Experience of Oncology Nurses and Cancer Survivors during Cancer Treatment Transition from Oncology Teams to Primary Care Providers Teams

by

Guang Sun

A thesis submitted to the
School of Graduate and Postdoctoral Studies in partial
fulfillment of the requirements for the degree of

Master of Health Sciences (MHSc)

in Community, Public and Population Health

Faculty of Health Sciences

Faculty of Health Sciences

University of Ontario Institute of Technology (Ontario Tech University)

Oshawa, Ontario, Canada

July, 2020

© Guang Sun, 2020

THESIS EXAMINATION INFORMATION

Submitted by: **Guang Sun**

Master of Health Sciences (MHSc)

Thesis title: Experience of Oncology Nurses and Cancer Survivors during Cancer Treatment Transition from Oncology Teams to Primary Care Providers Teams

An oral defense of this thesis took place on June 25, 2020 in front of the following examining committee:

Examining Committee:

Chair of Examining Committee	Dr. JOANNE ARCAND
Research Supervisor	Dr. MANON LEMONDE
Examining Committee Member	Dr. DOMINIQUE TREMBLAY
Examining Committee Member	Dr. BRENDA GAMBLE
Thesis Examiner	Dr. RAYMOND CHAN, Queensland University of Technology

The above committee determined that the thesis is acceptable in form and content and that a satisfactory knowledge of the field covered by the thesis was demonstrated by the candidate during an oral examination. A signed copy of the Certificate of Approval is available from the School of Graduate and Postdoctoral Studies.

ABSTRACT

Cancer care for cancer survivors in treatment transition is fragmented. This phenomenological study explored experience of oncology nurses and cancer survivors in treatment transition.

Patient and nurse participants were recruited by purposive sampling for individual semi-structured interview. Nursing Theory of Transition framework and Interpretative Phenomenological Analysis approach were applied to guide the study for data collection and analysis.

Cancer survivors had concerns under personal transition and faced challenges under care transition. Oncology nurses were well positioned to play key role to provide quality cancer care. However, cancer care received was not sufficient to address cancer survivor's concerns comprehensively. Positive experience and barriers for cancer care were explored. Implications and recommendations were suggested.

Facing current context of Canadian health system with limited resources, this study would potentially provide helpful information to establish a new model for continuous and coordinated cancer care for cancer survivors in treatment transition

Keywords: oncology nurses; cancer survivors; treatment transition;

AUTHOR’S DECLARATION

I hereby declare that this thesis consists of original work of which I have authored. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I authorize the University of Ontario Institute of Technology (Ontario Tech University) to lend this thesis to other institutions or individuals for the purpose of scholarly research. I further authorize University of Ontario Institute of Technology (Ontario Tech University) to reproduce this thesis by photocopying or by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research. I understand that my thesis will be made electronically available to the public.

The research work in this thesis that was performed in compliance with the regulations of Research Ethics Board of both **University of Ontario Institute of Technology (Ontario Tech University) under REB File # 14995 and The Lakeridge Health under REB RI-ID#: 2018-013.**

GUANG SUN

STATEMENT OF CONTRIBUTIONS

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication. I have used standard referencing practices to acknowledge ideas, research techniques, or other materials that belong to others. Furthermore, I hereby certify that I am the sole source of the creative works and/or inventive knowledge described in this thesis.

ACKNOWLEDGEMENTS

Firstly, I would like to highly thank my supervisor Dr. Manon Lemonde for your unconditional supports and meaningful guidance. Dr. Manon Lemonde demonstrates excellent mentoring, leadership, and supervision skills for my graduate research. I am exceedingly grateful for your motivation, critical insights, and invaluable comments and recommendations throughout the entire research process. Your enthusiasm and passionate for pursuit for knowledge and research always inspire me to go forwards. Under your supervision and mentoring, I am confident to achieve my master study. I highly appreciate all you have done for me.

Secondly, I would like to highly thank my thesis committee members, Dr. Dominique Tremblay and Dr. Brenda Gamble, for taking interest in my wok and guiding me in productive directions. I highly respect and appreciate your comments, recommendations, and positive feedback throughout my thesis journey. I admire the time and efforts you have put in ensuring I have been on the right track. Your expertise in research methodologies has greatly benefited towards my study. I am grateful to you. In addition, I want to thank the work of the External Examiner Dr. Raymond Chan.

Thirdly, I would like to thank Virginia Mulcahy, Darrilyn Lessels, Deborah Devitt, Yvonne Mais, and Ken.McFarlan. I sincerely appropriate your supports and constructive suggestions and recommendations that help promote my research.

Fourthly, I would like to thank all participants for your contributions to this study. I highly appreciate the time you spent. The information you shared with me has greatly benefited the outcomes of my research. I hope I have represented you well.

Lastly, I would like to thank my wife, Julia and my son, Tim for your unconditional love, supports, and motivation, especially during my lowest moments. I also want to thank my parents for instilling in me the importance of education and a strong work ethic. You are always here with me.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1

CHAPTER 2

CHAPTER 4

CHAPTER 5

LIST OF FIGURES

CHAPTER 2

CHAPTER 3

LIST OF ABBREVIATIONS AND SYMBOLS

ACS	American Cancer Society
ACSO	American Society of Clinical Oncology
AIHM	Academy of Integrative Health & Medicine
AHRQ	Agency for Healthcare Research and Quality
AL	Acute Leukemia
Allo-HSCT	Allogeneic Hematopoietic Stem Cell Transplantation
AML	Acute Myeloid Leukemia
CCO	Cancer Care Ontario
CCS	Canadian Cancer Society
CNA	Canadian Nurses Association
CPAC	Canadian Partnership Against Cancer
CSC	Cancer Survivorship Care
Dr. or PhD	Doctor of Philosophy
DRCC	R.S. McLaughlin Durham Regional Cancer Centre
GP	General Practitioner
HSCT	Hematopoietic Stem Cell Transplantation
ID	Identity Document
IFT	Illness Trajectory Framework
IOM	Institute of Medicine
IPA	Interpretative Phenomenological Analysis
LACE	Life After Cancer Epidemiology
NCI	National Cancer Institute
PCM	Patient Care Manager
PHO	Public Health Ontario
REB	Research Ethics Board
RN	Registered Nurse
SCP	Survivors Care Plan

SCT	Social-Cognitive Transition
TCC	Transition Care Clinic
The Class	After Cancer Group Teaching Class
UOIT	University of Ontario Institute of Technology
USA	United States of America
SES	Socioeconomic Status

Chapter 1. Introduction

The number of cancer survivors has been growing. Cancer survivors experience significant physical, psychological and socioeconomically issues during treatment transition. Treatment transition is defined as a phase for cancer survivors transitioning from oncology team for acute cancer treatment to primary care provider's team for follow-up cancer care. Treatment transition is considered as an important phase in the continuum of cancer care (Oliveira, Conceição, Araujo, & Zago, 2018). After completion of acute cancer treatment, the cancer survivors continue to experience lasting side effects for months to years from both the cancer and the treatment including high risks of morbidity, reduced quality of life, and premature mortality **(**McCabe, Partridge, Grunfeld, & Melissa, 2013). Coordinated and continuous cancer care for cancer survivors transitioning from oncology care to primary care after completion of acute cancer treatment is considered to improve their quality of life (Berg et al., 2014; Tremblay et al., 2016). Unfortunately, coordination and continuity of cancer care for the cancer survivors in treatment transition is fragmented (Keesing, McNamara, & Rosenwax, 2014; Nekhlyudov, O'Malley, & Hudson, 2017; Tremblay et al, 2017). Among healthcare professionals for cancer survivors, oncology nurses deliver direct cancer care, coordinate healthcare providers, and support cancer survivors and families in treatment transition (Canadian Nurses Association (CNA), 2015; Chapman & Wiernikowski, 2011). A comprehensive search of the literature found no Canadian studies examining experience of oncology nurses working with cancer survivors, one quantitative study, and a few qualitative studies exploring the experience of cancer survivors during treatment transition. Through a phenomenological study, the researcher identifies the experience of the oncology nurses and the cancer survivors in treatment transition. Exploring and analyzing the lived experience of both oncology nurse providing cancer care for cancer survivors and cancer survivors receiving cancer care in treatment transition would promote understanding of their experience, identifying their perspectives promoting or inhibiting delivery of quality cancer care, and obtaining their suggestions to improve cancer care. The purpose of this phenomenological study is to explore the experience of oncology nurses and cancer survivors in treatment transition to determine what their lived experiences in treatment transition are, why their lived experiences are important to them, and how the meaning of nurse's and survivor's lived experience have been described from the perspectives of both oncology nurse and cancer survivors in treatment transition.

1.1 Background and Research Gap

With advancement in cancer treatment, the number of cancer survivors has been growing. It was estimated that 206,200 Canadians were diagnosed with cancer in 2017, indicating 32% increase in comparison to 2007 (Canadian Cancer Society (CCS), 2018). 90,483 Ontarians were expected to be diagnosed with cancer in 2018 (Cancer Care Ontario (CCO), 2018). It is also predicted that annual increase of 84% in Canadian males and a 74% in Canadian females over the next 10 to 15 years (Government of Canada, 2015). The increasing rate of cancer survivors is more than the growth rate of population in Canada (Canada Population Growth Rate, 2019). The percentage of cancer survivors is increasing overtime. Cancer survivors allows for longer survival with advancement in cancer treatment. Therefore, the more people with cancer, the more cancer survivors. The increasing number of cancer survivors comes new challenges that affect sustainable development of health care systems across Canada because of tension between the growing demand and the scarcity of resources (Tremblay et al., 2017).

Cancer is considered a chronic disease (American Cancer Society (ACS), 2016; Boland, Bennett, & Connolly, 2018; Hewitt, Greenfield, & Stoval, 2005). With significant advances in cancer treatment, many cancers can be controlled and managed for long periods. However, cancer is different from other chronic diseases. Patients living with cancer face high risk of cancer recurrence and many other conditions express because of the cancer and its treatment. As a result, cancer survivors have a number of complex tasks to manage and control (Klimmek & Wenzel, 2012). Regardless of different types of cancer and treatment, general health and quality of life for cancer survivors tend to decrease due to impairment of physical, psychological and social functioning in treatment transition (Dunberger & Bergmark, 2012; Miyashita et al., 2015; So et al., 2014). Coordinated and continuous cancer care for the cancer survivors transitioning from oncology care to primary care is considered to improve the effectiveness of cancer care and enhance health outcomes of cancer survivors (Berg et al., 2014; Gorin et al., 2017; Tremblay et al., 2016). Coordination and continuity of cancer care are organizational characteristics to ensure fluid transition between milieus of cancer care. According to Haggerty et al (2003), oncology nurses have important roles to identify cancer survivor’s preferences, values, and context, facilitate healthcare team coordination, and manage conditions of cancer survivors to meet their changing needs in treatment transition. Continuity of cancer care is defined as the systematic assurance of uninterrupted, integrated medical and psychosocial care for cancer patients from diagnosis of cancer, throughout the phase of acute treatment, and for the duration of post-acute treatment until death, and it involves consistent information and flexibility in response to cancer patient's needs (King et al., 2008; Lauria, 1991). The coordinated cancer care for cancer survivors refers to cancer survivors-centered and interdisciplinary health team-based activities to optimize available health resources, apply up-to-date evidence -based practice, and effectively and efficiently deliver health service (Agency for Healthcare Research and Quality (AHRQ), 2014; Chapman & Wiernikowski, 2011; Segall & Fries, 2017; Tremblay et al., 2017). The coordinated cancer care would maximize involvement of cancer survivors and families for health care professionals to assess and meet their needs to achieve their optimal health and wellness across the cancer survivorship trajectory (AHRQ, 2014; Chapman & Wiernikowski, 2011; Segall & Fries, 2017; Tremblay et al., 2017).

