in the Middle East have indicated that these women perceive cancer survivorship journey as a major disruptive stage in their life in which they have to fight (Doumit et al., 2010; Nasrabadi, Bahabadi, Hashemi, Valiee, & Seif, 2011). Regardless of their religion, these women believe that cancer is a divine test, and they have to accept it. However, their positive relationship with God has been reported to have given them hope and strength and helped them to accept their diagnoses and to cope with the disease (Doumit et al., 2010; Goldblatt, Cohen, Azaiza, & Manassa, 2013; Joulaee et al., 2012; Nasrabadi et al., 2011). Due to a cultural belief that cancer is a stigma, Middle Eastern women in previous studies have tried to conceal the disease from their social environment, including extended family (Doumit et al., 2010; Goldblatt et al., 2013). These social and cultural attitudes increased their anxiety and stress due to the resulting limited social support. Similar to all cancer survivors in other studies around the world, social support

from family was very precious for them in order to fight cancer. Sharing their experiences with others who have similar experiences has helped them to improve their coping mechanisms and deal with cancer (Doumit et al., 2010; Gushulak et al., 2011).

### **Gaps in Research**

The population of Middle Eastern immigrant women in Canada is growing, and the probability of health services providers to interact with them is increasing as well. The population of immigrant women from Asia and the Middle East represents more than 50% of the total immigrant women population in Canada (Hudon, 2015). Most Canadian studies include Middle Eastern immigrant women with Muslim or Arab immigrant women (A. K. Lofters, Vahabi, Fardad, & Raza, 2017; McDonald et al., 2017). It is important to note that there are Muslim and Arab women in North Africa, and Muslim women all around the world, where the highest Muslim population is in South-Asia, and the highest Arab speaking population is in North-Africa ("10 countries with the largest Muslim populations, 2010 and 2050," 2015; "Arab countries 2019," 2019). However, Middle Eastern immigrant women are a heterogeneous group of different religions, languages, and backgrounds (Nasseri et al., 2007).

Furthermore, many Canadian studies focus on cancer prevalence and cancer screening rates (e.g., breast, cervical, and colorectal cancer screening) amongst immigrant women (McDonald et al., 2017; Vahabi & Lofters, 2016), but there is little known about their cancer survivorship experiences. In this research, I am interested in this group of women because they are a heterogeneous group and underrepresented in health research in Canada. Based on my knowledge, this research is the first research in

Canada to study the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey.

### **Chapter Summary**

Cancer is one of the major public health challenges in Canada due to high cancer prevalence rates. Although Canadian women have a higher risk to be diagnosed with cancer than men, the survival rates amongst Canadian females is higher than it is in males. Canadian immigrants enjoy the health immigration effect, whereby they have lower cancer incidence and mortality rates than the Canadian-born population. However, this healthy immigration effect declines with time while living in Canada, leading to cancer prevalence rates that are comparable to the Canadian-born population. This indicates that social factors, lifestyle changes, and environmental changes have a significant impact on the health of this population.

The cancer survivorship journey is not the same for every cancer survivor, which encourages the need for understanding all of the factors influencing this journey. Reviews of various qualitative studies indicated that cancer survivors have challenges to: articulate the meaning of cancer survivorship, manage fear, and accept the physical changes in their appearance. They value social support and provided knowledge and information, but they strive for quality cancer care. Although the Canadian healthcare system is universal, cancer survivors in Canada experience health inequity during their cancer survivorship. Furthermore, survivorship outcomes and experiences are profoundly affected by the social determinants of health. Racial, ethnic, educational, socioeconomic status, social support, and access to health services differences cause inequitable survivorship outcomes and experiences.

Immigrant women are considered a vulnerable group in Canada because they experience health inequity. Immigrant women have lower cancer incidence rates, but they have lower survival rates than Canadian-born women. Survivors who are ethnic minorities and/or have low socioeconomic status and/or have low educational levels will experience poor mental and physical health outcomes. This has been attributed to the lack of knowledge about the Canadian health care system, poor English/French proficiency, some cultural beliefs about the cancer diagnosis and cancer care process, and poor access to health services.

The population of Middle Eastern immigrant women is significantly increasing in Canada, however, there is little known about their cancer survivorship experiences. In previous research, it has been found that immigrant women have lower cancer incidence rates than Canadian-born women. Nonetheless, they have the highest risk of developing breast cancer compared with other immigrant women groups. In this research, I am interested in investigating the lived experiences of Middle Eastern women because they are underrepresented in health research and are a heterogeneous group of immigrant women. This research is the first research in Canada to focus on the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey.

## **Chapter 3: Methodology**

### **Introduction**

In this chapter, I discuss the methodology of the research study. The methodology is defined as the procedure of the qualitative research where the qualitative approach and plan of data collection and analysis are described (Creswell & Poth, 2017). It also aims to describe, evaluate, and justify the use of a particular method. The qualitative approach and the application of the philosophy and principles of Giorgi's (1970) descriptive phenomenology are discussed in this chapter. This chapter examines the philosophical underpinnings that led to the adoption of descriptive phenomenology and the appropriateness of the descriptive phenomenological approach for this qualitative research. In this chapter, the sample description, setting, data description, collection methods, and approach to data analysis are described. The criteria for establishing methodological rigour, trustworthiness, and ethical consideration for the study are also presented in this chapter.

### **Research Design**

A qualitative descriptive phenomenological methodology developed by Giorgi (1970, 1985; 2009) is used to uncover the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey. Phenomenology as a research methodology is a rigorous, critical, systematic, investigative methodology to study human lived experiences (Cilesiz, 2011). This method helps in describing and understanding the meaning of the phenomenon as described by those who have lived the consciousness experience (A. Giorgi, 2012; A. Giorgi & Giorgi, 2008).

Giorgi aimed to create a rigorous scientific phenomenological psychology that was inspired by Husserl's ideas of studying essences of phenomena as they appeared for the person's consciousness (Giorgi, 1985). Giorgi et al. (2017) have indicated that to establish qualified phenomenological qualitative research; the qualitative researcher has to employ three main steps. First, the qualitative researcher must determine the phenomenon that is going to be described. Since phenomenology is concerned with lived experiences, the description of the lived experiences must be attained from the experiencer. Second, the qualitative researcher must assume the attitude of the scientific phenomenological reduction, which is a very distinct feature of the epistemology of descriptive phenomenology. The phenomenological reduction aims for a completely purified human consciousness where the researcher concentrates on the description as a phenomenon. The researcher aims to be fully present to the research participants and their descriptions (A. Giorgi, 2012). In this step, the researcher must put his/her beliefs, theoretical knowledge, and experiences with the phenomenon aside (bracketing) to access pure consciousness. Therefore, the description of the phenomenon comes from a pure consciousness that is free of any empirical realities. Finally, the researcher constructs a generalized structural description of the phenomenon through carefully examining the descriptions and essences of the phenomenon. The phenomenological qualitative researcher seeks the essence of the experience of free imaginative variation by creatively varying the meanings of the experiences from different participant perspectives to distinguish essential features. These essences are considered to represent the nature of the phenomenon being studied and would be more generally to be experienced by people in relation to the phenomenon (Finlay, 2009). The scientific phenomenological attitude is also required in this step.

Giorgi's (2009) phenomenological method allows the researcher to have in-depth one-on-one interviews with participants and to ask one open-ended question, which allows the participants' descriptions to emerge in a natural setting with minimal interference from the researcher (Giorgi, 2009). It also allows the researcher to keep the participants' voices in the research without abstracting their perspectives out through analysis (Broome, 2011). Giorgi (1997; 2008) also indicated that a rigorous phenomenological study should comprehensibly combine a phenomenological philosophical background, phenomenological data collection and analysis-synthesis, and phenomenological descriptions of the experiences as its outcomes.

Giorgi (2012) has pointed out that the descriptive phenomenological method can be applied to any discipline, such as human science and social science, in viewing the phenomenon. This indicates that researchers from any discipline can use Giorgi's descriptive phenomenological method to view lived experiences from their own disciplinary lens. This feature of Giorgi's method help researchers to understand participants' lived experiences in a way that is meaningful for the researcher's profession (Giorgi, 2012). Since I am a master student in the Applied Health Services Research Program, I have used the population health lens to view the participants' language in order to describe the lived experiences. Health services research is concerned with the relationship between the population health needs and the provision, effectiveness, and efficient use of health services (Bowling, 2014). Health services research also aims to provide stakeholders and policymakers with research data that represents how appropriate, practical, cost-effective, efficient, satisfactory, and competent the health services are at the primary and secondary care levels (Bowling,

2014; Lohr & Steinwachs, 2002). Consequently, the description of the lived experiences in this phenomenological research will be meaningful to health policymakers, health services professionals, and healthcare professionals, whose practice is influenced by population health.

### **Research Philosophical Underpinnings**

In this study, I utilize the descriptive phenomenology to study the lived experiences of Middle Eastern immigrant women during their cancer survivorship. Phenomenology is rooted in the philosophical tradition and was first developed by Husserl, who was interested in the question, "what do we know as persons?" (Creswell & Poth, 2017; A. Giorgi, 2009). Phenomenology has been variously described as a research method, a philosophy, an approach, and a movement (Creswell & Poth, 2017; Dowling, 2007). Consequently, phenomenology encompasses a theoretical framework and a method design that is concerned with the deep understanding of the lived experiences of phenomena from the perspective of those who experience them (A. Giorgi, 1985). The philosophical assumptions of phenomenological studies rest on three main distinctive points, which are the lived experiences of persons; these experiences are conscious ones; and the development of the description of the essences of these experiences but not explaining or analyzing them (Creswell & Poth, 2017).

Husserl comprehended that consciousness is primarily a medium between a person and the world (A. Giorgi, 2012). Qualitative researchers can use the phenomenological research method to connect with the participants' consciousness and the participants' world (for example, how they experience the world and how they make meaning of their experiences) (A. Giorgi & Giorgi, 2008). Therefore, descriptive

phenomenologists are interested in discovering and describing persons' experiences as lived through their senses (e.g., hearing, seeing, feeling, remembering, and acting) as well as interactions with their context (Loiselle, Profetto-McGrath, Polit, & Beck, 2011). In other words, descriptive phenomenology is not only concerned with capturing the raw essence of the phenomena and how the phenomena were experienced, but also concerned with the nuances, contextual underpinning, the emotiveness, and the activities that were evoked in consciousness (M. Christensen, Welch, & Barr, 2017).

### **The Relevance of Descriptive Phenomenology for This Study**

The phenomenological research aims to explore the lived experiences with a particular phenomenon to provide the reader with a truthful understanding of the essential, invariant essence of an experience (Creswell & Poth, 2017). Many phenomenological studies have indicated that patients believe that illness is a lived experience that cannot be reduced merely to a number of variables or theories (Agazzi, 2001). Therefore, phenomenology has been progressively applied as a therapy and as rehabilitation research to explore the lived experiences with certain illnesses and the processes of recovery (Finlay, 2009, 2011). The cancer survivorship journey is a stressful process with various outcomes that become significant lived experiences for cancer survivors. Consequently, I choose descriptive phenomenology as the tradition of inquiry to explore the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey.

### **Population Health Model**

Evans et al. (1994) contributed substantially to the development of the population health approach, which was the outcome of the population health program of

the Canadian Institute for Advanced Research in 1989. The purpose of the population health model is to improve the health of populations and to decrease disparities. These populations can be located in geographical regions such as communities or can be any group, such as employees and ethnic groups (Kindig & Stoddart, 2003). Population health is shaped by public health, health promotion, and community health. Population health is concerned with the social determinants of health and the interaction between them because they influence health throughout persons' lives (Government of Canada 2004; Kindig & Stoddart, 2003).

The outcomes of population health are affected by many factors that are connected with very multifaceted networks. The population health approach contributes to the implementation of healthy policies that will improve health outcomes for various populations of persons. It is essential to point out that population health outcomes go beyond improving health status outcomes. In fact, a healthier population reflects more productive contributions to overall society and broader benefit to the society, economy, and environment (Government of Canada 2004). There are eight essential elements for implementing the population health approach within a system: (1) focus on the health of populations; (2) address the determinants of health and their interactions; (3) base decisions on evidence; (4) increase upstream investments; (5) apply multiple strategies; (6) collaborate across sectors and levels; (7) employ mechanism for public involvement; and (8) demonstrate accountability for health outcomes (Government of Canada, 2004).

The population health approach utilizes social determinants of health lens in multi sectors, such as employment, education, social assistance, and environments, to achieve better outcomes. The Canadian Government identified twelve social

determinants of health: income and social status, access to health services, biology and genetic endowment, education and literacy, employment and working conditions, childhood experiences, physical environment, social support and coping skills, healthy behaviours, gender, culture, and race (Government of Canada n.d.; Mikkonen & Raphael, 2010). These determinants are interrelated and are the underlying driving forces for health outcomes because they determine the ability of the population to have healthy lifestyles, healthy environments, and healthy relationships (Raphael, 2009).

As discussed in the literature review (chapter 2), there are so many social determinants of health, such as access to health services, culture, education, income and social status, and social support that have a significant impact on persons, who live with cancer, related to outcomes and survivorship experiences. Therefore, the population health model is the appropriate discipline for an applied health services researcher to understand the description of the experiences of Middle Eastern immigrant women during their cancer survivorship journey. The population health model also helped me to uncover the effects of various social determinants of health on the cancer survivorship outcomes for this group of women in Canada.

### **Research Sample**

The sample for this study is a purposeful, snowballing sample of Middle Eastern immigrant women cancer survivors in Canada. This group of women are the only legitimate informants who have lived the phenomenon-the reality and were able to describe what the experience was like for them in responding to the research question of this study. Participants were eligible to participate in this study if they met the following inclusion criteria:

1. Middle Eastern immigrant women
2. Diagnosed with cancer within the last five years,
3. Aged 20-65 years at the time of the interview,
4. Reside in Canada, and
5. Able to speak English or Arabic.

However, the perspectives of other immigrant women (e.g., South Asian and African) and women who could not speak English or Arabic were not obtained. The perspective of other cancer survivors, such as family members and healthcare providers who interact with this group of women, was not obtained either.

I chose the age category 20-65 years at the time of the interview because it was consistent with Canadian cancer statistics reports which indicated that women between the age of 20 and 59 years are at a higher risk of developing cancer than males (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017, 2019). I expanded the age range to 65 to help enhance the probability of finding more participants. The period of within five years of cancer diagnosis was chosen to allow the women to return to their everyday lives, prevent any unnecessary stress, and minimize intrusion. Participants' ability to speak English or Arabic was essential in this project, which enabled participants to express their feelings and experiences in their preferred language. The literature indicated that there is a connection between language and how individuals express their emotions, feelings, and how they experience these emotions (Besemeres, 2004). Furthermore, Costa (2010) has also declared that bilingual individuals prefer to express their feelings and experiences in their mother-tongue language.

Giorgi has stated that a research study could be composed of one participant (A. Giorgi, 2009), while Creswell and Poth (2016) stated that phenomenological studies could include 5 to 25 participants; Russell and Aquino-Russell (2011) recommended using an average of eight participants in descriptive phenomenological studies. In fact, Russell and Aquino-Russell (2011) had 15 participants in their research, which resulted in an enormous amount of data. Therefore, they concluded that an average of up to 8 participants is an adequate sample size for descriptive phenomenological studies.

In this study, three women were interested in participating in the study. These women lived in urban cities across Canada (the names of the cities are not included to protect the participants' anonymity). The women were diagnosed with breast cancer within the last five years. My aim was to recruit up to eight women for this study to elucidate the richness of the individual experiences. However, recruiting immigrant women in this study was challenging. In fact, this difficulty concurred with previous studies, which indicated that recruiting immigrant women and women from ethnic minorities is very complicated because of the same barriers for health disparities amongst immigrant women (such as cultural beliefs and language) (Renert, Russell-Mayhew, & Arthur, 2013).

At the beginning of this project, I aimed to recruit participants from New Brunswick (NB), but the number of Middle Eastern immigrant women is less than 5% of the total immigrant women population in NB. Consequently, the probability of attracting cancer survivors in NB was very small. With low recruitment rates amongst immigrant women in health research, finding participants for this project in NB was very

challenging. Therefore, I decided to change the research recruiting area to include any Middle Eastern immigrant women from across Canada.

### **Recruitment**

The recruitment for this study was purposeful and included snowballing sampling. In phenomenological studies, purposeful sampling is a common recruitment strategy because the researchers seek participants who have experienced the same phenomenon (Creswell & Poth, 2017). I used various approaches to recruit participants for this study. Recruitment of participants began following ethical approval was obtained from two Ethical Review Committees at the University of New Brunswick and the Research Ethics Board at Horizon Health Network-NB Health Authority.