Treatment transition in oncology is an important phase in the continuum of cancer care for cancer survivors (Oliveira et al., 2018). A treatment transition refers to a change in healthcare settings of cancer care, shift of healthcare teams, and types of cancer care. Treatment transition is defined as a phase for cancer survivors transitioning from oncology team for acute cancer treatment to primary care provider's team for follow-up cancer care. In 2005, the Institute of Medicine's (IOM) released a seminal report: From Cancer Patient to Cancer Survivors: Lost in Transition which indicated that the cancer survivors experienced significant physical, psychological and socioeconomically issues during treatment transition and also suggested the survivors care plans (SCPs) and coordination of healthcare teams to meet the cancer survivors' needs for information and supports (Hewitt et al., 2005; Lester, Wessels, & Jung, 2014). Professionals are not well prepared for the treatment transition and are not aware of the in-between experience of cancer survivors transitioning from oncology care to primary care (Hebdon, Abrahamson, Griggs, & McComb, 2018; Tomasone et al., 2016). Consequently, the coordination and continuity of cancer care in treatment transition is fragmented and suboptimal. This is reflected as uncoordinated cancer care between healthcare teams, work in silo for providing cancer care, ineffective symptoms and/or concerns management, and loss in contact with healthcare team in treatment transition (Keesing et al., 2014; Nekhlyudov et al., 2017; Tremblay et al., 2017). The lack of cancer care coordination lead to inefficiencies in care, increase in health care expenses, and reduced quality of life for cancer survivors (McCabe et al., 2013). For example, successful transition back to work were concerns for many cancer survivors. The cancer survivors experienced functional impairment and problems at work caused by ineffective and/or poor cancer treatment for symptoms burden (pain, fatigue and emotional distress) and lack of accommodation (e.g. flexible accommodation strategies) (Moskowitz, Todd, Chen, & Feuerstein, 2014; Pransky et al., 2016). Consequently, their ability retuning to work and/or remaining at work were impaired. Another study discussed a case of female adult cancer survivor undergoing many failure events caused by fragmented cancer care in treatment transition from oncology team to primary care provider's team (Tremblay et al., 2016). The study emphasized the importance of coordination towards quality and safety of cancer care and also indicated that shared leadership including shared responsibility and mutual influence among patients, families, oncology team and primary care provider's team promotes coordination of cancer care in treatment transition for cancer survivors (Tremblay et al., 2016).

Oncology team located at tertiary hospitals specializes in different areas of oncology and is responsible for diagnosing and treating cancer while primary care provider team located in community provides preventive care, identifies and treats common medical conditions, assesses the urgency of medical problems, and makes referrals to oncology specialists when necessary (American Society of Clinical Oncology (ASCO), 2018 A; Aubin et al., 2012; Sisler, Brown, & Stewart, 2004). Cancer patients received diagnosis and acute cancer care in the inpatient department of hospital from oncology team. After completion of cancer diagnosis and acute cancer treatment, cancer patients were transferred from inpatient department of hospital and oncology team to outpatient department and/or clinic and primary care provider's team. One qualitative study explored the experience of patients with adult acute myeloid leukemia (AML) in the transition from inpatient to outpatient settings for subsequent consolidation chemotherapy for cancer in Toronto, Canada (Nissim et al., 2014). Cancer patients were not well prepared for treatment transition since they were to assume greater responsibility for their care than expected and they also struggled to construct a new sense of identity. Nissim et al. (2014) believed that the AML patients left acute care setting sicker suggest that considering patients' perceptions can inform interventions to facilitate treatment transition from inpatient to outpatient care. Canadian Partnership against Cancer (CPAC, 2016) conducted a national online survey to measure the experiences of cancer patients in transition. The results indicated that many cancer survivors have physical, emotional and practical concerns and did not receive help to reduce suffering or alleviate concerns (Fitch et al., 2018). However, there are no qualitative study to investigate what new identities of Canadian cancer survivors are, the meaning of survivorship, how they adjust to new ‘normal’ life, how the physical, emotional and practical concerns affect their quality of life, what are cancer survivor’s perspectives promoting or inhibiting the delivery of quality cancer care, and what are their suggestions and recommendations to meet their needs and improve their quality of life in treatment transition. These significant knowledge gaps support the necessity and importance of this study on Canadian cancer survivors in treatment transition. The findings from investigating lived experience of cancer survivors will help add knowledge and fill in the literature gap.

Yuille, Bryant-Lukosius, Valaitis, and Dolovich (2016) conducted a research on oncology nurses but they only focused on oncology nurse’s roles in working with cancer survivors on primary care teams in an Ontario primary care setting. The authors indicated that participants' involvement in cancer survivorship care (CSC) was limited. It could be categorized into three themes: care coordination and system navigation, emotional support and facilitating access to community resources. This study claimed that factors such as individual, practice setting, and primary care team influenced nurses' involvement in CSC. However, the experience of oncology nurses providing cancer care for cancer survivors in treatment transition from oncology team to primary care provider’s team is unknown.

Researchers who explored the needs of cancer survivors and perspectives of physicians have indicated that oncology nurses play a vital role in development and implementation of coordinated and continuous cancer care for cancer survivors in treatment transition (Klemp, 2015; McCabe & Jacobs, 2008; Robinson, Piacentine, Waltke, Ng. & Tjoe, 2016). Transition is a nursing concern because it is associated with health and/or illness (Schumacher & Meleis, 1994). Nurse roles are helping patients complete healthy transitions. Schumacher and Meleis (1994) conceptualized nursing therapeutics as three measures those widely applicable to therapeutic nursing interventions during transition: assessment of readiness, the preparation for transition, and role of supplementation. The assessment of readiness refers to understanding patients, needing interdisciplinary efforts, and assessing each of the transition conditions to generate sketch of client readiness and allow clinicians and researchers to determine pattern of transition experience. The preparation for transition refers to applying therapeutic interventions such as education to generate the best conditions and ensure patient to be ready for a transition. Role supplementation refers to conveying information and providing support needed to bring role incumbent and significant others to full awareness of the anticipated behavior pattern, units, sensations, and goals involved in each role and its complement. However, little is known about the experience of the oncology nurses in treatment transition in Canada. This significant knowledge gap supports the necessity and importance of this study on oncology nurses. Under the guide of Nursing Theory of Transition framework (Schulman-Green et al., 2012; Schumacher & Meleis, 1994), this study is to explore the experience of oncology nurses providing cancer care for cancer survivors and cancer survivors receiving cancer care in treatment transition in order to add body of knowledge to the research gap.

1.2 Research Questions

The research questions are as follows:

- What is the experience of cancer survivors during cancer treatment transition from oncology teams to primary care provider’s teams?
- What is the experience of oncology nurses during cancer treatment transition from oncology teams to primary care provider’s teams?
- What are similarity and difference between experience of oncology nurses and cancer survivors during cancer treatment transition from oncology teams to primary care provider’s teams?

1.3 Research Purpose

The purpose of this study is to explore the lived experience of oncology nurses providing cancer care for cancer survivors during treatment transition, the lived experience of cancer survivors who receive cancer care from oncology nurses during treatment transition, and compare and contrast their experiences. The treatment transition includes personal transition and care transition according to the Nursing Theory of Transition framework that is used in this study. The personal transition is associated with physical, emotional, and social transition. The care transition is associated with transition from inpatient departments of hospital to outpatient departments/clinics/home, from oncology team to primary care provider team, from acute cancer treatment to follow-up cancer care. The details for the Nursing Theory of Transition framework will be discussed in Chapter Two. The objectives of the study on the lived experience of oncology nurses are to (1) describe what kinds of cancer care and/or services the oncology nurses provide and/or suggest for cancer survivors during treatment transition,

(2) What are their perspectives promoting or inhibiting delivery of quality cancer care, and (3) what are oncology nurse's suggestions and/or recommendations to improve cancer care to meet cancer survivor's needs and their quality of life. The objectives of the study on the lived experience of cancer survivors are to describe (1) what are cancer survivors' experience during treatment transition, (2) what kinds of cancer care and/or services cancer survivors receive during the treatment transition, (3) what are their perspectives promoting or inhibiting delivery of quality cancer care , and (4) what are cancer survivor's suggestions and/or recommendations to improve cancer care and meet their needs. The study also compares and contrasts the lived experience of oncology nurses and cancer survivors during treatment transition, their perspectives promoting or inhibiting delivery of quality cancer care, and suggestions and/or recommendations to improve cancer care, meet their needs, and improve their quality of life.

1.4 Significance

After the completion of the literature review, it seems that this is the very first Canadian study aimed to explore the experience of oncology nurses providing cancer care for cancer survivors during treatment transition from oncology teams to primary care provider's teams. A cancer survivor is a person with cancer of any type who is still living after completion of acute cancer treatment. The study will develop the essence of the lived experience of both oncology nurses and cancer survivors and add body of knowledge in literature gap by describing what oncology nurses and cancer survivors have experienced, interpreting how they experience it, and discussing what affects their experience. Findings of the research will promote better understanding of what cancer survivors experience and what oncology nurses practice and their contribution to cancer survivors in treatment transition. More importantly, the study will identify perspectives of oncology nurses and cancer survivors about what promote or hinder the delivery of quality cancer care in treatment transition. These results would potentially provide important information and suggestions to encourage involvement of cancer survivors, identify needs for education, and improve nursing care practice to meet cancer survivors' needs and improve quality of life for cancer survivors in treatment transition.

1.5 Summary

This chapter introduced background of the research topic and indicated the research gap. The research question and purposes were developed based on the research gap. In addition, the research significance was presented. In the following chapters, the researcher conducted literature review, reported method for data collection and analysis, described and analyzed results of data and information collected, discussed the research findings and compared them with other current research, and concluded the study.

In Chapter 2, the researcher demonstrated the process of literature review, identified knowledge gap and key themes in treatment transition, and justified Nursing Theory of Transition as the framework to guide this research. In Chapter 3, the researcher reported in detail for data collection and analysis method including ethical consideration, research design, setting and participants, data collection process, and data analysis method. In Chapter 4, the researcher presented the results of the experience of patient and nurse's participants in treatment transition. In Chapter 5, the researcher discussed the research findings, compared, and contrasted these findings with those in other current researches. In Chapter 6, the researcher concluded the study including summary, strengths, limitations, and implications and recommendations for practice, education, research, and policy. Table 1.1 provides outline for the six chapters. The Chapter 2 about literature review will be reported first.