I attempted to recruit participants through oncology clinics, various multicultural associations, and local cancer support groups and organizations (e.g., Canadian Cancer Society and NB Breast Cancer Network) in Atlantic Canada. I also tried to recruit participants by placing advertisements in public locations where Middle Eastern immigrant women and cancer survivors might frequent (e.g., mosque, library, etc.), through public service announcements, and social media (e.g., Facebook). My efforts in recruiting participants are detailed in Appendix G.

I contacted local cancer support groups and multicultural association centres (Appendix A) to obtain the permission to advertise on their bulletin boards (Research Advertisement; Appendix B) and social media (Research Poster; Appendix C) for participant recruitment. Once the permission from these institutions and organizations was attained, I placed the research advertisement (Appendix B) and poster (Appendix C). All recruitment posters and other advertisements for the study contained my phone

number and e-mail address for potential participants to contact me if they were interested in finding out more about the project. I am a Middle Eastern immigrant, and I can communicate in both English and Arabic languages proficiently. Therefore, I translated the research advertisements (Appendix B), poster (Appendix C), and information sheet (Appendix D) to make sure that they were available in both languages English and Arabic.

Furthermore, I contacted the nurse managers of the oncology clinics at Moncton, Saint John, and Fredericton hospitals to place my research advertisement and posters at the oncology clinics at these three hospitals. The nurse manager at the Moncton hospital requested to provide the research poster (Appendix C) in French to follow the Horizon Health Network's advisement regulations. Therefore, I translated the content of the research advertisement (Appendix B) and the research poster (Appendix C) into French and included them with my research package to Horizon Health Network. The nurse manager of the oncology clinic at the Moncton hospital also forwarded my email and research poster (Appendix C) to all oncology medical physicians across NB to help me recruit participants for this project.

I joined several social media support groups to reach out to the highest number of Middle Eastern immigrant women in Canada. Facebook support groups for Muslim women, Arab women, and Middle Eastern communities living in Canada helped me to reach out to two participants. WhatsApp support group for refugee women in New Brunswick helped to reach out to one participant. Social media such as Facebook and WhatsApp were the best method to reach out to this group of women. Potential participants, who contacted me, were offered an information sheet (Appendix D),

providing a brief explanation of the nature of the research study in their preferred language. Then, I arranged for the initial time/place of meeting with participants who would be interested in taking part in this qualitative study. The entire time for recruitment was six months, therefore, in light of the challenges in recruiting for my thesis process, my committee and I decided that 3 participants were a good number to go with for the analysis.

### **Data Collection**

I collected data from two unstructured interviews, and one written description by email, as per participants' choosing, as well as demographic data sheets from each participant (see appendix E). I also journaled my reflections during the whole research process.

### **Interviews**

In-depth one-on-one interviews are the most common data collection method in phenomenological studies (Creswell & Poth, 2017; A. Giorgi, 1997; Guerrero-Castañeda, Menezes, & Ojeda-Vargas, 2017). Giorgi's phenomenological method allows the researcher to have an in-depth one-one interview with the participants and to ask one open-ended question to let the participants' descriptions emerge in a natural setting with minimal interference from the researcher (A. Giorgi, 2009). In this study, the participants were asked to respond to the following open-ended statement: "*As a Middle Eastern immigrant woman in Canada, please describe your lived experiences during your cancer survivorship journey.*" Since this interview was an unstructured and in-depth interview, it allowed prolonging fieldwork (Jamshed, 2014). Further, whenever the participant started to generalize about the experience, questions were asked, such as:

*“can you tell more about---?”* and *“What was it like?”*. These questions allowed the participants to express their experiences in their own ways and at their own pace. Therefore, the length of the interview ended once the participant felt that she told me everything that she wanted me to know.

In this study, unstructured, in-depth interviews were conducted with two participants at a location and time that was most convenient for each participant. The participant, who lived in NB at the time of the interview, preferred in-person interview at her home. A phone interview was conducted with the other participant who was living in BC at the time of the interview. Interviews were conducted between December 2018 and May 2019. The length of the interviews was between 45-65 minutes. Follow-up interviews with participants for further clarification and understanding of their experiences were not required.

Since I am a Middle Eastern immigrant, I can communicate in both English and Arabic languages. Therefore, each interview was conducted in the participant’s preferred language. The participants preferred to conduct the interviews in Arabic as it was easier for them to express their feelings and experiences in Arabic rather than in English. The interviews were recorded on a digital recorder. Following my time with them, I transcribed and translated the interviews.

### **Email**

With improving technology and growing various media communication methods, researchers try to explore using various technologies in qualitative research (Branthwaite & Patterson, 2011). Email as a data collection method has been previously used by various researchers (Bowden & Galindo-Gonzalez, 2015; Gordon, 2009). One

participant, who lived in Ontario at the time of the interview, preferred to write down the description of her lived experience and send it to me via email. In accordance with Giorgi's (1985) method of data collection and analysis, this participant was requested by email to respond to one integratory statement "*as a middle eastern immigrant woman in Canada, please describe your lived experiences during your cancer survivorship journey.*"

The participant had the freedom to write as much information about her experiences as she wished. I gave the participant a period of up to one month to send me her description. It has been declared previously that one-month time frame is sufficient when email as a data collection method is used (Aquino-Russell, 2003; Gordon, 2009). After about three weeks, she sent her experiences to me by email in a word document format. When I requested further clarification and understanding of her experiences, the participant did not reply to my request. Non-response for clarification was experienced by Aquino-Russell (2003) as well, indicating that the participant wrote what it was she wished to share, and that was it.

### **Demographic Data Sheet**

After the interviews, participants filled out a demographic data sheet (Appendix E) that required less than five minutes to complete. The participant who emailed in her response also filled out this document. The demographic data sheet collected information about the participants, such as age, time living in Canada, and cancer history. I shaped this form for this study with specific elements related to the population health model in order to assist me in describing the context of the participants.

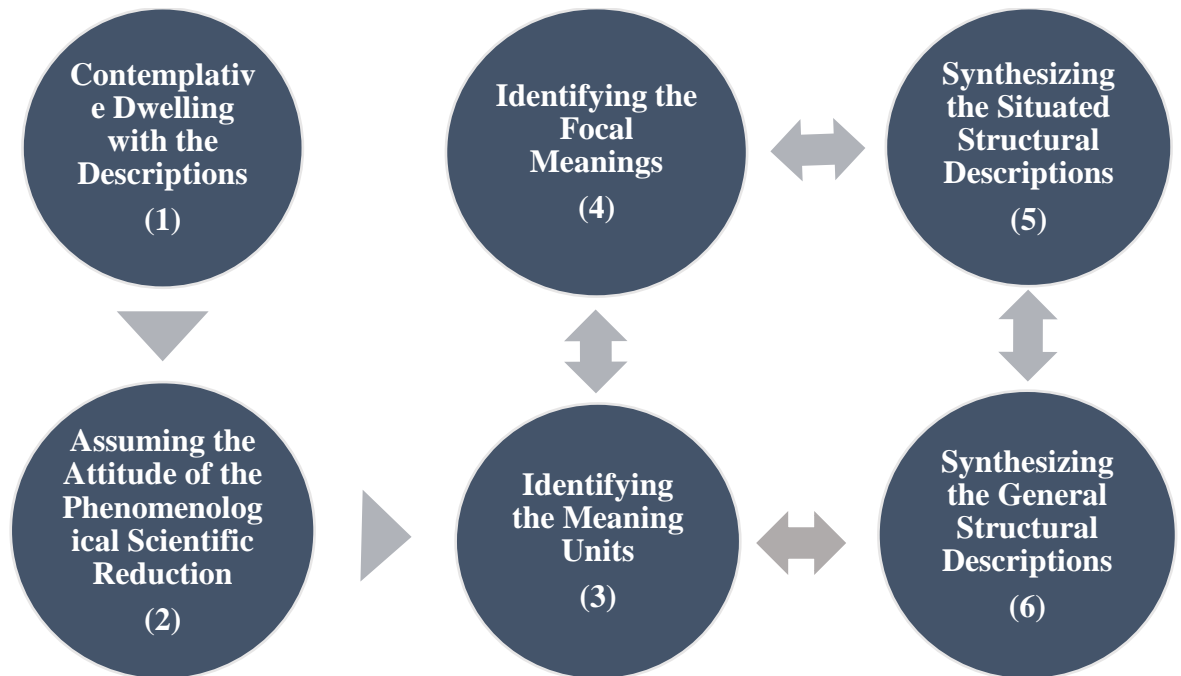
## **My Reflections and Notes**

The last source of data was notes of my reflections during the whole research process. I recorded all research patterns, changes, work progress while conducting the research project. I documented subsequent notes after each interview. I also recorded my thoughts and reminders during the research process. Regular meetings were held with my supervisor to discuss the progress of my research, data analysis-synthesis, and theoretical issues.

## **Data Analysis**

Verbatim transcription of each interview was completed within one week from the date of the interview. Guerrero-Castañeda et al. (2017) recommended that in phenomenological studies, it is best to avoid carrying out transcription on the same day as the interview, but to leave some-time between collection and transcription. This, they wrote, helps the researcher to recall the original statement without becoming overloaded. The interviews that were conducted in Arabic were translated into English. Once the interviews were transcribed and the text became the description to be analyzed, data analysis-synthesis was conducted using Giorgi's method to analyze-synthesize descriptive phenomenological studies (Figure 1) (Giorgi, 1970, 1985, 1992, 1997, 2012; Giorgi et al., 2017) . The procedure of each step and its purpose are described below.

*Figure 1: Giorgi's descriptive phenomenological method of synthesizing-analyzing data descriptions.*



**Step 1: Contemplative Dwelling with the Descriptions**

The participants' transcripts were read freely and openly by me many times to gain an overall sense of the descriptions of the whole statements and try to understand the participant's language. This was completed without any critical reflection on the experience.

**Step 2: Assuming the Attitude of the Phenomenological Scientific Reduction**

I assumed the attitude of the phenomenological scientific reduction. In this step, I assumed that the elements within the participant's transcript were the phenomenon that presents itself to the consciousness of the participant. They were incessantly understood to be realities to the consciousness of the participant. Giorgi et al. (2017) stated that the assumption of this attitude creates the phenomenological scientific (psychological) perception. It is vital to point out that I believe that I bracketed my proposition, culture, knowledge, and experiences with the phenomenon in order to be present to the data without judging its validity or existence.

### **Step 3: Identifying the Meaning Units**

Phenomenological transcripts are known to be very long. Therefore, it is essential in phenomenological studies to break down the long description into parts in order to facilitate data analysis. In this step, I carefully read the participant's transcript, and when I experienced a transition in the meaning from the previous statement, I made a mark in the description. This process is called constituting parts, in which each part represents a *meaning unit* that is arbitrary and does not carry theoretical weight. Therefore, meaning units are passages of text expressing the meaning in the participant's own words. It is important to note that, in phenomenological research, the meaning units are written in the participants' own words.

### **Step 4: Identifying the Focal Meanings**

Once the meaning units were identified, they were transformed into focal meanings. I re-expressed the meaning units as focal meanings while remaining faithful to the meaning expressed by the participant. In this step, the participants' language (*meaning units*) were transformed into scientific expressions (that being the researcher's / disciplinary language, which was the population health perspective) with an emphasis on the phenomenon being studied. In other words, the population health values of what the participant said were made clear to the phenomenon being studied. Giorgi (2012) described this step as the heart of the phenomenological method because it is not only an expression of the meanings directly concerning the phenomenon being investigated, but also generalizes the meaning so that the integration with other descriptions, which may be very different, becomes more practicable. This step of creating focal meanings also helps the researcher to remain in the phenomenological attitude.

### **Step 5: Synthesizing the Situated Structural Descriptions**

The focal meanings were transformed into a situated structural description for each participant's specific situation/context. The situated structural descriptions grasp the meaning from each participant's perspective. This step brings the population health lens to the forefront. This step of transforming focal meanings into situated structural descriptions requires the researcher to perform the imaginative variation by changing qualities of the subject being analyzed to decide which qualities are required and which are accidental (present but not essential) (A. Giorgi & Giorgi, 2008). Performing imaginative variation helps the researcher to determine the essence of the phenomenological structure of the lived experience. Since the researcher is still in the phenomenological attitude, the situated structural descriptions only describe how the phenomenon was experienced and understood by the individual participants, from their unique points of view without explaining "why."

### **Step 6: Synthesizing the General Structural Descriptions**

The general structural descriptions of the lived experiences of the research participants were synthesized from the three situated structural descriptions. The general structural description includes essences that were created from all of the participants. The specifics were left out, leaving a generalized perspective. Therefore, the general structural description is more general than specific and describes the lived experiences (or meaning) of Middle Eastern immigrant women's cancer survivorship journey as viewed through a population health lens.

## **Trustworthiness**

There are four different terms to describe operational techniques that facilitate the trustworthiness of qualitative research: credibility, dependability, confirmability, and transferability (Creswell & Poth, 2017; Guba & Lincoln, 1994; Loiselle et al., 2011). Therefore, in this study, I ensured that the descriptions of data collection, data analysis-synthesis, and the findings were rigorous and trustworthy.

### **Credibility**

Credibility represents the confidence in the truth of the data and their interpretations (Lincoln, Lynham, & Guba, 2011; Loiselle et al., 2011). The credibility of the findings of this research project was increased through various actions. First, lengthy engagement with participants by having in-depth one-on-one interviews with each of two participants. This activity also increased the trust between the participants and me. Second, peer debriefing by consulting and meeting with my supervisor to evaluate and explore various aspects of the analysis. This action exposed me to various questions and recommendations from my supervisory committee, who are experienced in phenomenology, qualitative research, and cancer survivorship. Third, in qualitative research, reflexivity among field notes and journaling (researcher credibility) is critical because the researcher is the data collecting and analysis instrument. Therefore, I have made sure that the data collecting and analysis procedures and any other notes are documented and presented in my thesis. Finally, presenting the participants' words in the discussion of the findings within the last chapter of this thesis to demonstrate how my analysis-synthesis comes full circle to the participants' meaning of the experience.

## **Dependability**

Dependability is defined as the consistency of qualitative data over time and conditions (Guba & Lincoln, 1994; Lincoln et al., 2011). Dependability can be achieved immediately if the researcher demonstrates the credibility of the findings (Loiselle et al., 2011; Speziale, Streubert, & Carpenter, 2011). I ensured dependability with the data descriptions that were collected and through the analysis-synthesis process by journaling during the whole research process, describing the changes that occurred, and how these changes affected the way that the research was approached.

## **Confirmability**

Confirmability represents the objectivity and neutrality of the data (Loiselle et al., 2011). Confirmability was enhanced through various actions. First, bracketing, which means that I held my knowledge, experiences, and beliefs about the phenomenon under study in abeyance while performing the analysis-synthesis of the descriptions. Second, journaling and documenting in detail the entire research process, such as data description collection and analysis-synthesis methods. Third, inquiry audits were used to establish confirmability and dependability of the data. An inquiry audit was done by creating an audit trail including all the research documents such as interviews transcripts and reflective notes, which would allow for an independent auditor to come to conclusions about the data descriptions (Loiselle et al., 2011). Once descriptions were transcribed, they were passed to my supervisory committee to audit the trustworthiness of the data descriptions.

## **Transferability**

Transferability refers to the capability in which the findings from the data descriptions could be transferred to other settings (Loiselle et al., 2011). This is, to some extent, related to the research method and research design rather than the trustworthiness of the data per se. Therefore, I determined that the general structural descriptions (data) do indeed have meaning to others in similar settings by providing sufficient descriptions (thick descriptions) here within my master's thesis and in future publications.

## **Timelines**

I defended my research proposal in October 2018. Then, ethical approval from the Research Ethics Board (REB) at the University of New Brunswick (UNB) was obtained by the end of November 2018. In December 2018, I began recruiting participants. Data were collected from participants between December 2018 and May 2019. Data analysis-synthesis was carried out one week after each interview.

## **Ethical Considerations**

This project was ethically approved by the Ethical Review Committee in the Faculty of Nursing (which is the faculty that my two supervisors hail from), as well as the main REB at UNB. It is on file as REB 2018-151. In February 2019, I requested modification on my ethics application at UNB to expand my research recruitment from oncology clinics in NB. This process required ethical approval from Horizon Health Network (HHN) in NB. By the end of March 2019, this project was ethically approved by the REB at HHN. It is on file as HHN REB 2019-2725. In April 2019, I requested a minor modification on my research ethics file at the UNB REB, whereby I requested to expand my research to site across Canada.