Table 1.1 Outline for chapters

Chapters	**Outline**
Chapter 1	• Background of research topic • Research gap • Research questions
Chapter 2	• Process of literature review • Knowledge gap and key themes • Nursing Theory of Transition
Chapter 3	• Ethical considerations • Research design • Setting and participants • Data collection process • Data analysis method
Chapter 4	• Results of the experience of patient's participants in treatment transition • Results of the experience of nurse's participants in treatment transition
Chapter 5	• Discuss the research findings • Compare and contrast similarities and differences between results of patient and nurse participants • Compare these findings with those in other current researches • Discuss methodology • Discuss issues to be considered
Chapter 6	• Summary • Strengths • Limitations • Implications and recommendations

Chapter 2. Literature Review

The literature review process provides necessary background information to situate this research project. In this chapter, researcher reports literature review process, summarizes results, justifies the most relevant framework, discusses key themes, and identifies research gap.

2.1 Process of Literature Review and Summary of Results

Researcher did two literature reviews since their methodology and purposes were different. One literature review was to identify knowledge gap and key themes and the other was to identify relevant frameworks. They were reported in the following two sub-sections.

- Knowledge Gap and Key Themes
- Frameworks

2.1.1 Knowledge Gap and Key Themes

The purpose of literature review in this sub-section synthesized results of studies completed for the experience of oncology nurses and cancer survivors in treatment transition. Objectives include summarizing knowledge and key themes, critically analyzing the articles to identify research gap, and developing focus of this study.

To focus on the study of experience of oncology nurses and cancer survivors during treatment transition, articles included in this literature review were published and written in English since 2005. The inclusion criteria are: (1) cancer survivors are adults and/or elders; (2) experience of cancer survivors in treatment transition; and (3) experience of oncology nurses providing cancer care for cancer survivors in treatment transition.

This research focuses on coordinated and continuous cancer care for cancer survivors in treatment transition rather than patients under acute treatment. Coordinated and continuous care aims to prevent and/or reduce risks of morbidity, prevent recurrence of cancer, and decrease premature mortality while palliative or hospice care is delivered to patients with serious illness in the end stage of life, aiming to providing relief from the symptoms and stress of the serious illness. The search focuses on government documents in Canada at all levels rather than those from other countries. For these reasons, articles that studied children or adolescent cancer survivors, diagnostic test, acute treatment or palliative and/or hospice care, government reports and documents from other countries, and those written in non-English will be excluded.

A literature review of the peer-reviewed articles on oncology nurses and/or cancer survivors written in English since January 01, 2005 to September 30, 2019 was conducted through PubMed and CINAHL with the assistance of a health librarian and through UOIT library database by researcher. Literature has consisted of mostly coordinated and continuous cancer care for cancer survivors in treatment transition. Keywords included cancer or neoplasm, oncology, oncology nursing, cancer survivors, cancer survivorship, treatment transition or transition of care, cancer care trajectory, and coordinated and continuous cancer care (Table 2.1). A total of 1,841 articles was found; 444 relevant articles were identified based on inclusion and exclusion criteria. 212 articles were included in the qualitative synthesis. Researcher used PRISMA to report the process of literature review (Figure 2.1).

According to inclusion and exclusion criteria, researcher extracted the following types of articles identified through literature review.

- Articles about diagnostic of cancer, lab works, and acute care treatment such as medications, chemotherapy, radiation, surgery as well as hormonal therapy
- Articles for cancer survivors receiving acute cancer treatment due to diagnosis of new cancer and/or due to cancer recurrence
- Articles for cancer survivors receiving hospice and/or palliative care
- Articles for children or young cancer survivor less than 18 years old
- Articles for oncology nurses providing acute cancer care, palliative care and/or hospice care
- Articles for nurse practitioners, nurse navigators, or oncology nurses for navigation services
- Articles for family members and/or caregivers rather than for cancer survivors and/or oncology nurses
- Articles in which results of nurse participants could not clearly be identified due to several types of healthcare professionals as participants or cancer care provided by nurse participants were not sure in cancer treatment transition.

Researcher synthesized knowledge and themes from included articles by the following process:

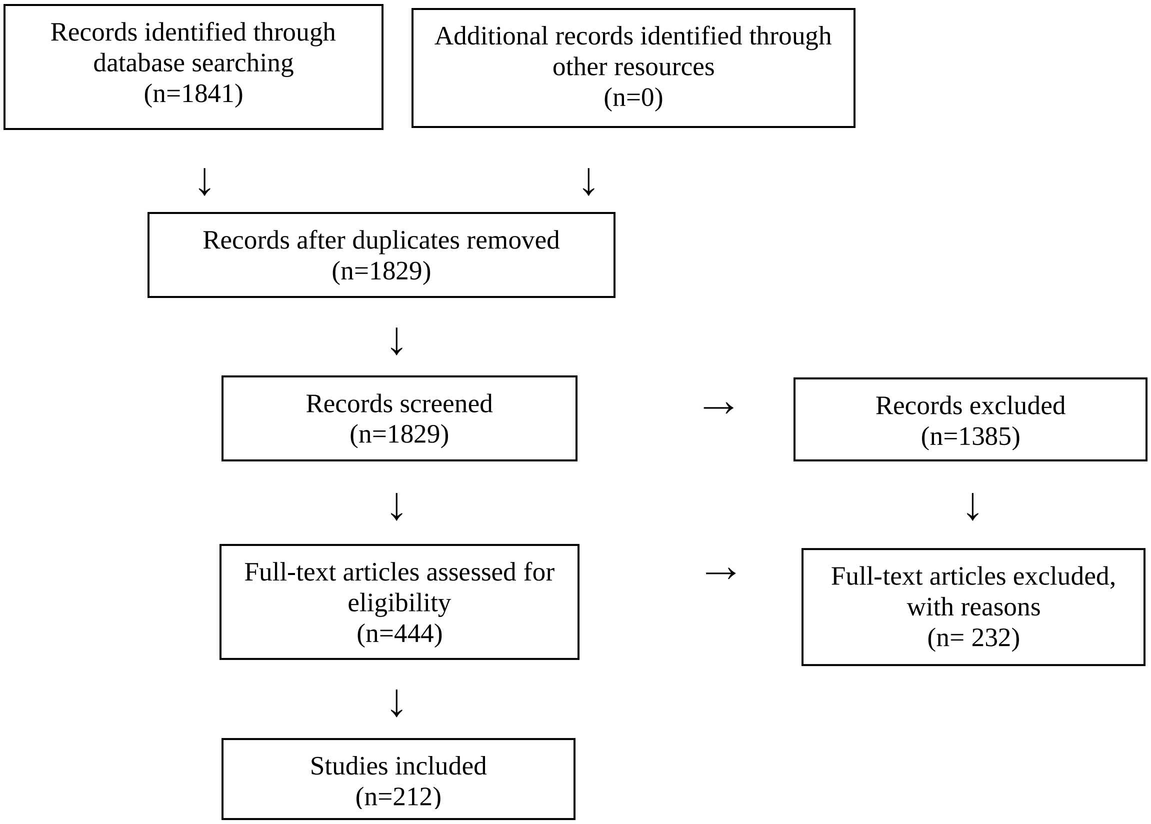
- Identify included articles
- Review one article first to identify themes for experiences of cancer survivors and/or oncology nurses in treatment transition
- Review and critically analyze other articles one by one to identify themes
- Develop a list of all themes identified
- Synthesize the results of themes and knowledge by deleting duplicate themes, grouping similar themes, and categorizing key themes

The key themes included definition of treatment transition; definition of cancer survivorship, cancer survivors and their needs; physical and emotional symptoms experience; new identity-cancer survivors; meaning of survivorship; getting back to “normal life”; return to work; regain sense of control; self-care management; coordination of healthcare teams; continuity of cancer care, and experience of oncology nurses in treatment transition. These key themes were discussed in the following sections from section 2.3 to section 2.14.

Table 2.1 Search terms for a literature review of the peer-reviewed articles

PubMed and CINAHL Key words	UOIT library database Key words
cancer survivor care in transition	cancer or neoplasm
cancer OR oncology AND "coordinated care"[Title] NOT palliative [Title/Abstract]	oncology
cancer OR oncology AND "coordinated care"[Title]	oncology nursing
cancer OR oncology	cancer survivors
coordinated care	cancer survivorship
	treatment transition or transition of care
	cancer care trajectory
	coordinated and continuous cancer care

Figure 2.1 PRISMA 2009 flow diagram for the literature review process



Main reasons for exclusion:

- Participants were not adult/elder cancer survivors
- Participants were not oncology nurses
- Oncology nurses did not provide cancer care in treatment transition
- Research topics were related to cancer diagnosis, treatment, and/or palliative care

2.1.2 Frameworks

The purpose of literature review in this sub-section identifies relevant frameworks to guide this study. Objectives include seeking out articles related to frameworks, and critically analyzing the articles, synthesizing results of frameworks, and identifying frameworks to guide research on care transition or treatment transition.

Literature review of the published articles on framework written in English since January 01, 1980 to September 30, 2019 was conducted through UOIT library database by researcher. Keywords included cancer survivors, cancer survivorship, treatment transition or transition of care, and framework (Table 2.2). Total 664 articles were found. 37 relevant articles were identified and 18 articles were included in synthesis. Researcher applied PRISMA to report the process of literature review (Figure 2.2).

According to inclusion and exclusion criteria, researcher extracted the following types of articles;

- Articles of frameworks on diagnosis, acute cancer treatment, follow-up cancer care, palliative care, or hospice care
- Articles about guidelines and/or protocols for healthcare professional practice
- Articles to guide healthcare interventions
- Articles of frameworks unrelated to health-illness transition, care transition, or treatment transition

Researcher synthesized knowledge and results of included articles for frameworks by the following process.

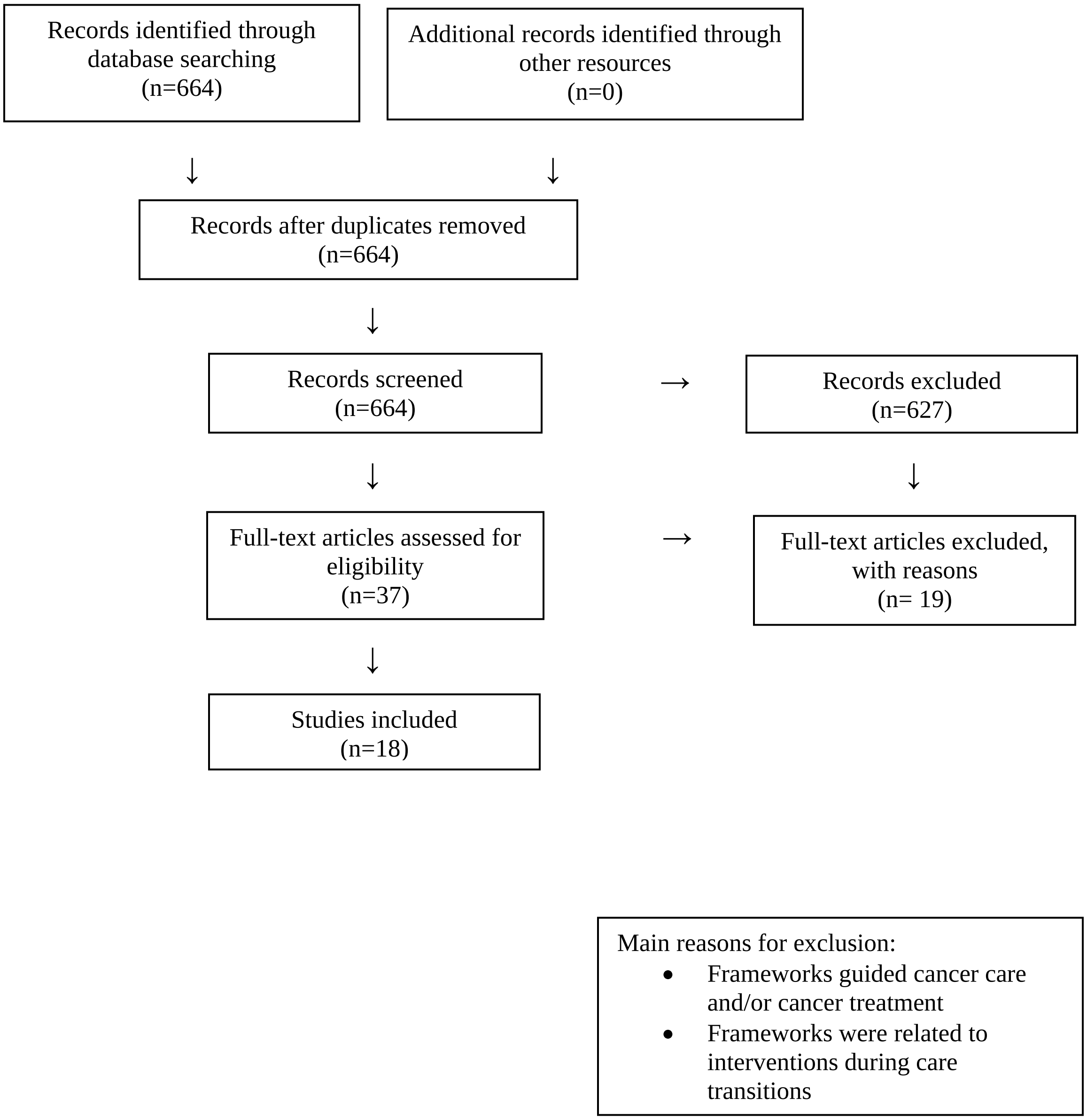
- Review included articles and understood properties of frameworks
- Seek application of frameworks in research
- Identify three relevant frameworks for this study.

There are three relevant research frameworks that may potentially guide this research study: Illness Trajectory Framework, Social-Cognitive Transition model, and Nursing Theory of Transition. These three frameworks were predominantly used in the literature review. They were described, compared and contrasted, and summarized how they were used in section 2.2. Nursing Theory of Transition was justified as the most relevant framework for this study in section 2.2.

Table 2.2 Search terms for a literature review of articles on framework

UOIT library database   Key words
cancer survivors
cancer survivorship
treatment transition or transition of care
framework

Figure 2.2 PRISMA 2009 flow diagram for the literature review process



2.2 Frameworks for Research

Researchers need frameworks to guide their studies, especially for novice researchers because applying a theoretical and conceptual framework for the research is a cornerstone for success (Gavin, 2016). A theory uses concepts, systems, and models to analyze events, processes consequences (Savin-Baden & Major, 2012). The theoretical framework is the frame for a researcher to interpret data or information. Theoretical frameworks are often used to confirm a research gap and to provide a justification for conducting a research. A researcher could think of a theoretical framework as being the way to describe the “why” or the “how” of a study (Ravitch & Riggan, 2012). Concepts are abstract ideas used to label phenomenon. Concepts are generalized from particulars to create the abstract idea. A conceptual framework is a system of concepts, assumptions, expectations and beliefs used to guide a research study. The conceptual framework helps researchers generate a systematic order to logic of the study. Miles and Huberman (1994) consider the conceptual framework as a way to focus and set boundaries for the research, especially for qualitative researchers. The researcher uses theoretical and conceptual frameworks to situate the research in order to gain insights by shaping the research’s methodology and design with the research question (Maxwell, 2013). When they are used well together, a theoretical and a conceptual framework provide a researcher with sufficient support to explain the need for the study in the field. To sum up, in a research based on a theory, the framework is theoretical framework while in a study based on a specified conceptual model, the framework is a conceptual framework (Polit & Beck, 2012). The Nursing Theory of Transition used in this study is a theoretical framework.

There are three relevant research frameworks that may potentially guide this research study: Illness Trajectory Framework, Social-Cognitive Transition model, and Nursing Theory of Transition. This section will describe, and compare and contrast the three frameworks at first. And then, the section will summarize how the three frameworks were used in the literature review. Finally, the section will justify Nursing Theory of Transition as the most relevant framework for this study and also discuss its application for this study.

2.2.1 Description of Three Frameworks and Their Properties

2.2.1.1 Illness Trajectory Framework (ITF)

Cancer can be a chronic illness much like diabetes or heart disease. Most chronic cancers cannot be cured, but some can be controlled for months or even years (Klimmek & Wenzel, 2012). Corbin and Strauss (1988) developed the ITF framework that focused on chronic disease management. The overall concept of chronic illness work extends to not only self-care or treatment efforts of patients and caregivers but to all aspect of their lives. Klimmek and Wenzel (2012) revised the ITF to describe the work of transitional cancer survivorship.

This framework includes three elements: illness-related work, biographical work, and everyday life work. Illness-related work remains substantial after completion of acute treatment. It refers to the tasks necessary to manage or treat cancer and the sequelae such as symptoms, disability, or loss of functions, including but not limited to: regimen work, symptom management, diagnostic and ongoing surveillance, crisis prevention and handling, and care-planning and maintaining continuum of care (Corbin & Strauss, 1988; Klimmek & Wenzel, 2012). Biographic work for cancer survivors involves maintaining or reconstructing one’s identity and self-concept (Corbin & Strauss, 1988; Klimmek & Wenzel, 2012). Cancer can cause serious disruption to survivors’ biography. Cancer survivors have repeatedly described cancer as a permanently life-changing experience that result in an ongoing process of adjustment throughout the duration of survivorship. The ITF describes biographical work in terms of a process involving four primary stages: contextualizing, coming to terms, reconstituting identity, and recasting biography (Corbin & Strauss, 1988; Klimmek & Wenzel, 2012). Everyday life work covers the remaining work context in which biographical and illness work occur (Corbin & Strauss, 1988; Klimmek & Wenzel, 2012). This work represents the activities and exertions that might have been part of a cancer survivor’s life in the absence of cancer, and into which the cancer experience must be integrated. Everyday life work includes concrete, externally focused tasks such as bill-paying, shopping, driving, cooking, and cleaning, as well as internal tasks, such as managing stress, anxiety, and emotion (Corbin & Strauss, 1988; Klimmek & Wenzel, 2012).

2.2.1.2 Social-Cognitive Transition (SCT) Model of Adjustment

Social-cognitive theorists regard cognitive and social transition as being the more critical issues (Towsley, Beck, & Watkins, 2007). Social-Cognitive Transition (SCT) model of adjustment framework combines coping theory and social-cognitive theory and proposes the Social-Cognitive Transition (SCT) model of adjustment, a clinical model that accounts for the frequent reports of healthy personal growth for people living with cancer (Brennan, 2001). The term ‘adjustment’ is widely used within the psycho-oncology to denote the absence of psychological morbidity and a return to premorbid function. Psychological adjustment is a topic of central importance to the lived experience of cancer survivors and an important concept for clinicians to consider in working with these survivors. Adjustment refers to the psychological process that occur over time as cancer survivors in their social world manage, learn from, and adapt to the multitude of changes which have been precipitated by cancer and its treatment (Brennan, 2001). However, these changes are not always, for the worse, sometimes they precipitate healthy personal growth in a number of areas. Social-Cognitive Transition model of adjustment is an attempt to account for both positive and negative adjustment for cancer survivorship. Importantly, this framework emphasizes the social context of experience for cancer survivors during treatment transition.

This framework includes three main elements: life trajectory, beliefs about the self, and nature of attachments. Life trajectory refers to cancer survivors' sense of themselves, or their identities that offer goals and rewards in their future. Beliefs about the self refers to cancer survivors' control and self-worth because belief in self-control is integral to their sense of safety, self-concept, and self-esteem to maintain non-depressed mood. Nature of attachments for cancer survivors may be threatened because whatever the objective prognosis, cancer confronts patients and those in their social world with the threat of permanent separation from loved ones (Brennan, 2001).

2.2.1.3 Nursing Theory of Transition

Transition is a nursing concern when they pertain to health and/or illness or when responses to transition include health-related behaviors (Schumacher & Meleis, 1994). Schumacher and Meleis (1994) developed a middle-range nursing theory of transition to supports the claim of centrality of transitions in nursing. They identified four types of transitions: developmental, situational, organizational, and health-illness transitions.

Developmental transition refers to shift of stages in the life cycle including birth, children, adolescence, becoming parents, menopause, aging, and death. A situational transition in particular is when a person experiences a reshaping in their career or lifestyle. Organizational transition refers to change from one organization to another in which the structure and function of organization are different. Organizational transition represents transitions in the environment. The change affects the lives of persons who experience organization transition. Health and illness transition include diagnostic illness, hospital discharge, and recovery process. A prominent concern is the transition from hospital to outpatient care and to the home environment (Schumacher & Meleis, 1994).

This research study focuses on health-illness transitions. Schulman-Green et al. (2012) proposed two types of health-illness transitions: personal and care transition. Personal transition includes (1) physical transitions (changes in symptom distress and functioning), (2) emotional transitions (times of psychological and emotional upheaval and adjustment), and (3) social transitions (shifts in family functioning, identities, relationship, and return to work). Care transitions include shifts in cancer status, treatment, or approach to care (curative care, follow-up care, palliative care, or hospice care.)

Despite the diversity of transitions, some commonalities are identified. One commonality is that transitions are processes that occur over time. The process involves development, flow, or movement from one condition to another. Many researchers have divided the transition process into stages or phases. Another universal property is found in the nature of changes that occur in transitions. Examples in cancer survivors include changes in identities, roles, relationships, abilities, and patterns of behavior. Conditions that may influence the quality of the transition experience and the consequences of transitions are meanings, expectations, level of knowledge and skill, environment, level of planning, and emotional and physical well-being. Indicators of successful transitions are subjective well-being, role mastery, and the well-being of relationships (Schulman-Green et al., 2012).