Based on the Tri-Council Policy Statement (2014), the researcher must respect human dignity, which is expressed through the core principles (respect of persons, concern for welfare, and justice) of the Tri-Council Policy Statement. Applying these ethical principles will ensure the balance between the potential benefits of scientific research and the protection of participants from research-related harm. To ensure that this research was following the Tri-Council Policy Statement, I considered the following ethical issues:

### **Informed Consent**

At the initial preliminary meeting (in person or via phone for women who lived across Canada) (i.e., before the formal interview) to build trust with the potential participants, I introduced myself and told them about my supervisor. At this time, the inclusion criteria were verified to ensure that the participants met them. The participants were given a verbal explanation of the purpose and process of the study and an opportunity to discuss the content of the study information sheet (Appendix D) in their preferred language. Prior to the interview, the consent form was explained to the participants (Appendix F), which was also available in both the English and Arabic languages.

The potential participant's privacy and confidentiality issues were discussed with the participants to allow them to play a collaborative role in the decision-making process regarding their ongoing participation (Canadian Institute of Health Research, 2005). I communicated research information to prospective participants in plain language (Grade 8 or less level) so that they could easily understand it. I also informed them that their participation was voluntary and they would not receive any honoraria, and they had the

freedom to withdraw from the study at any time without any consequences. I ensured that participants are aware of any potential benefits and risks associated with the study. I answered all of their questions. I reminded them that it was acceptable to refuse to answer any question if they were not comfortable in doing and that they did not have to give a rationale for refusing to answer a question. I obtained specific permission to record the interviews digitally and informed the participants how their descriptions would be disseminated and what would be used for (Appendix F).

Once the participants agreed to become involved in the research, their signatures on the consent form to participate in the study were obtained. One copy of the signed consent form was given to each participant. For the participants who lived in BC and ON, they received the consent form by email to sign and then send it back to me prior to the interview or their sending descriptions by email. Following this, I arranged a schedule for the interview according to my and the participant's schedules. The participants were given the choice of location and privacy arrangements for the interview. The participant, who chose to send her description by email, was given a month period to send her descriptions.

### **Benefits**

The data descriptions for this research were collected through unstructured one-on-one interviews with two participants at locations that were most convenient for each participant. The results of this research may not have a direct benefit to the participants. However, this research data collection method may have the potential to provide a therapeutic benefit for the participants because in-depth one-on-one research interviews can have a therapeutic effect on the participants (Finlay, 2011; Morecroft, Cantrill, &

Tully, 2010). These interviews may also help cancer survivors to develop a more meaningful appreciation of their survivorship journey. As well, the participant who wrote of her experiences had the opportunity to share what it was that she wanted to share. It has been suggested that putting thoughts on paper is also a helpful/beneficial way to deal with one's life situations (Crocker, Bennell, & Book, 2017). The results of this study will provide benefits for other female immigrant cancer patients and increase public awareness of the lived experience of cancer amongst immigrant women. Other female immigrant cancer patients may have an increased understanding of what the expected challenges are during the cancer survivorship journey and how to face these challenges from reading the results of this study.

The results will also be beneficial for healthcare providers and other health service providers who interact with Middle Eastern immigrant cancer patients to better support and deliver interventions and patient-oriented care that are most meaningful to this group of cancer patients. This study is foundational, and it can be used as a first step in the development of a research program where further action and interventional research can be built. These programs will give practical guidance to health care providers and policymakers to reform or promote cultural humility within culturally competent health services for immigrant cancer patients.

### **Risks**

In this research, the risk probability was expected to be minimal risk, which is defined as "the probability and magnitude of possible harm implied by participation in the research is no greater than those encountered by participants in those aspects of their everyday life" (Tri-Council Policy Statement, 2014, p. 23). For example, participants

could have become emotional or distressed while they were describing their experiences as they remembered it and how they interacted with the contexts. To minimize this risk, I took the following measures:

- (1) I was trained in interviewing and listening skills by my supervisor,
- (2) One participant became emotional during the interview. At that time, I listened and allowed time for her to be emotional, without trying to change her feelings, when she settled, I gave her the option of stopping the interview entirely, but she indicated that she was ready to proceed and that her emotions were released with someone genuinely listening to her story,
- (3) I gave each participant contact information for cancer support groups and volunteer support groups in order to provide other opportunities for the participants to gain further social support or directions should they so wish,
- (4) I called participants within 48-hours after interviewing to check up and see how they were feeling. The two women, whom I interviewed, were happy to hear from me and thanked me for listening to their stories. The one participant who sent in her description via email did not respond to my second email, so I can only assume that she wrote what she wished me to know.

### **Protection of Human Rights**

A range of steps was conducted to ensure the protection of human rights for the participants of this study. I worked closely with the Research Ethics Board at the University of New Brunswick. I am a responsible researcher and treated all participants with respect and equitability. Once ethical approval was received from Research Ethics

Boards at the University of New Brunswick, participants were sought in ways outlined earlier in the recruitment section. Before the interview with each participant, a complete description of the study was shared, and a signed consent form was obtained from each participant.

### **Confidentiality and Anonymity**

In qualitative research, sensitivity to participants' privacy is required because it involves an in-depth exploration of highly personal areas (Tri-Council Policy Statement, 2014). Therefore, participants' privacy was assured by providing participants with information about the study and the consent form, which explicates that any information they provided would not be publicly reported or made accessible to parties that were not involved in the research. Measures were also taken to ensure the confidentiality and anonymity of the participants.

1. I ensured privacy by conducting the interviews in a private, safe, comfortable place chosen by the participant.
2. I protected the participants' identities. In this case, the confidentiality of information was ensured by allowing the participants to choose their own pseudonym that will be used in all papers and electronic documents.
3. I assured the participants that the research results would be published in peer-reviewed journals and conferences. These publications will consist of research results, conclusions, and recommendations; however, publications will not contain personal or identifying information. Publishing articles in journals, media, or conferences will strictly follow ethical publishing instructions.

4. All data that included participants' identities (hard copies, soft copies, and digital audio files) were secured in a locked filing cabinet in my personal home office and were accessible only by me.
5. The computerized research information that did not include participants' identities was stored in specially created research, password-protected files that were accessible only by me.
6. If a secondary analysis would be possible, participants were informed that they would be re-contacted, and consent would be obtained. Permission to re-contact people should their data be used in a future study was part of the consent process for this study and is detailed on the consent form (Appendix F).
7. All the research documents (hard copies, soft copies, and records) will be kept for seven years. After seven years, they will be securely destroyed through a professional, confidential shredding service at UNB.

### **Chapter Summary**

This phenomenological study was designed to gain an understanding of what is it like for Middle Eastern immigrant women to be cancer survivors in Canada. This study included Middle Eastern immigrant women who were between 20 and 65 years of age, diagnosed with cancer within the last five years, and who resided in Canada. Details of recruitment efforts, procedures, and the challenges in recruiting immigrant women for the study were described. In this study, a descriptive phenomenological approach developed by Giorgi (2009) was used to conduct this qualitative research. Data was collected through unstructured one-on-one interviews (in person and via phone) and via email, demographic information, and my reflection journal. Measures were taken to

protect participants' human rights, confidentiality and anonymity, and to ensure the trustworthiness of the data collection, descriptions, and findings.

## **Chapter 4: The Results**

### **Introduction**

This chapter presents the findings from this descriptive phenomenological study obtained through in-depth interviews and a written description. The chapter begins with a description of the three women who participated in this study. The general structural descriptions, which represent the overall essences of the phenomenon follow. The theoretical perspective from a population health lens was used as a lens during data analysis-synthesis, which revealed the essence of the lived experience of Middle Eastern immigrant women during their cancer survivorship journey in Canada.

### **Description of Participants**

A description of the life world of Middle Eastern immigrant women during their cancer survivorship journey was sought. In this project, I recruited women from across Canada, which assisted in attaining different perspectives on the lived experiences from different regions. Due to limited resources in this study, I found internet-based recruitment strategies (social media, please see Appendix G) were the most successful methods of reaching out to this group of women. These recruitment strategies yielded three participants who met the inclusion criteria and agreed to participate in this study.

### **Participants' Demographic Data**

The three women who participated in this study averaged 44 years in age, with an age range of 41 to 47 years at the time of the interview (Table 1). The three participants lived in urban cities across Canada. Two of them have been living in Canada for less than five years, while one participant has been living in Canada for a period between 5 and 10 years. One participant was employed, and two participants were not

employed. Education levels between the three participants differed in which one participant had a university degree, one participant had a college education, and one participant had no high school education. One participant mentioned in her description that she was a graduate student. Table 1 presents a summary of the participants' demographics.

**Table 1: participants Demographics (n =3)**

<b>Characteristics</b>	<b>Number</b>
Age Range	41-47
Time lived in Canada	
Less than 5 years	2
Between 5 and 10 years	1
Between 10 and 20 years	0
More than 20 years	0
Education level	
No high school Diploma	1
High school Diploma	0
College	1
Bachelor's degree	0
Master's Degree	1
PhD	0
Employment	
Yes	1
No	2
Living area	
Urban	3
Rural	0
Have children	
Yes	2
No	1
Time diagnosed with Cancer	
	1 (3 years ago)
	2 (4 years ago)
Type of cancer	3 (breast cancer)
Cancer history in the family	
Yes	3
No	0

Furthermore, participants' demographic data (see *Table 1*) shows that these women were diagnosed with breast cancer between the ages of 37 to 43, with an average age at diagnoses of 40 years. The women were diagnosed with breast cancer on average 3.7 years ago. They have a history of cancer in their families. As shown in *Table 2*, all underwent similar cancer treatment, including mastectomy, chemotherapy, radiotherapy, and hormonal therapy (except one participant did not undergo hormonal therapy). During the interviews, the participants described the locations of their treatment, in which two participants were treated at hospitals, and one woman was treated at a cancer care center.

**Table 2: Characteristics of the Middle Eastern immigrant women participants.**

<b>Pseudonym</b>	<b>Age</b>	<b>Cancer treatment</b>	<b>Relationship status</b>	<b>Immigration category</b>
Marwa	47	Mastectomy Chemotherapy Radiotherapy	Married	Refugee category
Nora	41	Chemotherapy Mastectomy Hormonotherapy Radiotherapy	Divorced	Economic category
Eman	44	Chemotherapy Mastectomy Radiotherapy Hormonotherapy	Married	Family category

Table 2 presents the characteristics of each participant. Participants' characteristics were pulled from descriptive data to help better understand the lived experiences of the three women who took part in this study. Each participant chose a pseudonym to maintain anonymity and confidentiality. It can be noted that two participants were married, and one participant was divorced and a single mother.

Further, the three women are from three different Canadian immigration categories, those being refugee, economic, and family category.

### **Main Findings of the Qualitative Study**

The general structural description (the essences or meaning) of the Middle Eastern immigrant women's experiences during their cancer survivorship journey are presented and described in this section. The essences of their lived experiences address the research question using the population health theory as a lens to analyze-synthesize the phenomenon under study. In this study, the meaning of these women's lived experiences were affected and shaped by the social determinants of health that are shown in Figure 2. In this framework (Figure 2), the social determinants of health are depicted as being in interrelationship with each other, and social support is the main social determinant of health that impacts their lived experiences and is connected to every essence. This framework also suggests that the essences of the lived experiences of Middle Eastern are interrelationships with each other. The meaning of the experience of Middle Eastern women's cancer survivorship journey involves ten essences:

- Their perspectives on cancer risk factors were considered as being the cause of their cancer;
- Their cancer survivorship journey was fear-inducing and anxiety-provoking which was persistent throughout the entire journey;
- Their quality care was accompanied by delays and unmet needs;
- Provided knowledge and information were helpful for them;
- Having knowledge of the English language was equal to empowerment for each of them;

- Social support was the key to persistence for participants;
- They used various coping mechanisms to harmonize their life;
- They faced cultural stigmatization of mental health issues;
- Their survivorship journey was combined with changes in their physical and social environments; and
- As women, their self-image was impacted greatly.

*Figure 2:* A framework represents how social determinants of health were shaping the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey.



## **Their Perspectives on Cancer Risk Factors were Considered as being the Cause of their Cancer**

The meaning of living the cancer survivorship journey for the immigrant women of this research involved perceptions that cancer was caused by risk factors: (1) biological factors, (2) experiencing psychological distress, (3) experiencing challenging life events, (4) having low socioeconomic status, and (5) and lack of social support due to living distantly from supportive and loving family. The following are participants' words (meaning units) which depict the essence.

Eman (44 years-old):

*I have a family history of cancer. My aunt, my mother's cousin, and my aunt from my dad's side all had breast cancer. So, we have it from both sides of my family, my dad's side, and my mom's side. So, I started doing mammogram four years before the diagnosis. I did it every year. You know... (1)*

Marwa (47 years-old):

*I think that the reasons behind developing cancer are from being sad all the time, living a very stressful life, and the war. I have been through so many hard things in my life, such as the war, being poor, living far from my loved family, and moving a lot to find a safe place. It is all a stressful life. (2, 3, 4, 5)*

\*\*\*\*\*

*I went to see the same doctor who recommended that I do all the tests. He said: The results show that you have breast cancer, and we must remove your right breast with all the lymph glands that are located under your arm bite. At that moment, I was shocked... I cried. I screamed at my husband and told him that all the stress caused this... My stressful life is the reason. (2)*

Nora (41 years-old):

*Before I was diagnosed with cancer, I had family problems as well as my life was not stable. (2,3)*

## **Their Cancer Survivorship Journey was Fear-Inducing and Anxiety-Provoking which was Persistent Throughout the Entire Journey**

For the women, this journey was extraordinarily fear-inducing and anxiety-provoking because of their cultural beliefs and previous experiences. (1) A cancer diagnosis created fear and sadness because cancer had taken the lives of their family members. (2) Their lifestyle and social environments were dramatically altered with changes in physical and psychological health and wellbeing, body image, and relationships, which caused fear and anxiety for them. (3) Being a cancer survivor increased their distress with fear of cancer metastasis and worry about their children's future. The following are participants' words (meaning units) that depict the essence.

Marwa (47 years-old):

*I lost my dad to blood cancer... So, telling them [her family] that I have cancer was very hard. I was very sad and upset. I started to think that death is coming soon. (1)*

\*\*\*\*\*

*If anything happens to me here in Canada, I feel my children will not have anybody to support them. I do not want to lose my children, and I do not want my children to lose me. (3)*

Nora (41 years-old):

*I started chemotherapy. I had eight chemotherapy sessions, and my life was going to the abyss. In every single chemotherapy session, I was afraid of death because my dad had died after three hours of his first chemotherapy dose. I became weaker; my appearance changed as well as my husband's treatment to me had changed. (1, 2)*

\*\*\*\*\*

*During my treatment period, I was mentally suffering in all aspects of life: Health, social, marital, physical and income status.*

Eman (44 years-old):

*I remember when my doctor asked me to do CT-scan for my bones to see if cancer had spread to all over my body. I was very scared; I cried; I was shaking. They gave medication to make me relax. (2)*

### **Their Quality Care was Accompanied by Delays and Unmet Needs**

In relation to their experiences with health care services, (1) participants received quality care during their cancer survivorship journey from supportive, friendly, and professional healthcare providers. (2) The support services provided much-needed transportation to access health services, yet anxiety and stress-filled delays in acquiring health services were a result of healthcare system policies or poor communication between different healthcare facilities. (3) Participants were challenged in finding childcare services needed during medical appointments, treatment sessions, or visits to the emergency department. The following are participants' words (meaning units) that depict the essence.

Eman (44 years-old):

*My family doctor referred me to another doctor at the [provincial] cancer agency in September. It was the oncologist. In the cancer agency, everyone was amazing there... .. It is an amazing place that has everything for cancer patients. I wish there was a similar center everywhere around the world. (1)*

\*\*\*\*\*

*My husband called the health insurance ....., and it took some time to receive it. Then, I got my health insurance in less than 3 months. They issued the health card for me a few days before my biopsy appointment. That was very considerate, you know. (2)*

\*\*\*\*\*

*The volunteering drivers providing a ride for patients was really mercy. Yeah, it was amazing..... They used to take me from my house to the cancer agency for*

*the chemo and bringing me back home. That was a big relief for me because we did not have a car. It was very helpful and comfortable for me. (2)*

\*\*\*\*\*

*When the results came back, the doctor said that there is something suspicious, and we have to do a biopsy for the right side [right breast] ... .. I expected them to call me after two weeks for the biopsy, but they were late. I called the clinic, but it seemed that the biopsy clinic did not receive any referral from the doctor at the family clinic. I waited for more than 4 weeks. Then I called the family clinic, asking them to send my mammogram report to the biopsy clinic. I was very stressed because, in 4 weeks, cancer would spread. (2)*

Marwa (47 years-old):

*I find doctors and nurses are very friendly to me; I never felt discriminated. (1)*

\*\*\*\*\*

*In the beginning, the multicultural association used to arrange all my appointments with family doctors and specialists. They also used to give me a ride to the clinic because we were newcomers. Sometime my Canadian sponsor would take me to my appointments. The multicultural association would also provide an interpreter for me to facilitate communication with the doctors. After one year in Canada, we got our family car, and we started going to the clinics by ourselves. (2)*

\*\*\*\*\*

*One day, I had pills, then I got an allergic reaction from those pills. I had to go to the emergency department. Unfortunately, I could not find anybody to stay with my children. (3)*

Nora (41 years-old):

*After getting the immigration visa, I learned from the oncologist that I have cancer....I remember that when I landed in Canada and received my official documents, the weather was very cold and we had no accommodation, so we stayed in a hotel. I went to a walk-in clinic, and the surprise was that I had to pay for health care out of my pocket. Then I told her that I am a permanent residence in Canada. Then she said: "it does not matter what your status in Canada; what we care about is the healthcare card." Then, I went to [the local] Hospital, and they told me that they were sorry because they could not offer any services, and the system here is that I should have been transferred from a family*

*doctor. I did not have a family doctor then. So, I decided to go to get a healthcare card, and they refused my request because I was staying in a hotel, and I did not have a permanent address. In addition to that, there are three months waiting time for the [provincial health] card to be issued. (2)*

### **Provided Knowledge and Information were Helpful for Them**

Patients appreciated learning about their diagnosis, treatment, and what to expect. To increase the health literacy of cancer patients and their families about the cancer care process and expectations, (1) cancer care centers and health care professionals provided the participants with information and knowledge about every treatment stage, expected health outcomes, available programs, and how to take care of their health and well-being during this journey. (2) Participants desired more health promotion and prevention programs for immigrant women in their language. (3) They also expressed desires for education programs for their children to teach them about their parents' challenges during the cancer survivorship journey and how to adjust to changes in their social environment. The following are participants' words (meaning units) that depict the essence.