2.2.2 Compare and Contrast Three Frameworks

In 2005, the Institute of Medicine's (IOM) released a seminal report: From Cancer Patient to Cancer Survivors: Lost in Transition which indicated that cancer survivors experienced significant physical, psychological, and socioeconomically issues during treatment transition (Hewitt et al., 2005). My research question is "What is the experience of oncology nurses and cancer survivors during cancer treatment transition from oncology teams to primary care provider's teams?" To answer this question, researcher needs to explore the experience of the research participants about physical, psychological, and socioeconomically issues during cancer treatment transition.

2.2.2.1 Regarding Physical Issues during Cancer Treatment Transition

2.2.2.1.1 The Framework of the Illness Trajectory Framework (ITF)

The ITF guides researcher to study illness-related work that refers to the tasks necessary to manage or treat cancer and its sequelae including regimen work and symptoms management (Corbin & Strauss, 1988; Klimmek & Wenzel, 2012). The regimen work is related to maintenance of secondary and adjuvant therapy, treatment of function loss and physical changes arising post-treatment completion, and recommended modifications to lifestyle and diet designed to maintain optimal health and prevent recurrence. The symptoms management include fatigue, pain, taste changes, anorexia, malnutrition, nausea and vomiting, and challenges related to changes in sexual function (Klimmek & Wenzel, 2012). The framework is relevant to this research study.

2.2.2.1.2 Social-Cognitive Transition (SCT) Model of Adjustment

Social-Cognitive Transition (SCT) model of adjustment guides researcher to identify positive and negative experience during physical transition (Brennan, 2001). The positive transition means that a number of cancer survivors believe that their cancer life trajectory may help them to develop entirely new motivational priorities. However, many cancer survivors may experience the negative transition (Brennan, 2001). Cancer usually lead to a shortened life-expectancy and cancer survivors naturally have a preoccupation with the loss of goals, aspirations, and motivational structure in their lives that consequently result in an experience of hopelessness and depression (Brennan, 2001). The SCT model focuses on psychological adjustment to the results of cancer and its treatment, rather than physical transition. This is the weakness of the SCT model to explore experience of my research participants for physical transition such as symptoms management and recovery of body function.

2.2.2.1.3 Nursing Theory of Transition

Nursing Theory of Transition guides researcher to explore experience of cancer survivors and oncology nurses during physical transitions (Schulman-Green et al., 2012; Schumacher & Meleis, 1994). The Nursing Theory of Transition focuses on physical changes in symptom distress, changes in body image, loss of body functioning, and sexual function changes for cancer survivors during cancer treatment transition. The framework is relevant to this research study.

To sum up, the Nursing Theory of Transition and the revised Illness Trajectory Framework are more relevant than the Social-Cognitive Transition (SCT) model of adjustment to explore the experience of these research participants during physical transition.

2.2.2.2 Regarding Psychological Issues during Cancer Treatment Transition

2.2.2.2.1 The Revised Framework of Illness Trajectory Framework (ITF)

The ITF categorizes psychological work as a part of everyday life routine work that covers the remaining work context in which biographical and illness work occur (Klimmek & Wenzel, 2012). The psychological work in ITF refers to maintaining or improving psychological well-being through activities such as managing daily stress. The ITF mainly focuses on routine activities of daily life rather than the psychological issues. This is the weakness of ITF when researchers use it to explore emotional or psychologic experience of participants during cancer treatment transition.

2.2.2.2.2 Social-Cognitive Transition (SCT) Model of Adjustment

The SCT model guides researcher to identify both positive and negative experience of cancer survivors during psychological transition though beliefs about the self: control and self-worth (Brennan, 2001). Over the course of their cancer trajectory, many cancer survivors choose to collaborate more closely with their healthcare professionals and become better informed about their cancer and treatment and then they prefer to contribute actively to their treatment. This promotes positive psychological transition. However, some cancer survivors experience negative psychological transition. They perceive loss of personal control that develop from many sources such as high level of uncertainty concerning prognosis, and social discrimination (e.g. employment) towards cancer and disability. Consequently, cancer survivors lose confidence and increase anxiety (Brennan, 2001). This framework encourages cancer survivors to adjust to survivorship by assimilation, accommodation, and coping strategy. Guiding researchers to explore experience of participants during psychological transition is a strength of this framework.

2.2.2.2.3 Nursing Theory of Transition

Nursing Theory of Transition guides researcher to explore experience of cancer survivors and oncology nurses during psychological transition (Schulman-Green et al., 2012; Schumacher & Meleis, 1994). Schulman-Green et al. (2012) proposed two types of health-illness transitions: personal and care transition. Personal transition emphasizes emotional issues that focus on psychological upheaval and adjustment for cancer survivors during psychological transition. Care transitions include shifts in cancer status, treatment, approach to care and/or health settings.

To sum up, the Nursing Theory of Transition and the Social-Cognitive Transition model of adjustment are more relevant than the revised Illness Trajectory Framework to explore the experience of these research participants during psychological transition.

2.2.2.3 Regarding Socioeconomic Issues during Cancer Treatment Transition

2.2.2.3.1 The Revised Framework of Illness Trajectory Framework (ITF)

The revised framework of ITF developed by Klimmek and Wenzel (2012) categorizes socioeconomic issues in biographical work. The biographical work for cancer survivors involves maintaining or reconstructing one’s identity and self-concept. The conditions impacting cancer survivors' biography include life stage, salient aspect of self-loss that arise during cancer trajectory and ability to adapt, come to terms with losses, and move on (Klimmek & Wenzel, 2012). This model is not involved in economic issues such as employment for cancer survivors during treatment transition.

2.2.2.3.2 Social-Cognitive Transition (SCT) Model of Adjustment

The SCT model of adjustment guides researcher to identify positive and negative experience of social transition through a category of Nature of Attachments (Brennan, 2001). The re-examination and alteration of attachments and interpersonal roles can foster more creative, valued, and engaged relationships and some restoration of emotional honesty. The primary threat that cancer poses to relationships for cancer survivors is separation that result in stress and is associated with physical illness (Brennan, 2001). The SCT model of adjustment focuses on narrow topics such attachment and is not involved in other important socioeconomic issues such as return to normal life, return to work, and social roles changes.

2.2.2.3.3 Nursing Theory of Transition

Nursing Theory of Transition guides researcher to explore experience of cancer survivors and oncology nurses during social transition (Schulman-Green et al., 2012; Schumacher & Meleis, 1994). This framework draws researcher's attention to socioeconomic issues of cancer survivors on their shifts in family functioning, social relationship, return to normal life, and return to work during cancer treatment transition (Schulman-Green et al., 2012).

To sum up, the Nursing Theory of Transition is more relevant than both the Social-Cognitive Transition model of adjustment and the revised Illness Trajectory Framework to explore the experience of these research participants during social transition.

2.2.2.4 Regarding Cancer Treatment Transition from Oncology Care to Primary Care

This research study needs a relevant framework as a guide to explore the experience of oncology nurses and cancer survivors during cancer treatment transition from oncology teams to primary care providers teams

2.2.2.4.1 The Revised Framework of Illness Trajectory Framework (ITF)

The revised framework of the ITF developed by Klimmek and Wenzel (2012) categorizes cancer treatment transition in care-planning and maintaining continuum of care, which is one sub-category of Illness-related work. Unlike other chronic disease process, which can be managed continuously by primary care provider teams over the life course, oncology specialist teams whose roles shift to primary care provider team after cancer survivors have completed acute cancer treatment (Klimmek & Wenzel, 2012) generally treat cancer. Unfortunately, the cancer survivors can usually find themselves in a sort of limbo between two sets of providers' teams-the multidisciplinary oncology team that has managed their acute cancer treatment during the preceding months and primary care provider team who will continue to support them in the community. The revised framework of the ITF does not reflect on this transition characteristics regarding shifts between healthcare teams, healthcare settings, and cancer care during treatment transition from oncology team to primary care provider team. This is the weakness of the revised framework of the ITF because treatment transition not only include care planning for cancer disease but also related to psychologic work and social-economic work such as return to normal life, return to work, and relationship with others.

2.2.2.4.2 Social-Cognitive Transition (SCT) Model of Adjustment

The SCT model of adjustment focuses on encouraging the capsulation of cancer and adjust to cancer survivorship by applying coping strategies and accommodating limitation imposed by cancer (Brennan, 2001), rather than on the experience of cancer treatment transition between healthcare teams, healthcare setting, and cancer care from oncology team to primary care provider team.

2.2.2.4.3 Nursing Theory of Transition

Schulman-Green et al. (2012) proposed two types of health-illness transitions: personal and care transition. Care transition highlights importance of shifts in cancer status, treatment, or approach to care (Schulman-Green et al., 2012). Successful treatment transition from oncology care to primary care is considered to improve effectiveness of cancer care and quality of life for cancer survivors.

To sum up, the Nursing Theory of Transition is more relevant than both the revised framework of Illness Trajectory Framework and Social-Cognitive Transition (SCT) model of adjustment for researcher to explore the experience of my research participants during cancer care transition.

2.2.3 Application of Three Frameworks in Literature and Analysis

2.2.3.1 Illness Trajectory Framework (ITF)

Halcomb and Davidson (2005) demonstrated Corbin and Strauss Chronic Illness Trajectory Framework as a useful structure in describing survivor’s recovery from traumatic injury and enhancing the development of post-discharge interventions. Reed and Corner (2015) used the Corbin and Strauss Chronic Illness Trajectory Framework as a theoretical framework to explore and define the illness trajectory of metastatic breast cancer. They indicated that lives of women diagnosed with metastatic breast cancer were negatively affected by cancer and treatment with little evidence of symptom control or support. These two studies highlighted the utility of Corbin and Strauss Chronic Illness Trajectory Framework (1988) for chronic disease management, especially impact of physical symptoms experience of chronic diseases and treatment on patient’s lives. After Klimmek and Wenzel (2012) revised the ITF to describe the work of transitional cancer survivorship and experience of cancer survivors during treatment transition, it seems that no studies use this revised ITF to explore experience of oncology nurses and cancer survivors during treatment transition.

2.2.3.2 Social-Cognitive Transition (SCT) Model of Adjustment

Social Cognitive Transition model is a psychosocial framework that attempts to explain adjustment experiences among cancer patients (Brennan, 2001). Taylor, Todman, and Broomfield (2011) claimed that the SCT model provided a sound theoretical basis to understand patients diagnosed with stroke in treatment transition. Many patients following stroke faced challenges for their rehabilitation caused by increased emotional distress such as fear of recurrence, anxiety, frustration and cognitive changes such as deficits in attention and memory during post-stroke adjustment. It seems that no studies use this SCT Model of Adjustment to explore experience of oncology nurses and cancer survivors during treatment transition.

2.2.3.3 Nursing Theory of Transition

Schulman-Green et al. (2012) successfully used this framework to conduct a research in which they purposively selected women participants with ovarian cancer in the United States of America (USA) and applied individual interviews to explore women's self-management experience during treatment transition. This study highlighted the importance of Nursing Theory of Transition to explore experiences of cancer survivors during treatment transition.