Eman (44 years-old):

*[Provincial] cancer agency was really very helpful. They gave us a tour of the center and information sessions. The effect of chemotherapy on the body. All the resources they have and the volunteers they have. It was mind-blowing. They talked about the volunteering programs they have. (1)*

\*\*\*\*\*

*The informational sessions were very helpful, providing all expected outcomes from physical to psychological changes. My doctor also discussed with me different chemotherapy options like four strong sessions than another mild session, and what the expecting changes and outcomes. (1)*

Marwa (47 years-old):

*I went to the hospital for chemotherapy. In my first appointment with the doctor, before starting chemotherapy, he explained everything to me. .... He told me: "first you need to take care of your mental health and be relaxed and stay away from negative people because they are going to increase your stress levels. .... Second you will be weak, and your appearance will change because you are going to lose your hair.... you will not have an appetite for food... and your physical and psychological health will change". (1)*

Nora (44 years-old):

*I wish if there were health awareness from health care providers for cancer patients. I wish there were more courage for the patients to continue their life normally without overwhelming them with the cancer care process. I wish there were a place for me to enrol my children to learn more about their parent's struggle in such cases. (2, 3)*

### **Having Knowledge of the English Language was Equal to Empowerment for each of Them**

Research participants indicated how critical it was for immigrant women to be able to communicate in the English language in order to help them to (1) access health services, communicate with healthcare providers, understand all the cancer care educational materials, and be part of support groups. (2) They desired to have cancer educational materials in the Arabic language to help those immigrant women who cannot speak English. The following are participants' words (meaning units) that depict the essence.

Eman (44 years-old):

*They also gave me books providing all the required information. They also showed me videos with all expected outcomes and what to do. To be honest, it was very informative. However, everything was in English (books, videos, and other resources). It was fine with me because I already speak English. However, if a woman does not speak English, it will be hard for her to go through all that material and information. They may need someone to help them translate the material. I am not sure if it is available in other languages. As a cancer patient,*

*you feel that you are lost as you do not know what to expect if no one provides you with the right information. For me, it was good because I was able to read and write in English. (1, 2)*

\*\*\*\*\*

*Many booklets and information sessions were in English, and I think they are available in Chinese and Panjabi because there are big Chinese and Indian communities in [the province]. Recently, the Arab speaking community has increased, but there is nothing available in Arabic for this community. You know, if you do not know English, you will not understand all the information sessions (physiotherapist, nutritional information) and communication with doctors, nurses, counselling, and support groups. (1, 2)*

Marwa (47 years-old):

*I am still struggling to learn the English language because I am busy with my children. I have no time to study at home. I do not have anybody to help me. And I hope to improve my English language skills to help improve my communication skills when I go to the hospital. (1, 2)*

### **Social Support is the Key to Persistence for Participants**

As cancer survivors, social support was precious for them during the cancer survivorship journey. The participants in this study received exceptional and sympathetic social support from their health care providers and communities. (1) Some of the participants appreciated the support from close family members who lived with them in Canada, while others struggled with a lack of social support. However, living distant from their beloved families increased their anxiety because physical presence for support was not possible. (2) The social support from family members was perceived differently from the support that was provided by health service providers because their family members would understand their cultural needs. (3) The following are participants' words (meaning units) that depict the essence.

Eman (44 years-old):

*I was angry, very angry most of the time. My husband was very calm and supportive, and he tolerated me and respected my feelings. Between my husband and my mother, I would not make it. They were there for me. (1)*

\*\*\*\*\*

*My mom was a great support for me because my husband used to go to work, and my mom would be with me. Being alone would be so hard. Talking to someone who understands your culture and belief was a relief as well because she understands our culture and responsibilities. Her support was not like councillor. Like we were on the same page understanding each other and know everything about our cultural needs. (2,3)*

Marwa (47 years-old):

*Sometimes, I feel distressed because I live very far from my family [parents and siblings]. Sometimes, I feel distressed because living far from your loved family means no social support. I feel that I want to go back there and be with them. However, I think about my kids, who are everything for me in this life. (2)*

\*\*\*\*\*

*When I go for English classes, all the instructors at the multicultural associations are very supportive. They give me hugs when I go there. I love to cook and share it with them. (1)*

Nora (41 years-old):

*If I decide to forget the psychological pressures..., I cannot forget the kindness of the medical staff. The nurses were compassionate and kind, as well as the doctors. (1)*

\*\*\*\*\*

*He did not really support me psychologically....I used to go to the hospital on my own, where my husband did not like to accompany me, and how much I wished as one of the newcomers to have company at that time. (2)*

\*\*\*\*\*

*I then decided to invite my mother to stay with me. How happy I was! The Canadian Embassy and the medical staff were very helpful in issuing a visa visit despite its difficulties in the Middle East. The tumour was removed, and my mother was always reunited with me. (1,2)*

### **They Used Various Coping Mechanisms to Harmonize their Life**

The participants used several coping mechanisms to mitigate their distress levels and to maintain strength during their cancer survivorship journey. (1) During the treatment stage, they practiced religious prayers and turned to God to maintain control of their feelings. (2) They also tried to hide their physical and psychological features associated with the treatment stage because they were worried about their family members' feelings. (3) They used venting mechanisms by expressing and sharing all their feelings and life challenges with others. (4) During the follow-up care stage, they attempted to regain control of their lifestyle by making their life busy and full of activities such as pursuing education, learning English, reaching out/meeting new people, surrounding themselves with sympathetic people, volunteering, finding employment, and supporting people from their communities. The following are participants' words (meaning units) that depict the essence.

Marwa (47 years-old):

*During Chemotherapy, I lost my hair and my eyebrows. I also got a wig. That really affected my mental health. I tried to hide the symptoms from my children and my husband by covering my head all the time. I did not want them to feel sad. (2)*

\*\*\*\*\*

*Before the surgery, I was very scared, and then I started to read the Quran [Muslim's holy book] and prayed and asked Allah [God] to help me to go through this. (1)*

\*\*\*\*\*

*Sometimes, when I feel distressed, I go to my neighbour. She is my friend. I tell her about everything inside me to release the stress.... Here in Canada, I try to surround myself with positive and good people because they help me to continue being a strong woman and support me. I try to stay away from negative people because they would cause trouble and increase my stress. I also try to forget people who hurt me. I want to continue my life strong for my kids. (3, 4)*

\*\*\*\*\*

*I always say Alhamdulillah [Praise to God]. This is my destiny, and I must accept it. (1)*

Eman (44 years-old):

*Faith and prayers were also great to go through the whole process, especially when I was weak and had no interest in anything.... I had suicidal thoughts, but I could not do it... you know... I am a Muslim, and this action is prohibited in our faith. (1)*

\*\*\*\*\*

*Between the radiation and second operation, I tried to push myself by taking a course...I got a course in immigration counselling... and volunteering. I tried to make myself busy. (4)*

\*\*\*\*\*

*I found a job at the airport. I was very happy at work. I felt that I am back to my normal life. I felt empowered. (4)*

Nora (41 years old):

*During that period, I was trying hard to recover my life and to make another meaning to my life. So, I decided to pursue my studies and meet the requirements of the doctoral program. Alhamdulillah [Thank God], I was accepted. Although it was a period of change and transition from life to life, I felt I was wrong in*

*timing. I had to take a breather from the disease and try other treatments/healing methods such as weight loss, regeneration and self-development. I tried to get myself out of a suffocating psychological pressure into a more complicated and exhausting life - the life of graduate students. The stage was particularly memorable that in the first year I had so many psychological problems and stressful and difficult issues related to divorce, custody, etc.. (1, 4)*

### **They Faced Cultural Stigmatization of Mental Health Issues**

The participants declared that the cancer survivorship journey was an arduous journey for them and their family members, which required psychotherapy because they experienced stress, depression, and anxiety. (1) Those women who accessed psychotherapy during their cancer survivorship journey found it very obliging and beneficial. (2) On the other hand, there were others and their family members who did not access these services because of the preconceived belief that psychotherapy is a disgrace and is stigmatized in their culture. The following are participants' words (meaning units) that depict the essence.

Eman (44 years-old):

*You know there were things I could not say to my mom and my husband. However, when I went to the counselling session, I would say everything inside me. After every session, I felt very light and better. In our culture, many people refuse to go to a psychiatrist or counsellor because it is a stigma in our culture. They would say I am not crazy to go there. I found it very helpful to see a counsellor. It helps allot as part of the cancer care plan. (1, 2)*

Nora (41 years-old):

*I was also surprised when the oncologist suggested that I be referred to a psychiatrist, myself and my husband, but my husband refused categorically. (1, 2)*

Marwa (47 years-old):

*Nowadays, everything makes me mentally tired. I get stressed out very quickly, and I get angry and emotional very quickly. I get mad at my kids, the house, and my husband. I am very sensitive now. I go to the oncology clinic, and the doctor tells me everything looks fine, but I do not see any mental health specialist. My doctor tells me everything is fine. Alhamdulillah [Praise to God] .... (2)*

## **Survivorship Journey is Combined with Changes in their Physical and Social Environments**

The women experienced changes in their social and physical environments during their cancer survivorship journey that affected their health and wellbeing. (1)

They were new immigrants to Canada, which was a novel physical and social environment for them that requires physical and psychological efforts to acculturate. (2)

Their social cohesion and social support network, such as relationships with spouses and making friends, have significantly been affected by the journey. The following are participants' words (meaning units) that depict the essence.

Nora (41 years-old):

*What I remember during my treatment period that I was mentally suffering in all aspects of life: Health, social, marital, and economic status. I could not find a person to help me, and my life system was only a housewife. My husband did not allow me to go out or even to the library. My job was to look after the family only. I felt that my life had not any meaning. My marital life was going from bad to worse. Until I started to experience severe bleeding. Then it turned out to be ovarian cancer..... Then, my husband decided to leave our two daughters and me; the eldest is seven years old. (2)*

Eman (44 years-old):

*Before I moved to Canada, I used to work had my car, travel with my friends. Then I moved to Canada. I found my self without a job, no car, and no friend. It was really hard; everything was new to me. I did not have Arab friends. (1)*

Marwa (47 years old):

*I feel that my relationship with my husband has been affected. Maybe he feels distressed when he sees me with one breast. In addition to that, I am older than him. So, I think that he mentally affected by the whole process. (2)*

### **As Women, Their Self-image was Impacted Greatly**

The women in this research perceived their self-image as self-discipline, active, and amiable. (1) However, changes in their body image and physiological health during the treatment stage impacted their psychological health, self-confidence, and social support network (relationships). (2) During the follow-up care stage, they focussed on improving their body-image and self-image to regain confidence. The following are participants' words (meaning units) that depict the essence.

Marwa (47 years-old):

*I am very good at doing so many things and consider my self a strong woman. I like to keep my self busy with all my housework and my kids..... I am also very nice to people and easy-going person..... My husband is even surprised by how I make friends very quickly, and everybody is supporting me. (2)*

\*\*\*\*\*

*During Chemotherapy, I lost my hair and my eyebrows. I also got a wig. .... I also did not feel comfortable to let my kids and husband see me in this shape. It really affected my mental health, and I was distressed all the time. I felt that I lost part of my body.... Whenever I want to change my clothes, I look in the mirror; I start to cry. It is painful and sad to lose part of your body. (1)*

Nora (41 years-old):

*And then, I moved to the surgery stage [Mastectomy], and it was a difficult step. It was done successfully (Alhamdulillah); [praise to God]. .... The shock was when I came out of the hospital; I noticed my husband's distaste. He did not even accept to see me changing my clothes in front of him. He even told me literally that "the look and signs of your operation disgust and disturb me." (2)*

Eman (44 years old):

*During the treatment stage, I did not have a mode for anything. I used to be a very active and energetic person..... you know during treatment, I did not try to find a job. I did not have the energy to give any commitment during the treatment stage. I was emotionally not stable; I lost all my hair. I used to wear a bandana all the time. I lost my hair after my second chemo session. (1)*

\*\*\*\*\*

*I did not have my period during the chemotherapy treatment stage, and that really embarrassed me a lot....I do not have children...When I was diagnosed with cancer, I was newly married. We were married for one year and a half. (1)*

### **Chapter Summary**

In this chapter, I presented the findings of this qualitative study. A demographic profile and personal characteristics of the Middle Eastern immigrant women were described to act as a background or context for their stories. This was followed by a discussion of the ten essences of the general structural description, which is the meaning of these women's lived experiences during their cancer survivorship journey in Canada. The ten essences of the immigrant women's experiences during their cancer survivorship journey were viewed using the lens of the population health theory and from the perspective of an applied health services researcher (myself). In this qualitative analysis, I identified ten essences: Their perspectives on cancer risk factors were considered as being the cause of their cancer; The fact that their cancer survivorship journey was fear-inducing and anxiety-provoking; Their quality care was accompanied by delays and unmet needs; Provided knowledge and information were helpful for them; Having knowledge of the English language was equal to empowerment for each of them; Social support was the key to persistence for participants; They used various coping mechanisms to harmonize their life; They faced cultural stigmatization of mental health issues; Their survivorship journey was combined with changes in their physical and social environments; and As women, their self-image was impacted greatly. Quotes from

the interviews support the essence of the lived experiences of these women. In the next chapter, I will discuss these findings as they relate to the literature and recommendations for further research in more detail.

## **Chapter 5: Discussion**

### **Introduction**

The purpose of this phenomenological study was to develop a deepened understanding of the lived experience of Middle Eastern Immigrant women during their cancer survivorship journey. In this chapter, I discuss in detail the findings that have emerged from this phenomenological study in relation to the descriptions from the participants and the theoretical perspectives of the population health theory. In addition, I discuss the research finding in relation to the relevant literature in the field of cancer research. The methodological strengths and limitations of the study are described. This chapter also provides implications for health care practice, education, and future research based on the knowledge gained from this group of immigrant women.

### **Discussion**

This descriptive phenomenological study examined the lived experiences of three Middle Eastern immigrant women with breast cancer. To date, this has been the first qualitative study that has examined the meaning of the cancer survivorship journey for Middle Eastern immigrant women in Canada. Previous studies have examined cancer prevalence, mortality, and screening (e.g., breast and cervical) rates among immigrant women in Canada including the Middle Eastern immigrant women (A. K. Lofters et al., 2019; McDonald et al., 2017; Vahabi et al., 2016; Woods, Kliewer, McGrail, & Spinelli, 2019). However, no Canadian studies have been found that focus on the lived experiences of this group of immigrant women during their cancer survivorship journey.

The cancer survivorship journey is challenging and stressful for all cancer survivors and their families. However, for these women, being immigrants made this

journey more complicated and stressful. This study has not only explored the meaning of the cancer survivorship journey of these immigrant women but also sheds light on the importance of the social determinants of health in shaping these women's experiences (see Figure 2). It is important to point out that the interrelated relationship between the meanings of the lived experiences of these women reflects the complex and interrelated relationship between the social determinants of health. The essences of the general structural description (or meaning) of these lived experiences are discussed in detail in this section.

### **Their Perspectives on Cancer Risk Factors were Considered as being the Cause of their Cancer**

The meaning of living the cancer survivorship journey for the immigrant women of this research involved perceptions that cancer was caused by risk factors. This perspective is consistent with results recorded by Holst-Hansson et al. (2018) who found that immigrant women in Sweden tried to understand what caused their illness (cancer diagnosis). Although other studies found that immigrant women and women from ethnic minorities believed that cancer was caused by God's will or God's punishment (K. T. Ashing-Giwa et al., 2004; Holst-Hansson et al., 2018), the participants in this study did not express this perspective. Women in this study perceived different risk factors for their cancer diagnosis based on each woman's experiences and beliefs. Women in this study had a family history of cancer, and they were diagnosed with breast cancer between the ages of 37 to 43, with an average age at diagnoses of 40 years (Table 1). Participant Eman described her family history of breast cancer "*My aunt, my mother's cousin, and my aunt from my dad's side all had breast cancer.*" She believed that

biological factors and family history of cancer could have been the reason for developing breast cancer in her lifetime. For this reason, she started annual mammogram screening at an early age (36 years) as she described, “*So, I started doing mammogram four years before the diagnosis. I did it every year*”. Eman perceived early and annual mammogram screening as a health prevention action to detect cancer at an early stage when it is most treatable.

Previous studies have indicated that genetic predisposition is responsible for up to 10% of breast cancer in Western countries (McPherson, Steel, & Dixon, 2000). Two breast cancer genes, BRCA1 and BRCA2, are the most common identified genes that are responsible for very high-risk families. There are variations in BRCA1 and BRCA2 mutations in the Middle East. For example, the percentage of BRCA1 and BRCA2 mutation in Arab women in Lebanon is 5.6% (El Saghir et al., 2015), while it is 25% in Egypt (Ibrahim, Hafez, & Hashishe, 2010). However, the incidence rate among Arab women in Lebanon, with a family history of breast cancer and the age of  $\leq 40$  years, is 10.8% (El Saghir et al., 2015). Furthermore, one might assume that participant could be carrying a genetic mutation because it has been indicated in previous studies that women who develop breast cancer at an early age (before the age of 65) and have family history of breast cancer are most likely carrying a genetic mutation (McPherson et al., 2000).

Women in this study also perceived experiencing psychological distress as a risk factor for developing breast cancer in their lives. For example, Marwa described the time when she was informed about her breast cancer diagnosis, stating, “*I screamed at my husband and told him that all the stress caused this... My stressful life is the reason.*” Marwa was a Refugee immigrant woman in this study. She described all of the

challenging life events she had experienced in her life, such as experiencing war, losing loved ones, searching for a safe physical environment for her family, and living under low socioeconomic status. It was clear that she experienced the highest number of life challenging events in her life (*see Marwa's quote in chapter 4, on page 66*). Nora described her unbalanced social and physical environments as the reasons for developing cancer, stating, "*Before I was diagnosed with cancer, I had family problems as well as my life was not stable.*" These women believed that their psychological distress was caused by challenging life events, having low socioeconomic status, lack of social support due to living at a distance from supportive and loving family members, in addition to living in an unbalanced social and physical environment.

Although it is not yet well understood how psychological distress plays a role in developing cancer, there are many epidemiological studies demonstrating the connection between psychosocial factors, social support, life events, and breast cancer (Kruk & Aboul-Enein, 2004; Ollonen, Lehtonen, & Eskelinen, 2005; Peled, Carmil, Siboni-Samocho, & Shoham-Vardi, 2008). It has been declared by Peled et al. (2008) that the exposure to a cumulative number (more than one) of challenging and meaningful life events is positively associated with breast cancer among young women. Therefore, women who experience more than one severe to mild traumatic life event are at higher risk of developing cancer in their lifetime.

Furthermore, women in this study perceived that the meaning of being diagnosed with breast cancer was caused by living within a low socioeconomic status. Numerous studies have given tremendous attention to the impact of income and social status on cancer incidence, mortality, and outcomes, which revealed a secure connection between

socioeconomic status and cancer incidence rates, stage at diagnosis, and mortality rates (Kumachev et al., 2016; Merletti et al., 2011; Shields & Wilkins, 2009). Lower socioeconomic status is always associated with higher cancer mortality rates and developed cancer stage at diagnosis (Donnelly et al., 2015; Kumachev et al., 2016; Merletti et al., 2011). However, it is not always associated with higher cancer incidence rates (Coughlin, 2019). There have been different hypotheses to explain the lower cancer outcomes among women with low socioeconomic status. Income and social status have a significant impact on the individual's lifestyle as they shape housing, food security, education, healthy personal behaviour and coping mechanisms, child development, and social life (Evans et al., 1994; Marmot et al., 2008). An unhealthy lifestyle, food, personal behaviour and coping mechanisms are linked to cancer (Dieterich, Stubert, Reimer, Erickson, & Berling, 2014; Monfared et al., 2017) Patients with lower socioeconomic status also experience inadequate access to health services and postponed action in seeking help leading to delayed diagnosis. Different treatments are also offered to patients from different socioeconomic status levels (Kumachev et al., 2016; Merletti et al., 2011; Sprague et al., 2011).

### **Their Cancer Survivorship Journey was Fear-inducing and Anxiety-Provoking which Persistent Throughout the Entire Journey**

For the participants, this journey was extraordinarily fear-inducing and anxiety-provoking because of their cultural beliefs and previous experiences. This is consistent with previous studies that indicated women's cancer survivor experience elicited fears and concerns during their cancer survivorship journey (Obeidat, Dickerson, Homish, Alqaissi, & Lally, 2013; F. Williams & Jeanetta, 2016). Syrowatka et al. (2018)

indicated in their study that anxiety was the most prevalent psychological disorder that female breast cancer survivors experienced during their cancer survivorship journey. For the participants in this study, fear and anxiety started as soon as they were diagnosed with cancer because they perceived the cancer diagnosis as a “*death sentence*.” This view of cancer is associated with their cultural belief that cancer is an incurable illness. It is also associated with their previous experiences because cancer has taken the lives of family members. For example, Nora described her extreme anxiety during her chemotherapy treatment stage as “*In every single chemotherapy session, I was afraid of death because my dad had died after three hours of his first chemotherapy dose.*” Different studies have indicated that immigrants, ethnic minorities, and Middle Eastern women view cancer as a “death sentence” because they have the cultural belief that cancer is a fatal illness (Goldblatt et al., 2013; Holst-Hansson et al., 2018; Obeidat et al., 2013).

For the women in this study, changes in physical and psychological health and body images caused by the chemotherapy treatment and mastectomy made a dramatic change in their lifestyle and social environments. Physiological and psychological health changes, in addition to the thought of recurrence and metastases, were a source of fear and anxiety for these women. Eman shared how going for a CT-Scan test was a source of anxiety for her: “*I was very scared; I cried; I was shaking. They gave medication to make me relax.*” While participant Nora described the treatment stage as being a very hard stage because she perceived her life with no essence, “*I felt that my life had not any meaning.*” Nora perceived her treatment stage as a life challenging event, which made her perceive that living in this world did not have any indispensable

quality. This was due to the dramatic changes in her lifestyle combined with the cancer treatment side effects, lack of social support, and low economic status, which negatively affected her psychological health as shown in her quote below.

*During my treatment period, I was mentally suffering in all aspects of life: Health, social, marital, physical, and income status... I became weaker, and my appearance had changed as well as my husband's treatment to me had changed. He did not really support me psychologically. (Nora)*

These findings are aligned with previous studies, which indicated that breast cancer survivors experience fear related to the treatment stage, body-image loss, sexuality loss, and recurrence (Buki et al., 2008; F. Williams & Jeanetta, 2016). Further, cancer-related stressors combined with external life stressors such as low income and social status, poor access to health services, and challenging life events lead to poor health outcomes among immigrant women (Paek & Lim, 2016).

Furthermore, being a cancer survivor and thoughts of death increased the participants' fear of not being able to be in the lives of their children, to take care of them, and to support them. Marwa expressed this feeling of worry and concern about her children's future as *"If anything happens to me here in Canada, I feel my children will not have anybody to support them. I do not want to lose my children, and I do not want my children to lose me."* This quotation shows what it means to be an immigrant in Canada and a cancer survivor for her as a mother. It increased her fear and uncertainty about her children's future. Children in Canada depend entirely on their parents for support. Therefore, they would not have enough social support from extended family members who do not live in Canada should something happen to Marwa.

In the Middle Eastern culture, mothers play an essential role in their families, where they are the pillar of their homes, and provide physical and emotional support for their family members at the expense of their own needs and difficulties (Doumit et al., 2010; Goldblatt et al., 2013; Ziadeh et al., 2018). These responsibilities towards their families and children increased their fear and anxiety levels during their cancer survivorship journey. Various other studies also indicated that Asian immigrant women believed that obligation and duty to their family increased their stress and made them work harder to stay healthy (Ashing-Giwa et al. 2004; Ashing et al. 2003).

### **Their Quality Care was Accompanied by Delays and Needs**

Participants in this study received quality care with no discrimination during their cancer survivorship journey from supportive, friendly, and professional healthcare providers. The participants were satisfied with the quality of health care that was provided for them. They also described how health care professionals made a difference in their cancer survivorship experiences, and they would not forget the sympathy of health care providers. For example, Nora described her feelings whenever she made an effort to erase the painful memories of her mental and emotional experiences during the treatment stage, she would recall the support and empathy of the health care providers: *“If I decide to forget the psychological pressures, I can’t forget the kindness of the medical staff. The nurses were compassionate and kind as well as the doctors”*. Duffy and Aquino-Russell (2007) indicated in their study that Canadian-born female cancer survivors had memorable connections with nurses who made a difference in their cancer journey.

This study was unique because the participants of this study were from three different immigration categories: refugee, family, and economic categories. These variations in immigration categories resulted in various experiences with the health care system in Canada. Although the participants received quality care, they experienced delays in accessing health services and had unmet needs that increased their anxiety during their cancer survivorship journey. These unmet needs and delays were attributed to current health care policies in Canada, poor communications between health care facilities, and lack of support services for cancer patients and new immigrants. This finding was consistent with the other Canadian studies, which indicated that some immigrant women (e.g., visible minorities) in Canada reported long waiting times to access health services and unmet health care needs (Setia, Quesnel-Vallee, Abrahamowicz, Tousignant, & Lynch, 2011).

Marwa was from the refugee immigration category and could not speak English. For her, accessing health services was facilitated by other agencies and Canadian community members, which was a positive experience for her without any delays or impediments. The local multicultural association assisted her in accessing various health services, including interpreter services, transportation, arranging medical appointments, and finding primary health care providers (*See Marwa's quote in chapter 4, on p. 69*). Marwa was able to access health service as soon as she arrived in Canada because the federal government insured her under the Interim Federal Health Program (IFHP). This program provides limited (in-patient and out-patient hospital services, services from medical doctors, registered nurses, and other health-care professionals licensed in Canada, including pre- and post-natal care, laboratory, diagnostic and ambulance

services) and temporary coverage of health-care benefits for refugees (Government of Canada, 2019). Federal and provincial governments also support multicultural associations to support newcomers and to provide them with various settlement services in Canada.

On the other hand, Marwa was challenged in finding childcare services whenever she needed to access health services (e.g., emergency department visits, appointments, and treatment sessions) (*see Marwa's quote in chapter 4, on p.69*). This lack of childcare services for cancer patients increased her worry and stress. In fact, different provinces have different cancer patient support services, but not all provinces have childcare services for parents with cancer. For example, Nanny Angel Network: Child Care for Mothers with Cancer provides free childcare services for mothers with cancer during their treatments or any medical appointments in Ontario ("Nanny Angel Network," n.d.). Kelly Shires Breast Cancer Foundation can provide financial assistance for breast cancer patients across Canada, which can be used for childcare services or any other needed services ("The Kelly Shires Breast Cancer Foundation," n.d.). However, the patient can apply once a year, and she can not receive more than \$1000 at a time. This finding also indicates that perhaps the participants in this study lacked knowledge about these support services for cancer patients across Canada.

Eman was from the family immigration category where her family member (spouse), who was already living in Canada, helped her to access health services and to obtain health insurance for her. When she began her cancer treatment stage at the cancer agency, she received excellent health care services and transportation to access health services from the provincial cancer agency (*see Eman's quote in chapter 4, on p. 68*).

However, she was very distressed during the diagnosis stage of her cancer survivorship journey because she experienced a delay in accessing health services. This delay was attributed to poor communication between different health care facilities. Tudor Car et al. (2016) have identified that poor communication between primary and secondary care and health system regulations are the primary main problems causing delays in diagnosis. In fact, inefficient communication between healthcare professionals has a potentially negative impact on patient safety and continuity of care, which leads to delayed diagnosis and treatment, decreased patient confidence and satisfaction, and increased unnecessary and avoidable costs (Vermeir et al., 2015).

Nora, who was from the economic immigration category, had no one to help her to navigate the health care system and direct her. This woman experienced delays and a decline in acquiring health services as a result of healthcare system policies (*see Nora's quote in chapter 4, p. 69*). When Nora needed to access health services, she was required to pay for health services because she did not have a Medicare card. Her request for a Medicare card was also declined because she did not meet the Canada Health Act requirements of time being a resident in order to become insured. This requirement is defined as, "*a resident of the province who has not completed such minimum period of residence or waiting period, not exceeding three months, as may be required by the province for eligibility for or entitlement to insured health services*" (*Canada Health Act, n.d, p 6*). This experience elevated her stress because she required urgent health care but could not access it due to the current public health care policies in Canada. Further, her lack of knowledge of the health care system and how to navigate the system, in addition to her low economic status, did not allow her to find alternatives

or to defray the costs of health services. These findings are in agreement with many previous studies that have indicated recent Canadian immigrant experience inadequate access to health services due to lack of knowledge of the health care system and navigating the system, financial barriers, and social isolation (Cheung et al., 2017; Setia et al., 2011).

### **Provided Knowledge and Information were Helpful for Them**

To increase the health literacy of cancer patients and their families about the cancer care process and expectations, cancer care centers and health care professionals provided the participants with information and knowledge about every treatment stage, expected health outcomes, available programs, and how to take care of their health and well-being during their journeys. The participants found knowledge and information that were provided to them to be very helpful at improving their health literacy and empowering them (*See Eman's quotes in chapter 4, on p. 70*). This is in line with many other studies which indicated that knowledge and information empower cancer survivors to make the best decisions concerning their health, to have the best health and well-being outcomes, to gain a sense of control over their situation, reduce anxiety, and formulate plans for the future (Duffy & Aquino-Russell, 2007; Halkett et al., 2005; F. Williams & Jeanetta, 2016).

Participants in this study desired more health promotion and prevention programs specifically for immigrant women in their language (Arabic). This indicates the women in the study showed positive attitudes towards improving their health literacy, getting involved in health promotion and prevention programs, and staying healthy. These results concur with previous studies conducted in Ontario, including

Arab, African, South-Asian, and East-Asian immigrant women (J. Hulme et al., 2016; Redwood-Campbell et al., 2011). There are many Canadian studies which recommended the need to increase breast and cervical cancer awareness amongst immigrant women by providing health promotion and prevention programs that consider language barriers, cultural competency, and structural barriers to access health services (Aery, 2018; Jennifer Hulme et al., 2016; Vahabi & Lofters, 2016). Although there is a limited number of health intervention and promotion programs targeting immigrant women across Canada, there are a couple of programs that were conducted in Ontario. These programs presented a positive impact on improving immigrant women's knowledge of cancer screening programs and cancer care (Aery, 2018). These programs used culturally-tailored interventions, community-based care models, and innovative screening tools.

The participant Nora would have liked to have been offered education programs for her children in order to teach them about their parents' challenges during the cancer survivorship journey and how to adjust to changes in their social environment (*see Nora's quote in chapter 4, page 72*). Parental cancer leads to a disproportion in family life and their ability to handle the situation. Parents with cancer also notice fear and stress among their children (Inhestern & Bergelt, 2018). It is important to point out that parents newly diagnosed with cancer find that communicating the news with their children is very difficult (Forrest, Plumb, Ziebland, & Stein, 2006; Holst-Hansson et al., 2018). If children are not informed about their parents' cancer diagnoses, children can draw meaning from the changes in their family (changes in physical and psychological health) (Forrest et al., 2006). Nora had experienced difficulties in communicating cancer

information with her children and noticed changes in her children's emotions. Nora experienced conflicts with her partner and low social support from him and became a single mother during her cancer survivorship journey as she described it: "*my husband decided to leave our two daughters and me*" (see also other Nora's quotes in Chapter 4, p, 72 and 76). Nora's children's adjustment to cancer and family separation was adverse. Previous studies have indicated that children of single mothers with cancer experience poor adjustment and more problems due to poor social support from the partner and family conflicts (Morris, Martini, & Preen, 2016).