However, Schulman-Green et al. (2012) only use this framework to explore the experience of ovarian cancer women for self-management in treatment transition. They (1) did not explore physical symptoms and emotional distress experience and their impact on cancer survivor's quality of life, (2) did not explore social experience of cancer survivor such as new identity, meaning of survivorship, and return to work of cancer, and (3) did not explore the experience of cancer survivors on healthcare team coordination and continuity of cancer care during shift of health settings and healthcare team in treatment transition. It seems that no Canadian studies use the Nursing Theory of Transition to explore experience of oncology nurses and cancer survivors during treatment transition.

2.2.4 Justify the Most Relevant Framework

The purpose of this research study is to explore the experience of oncology nurses providing cancer care for cancer survivors in treatment transition and the experience of cancer survivors who receive cancer care from oncology nurses. By comparing and contrasting the three relevant frameworks and analyzing the application of the three frameworks in literature, the Nursing Theory of Transition is the most relevant framework among the three potential frameworks for this research study because it has strength in physical, psychological and social transition as well as cancer care transition and it has also been successfully used to explore experience of cancer survivors in treatment transition in USA.

2.2.5 Application of the Nursing Theory of Transition in this Study

This research study focuses on health-illness transition. Schulman-Green et al. (2012) proposed two types of health-illness transitions: personal and care transition. This study explores the experience of oncology nurses and cancer survivors during cancer treatment transition from oncology team to primary care provider team. The researcher does not use transition from one care provider to another since acute cancer treatment is provided by the oncology team rather than one care provider and follow-up cancer care is provided by the primary care provider's team not another care provider. The oncology team includes various cancer care providers/professionals such as oncologists, palliative care doctors, nurse practitioners, oncology nurses, pathologists, registered dietitians, diagnostic radiologists, rehabilitation therapists, social workers, and patient navigators (ASCO, 2018C). The primary care provider's team includes various healthcare providers/professionals such as general practitioners, registered nurses, pharmacists, psychologists, dentists, physiotherapists, occupational therapists, counselors, and podiatrists (Smith, 2018).

2.2.5.1 Personal Transitions

Persona transition includes physical, emotional, and social transitions.

2.2.5.1.1 Physical Transition (changes in symptom distress and body functioning)

This framework can guide the researcher to explore experience of cancer survivors and oncology nurses about how to manage physical concerns and regain control of body for cancer survivors and what type of information and/or resources about physical care oncology nurses provide to help meet the need of cancer survivors during treatment transition.

2.2.5.1.2 Emotional Transition (times of psychological and emotional upheaval and adjustment)

This framework can guide the researcher to explore experience of cancer survivors and oncology nurses about how to manage emotional distress and how oncology nurses facilitate cancer survivors’ emotional adjustment and promote their psychological well-being during treatment transition.

2.2.5.1.3 Social Transition (shifts in identity, survivorship, normal life, return to work, relationship)

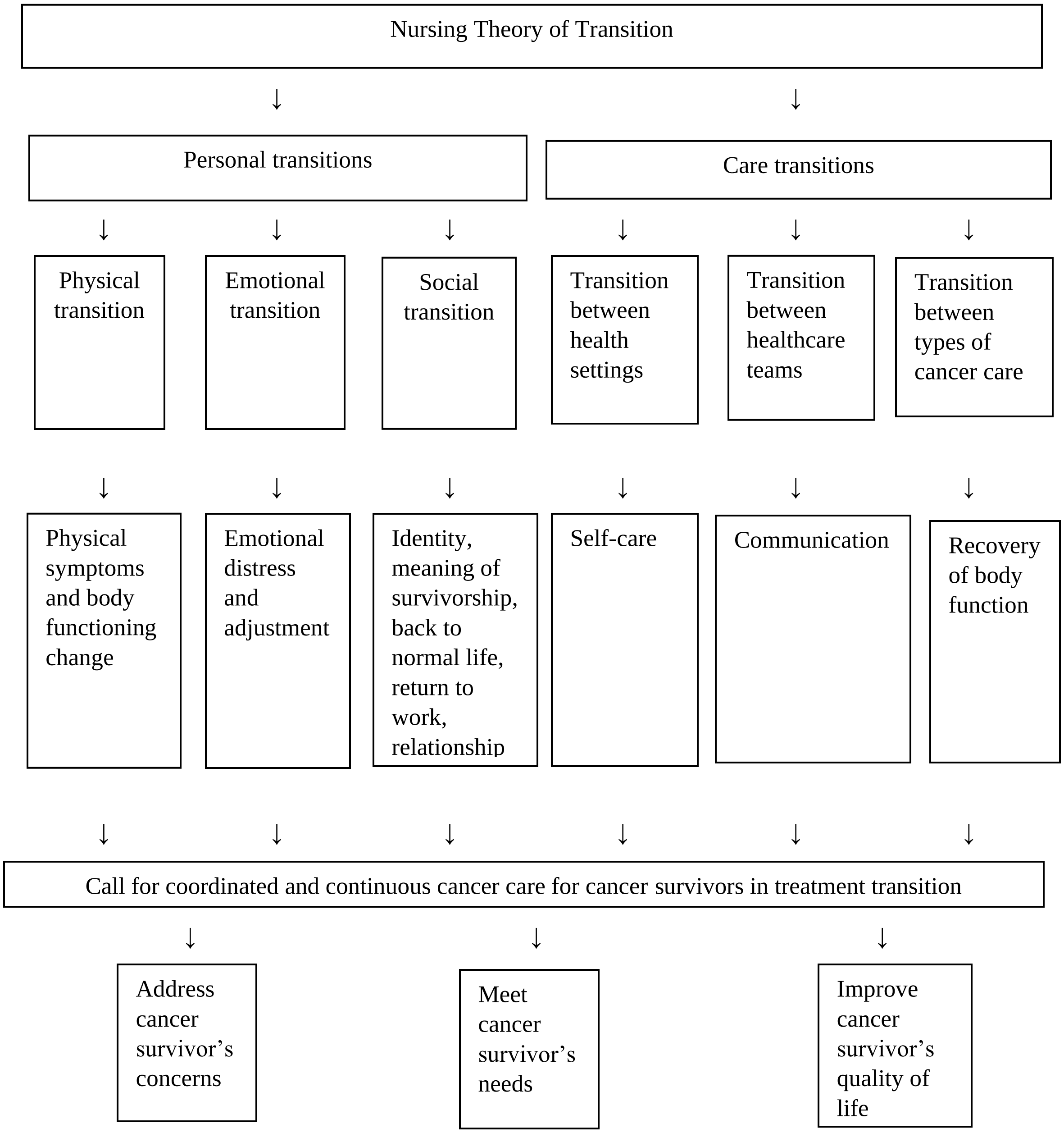
This framework can guide the researchers to explore experience of cancer survivors and oncology nurses about meaning of survivorship of cancer survivors, how oncology nurses support cancer survivors to identify and adjust their identity, changes of relationship to significant others during treatment transition as well as how oncology nurses promote cancer survivors' return to "normal" life and/or return to work.

2.2.5.2 Care Transitions

Care transition refers to shifts in cancer status, treatment, and approach to care and/or settings. This framework can guide researcher to explore experience of cancer survivors and oncology nurses about cancer survivors' self-care management; in addition, it can help in identifying what type of care/services oncology nurses provide and/or suggest to promote maximal recovery of body function during treatment transition as well. Their perspectives are important in promoting or inhibiting cancer survivors' needs and improve their quality of life during treatment transition.

Figure 2.3 is an illustration of the conceptual map for the Nursing Theory of Transition for cancer survivors in treatment transition.

Figure 2.3 Conceptual map for Nursing Theory of Transition for cancer survivors in treatment transition



2.3 Definition of Treatment Transition

Treatment transition for cancer survivor care has received increasing attention since the release of the 2005 IOM report – From Cancer Patient to Cancer Survivor: Lost in Transition that strongly recommends that at completion of cancer treatment, continuous cancer care contribute to quality of life for the cancer survivor (Boyle, 2009; Grant, Economou, Ferrell, & Uman, 2012; Hewitt et al., 2005). Treatment transition in oncology is an important phase in the continuum of cancer care for people living with cancer (Oliveira et al., 2018). A treatment transition denotes movement from one condition to another, resulting in changes and stress with either growth or deterioration (Wood, 2017). Concept of treatment transition has been widely used in the cancer lexicon. However, there is lack of a consensus definition of treatment transition in oncology (Wood, 2017). The confusion concerning the definition of treatment transition hinder understanding of cancer treatment transition and its importance in the coordinated and continuous cancer care for cancer survivors. In the literature, there is a variety of definitions of treatment transition in oncology based on transition of cancer care for growth and development of people living with cancer, movement between different healthcare settings, shift from one type of cancer care to another, and change between health care providers teams (Hebdon, Foli, & McComb, 2015; Oliveira et al., 2018; Thomson, Gorospe, Cooke, Giesie, & Johnson, 2015; Wood, 2017).

One definition for cancer treatment transition is related to growth and development of young cancer survivors. With advance in cancer treatment, most of children and adolescents with cancer has been surviving to adulthood (Hallowell, 2014; Hallowell, Boitnott, Epstein, & Schneider, 2013; Masterton & Tariman, 2016). Cancer patients and survivors, families, and health care providers face the need to move from pediatric- or adolescent- to adult-focused cancer care, which facilitate a successful treatment transfer and prepare them for achievement of developmental goals. The treatment transition in oncology for this growing population is defined as a purposeful, planned process with a goal of providing long term continuity of cancer care and preparing the young cancer survivors for great independence (Bryant, Porter, & Sobota, 2015; Svedberg et al., 2016). Likely, cancer treatment for young adult with cancer should consider their age-specific needs to enable better preparation for transitioning to adulthood such as body image, fertility, sexual relationship, work, and socializing (Matheson et al., 2016). The definition of treatment transition from acute treatment completion to follow-up care can be defined as a dynamic and ongoing adjustment process for young adult cancer survivors which facilitates recover and reentry to everyday life and achieves their developmental goals (Hauken, Larsen, & Holsen, 2013; Matheson et al., 2016). Therefore, treatment transition for children, adolescents and young adults living with cancer to their adulthood should consider for both recovery and age-specific developmental goals.