Previous studies have shown that providing children with appropriate information about cancer, quality communication, and the quality of the relationship with their parents can reduce children's anxiety and any long-term adverse consequences (Forrest et al., 2006; Inhestern & Bergelt, 2018). It is also recommended that health care professionals consider children's perspectives in order to develop appropriate interventions to support children and their parents. Parents who choose healthy coping mechanisms during their cancer survivorship can enhance their children's ability to cope (Forrest et al., 2006). The ability to use available resources, finding support groups for families with cancer, asking for help from health care providers and the counsellor can also help both the children and their parents to cope successfully during the cancer survivorship journey (Inhestern & Bergelt, 2018). The Canadian Cancer Society (n.d.) provides detailed information about how to find support and support groups to help family members to cope with cancer, in addition to available resources for families with cancer. For Nora, living in isolation and extreme psychological distress did not permit her to search for available resources for cancer patients and their families, nor to

navigate the health care system, and ask for help from her healthcare provider or other resources.

### **Having Knowledge of the English Language was Equal to Empowerment for Them**

Research participants indicated how critical it was for immigrant women to be able to communicate in the English language in order to help them to access health services, communicate with health care providers, understand all the cancer care educational materials, and participate in support groups. This study showed the noteworthy difference between an immigrant woman who could communicate in English and one who could not. The participant who was able to communicate in English described her ability to communicate in English as empowerment for her to access various health services, understand various health educational materials, communicate with health services providers, join support groups, and reach out. However, the participant, who was not able to communicate in English, found it challenging to access various health services by herself because she could not adequately communicate with health care providers. She would also always look for an interpreter to translate medical information for her. These findings are in agreement with various Canadian and international studies which convey that poor English proficiency is one of the significant barriers for immigrant and refugee women to access health services (Aery, 2018; K. T. Ashing-Giwa et al., 2004; Gele, Qureshi, Kour, Kumar, & Diaz, 2017; J. Hulme et al., 2016).

The participants also desired to have cancer educational materials in the Arabic language to help those immigrant women who can not speak English. The participants suggested that having the cancer informational sessions, videos, and readable material in

Arabic will help them to manage their fear and reduce the feel of uncertainty during their cancer survivorship journey. Previous research, including Chinese immigrant women, provided language-specific information through videos and brochures about cervical cancer risk factors, available health facilities, and addressing the barrier to screening led to double the uptake of cervical screening (Taylor et al., 2002). Another study included South-Asian immigrant women; the research team published culturally appropriate information about breast cancer screening in Hindi and Urdu in community newspapers. This method not only increased health literacy about breast cancer among South-Asian women and their families, but also showed a significant increase in self-reporting, having a routine physical checkup, and clinical breast examinations (Ahmad, Cameron, & Stewart, 2005). These empirical studies indicated the importance of providing culturally appropriate and language-specific cancer care intervention materials to help immigrant cancer patients and their families to improve their health literacy.

### **Social Support is the Key to Persistence for Participants**

The participants in this study received exceptional and sympathetic social support from their health care providers and communities (i.e., cancer agency and multicultural association). They also received unconditional support from at least one family member (i.e., mother, spouse) who accompanied them in Canada. This support was precious and a source of strength for them during the cancer survivorship journey. It is consistent with other studies which revealed that social support from family, friends, health care providers, coworkers, and other cancer survivors was very helpful because it provided them with: the strength to fight cancer, hope, and the ability to accept their

conditions (Doumit et al., 2010; Duffy & Aquino-Russell, 2007; F. Williams & Jeanetta, 2016).

The social support provided by health care providers assists in the development of a sense of emotional comfort and security among breast cancer patients (Holst-Hansson et al., 2018). For the participants in this study, social support from family members was perceived differently from the support that was provided by health service providers because their family members could understand their cultural needs. This is because of the strong cohesion amongst family members, which is very common in the Middle-Eastern culture. Stronger emotional support is associated with family cohesion, which is positively related to better adjustment to illness in breast cancer patients (Muhamad, Afshari, & Kazilan, 2011). Previous studies have also indicated that family support encourages cancer survivors to practice healthy behaviours in order to cope with the stressful cancer survivorship journey, to enhance their health and well-being, and to have a better quality of life (Bevan & Pecchioni, 2008; Muhamad et al., 2011; F. Williams & Jeanetta, 2016).

In the Middle Eastern culture, the family is a fundamental social unit that presents the primary sources of support and care for cancer survivors. For the participants, cancer survivorship was very challenging and increased their anxiety because living at a far distance from their beloved families meant limited social support. Family physical presence for support was not possible to provide the required support care. In addition, immigrant and ethnic minority women are less likely to participate in support group programs due to difficulty in locating culturally competent and language-specific support groups (Leng et al., 2014). This limited social support is associated

with social isolation, psychological distress, and limited communication with the cancer care team (Goldblatt et al., 2013; Holst-Hansson et al., 2018; Joulaei et al., 2012).

The findings of this study revealed the impact of a spouse's social support on the women's cancer survivorship journey. According to Muhamad et al. (2011), a partner's social support is essential and can not be compared with any other resources.

Furthermore, this support depends on the strength of the relationship and significantly influences the cancer patient's health and well-being. One participant, in a positive and healthy relationship with her spouse, received unconditional support that contributed positively to her cancer survivorship journey, while another participant, who was in a distressed relationship with her spouse, did not receive any social support, which negatively impacted her journey and her survivorship experience. For example, Eman described how her partner was supportive, understanding, and patient, which made her appreciate his unconditional support: *"I was angry, very angry most of the time. My husband was very calm and supportive, and he tolerated me and respected my feelings"*. Nora, on the other hand, experienced continuous psychological distress during her cancer survivorship journey because her partner was not supportive and did not try to be involved in her cancer care process as she described it:

*He did not really support me psychologically....I used to go to the hospital on my own, where my husband did not like to accompany me, and how much I wished as one of the newcomers to have company at that time. (Nora)*

### **They Used Various Coping Mechanisms to Harmonize their Life**

The participants in this study went through five major cancer care stages: diagnosis, chemotherapy, mastectomy, radiotherapy, hormone therapy (excluding the

participant Marwa), and follow up care (see Table 2). The participants used several coping mechanisms to mitigate their distress levels and to maintain strength during their cancer survivorship journey. They also used a combination of problem-focused coping strategies and emotional-focused strategies. Problem-focused coping strategies such as acceptance, emotional support, planning, and religion are considered active coping mechanisms (Barinková & Mesároová, 2013; Tuncay, 2014). Conversely, emotional-focused strategies such as self-distraction, venting, and behavioural disengagement are considered non-active coping mechanisms (Barinková & Mesároová, 2013; Tuncay, 2014). Using a combination of both active and inactive coping mechanisms reflects the realistic acknowledgment of the meaning of the cancer survivorship journey for these participants and their exploration of the effective ways to cope with their cancer survivorship journey.

During the whole journey, the participants practiced religious prayers and turned to God to maintain control of their feelings. They also used the Arabic phrase “*Alhamdulillah*” many times during the interview. This term means “*Praise be to Allah,*” or *God* or “*Thank God,*” which is used by Muslims, Arab Christians, and Arab Jewish conversations. The phrase is a complimentary act that praises God for what he is, for his virtues and excellence, as well as for what he has done for us (Huda, 2019). Faith in God and using this religious phrase and prayers indicated the participants’ coping, acceptance of their illness, and gave them optimism in order to survive. Their religious beliefs also stopped them from doing any harm to their bodies. For example, Eman described how her faith and prayers were sources of strength during her cancer survivorship journey, and they prevented her from contemplating suicide when she was

desperate: *“Faith and prayers were also great to go through the whole process, especially when I was weak and had no interest in anything.... I had suicidal thoughts, but I could not do it... I am a Muslim, and this action is prohibited in our faith.”* Numerous studies from around the world reported that religious beliefs in God and spirituality provided strength, hope, and a better quality of life for cancer survivors (Doumit et al., 2010; Gurm et al., 2008; Holst-Hansson et al., 2018). They also give cancer patients the ability to accept their illness, cope, and long-term psychological adjustment (Alhusban, 2019; Doumit et al., 2010; Joulaee et al., 2012).

During the diagnosis stage, participants experienced fear and anxiety of their cancer diagnoses, but they had different reactions to their cancer diagnosis. The participant, Nora, tried to hide her feeling of fear and worry in front of her healthcare providers. Marwa, on the other hand, expressed feelings of fear and anxiety through crying and voicing her feelings to her spouse and healthcare providers. Eman, however, was calm but afraid to deliver the news to her family; she communicated her diagnosis to her spouse, who, in turn, communicated the news to the rest of the family. During the treatment stage, the participants tried to hide their physical and psychological features associated with the treatment stage because they were worried about their family members' feelings. For example, Marwa and Eman covered their heads all the time; thus, no one would notice that they lost their hair, and they tried to avoid leaving the house, leading to social isolation. Hiding and avoidance are considered self-disengagement coping strategies that are associated with adverse health outcomes among cancer patients (Tuncay, 2014).

It is common in the Middle-Eastern culture that breast cancer patients conceal their cancer diagnosis, illness, and their physiological and psychological changes associated with cancer treatment (Doumit et al., 2010; Goldblatt et al., 2013; Obeidat et al., 2013). Middle-Eastern women have concealed their feelings and illness to avoid being pitied by others, the negative cancer stigma, losing their employment, as well, to prevent harm to their children's' emotions. These cultural attitudes regarding cancer diagnosis lead to social isolation, lower social support, and increasing of women's psychological distress (Doumit et al., 2010; Goldblatt et al., 2013).

Two participants in this study used venting mechanisms by expressing and sharing all their feelings and cancer survivorship and life challenges with others. Marwa shared her feelings and her everyday challenges with her friend. Eman found that sharing her feelings with a counsellor and her mother was very helpful and relieved her stress. Nora, however, could not find anyone to communicate her feelings to; thus, she lived in isolation and anxiety during two stages of her cancer survivorship journey. Venting is a coping mechanism used by cancer patients. However, various studies have indicated that lack of venting as an emotional coping strategy has been linked with poor quality of life and higher depression and anxiety levels, and adverse health outcomes (Barinková & Mesároová, 2013; Tuncay, 2014). It has been suggested by Tuncay (2014) that emotional-focused coping mechanisms may likely reduce cancer patient's problem-solving capacity.

During the follow-up care stage, participants attempted to regain control of their lifestyle and give meaning to their new life as cancer survivors. The participants decided to face the changes in their lives by planning for their futures and trying to grow. The

participants endeavoured to make their life busy, full of activities, and surrounding themselves with sympathetic people to minimize their stress. For example, Eman tried to make her life full of activities by reaching out/meeting new people, volunteering, finding employment, and supporting people from her community (*see Eman's quote in chapter 4, p. 74*). The participants decided to go back to school and pursue education or learn the English language. For example, Marwa started to learn English to improve her communication skills in order to improve her ability to access various services. The participants had a sense of empowerment during this stage of their cancer survivorship journey because they started to perceive control of their lives. In fact, participant, Nora, realized the importance of planning for her future when she decided to pursue her education, nevertheless, she found it very demanding and stressful as she was still experiencing other life challenges such as her physiological and psychological health, divorce, child guardianship issues, and low income (*see Nora's quote in chapter 4, on p.75*). She realized that she should have focused on controlling these problems and improving her self-image before going back to school. These findings confirmed the importance of planning for the future as a coping mechanism to confront problems, perceive control, reduce psychological distress, and enhance satisfaction with life (Dubey & Agarwal, 2007).

### **They Faced Cultural Stigmatization of Mental Health Issues**

As discussed earlier in this chapter, the cancer survivorship journey was fear-inducing and anxiety-provoking for the women in this study, particularly during the treatment stage. All participants described how the chemotherapy treatment stage was the most stressful in this journey due to all the physiological and psychological health

changes. This is in agreement with many studies which declared that cancer survivors start experiencing psychological disorders as soon as they are diagnosed with cancer (Syrowatka et al., 2018), and the chemotherapy treatment stage is the hardest stage with the highest levels of distress (Nasrabadi et al., 2011).

The participants declared that the cancer survivorship journey was an arduous journey for them and their family members, which required psychotherapy because they experienced stress, depression, and anxiety. In the Middle Eastern culture, family is the dominant social unit and women represent the backbone of the family. If a woman experiences any chronic illness (e.g., cancer) with psychological distress, it will impact the whole family. This is also common in various international publications, as the family is the primary source for social support and home caregivers during the cancer survivorship journey (Alexander et al., 2019; Woźniak & Iżycki, 2014). Further, cancer is considered an onerous experience for the family because it affects the family stability, relationship within the family, the family's ability to cope with considerable stress. The cancer survivorship journey also causes burden, unwanted changes, distress, depression, and anxiety to family members (Woźniak & Iżycki, 2014). Consequently, accessing family psychotherapeutic interventions can have great potential for families at improving their communication, identifying their needs, increasing their role flexibility, coping, and enhancing their adjustment to the new social, vocational and financial realities (Spiegel & Riba, 2015).

The participants in this study recognized the importance of psychotherapy for themselves and their family members during the cancer care process to enhance their health and well-being. This perception of mental health services indicated the

acculturation of these women to the Canadian culture. For example, Eman described that mental illness is hugely stigmatized in her culture, and many people avoid psychotherapy because it is associated with the term “crazy.” However, her perception of psychotherapy changed when she accessed individual and group psychotherapy during her cancer survivorship journey, because she found it very obliging, beneficial, and provided her with the strength to fight cancer. Many groups or individual psychotherapy treatments are effective and efficient in improving cancer patients’ quality of life and reduce emotional distress (Spiegel & Riba, 2015). These groups or individual psychotherapy programs provide cancer patients with information about how to cope, manage cancer treatment-related pain or side effects, and reduce anxiety and depression (Spiegel & Riba, 2015).

On the other hand, the other participants and their family members who did not access psychotherapy services or counsellors because of their preconceived beliefs that psychotherapy is a disgrace and is stigmatized in their culture. For example, the participant, Nora, described her reaction as astonished with a shock when her spouse outrightly rejected going to the psychotherapy. Sewilam et al. (2014), in their literature review about mental illness in the Middle East, have indicated that mental illnesses are highly stigmatized and faced with social rejection because they are viewed as a weakness, shameful, and disgraceful. This cultural belief of mental illness in the Middle East leads to discrimination and social isolation because mental illness is associated with the terms “crazy,” “mad,” and “harmful.” With the stigma of mental comes a devaluation of families with mentally ill individuals and diminished marital prospects (Sewilam et al., 2014).

The participant Marwa described her anger and mental health struggles (See Marwa's quote on page 77), but she reacted to this psychological distress with denial. Therefore, she praised God that she does not see a psychiatrist. This likely due to the stigma of mental health or poor communication with health care providers about their mental health. Immigrant women and their families are less likely to discuss mental health issues with their health care providers (Aery, 2018). Therefore, newcomers to Canada have lower rates of visiting mental health services compared to longer-term immigrants (Aery & McKenzie, 2018). Various studies have indicated that female immigrants and ethnic minority cancer survivors experience lower rates of emotional well-being, higher rates of fear of recurrence, low quality of life, and more symptoms of depression than non-minority women (K. T. Ashing-Giwa & Lim, 2011; S. Christensen et al., 2009; Sammarco & Konecny, 2010; Sze et al., 2015). This is likely attributed to the fact that female immigrant cancer survivors are less likely to join individual or group psychotherapy programs (Leng et al., 2014), lack of adherence to treatment sessions (Costas-Muniz et al., 2015), as well as the other systematic barriers (i.e., cultural beliefs of mental health, or lack of English proficiency and communication skills, and lower socioeconomic status) (K. T. Ashing-Giwa & Lim, 2009).

### **Survivorship Journey is combined with Changes in their Physical and Social Environments**

The participants experienced changes in their social and physical environments during their cancer survivorship journey that affected their health and wellbeing. The participants were new immigrants to Canada, which was a new physical and social environment for them that requires physical and psychological efforts to acculturate and

integrate into society. Before moving to Canada, the participants in this study were used to having active lives, employment, and friends in their homeland. When they immigrated to Canada, they found themselves without employment, income, friends, and support while living in a system and culture that was novel for them. This experience caused distress and uncertainty for them. The participants in the study were experiencing immigration stressors combined with cancer-related distress.

Previous studies indicated that the physical and psychological health of refugee and immigrant families at high risk because of the experience of various sources of stressors in the new host country including culture shock, acculturation, unemployment, lack of social support, new physical environment, low income, and discrimination (Dow, 2011; Thomas, 1995). Other researchers studied the impact of acculturation and social support on immigrant cancer survivors' quality of life in the USA, which identified that acculturation was connected to a better quality of life through the development of a social network (Lim & Ashing-Giwa, 2013; Lim, Gonzalez, Wang-Letzkus, & Ashing-Giwa, 2009). Therefore, female immigrant cancer survivors experience a better quality of life with fewer depression symptoms when they have more social networks and are more acculturated, while less acculturated women experience lower social support, lower quality of life, and more depression symptoms.

Furthermore, the social cohesion, social connection, social network, such as relationships with spouse and making friends, have been significantly affected by the journey. The participants have experienced changes in their relationships and social roles. For example, Nora's relationship with her spouse was negatively affected by the cancer survivorship journey, leading to the loss of the stability of the social composition

of her household. Harmful changes in relationships and social networks with family members and friends among different ethnic groups during the cancer survivorship journey has been previously reported (Joulaee et al., 2012; Schultz et al., 2004). In the Middle Eastern culture, marriage relationships are very important, thus losing the support of a partner during this challenging stage is commonly very difficult (Joulaee et al., 2012). Various studies indicated that a spouse's support is vital for breast cancer patients as spouses can enhance women's self-esteem and coping strategies (Muhamad et al., 2011).

### **As Women, Their Self-image was Impacted Greatly**

The women in this research perceived their self-image as self-discipline, active, and amiable. However, changes in their body image (losing their hair, and a part of their body) and physiological health (fatigue, nausea, loss of appetite, pain in the bones, ceasing of menstruation) during the treatment stage impacted their psychological health, self-confidence, social support network (relationships), and sexuality. For example, Marwa described how losing her hair and the mastectomy were very perplexing and negatively affected her psychological health; whenever she looked in the mirror, she expressed her distress:

*I was distressed all the time. I felt that I lost part of my body.... Whenever I want to change my clothes, I look in the mirror; I start to cry. It is painful and sad to lose part of your body. (Marwa)*

The participants in this study lived in depression and isolation during the treatment stage, particularly the chemotherapy stage. They tried to hide all the physical changes in their bodies by covering their bodies and head all the time, even in front of

their spouses and children. Using this ineffective coping strategy indicates losing control of health and well-being (Doumit et al., 2010; Holst-Hansson et al., 2018). In fact, changes in physical appearance (e.g., losing hair) during the treatment stage was a significant factor that negatively affected cancer survivors' ability to cope during the treatment stage (Doumit et al., 2010; F. Williams & Jeanetta, 2016). Further, poor body image in young breast cancer survivors is associated with lower quality of life, chronic fatigue, and mental distress (Paterson, Lengacher, Donovan, Kip, & Tofthagen, 2016).

These findings are in parallel with previous studies, which showed that changes in physical health and appearance caused anxiety, isolation, and emotional distress for many female breast cancer survivors (Alhusban, 2019; Joulaee et al., 2012). Reed (n.d.) indicated that Middle Eastern women perceive themselves as open-minded and empowered women. Obeidat et al. (2013) indicated that health and changes in appearance associated with the cancer diagnosis and treatment negatively challenged Jordanian women's self-image as strong and independent women.

Middle Eastern women perceive femininity, similar to other cultures, as a perfect and attractive body with a beautiful hair and breasts (Alhusban, 2019; Archangelo, Sabino Neto, Veiga, Garcia, & Ferreira, 2019). In the Middle Eastern culture, women still like to have a partner, family, and children (Doumit et al., 2010; Joulaee et al., 2012). Therefore, for breast cancer survivors, losing femininity and attractiveness after the treatment stage impacts their sexual life, relationships, and psychological health (Archangelo et al., 2019; Joulaee et al., 2012).

It has been suggested by Joulaee et al. (2012) and Alhusban (2019) that the spouse's positive reaction to the physical and psychological changes caused by breast

cancer can have a significant impact on the relationship, women's self-confidence, and psychological health. In this study, Marwa's and Nora's partners negatively reacted to the changes in their wives' body-image leading to emotional distress and separation. For example, Nora described her sudden surprise of her spouse's reaction after the mastectomy as: "*The shock was when I came out of the hospital, I noticed my husband's distaste. He did not even accept to see me changing my clothes in front of him*". Eman described her concerns and discomfiture during the chemotherapy stage because her menstrual period stopped. Since she was newly married and did not have children, this physiological change made her feel self-conscious about her relationship with her spouse (see Eman's quote in chapter 4, on p. 79). However, her partner showed a positive reaction and respect to all changes, which positively impacted their relationship and her health.

During the follow-up care stage, the women focussed on improving their body-image and self-image to regain their confidence. The participants underwent breast reconstruction procedures to improve their body-image and self-confidence. Archangelo et al. (2019) compared breast cancer survivors who had undergone breast reconstruction and who underwent mastectomy alone and found that women who did breast reconstruction surgery, experienced better sexual function, fewer depressive symptoms, and better body-image. In this study, the participant Marwa perceived more confidence in her self-image through dressing well, wearing make-up every day, and maintaining her social role (housekeeping, taking care of her children).

These findings are in agreement with previous studies which indicated that body image in women with breast cancer have three characteristics: (1) affective which is

related to feeling feminine and attractive, (2) behavioural which is related to avoiding people and hiding, and (3) cognitive which is related to the satisfaction with appearance and scar (Paterson et al., 2016). Using multidimensional strategies, such as self-care, physical appearance improvement, and maintaining wife roles, by breast cancer survivors to recall femininity has also been reported (Mohammadi, Khan, & Vanaki, 2018).

### **Strengths and Limitations of the Study**

In this section, I discuss the strengths and limitations of this study and the methodology used to explore the meaning of the lived experiences of Middle Eastern Immigrant women during their cancer survivorship journey.

#### **Strengths**

This study contributed to the current knowledge by exploring the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey. To the best of my knowledge, this study was the first of its kind to explore the lived experience of Middle-Eastern immigrant women during their cancer survivorship journey in Canada. Previous research focused primarily on cancer prevalence and cancer screening rates among immigrant women in Canada (Cheung et al., 2017; A. K. Lofters et al., 2019; Shuldiner et al., 2018). Plus, there are not many studies exploring the lived experiences of immigrant women's cancer survivorship journey in Canada.

A significant strength of this study is that the research focused solely on Middle Eastern immigrant women's lived experiences and the impact of social determinants of health in shaping these experiences. This study explored the experiences of women aged 41-47 years, who had breast cancer, were from three different immigration categories

and educational levels and lived across Canada. These characteristics might be considered optimal to capture the many differences and similarities in their cancer lived experiences.

The epistemic stance of this study was to uncover the meaning of the lived experiences of Middle-Eastern immigrant women during their cancer survivorship journey. The descriptive phenomenological method developed by Giorgi (1970) was an appropriate methodology to deepen my understanding of the phenomenon under study. The epistemology of phenomenology is the development of the understanding of the essences of people's experiences but not explaining or analyzing them (Creswell & Poth, 2017). Giorgi's phenomenological approach also allows the researcher to ask one open-ended question to let the participants' descriptions emerge in a natural setting with minimal interference from the researcher (Giorgi, 2009). It also allows the researcher to keep the participants' voices in the research without abstracting their perspectives out through analysis (Broome, 2011). As an Applied Health Services Researcher, Giorgi's descriptive phenomenological method allowed me to use the population health theory as a lens to draw the essences of the lived experiences of these women.

### **Limitations**

The findings in the study are not generalizable but are circumscribed to the stories of the three immigrant women who participated in this study and to my ability to translate, transcribe and describe, the text through writing. However, I believe the stories of these women offered an empirical understanding of the phenomenon under study. The sample size of this study was small ( $n = 3$ ) but was enough to understand this unexplored area of research in Canada. Further, recruiting immigrant women for this

study was difficult and a challenging process. Limited participation of immigrant women in health research is widespread (Renert et al., 2013; Waheed, Hughes-Morley, Woodham, Allen, & Bower, 2015).

### **Implications**

The study findings have several implications for the care of immigrant women, particularly in cancer care. In this section, I present implications for healthcare practice, education, healthcare policy, and future research.

#### **Healthcare Practice**

The findings in this study can help health care providers to understand the lived experiences of Middle-Eastern immigrant women during their cancer survivorship journey and provide them with holistic care. Healthcare professionals need to be observant of the multitude of factors and barriers that affect immigrant women's cancer survivorship outcomes.

Communication in cancer care can help cancer survivors to cope and improve their experiences (Sheppard, Adams, Lamdan, & Taylor, 2011). Therefore, health care professionals are encouraged to communicate with Middle Eastern immigrant women to identify their unmet needs of support during their cancer survivorship journey. This particularly applies to women who manage their cancer survivorship journey without support from family, or who can not speak the English language. Healthcare professionals can encourage Middle-Eastern immigrants to communicate their feelings and concerns with them, through interpreters, if needed. Healthcare professionals can increase immigrant women's awareness that lack of communication and concealing their

feelings and illness can reduce their ability to access various support resources that might help them improve their health and well-being.

Healthcare professionals must be aware of the women's psychosocial responses to the cancer diagnosis and treatment stages throughout the cancer survivorship journey to help them to cope and manage their health and well-being. Provincial health services also need to provide culturally competent and language-specific individual and group cancer support services for immigrants in Canada. This can be done by providing interpreters for the individuals when they visit counsellor or psychotherapy or providing the environment at a health facility that encourages immigrant cancer survivors from the same community to create and participate in support groups.

Health care providers need to investigate any family history of breast cancer of their immigrant patients to refer them to mammogram screening. Ziadeh et al. (2018) suggested that Middle Eastern immigrant women should consider breast cancer screening at a younger age and probably should screen more frequent.

### **Education for Immigrant Women**

Middle Eastern immigrant women experience continuous fear of breast cancer. Therefore, more health education interventions and promotion programs at the community level for immigrant women are needed in order to increase their breast cancer awareness and the importance of screening programs. These programs can be culturally appropriate and language-specific, for certain immigrant groups, but also consider the transition toward Westernized perceptions to reduce the fear of cancer diagnosis.

They also need extra information and help in identifying possible resources of support for them. The participants in the study requested language-specific cancer care interventions and promotion programs to help women who cannot speak the English language in order to help them to understand the cancer care process and expected outcomes and how to cope. Culturally appropriate and language-specific psychoeducational interventions are required for cancer patients and their families to help them learn how to cope and look for support in their community. The participants in this study also required health education programs for children of patients with cancer to help children learn more about cancer, how to adjust to the changes in the family, and to learn the best coping strategies.

### **Education for Healthcare Providers**

Healthcare providers need education about how to provide culturally competent care and tools to learn more about their patients. This can be done by incorporating educational programs and courses into the curricula of nursing, medicine and other health sciences and health services programs. Continuing healthcare training on culturally competent care can be achieved through educational workshops and assessment tools.

### **Healthcare Policy**

To reduce disparities in health care services, the federal government should consider providing Interim Federal Health Program (IFHP) (Government of Canada, 2019) to all new immigrants from all immigration categories during the first three months of arrival to Canada. This program can provide limited and temporary coverage

of health-care benefits for all new immigrants until they receive their provincial health care cards that allow them to access various provincial health care services.

Some Canadian provinces, such as Nova Scotia, Quebec, and Ontario, have cancer care navigators to help cancer patients and their families ("Health system navigators: Band-Aid or cure?," 2013). However, new immigrants have difficulties navigating the health care system. Therefore, the federal and provincial governments should fund programs to facilitate navigating not only cancer care programs but the whole health care system as well. This service can help new immigrants and Canadian residents navigate the health care system and find available health services, resources, facilities, and support programs.

The federal and provincial governments should stress increasing, integrating, and providing culturally competent care within the Canadian health care system. This can be done by providing interpreters, workshops, and training for health care providers, and recruiting minorities to work in the health care system. Federal and Provincial governments must also provide more resources for parents with cancer to help them find childcare services and any other necessary services for their children.

### **Future Research**

The findings from this study add to the knowledge of perceptions, reactions, and coping strategies of Middle Eastern immigrant women during their cancer survivorship journey. This study also adds to the knowledge of the impact of various social determinants of health on immigrant women's cancer survivorship experiences and outcomes.

- The findings from this study can be used to develop a quantitative research program to study the effects of cancer on the quality of life of immigrants and their families in Canada. This can be done by developing culturally sensitive questionnaires, or follow a research protocol similar to the ones applied by Ashing- Giwa et al., (2013) and Sammarco and Konecny (2010).
- The findings from this study can be used to develop an assessment tool to understand immigrants' perceptions of cancer, coping strategies, socioeconomic status, social and physical environments, and cultural beliefs as an approach to patient-centered care.
- The participants used various coping strategies to manage their cancer survivorship journey, but they were not all active strategies. Therefore, further mixed method research is needed to address the impact of various coping strategies used by immigrant women in Canada during their cancer survivorship journey on their quality of life and psychological health.
- In this study, I used the population health theory as a lens to study the phenomenon under study. The same results can be analyzed using different lenses such as Nursing or another health-focused theoretical framework.
- Recruiting participants for this study was challenging. Therefore, future studies could invest more resources in recruiting immigrant women in health research.

### **Chapter Summary**

This Chapter provided a discussion of the findings of this descriptive phenomenological study. The essences of the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey in Canada are discussed in

detail in this chapter. The findings provided an insight into the meaning of living with cancer as perceived by Middle Eastern immigrant women in Canada, and the impact of the social determinants of health in shaping the experiences of these women.

Participants believed that their perspectives on cancer risk factors were considered the cause of their cancer. Their cancer survivorship journey was fear-inducing and anxiety-provoking because of their previous experiences, cultural beliefs, and social roles. They received quality care, but it was accompanied by delays and unmet needs due to poor communications between healthcare facilities and Canadian public health policies. However, health care providers and cancer agencies provided knowledge and information that were helpful for them to understand the cancer care process and manage their health and well-being. Knowing the English language equals empowerment, while social support was key to persistence. For participants, various coping mechanisms helped them to harmonize their lives, but not all of them employed effective coping strategies. As women, their self-image was significantly impacted by the cancer experience causing significant psychological distress and anxiety. In addition, they found that there was cultural stigmatization of mental health issues, while their cancer survivorship journey was also combined with changes in their physical and social environments.

Healthcare professionals need to identify immigrant women's unmet needs of support during their cancer survivorship journey. Professionals must be aware of immigrant women's psychosocial responses to cancer throughout the cancer survivorship journey in order to help them manage their health and wellbeing. The development of language-specific and culturally competent cancer-care intervention

programs are required within the Canadian healthcare system in order to improve immigrant women's health literacy in this country. The Federal government must consider providing the IFHP to all new immigrants during the first 3 months of stay to reduce health disparities in Canada.

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## Appendices

### Appendix A: Letter to local breast cancer support groups and multicultural associations



University of New Brunswick  
3 Bailey Drive  
PO Box 4400  
Fredericton, NB  
Canada  
E3B 5A3

**Date:** \_\_\_\_\_

**Dear** \_\_\_\_\_

I am a student in the Applied Health Services Research Program from the University of New Brunswick, and I am currently conducting a research project called: "The Lived Experiences of Middle Eastern Immigrant Women during their Cancer Survivorship Journey." This study has been reviewed by the Research Ethics Board of the University of New Brunswick and is on file as UNB REB 2018-151.

The purpose of this study is to discover the lived experiences of Middle Eastern immigrant women during their cancer survivorship. The result of this study will be beneficial for healthcare providers and other health service professionals who work with immigrant cancer patients to better support and deliver interventions and care that are culturally competent and patient-oriented to this group of people.

I appreciate the role you play to support (cancer patients /cancer survivors/immigrants), and I am seeking your assistance in recruiting participants for this research study. I hope that you provide an opportunity for me to advertise for my study through placing the research poster on bulletin boards or advertise on your social media network groups (Facebook, Twitter, Instagram, etc.) in order to recruit interested participants. This would enable potential participants to contact me should they have the interest to learn more about the research. Any participants who reach me will be given more details

about the research. If they decide to participate, they will be asked to sign an informed consent once all questions have been answered to their satisfaction.

Enclosed is a copy of the participant information sheet, a copy of the research poster, and a copy of the proposal.

I look forward to your response at your earliest convenience. Should you have any questions, please feel free to contact me or alternatively my supervisors, Dr. Catherine Aquino Russell (Professor of Nursing University of New Brunswick- Faculty of Nursing-Moncton site) at phone: 506-856-2682 email: [caquinor@unb.ca](mailto:caquinor@unb.ca)

Best Regards,

Enam Alsayheen (Masters student of Applied Health Services Research)  
University of New Brunswick  
Atlantic Regional Training Center  
e-mail: [ealsayh@unb.ca](mailto:ealsayh@unb.ca)  
phone: 506-962-3734

## Appendix B: Call for participants (advertisement)

“The Lived Experiences of Middle Eastern Immigrant Women during their Cancer Survivorship Journey.”

I am a student in the Applied Health Services Research Program from the University of New Brunswick. I am interested in exploring the experiences of female Middle Eastern immigrant women during their cancer survivorship.