Another definition of treatment transition is related to movement of cancer survivors from one healthcare setting to another (Naylor & Keating, 2008). Treatment transition trajectory differs when cancer patients complete acute treatment in inpatient units of hospitals to become cancer survivors. Some cancer survivors may receive home cancer care while others may receive follow-up care in clinics and/or in outpatient settings of hospital. Treatment transition for cancer patients to receive home care as cancer survivors is defined as a phase that a broad range of service is designed to promote the safe and timely passage of patients between hospital and home and provide cancer survivors and their care givers with an ability to regain control and normality in their lives, to care for themselves, and manage physical and psychological distress from cancer and treatment while at home (Ang, Lang, Ang, & Lopez, 2016; Missel, Hansen, Jackson, Siemsen, & Schønau, 2018). However, definition of treatment transition for cancer patients to receive follow-up care in clinics is defined as a turning point which describes shift of healthcare settings from hospitals to clinics and/or outpatient settings of hospital and denotes ongoing cancer care provided by oncologist as per protocols and/or reentry to usual care provided by primary care providers teams (Hebdon et al., 2018; Hsueh & Dorcy, 2016; Wood, 2017). The treatment transition is defined as transition of cancer survivors from inpatient departments of hospital to clinics and/or outpatient setting. Determinants such as communication, complete transfer of information, adequate education of patients and their family caregivers and access to essential services ensure continuous and coordinated cancer care for cancer survivors during treatment transitions (Hsueh & Dorcy, 2016; Naylor & Keating, 2008). The expected outcomes are to promote the safe and timely passage of patients between healthcare settings (Naylor & Keating, 2008).

Third definition of treatment transition is related to shift from one type of cancer care to another for cancer survivors (Schulman-Green et al., 2012). People living with cancer usually have a cancer treatment trajectory from diagnosis, acute treatment, follow-up care, and cured, control, palliative care, or end-of-life care. Cancer patients may experience a precipitous change in their lives after a diagnosis of cancer. They mentally and emotionally approach diagnosis and treatment that affect their symptom experience and outcomes (Boehmke & Dickerson, 2006). Definition of treatment transition from health to cancer illness is defined as a shift from health promotion to acute cancer treatment for curing or controlling cancer (Boehmke & Dickerson, 2006). After cancer patients complete acute treatment, they may transition to follow-up care, self-management care, or palliative care. Regarding developing self-management care, treatment transition is defined as shifting cancer care from completion of acute cancer treatment to self-managed care by developing skills, becoming empowered, and creating supportive networks (Boland et al., 2018; Foster et al., 2015; Goldberg, Hinchey, Feder, & Schulman-Green, 2016). As for shift to follow-up care, treatment transition is defined as the period from completion of acute treatment to follow-up care for cancer survivors (White & Newman, 2016). This period refers to the phase where cancer patients are expected to become cancer survivors and return to new normal life activities and pattern (Mollica & Newman, 2014). The transition from cancer patients to survivors may be a particular important point in recovery as the quality of this transition may affect the level of stress and quality of life for cancer survivors (Tremblay et al., 2017). Treatment transition needs to address issues such as uncertainty and ambiguity of their illness state, treatment complexity, information gap, and unpredictable disease courses (Johnson & Cadogan, 2013; Mollica & Nemeth, 2015; Walker, Szanton, & Wenzel, 2015). With regard to movement to end of life care, treatment transition is defined as a process from acute oncological to palliative care and/or hospice care (Wang et al., 2017). The purpose is to shift cancer care from curative or survival treatment to managing symptoms and providing relief from the symptoms such as pain. The goals are to improve quality of both life and death (Ullgren, Kirkpatrick, Kilpeläinen, & Sharp, 2017; Wang et al., 2017).

The fourth definition of treatment transition is related to change of health care providers. When cancer patients complete acute oncological treatment in hospital and become cancer survivors for follow-up care, cancer care provider's teams change. Treatment transition is defined as a shift from specialized oncology teams to primary care provider's teams (Dudley et al., 2016; Hebdon et al., 2018). The two teams need coordination to promote continuity of cancer care. Roles of oncology team providers are responsible for cancer diagnosis and treatment and high-risk follow-up care while the roles of primary care provider teams are responsible for preventive care, comorbid illness management, and health promotion (Hebdon et al., 2018; Johnson & Cadogan, 2013). When cancer patients or survivors shift to palliative care, treatment transition is defined as movement from cancer care provider teams for curative or survival intention to end-of-life care provider teams for symptom management to promote comfort (Wang et al., 2017).

Treatment transition in oncology have a variety of definitions. However, they have shared common characteristics. Summary of Hebdon et al. (2015), Oliveira et al. (2018) and Wood, (2017) on characteristics of treatment transition is as follows:

Table 2.3 Characteristics of treatment transition

Characteristics	Explanation
A turning point	Treatment transition is a turning point from completion of one type of treatment to the beginning of another type of treatment because of change of conditions and shift of cancer care, health settings, and health care provider teams.
Liminality	Transition from cancer patients to cancer survivors can be characterized as a liminal space in time when cancer patients complete acute cancer treatment before enter a new treatment. Treatment transition is to help reduce ambiguity and move cancer survivors going through the transition, ending the liminal state, and entering into survivorship.
Changes	During transition in oncology, cancer survivors experience physical, psychological, social, and spiritual changes.
Passage	Transition is a time with movement in the continuum of cancer care. Treatment transition helps cancer survivors to move from previous life towards a new normal life.
Reforming self-identity	Cancer survivors change previous self-identity in treatment transition. Treatment transition help them to establish new self-identity.
New needs	Needs at the time diagnosis, during acute treatment, completion of acute treatment, and towards survivorship are different. Treatment transition should help meet the individualized needs and address multidimensional concerns.

In this study, treatment transition is defined as a turning point after completion of acute cancer treatment, with movement to survivorship, and in-between points of time after acute cancer treatment and life as cancer survivors (Wood, 2017).

2.4 Definition of Cancer Survivorship, Cancer Survivors, and Their Needs

Treatment transition in oncology is highly associated with two concepts of cancer survivor and cancer survivorship. However, these two concepts are not well defined. Overlap of cancer survivors and survivorship occurs frequently throughout the literature.

Definition of cancer survivorship is complicated and the concept has many different meanings to different people. Some people define cancer survivorship to begin at diagnosis and continue until the end of life while others consider that definition to be reserved to those who have lived beyond the 5-year marks (Oliveira et al., 2018). Some others define cancer survivorship to begin at a point after diagnosis or treatment (Johnson

& Cadogan, 2013; Oliveira et al., 2018). Fitzhugh Mullan, a physician, defined the whole cancer journey as three stages of survivorship. He published an article about his own cancer experience called “Seasons of Survival: Reflections of a Physician with Cancer” in 1985. Seasons of Survival” became the foundation for recognizing the stages of the cancer journey. Mullan (1985) identified what he called the “seasons” of cancer survivorship: acute survivorship, extended survivorship, and permanent survivorship. The acute survivorship phase involves diagnosis and initial treatment-medical, surgical, radiologic. The extended survivorship phase refers a time of watchful waiting with periodic examination and consolidation or intermittent therapy. The permanent survivorship phase is the season of gradual confidence that there would be a future free of cancer (Mullan, 1985). Feuerstein (2007) defines survivorship “As evidence accumulates regarding adult cancer patients following primary treatment until end of life, a more complete definition of cancer survivorship will emerge”. Grunfeld and Earle (2010) defined cancer survivorship as a time of transition between completion of primary and adjuvant cancer treatment and recurrence or death. In their study, cancer survivorship begins at a point after completion of acute cancer treatment and continue until end of life. The researcher does not use the definition of survivorship beginning at the time of diagnosis because some cancer patients would move from acute cancer treatment to palliative care and they are not the target participants in this study.

Concept of cancer survivors has been widely used. However, there are several main professional definitions of cancer survivors. Hebdon et al. (2015) defined cancer survivors as people who have completed acute cancer treatment and are in a post intervention phase. The National Coalition of Cancer Survivors proposes that a survivor is defined as a person from the time of diagnosis of cancer and for the balance of life (Mollica & Nemeth, 2015). Mullan (1985) claimed that a cancer patient can be called a survivor in the permanent survivorship phase because “the activity of disease or likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested” (p. 272). Distinct differences exist in the needs of cancer patients in acute cancer treatment versus cancer survivors in follow-up cancer care (Hebdon et al., 2018). According to Mullan (1985), in the acute survivorship, fear of death and anxiety are the main element and confronting one’s own mortality is the main needs in this phase. In extended survivorship, fear of recurrence and physical limitation are main elements and their needs is to deal with issues in the home, the community, and work place. In the permanent survivorship phase, a cancer patient is a survivor because the person who has come through a cancer experience is indelibly affected by it. Problems with employment and insurance are common for persons who have been treated for cancer and are ready to resume a full life. In addition, people living with cancer may have different understandings for cancer survivors. Some people with cancer believed that a survivor is someone who “is currently free of any evidence of cancer” while others state that “you don’t have to be in remission to be a survivor” (Hebdon et al., 2018, p.5). In this study, cancer patients who receive palliative care are excluded from this research. Cancer survivors are defined as adults and/or elders who are diagnosed with cancer, complete acute cancer treatment, and are in a follow-up cancer care phase (Belansky & Mahon, 2012; Feuerstein, 2007; Hebdon et al., 2018; Mollica & Nemeth, 2015). Cancer survivors need cancer treatment transitioning from completion of acute treatment provided by specialized oncology teams in hospitals to follow-up care provided by primary care provider teams in clinics.

Although cancer survivor's needs are unique based on different type of cancer and treatment, age, gender, culture, religion, education, and social-economic status, they may share common needs in treatment transition. Summary of cancer survivor's needs in treatment transition includes cancer treatment report, who they will contact, follow-up care plan, education on healthy life style, resources for rehabilitation services, supports for return to work, and adjustment to new normal life (Butt, 2012; Dunberger & Bergmark, 2012; Galbraith, Hays, & Tanner, 2012; Lauver, Connolly-Nelson, & Vang, 2007; McCabe & Jacobs, 2008; Meade et al., 2017; Nachreiner et al.,, 2007; Robinson et al., 2016; Segall & Fries, 2017; Shen et al.,, 2016; Sheppard, 2007; Vachon, 2008).

2.5 Physical and Emotional Symptoms Experience

Research on the experience of cancer survivors indicates that their needs are unmet. At completion of acute cancer treatment, the survivors do not know what will happen next to them physically and emotionally and thus continue to be frustrated and anxious about their health problems (Shen et al., 2016). The survivors have unmet needs for information on signs and symptoms of cancer recurrence, management of side effects, health-related lifestyle, and follow-up care plan to watch for new primary cancer and recurrence (Harrison et al., 2012; Meade et al., 2017). The main concerns of the survivors include fatigue, sleep disturbance, living with uncertainty, fear of recurrence, and stress (Butt, 2012; McCabe & Jacobs, 2008).

Cheng, Sit, and Cheng (2016) conducted a qualitative study to explore both negative and positive aspects of Chinese cancer survivor's experience following completion of acute cancer treatment. Two predetermined categories were identified. Negative experience included symptoms experience, fear of recurrence, poor body image, altered sexuality and intimacy, and financial burden. Positive experience consisted of new life perspectives, personal growth, and enhanced relationships with family (Cheng et al., 2016).

In Canada, Fitch et al. (2018) conducted a national online survey to measure the experiences of cancer patients in transition. Eighty seven percent of participants experienced at least one physical concern such as fatigue, 78% of participants experienced at least one emotional concern such as anxiety, and 44% of participants experienced one practical concern such as return to work (Fitch et al., 2018). A third of participants who sought help did not receive it or had difficulty receiving the service (Fitch et al., 2018). The results indicated that many cancer survivors have physical, emotional and practical concerns and did not receive help to reduce the suffering from their concerns (Fitch et al., 2018).