I am looking for participants for my research study  
I am interested in your efforts to make sense of this experience

If you meet the following criteria, please think about taking part in this study:


- You are a Middle Eastern immigrant woman
- You have been diagnosed with cancer within the last five years
- You are between 20 and 65 years of age
- You can communicate in English or Arabic

Your participation in this study:

- Voluntary
- Involves talking with me about your experiences through an interview
- The interview will take place at a time and a place, that are most convenient for you
- The information that you share will be confidential and anonymous

If you are interested in participating in this research project, please contact me at:

Enam Alsayheen (PhD)

 506-962-3734

 [ealsrayh@unb.ca](mailto:ealsrayh@unb.ca)

This project has been reviewed by the University of New Brunswick Research Ethics Board and is on file as UNB REB 2018-151

This project has been reviewed by Horizon Health Network Research Ethics Board and is on file as HHN REB 2019-2725

## Appendix C: Research poster

**Are you A Middle Eastern Immigrant Woman?**

*"I am interested in talking to Middle Eastern immigrant women about their cancer survivorship experiences"*



**If you meet the following criteria, please think about taking part in this study:**

- ✓ Diagnosed with cancer within the last 5 years
- ✓ Ages 20 - 65 years
- ✓ Able to speak English or Arabic

**For more information contact:**  
Enam Alsayheen (PhD)  
506-962-3734  
[ealsrayh@unb.ca](mailto:ealsrayh@unb.ca)

**participation in this study:**

- ✓ Voluntary
- ✓ Involves interview
- ✓ Confidential

This project has been reviewed by the University of New Brunswick Research Ethics Board and is on file as REB 2018-151.

This project has been reviewed by the Horizon Health Network Research Ethics Board and is on File REB 2019-2725.

## Appendix D: Information Sheet for Participants

**Research study:** The Lived Experiences of Middle Eastern Immigrant Women during their Cancer Survivorship Journey

**This research is conducted by:** Enam Alsayheen (Master student of Applied Health Service Research, University of New Brunswick, Atlantic Regional Training Center)

**Supervisor:** Dr. Catherine Aquino Russell (Professor of Nursing, University of New Brunswick- Faculty of Nursing-Moncton site, Email: [caquinor@unb.ca](mailto:caquinor@unb.ca), Phone: 506-856-2682)

**Purpose:** This study aims to understand the lived experiences of Middle Eastern immigrant women during their cancer survivorship journey. The result of this study will be helpful for health care providers and other health service professionals who work with immigrant cancer patients to better support and deliver health services that are culturally competent and patient-oriented care to this group of people.

**Process:** Taking part in this project means the following:



In a face to face interview, you will be asked to respond to the following statement: *"As a Middle Eastern immigrant woman, please describe your experiences during your cancer survivorship."*



You can express your experiences in your own way and pace.



The interview will take place at a time and method that are most convenient for you.



You will be asked to share as much or as little as you wish about your experiences.



The information that you share will be firmly confidential.



Your name, personal information will not appear in any written report or publication of the study.



You will choose a false name for the study.



If you are ready to take part in this study, please contact me.



I will explain the study to you and answer all your questions



You will sign a consent form after I answer all your questions.



I will ask you to fill out a demographic information sheet



If you choose to withdraw from the study at any time, for any reason, your choice will be respected.



If you agree to participate later, you may email or call me.



This project has been reviewed by the University of New Brunswick Research Ethics Board and is on file as UNB REB 2018-151

This project has been reviewed by Horizon Health Network Research Ethics Board and is on file as HHN REB 2019-2725

You can contact me at any time about any questions you have regarding this study at:



506-962-3734



[ealsrayh@unb.ca](mailto:ealsrayh@unb.ca)

If you would like to know more about your rights as a participant in a research study, you can contact Dr. Steven Turner (Chair, University of New Brunswick Ethics Board) University of New Brunswick, Phone: 506 453-5189

Thank you for considering taking part in this research study

Sincerely,

Enam Alsayheen (Ph.D.)

Phone: 506-962-3734

Email: [ealsrayh@unb.ca](mailto:ealsrayh@unb.ca)

## Appendix E: Demographic Data Sheet

**Research title:** The Lived Experiences of Middle Eastern Immigrant Women during their Cancer Survivorship Journey

- I aim to collect some information about you.
  - All information will remain confidential and anonymous.
  - Please respond to the following questions.
  - Please use your own words/numbers to fill the blanks or circle the answer that is best for you.
- 

1. What is your Age? \_\_\_\_\_ years
2. How long have you been in Canada?
  - Less than 5 years
  - Between 5 and 10 years
  - Between 10 and 20 years
  - More than 20 years
3. What is the highest level of education you have obtained?
  - No high school Diploma
  - High school Diploma
  - College
  - Bachelor's degree
  - Master's Degree
  - PhD
4. Are you employed?
  - Yes
  - No
5. Do you have children?
  - Yes
  - No
6. When were you diagnosed with cancer? \_\_\_\_\_ years ago
7. What type of cancer do you have? \_  

---
8. Do you have a family history of cancer?
  - Yes
  - No
9. Do you live in a rural area?
  - Yes

- No

10. Would you like a copy of the research findings?

- Yes
- No

If yes, please provide contact information:

Email: \_\_\_\_\_

Address: \_\_\_\_\_

Signature: \_\_\_\_\_ Date:

\_\_\_\_\_

Thank You Very Much

This project has been reviewed by the University of New Brunswick Research Ethics Board and is on file as REB 2018-151

This project has been reviewed by Horizon Health Network Research Ethics Board and is on file as HHN REB 2019-2725

## Appendix F: Consent Form

Research Study Title: “The Lived Experiences of Middle Eastern Immigrant Women during their Cancer Survivorship Journey.”

Researcher: Dr. Enam Alsayheen

Masters student in Applied Health Services Research, Atlantic Regional Training Center, University of New Brunswick, NB,

Email: [ealsrayh@unb.ca](mailto:ealsrayh@unb.ca)

Phone: 506-962-3734.

Supervisors: Dr. Catherine Aquino-Russell<sup>1</sup> and Dr. Krista Wilkins<sup>2</sup>

<sup>1</sup> Professor of Nursing, University of New Brunswick- Faculty of Nursing-Moncton site,

Email: [caquinor@unb.ca](mailto:caquinor@unb.ca)

Phone: 506-856-2682, and



You are interested in taking part in a research study. It is your decision to participate in this study. Before you decide, it is essential to understand: the purpose of the study, what participation in the study would involve, and any risks and benefits.

### Purpose

In this study, I am hoping to understand Middle Eastern immigrant women’s cancer survivorship experiences. This study will help healthcare providers and health service providers, who work with immigrant women, to better support and deliver care that is meaningful, culturally competent, and patient-oriented to this group of people. The results of this study may give practical guidance to health care providers and policymakers to reform or promote the health services for immigrant cancer patients.

The researcher gave you full information about the study; please read the following carefully. Please ask questions about anything that needs more clarification.



The researcher will answer any question that I have about this study. She provided her contact information on this form.



The purpose of this study is to understand the experience of Middle Eastern immigrant women during their cancer survivorship journey.



My participation is voluntary. I will not be paid for taking part in the study. I do not have to pay to be in the study. I will not be penalized if I step out of the study.



I agree to have a face to face/phone interview with the researcher.



I will fill out a demographic data sheet.



I agree to be audio-recorded. I agree with any recording and notes to be kept privately by the researcher as a source of data.



The researcher will ask me one open-ended question. I will describe my experience as a cancer survivor.



I can share as much or as little information as I wish in the interview. The interview is going to be in a private, safe, and comfortable place chosen by me.



There might be no direct benefit to me from my participation. My ideas may give practical guidance to health care providers and policymakers to reform or promote the health services for immigrant cancer patients. Some people, however, do think it is helpful to talk about their experiences.



There are no physical risks associated with this study.



If I become distressed/emotional during the interview, the researcher will stay with me until I feel better or until a friend or a family member is with me. However, if I experience signs of increased distress, the interview will be stopped and only resumed, if and when, I feel comfortable to continue. The researcher will assist with seeking professional help if needed.



The researcher will call me within 48-hours after the interview to make sure I am fine.



The researcher may write papers for presentation at professional meetings. She may publish articles in professional scientific journals. The researcher can share the final study report with decision makers.



All materials and data will be used for research purposes only.



A summary of the findings will be sent to me in English or Arabic if I request.



All identifying information will be removed from the interview transcripts. I will choose a false name to be used.



All information and data will be treated with confidence. All information will be stored in a locked cabinet in the principal researcher's office. The researcher of this study has access to my data, which will be destroyed after seven years.



It is possible that data from this study may be used in another research study. However, this would only occur with my permission.



I may withdraw from the study at any time without any penalty and without giving any reasons.



If I withdraw from the study, my information and data will be destroyed.



One copy of this signed consent form will be given to me.



I have read the consent form and agreed to participate in this project.

Signing this form indicates your willingness to participate in this study. It informs the researcher that you understand the information about the research study. However, signing this form does not mean that you give up your rights. You are free to withdraw from the study at any time.

You can also talk to Dr. Steven Turner from the University of New Brunswick to know more about your rights as a participant in a research study. Dr. Steven Turner (Chair, University of New Brunswick Ethics Board) University of New Brunswick, Phone: 506 453-5189

This project has been reviewed by the University of New Brunswick Research Ethics Board and is on file as REB 2018-151

This project has been reviewed by Horizon Health Network Research Ethics Board and is on file as HHN REB 2019-2725

Please, see the signature page,

### Signature Checklist

**Study title:** The Lived Experiences of Middle Eastern Immigrant Women during their Cancer Survivorship journey

To be filled out and signed by the participant:

Please check as appropriate:

#	Checklist	Yes	No
1	I have read the consent form, or had it read to me by the researcher.		
2	I have been given sufficient information about the study.		
3	I have had the opportunity to ask questions.		
4	I have been given satisfactory answers to all my questions.		
5	I understand that my participation in this study is voluntary and that I may not benefit.		
6	I agree to participate in this research study.		
7	I agree to have my interview audio-recorded/or send my description by email.		
8	I understand that I can withdraw from the study at any time and without having to give a reason		
9	I have had the limits to confidentiality, risks, and benefits related to this study clarified.		
10	I agree to be contacted in the future to permit for my data to be used in another study that has been approved by a Research Ethics Board.		
11	I would like to receive a summary of the research results.		

To be signed by the participant:

Name \_\_\_\_\_ Signature

\_\_\_\_\_

Date \_\_\_\_\_

To be signed by the researcher:

Name \_\_\_\_\_ Signature

\_\_\_\_\_

Date \_\_\_\_\_

## Appendix G: Recruitment Efforts

Recruitment Medium (Success)	Name
Cancer Support Group (n = 0)	Canadian Cancer Society New Brunswick Breast & Women's Cancer Partnership New Brunswick Breast Cancer Network
Multicultural Associations (n = 0)	Multicultural Association of Great Moncton Area Multicultural Association of Fredericton Multicultural Association of Saint John Association for New Canadians (Newfoundland and Labrador) Moncton Lebanese Association
Public places Posters (n = 0)	Moncton public library YMCA Moncton Muslim Association
Oncology Clinics (n = 0)	Moncton Hospital (Moncton) Dr. Everett Chalmers Regional Hospital (Fredericton) Saint John Regional Hospital (Saint John) St. Joseph's Hospital
Social Media and Networking (n = 3)	Facebook community support groups * WhatsApp community support groups
Snowballing (n = 0)	

\*I posted the research poster on various immigrant women's Facebook support groups, multicultural Facebook groups, breast cancer Facebook support groups, immigrants' Facebook groups. Some of these groups have over 500 followers others, such as the Arab immigrant women from the Middle-East, which has more than 17,000 followers.

## Curriculum Vitae

Candidate's full name: Enam Alsayheen

Universities attended (with dates and degrees obtained): Education

**Master's in Applied Health Services Research** | University of New Brunswick

SEP 2017 – DEC 2019

**Certificate in Occupational Health & Safety** | University of Northern British Columbia

JAN 2013– DEC 2013

**Ph.D. in Chemistry** | University of Calgary

JAN 2007– JUN 2012

**MSc. in Chemistry** | Jordan University of Science and Technology

SEP 2003 – JUN 2005

**BSc. In Applied Chemistry** | Jordan University of Science and Technology

SEP 1999– FEB 2003

Publications:

**E. Alsayheen** & K. Aldiabat, Nicotine Vaccines for Smoking Prevention and Treatment from Utilitarian and Deontological Ethical Perspectives, *Online Journal of Health Ethics*, 14 (2) (2018).

**E. Alsayheen** & K. Aldiabat, Applied Health Services Research as a Framework for Patient-Oriented Research: A Suggested Framework for Health Care Researchers, *the International Journal of Nursing Student Scholarship*, 5 (2018) 1-9.

**E. Alsayheen**, B. Campbell, R. Rateick, and V. Birss, Effect of AC/DC Spark Anodization Current and Time on the Oxidation of Al-Cu Alloy, *Journal of the Electrochemical Society* 160 (2013) C369-C379.

**E. Alsayheen**, B. Campbell, E. McLeod, R. Rateick, and V. Birss, Exploring the Effect of Alkaline Silicate Solution Composition on the AC/DC Spark Anodization of Al-Cu Alloys, *Electrochimica Acta* 60 (2012) 102-111.

**E. Alsayheen**, E. McLeod, R. Rateick, H. Molereo, and V. Birss, Impact of AC/DC Spark Anodizing to Enhance the Corrosion Resistance of Al-Cu Alloys, *Electrochimica Acta*, 56 (2011) 6041-6048.

**E. Alsayheen**, E. McLeod, R. Rateick, and V. Birss, Effect of Solution Properties on the AC/DC Spark Anodizing of Al-Cu alloy AA2219, *Electrochem. Soc. Trans.* 25 (2010) 57-68

D. Banham, F. Feng, J. Burt, **E. Alsayheen**, and Viola Birss, Bimodal Templated Mesoporous Carbons for Capacitor Applications, Carbon 28 (2010) 1056-1069

Conference Presentations:

#### **Abstracts Accepted for Oral Presentation**

**E. Alsayheen** (presenter), H. Molero, R. Rateick, and V. Birss, Oxide film Growth by AC/DC Spark anodization on Al-Cu Alloys, Presentation Abstract #: 1636, The Electrochemical Society 220 Meeting, Boston, USA (2011).

**E. Alsayheen** (presenter), B. Sebastian, R. Rateick, V. Birss, Effect of Current Density and Time on the Spark Anodization of the Al-Cu Alloys. Presentation Abstract #: 883, the Electrochemical Society 217 Meeting, Vancouver, Canada (2010).

**E. Alsayheen** (presenter), E. McLeod, R. Rateick, V. Birss, Effect of Solution Properties on the AC/DC Spark Anodizing of Al-Cu alloy AA2219, presentation Abstract #: 1920, The Electrochemical Society 216 Meeting, Vienna, Austria (2009).

D. Banham, F. Feng, **E. Alsayheen**, J. Burt, V. Birss, Synthesis of High Capacitance Ordered Mesoporous Carbon Material. Poster Abstract #: 467, the Electrochemical Society 215 Meeting. San Francisco, USA (2009).

#### **Abstracts Accepted for Poster Presentation**

K. Aldiabat, **E. Alsayheen** (presenter), C. Aquino-Russell, M. Clinton, Roger Russell, The Lived Experience of Syrian Refugees/Newcomers in New Brunswick-Canada a Descriptive Phenomenological Study, Poster Abstract #: 599851, North American Refugee Health Conference, Toronto (2019)

**E. Alsayheen** (presenter), The Lived Experiences of Middle Eastern Immigrant women during their Cancer Survivorship journey, Poster abstract # 167, CAHSPR Conference, Halifax (2019)

K. Aldiabat, **E. Alsayheen** (presenter), C. Aquino-Russell, M. Clinton, Roger Russell, The Lived Experiences of Syrian Refugees/Newcomers in New Brunswick-Canada a Descriptive Phenomenological Study, Poster Abstract #: 64, The New Brunswick Health Foundation Conference, Fredericton (2018).

Honours & Awards:

Faculty of Graduate Student Travel Award (national conference), University of New Brunswick, Fredericton, NB (2019) (CAD 500)

Master of Applied Health Services Research/Maritime SPOR Support Unit special scholarship, (2019) (CAD 6000)

Dr. Nora Ni Chuiv CFUW Fredericton Graduate Scholarship, University of New Brunswick, NB (2018) (CAD 2000)

Faculty of Graduate Studies Travel Award (national conference), University of Calgary, Calgary, AB (2010) (CAD 500)

Faculty of Graduate Studies Travel Award (international conference), University of Calgary, Calgary, AB (2011) (CAD 1000)

Graduate Student Association Bursary: University of Calgary, Calgary, AB (2010) (CAD 1000)

Faculty of Graduate Studies Award (two times): University of Calgary, Calgary, AB (2008, 2010) (CAD 5000 each)

Faculty of Graduate Studies Scholarship: University of Calgary, Calgary, AB (2007-2011) (22,000 CAD/year for 5 years)