2.6 New Identity-Cancer Survivors

Transition from cancer patients to cancer survivors is a critical phase in cancer trajectory. Cancer survivors in treatment transition are likely to experience different physical, emotional and social needs compared to cancer patients in the diagnosis and acute treatment phase. Their self-identity may change and they have a new self-identity for themselves. However, cancer survivors have different or opposite point of view about how they understand the meaning of cancer survivors and whether or not they accept the label “cancer survivors” for them. Some of cancer survivors think that a survivor is “someone who is currently free of any evidence of cancer” while others state “you don’t have to be in remission to be a survivor” (Hebdon et al., 2018, p.5).

Davis, Myers, Nyamathi, Lewis, and Brecht (2016) explored the understanding of cancer survivors among community-dwelling African American breast cancer survivors (AABCS). Their study indicated that majority of the participants felt that they were cancer survivors and accepted the new identity for advocacy (Davis et al., 2016). The term ‘cancer survivor’ was first created in the USA and widely used as a term to encourage patients’ advocacy that is a fundamental aspect of cancer survivorship in the USA. However, Khan, Harrison, Rose, Ward, and Evans (2012) had opposite findings when they explored interpretation of the term ‘cancer survivors’ amongst British people living with cancer. The majority of participants did not accept the term ‘cancer survivors’ because they think the term implied a high risk of death that did not reflect their experience (Khan et al., 2012). The participants felt that they were cured despite the possibility of recurrence. In addition, most of participants felt ‘cancer survivors’ was a label that did not describe their identity or that implied an advocacy role they did not want to take on (Khan et al., 2012). These findings demonstrated that there were wide variations in the meaning of cancer survivors that influenced whether or not people living with cancer accepted the term ‘cancer survivor’. No research studied if Canadian people living with cancer accept or reject the term ‘cancer survivor’ after completion of acute cancer treatment.

2.7 Meaning of Survivorship

The concept of survivorship was first stated by Fitzhugh Mullan, an American physician, diagnosed with cancer in the 1980s (Khan et al., 2012). Mullan considered survivorship as an independent phenomenon and claimed that cancer survivor experienced unique issues as they moved into the permanent survival stage. Davis et al. (2016) explored the meaning of survivorship among community-dwelling African American breast cancer survivors (AABCS) in California, USA. The study indicated that survivorship meant exuding spirituality, thriving, being resilient, and showing altruism towards others (Davis et al., 2016). Many participants described their spirituality as multidimensional and holistic that covered their lives from diagnosis, treatment, and after treatment. Some participants believed that survivorship meant creating a new thriving life, not just being alive such as eating balanced healthy foods, beginning the process of healing as well as coping with the challenges caused by cancer and treatment. Davis et al. (2016) valued the importance of spirituality among AABCS. However, Cheng et al. (2016) did not consider spirituality as a priority for Chinese breast cancer survivors. Culture and social milieu affect the meaning of cancer survivorship in these two studies. Both Davis et al. (2016) and Cheng et al. (2016) share one issue in common: quality of life is a priority for cancer survivors and during survivorship.

2.8 Getting Back to “Normal’ Life”

Cancer survivors commonly have an expectation or desire to ‘get back to normal’ following acute cancer treatment. However, what they meant by ‘normal’ varied. Baker et al. (2016) explored cancer survivors’ perspective of ‘getting back to normal’. Cancer survivor participants with breast, prostate or lung cancer were recruited from clinics at three hospitals in North West England (Baker et al., 2016). The participants emphasized the need to live a ‘normal’ life. However, they articulated two distinct meanings of normality. Some cancer survivors, particular those early in the cancer trajectory, maintained continuity to their past identity and wanted to get back to their previous self because they described cancer as a minor inconvenience (Baker et al., 2016). Others, particularly those later in cancer trajectory who had completed acute treatment, described a new ‘normality’ discontinuous with their past because they considered themselves as permanently changed by cancer and treatment and cancer became a defining feature of the self (Baker et al., 2016). Most participants held different views, sometimes even contradictory views simultaneously, especially for cancer patients towards cancer survivors in transition (Baker et al., 2016). The treatment transition is particularly important as an intermediate stage of adjustment. Therefore, cancer survivor’s statement of a desire to ‘get back to normal’ need careful interpretation rather than to be taken literally.

2.9 Return to Work

After completion of acute cancer treatment, cancer survivors would like to return to work and/or sustainable work. Working life is considered valuable because it represents identity, normality, self-esteem, psychological well-being, financial security, and a contribution to the community (Bilodeau, Tremblay, & Durand, 2017; Brusletto, Torp, Ihlebæk, & Vinje, 2018). On the contrary, being unable to return to work can represent a person defeat that may lead to lasting obstacles such as lost self-identity, low self-esteem, and financial insecurity. In previous research, the aim in investigating process of return to work have often considered the initial phases and have rarely examined the lasting outcomes (Barnard, Clur, & Joubert, 2016; Mehnert, De Boer, & Feuerstein, 2013; Torp, Nielsen, Gudbergsson, & Dahl, 2012). Sustainable work supports people in engaging and remaining in work throughout an extended working life. Brusletto et al. (2018) explored experience of cancer survivors in returning to sustainable work. Four men and four women aged from 42-59 years were recruited on Facebook, the websites of the University College of Southeast Norway, and Norwegian Cancer Society (Brusletto et al., 2018). The Interpretative Phenomenological Analysis (IPA) was applied in accordance with Smith, Flowers, and Larkin (2009) recommendations. Brusletto et al. (2018) developed a five-phase process model that described the return to sustainable work of people living with cancer: Phase 1 – Departure to the world of cancer, Phase 2 - Fighting for life, Phase 3 – The transformational phase, Phase 4 – Creating a new reality, and Phase 5 – The new reality. The phase 3 represents a turning point in transition from completion of acute treatment to survivorship. The reason for cancer survivors who want to return to work immediately after completion of acute treatment was not solely economic. It socially stimulated cancer survivors to engage with people with and/or without cancer and embrace other aspects of life (Brusletto et al., 2018). However, discrepancy between perceiving ability to work and managing at work exist for many of the cancer survivors. They misjudged their own strengths and abilities to work. Almost all participants said that they were not well prepared (Brusletto et al., 2018). The phase 3 may last longer than expected. Although cancer survivors have their own most important asset: strength and determinations in return to sustainable work, they strongly need support and interventions from health care professionals, families, friends, and colleagues (Brusletto et al., 2018). Unfortunately, in practice, healthcare professionals intervene in silo when providing survivors with support, education and/or consultation (Bilodeau et al., 2017). Therefore, coordination of cancer care in treatment transition is important to address cancer survivor’s concerns and help them to return to work, establish a new self-identity, and ensure financial security.

2.10 Regain Sense of Control

Missel et al. (2018) conducted a study and provided in-depth insight into patient’s lived experience of participating in education and counselling nutritional intervention after curative surgery for esophageal cancer. The aim of the intervention was to support participants in changing their eating habits and adapting to their new esophagus during the postoperative period. The intervention included four sessions between patients and nurses with expertise in nutritional therapy (Missel et al., 2018). Participants in the intervention were patients admitted for surgery for esophageal squamous-cell carcinoma at the Department of Cardiothoracic Surgery, University of Copenhagen. Three themes were developed from experiencing the education and counselling nutritional interventions: embodied disorientation, living with increased attention to bodily functions, and re-embodying eating. Despite the embodied perception of alteration following esophageal cancer surgery, the participants developed high levels of bodily awareness and skills in self-management (Missel et al., 2018). At the hospital, they largely depended on the dietary recommendations and advice received during sessions with the nurses. When at home, they established a daily routine based on the advice received to make it fit in their daily lives. In the transition process, the participants changed their focus from solely caring about the bodily changes to being on the road to recovery, reconnecting to the body and re-embodying eating (Missel et al., 2018). The participants considered the advice and knowledge provided by the nurses as important and supportive. The intervention empowered the participants to regain some control of their own body and in their own lives (Missel et al., 2018).

The findings of importance of regaining control for cancer survivors by Missel et al. (2018) is consistent with Schulman-Green et al. (2012). Schulman-Green et al. (2012) believed that effective self-management of the cancer and its psychosocial consequence is critical to women's quality of life. Self-management included the tasks to deal with the medical and emotional management of their health condition and skills such as problem solving, goal setting, decision making, resource use, forming patient-provider partnerships, action planning, and self-tailoring (Schulman-Green et al., 2012). Task performance and skills development for self-management was particularly urgent for women with ovarian cancer as frequent recurrence, limited treatment options, and an often-short prognosis abruptly propel these women into a period of intense transitions. Schulman-Green et al. (2012) explored the experience of how American women with ovarian cancer self-manage. All of the participants were interested in self-management. The main reasons that participants wanted to self-manage were to have a sense of control over what was happening to them and to be their own advocate (Schulman-Green et al., 2012). Understanding their cancer treatment, prognosis, and what to expect over time helped participants to maintain a sense of control over what was happening to them (Schulman-Green et al., 2012).

2.11 Self-care Management

After completion of acute cancer treatment, cancer survivors discharge home from hospital. They need follow-up care at clinic and/or outpatient setting of hospitals.

Jepsen, Høybye, Hansen, Marcher, and Friis (2016) explored experience of Danish cancer survivors transitioning from inpatient to outpatient settings and how they reflect on these treatment transitions. Jepsen et al. (2016) applied qualitative semi-structured individual interview with each acute leukemia (AL) patient, focusing on outpatient settings, impact on everyday life, responsibility, and the home. They believed that the participants were highly valued for being able to maintain everyday life and routine throughout the treatment trajectory and that life, as closely as possible, resemble life before the diagnosis of AL (Jepsen et al., 2016). Compared to being an inpatient at the hospital 24/7, everyday life as an outpatient consisted of both days at home and days of follow-up visit at the outpatient settings. Outpatients and families could more freely plan their own time and made schedule that enabled them to maintain everyday life routine while inpatient days consisted of different necessary tasks and activities that required interaction with other people and left the inpatients no possibility for individual planning of their time (Jepsen et al., 2016). However, outpatients were generally surprised to realize that the healthcare professionals expected them to take an active part in their treatment. Particularly, outpatients had to manage special precautions and take responsibility for their own care. For many outpatients, this seemed like an overwhelming responsibility (Jepsen et al., 2016). The participants did recognize that the precautions limited everyday life. While they were inpatients in the hospital, they did not feel the same responsibility as outpatients at home. The inpatients had only few tasks to perform and it was easy to get help when needed. The sense of responsibility for management of own care was experienced to a much higher degree by outpatients, in the context of their own home, without health care professionals around (Jepsen et al., 2016).

Nissim et al. (2014) conducted a qualitative study that explored the experience of cancer survivors with adult acute myeloid leukemia (AML) transitioning from inpatient to outpatient setting for subsequent consolidation chemotherapy. Thirty-five AML patients at the Princess Margaret Cancer Centre, University Health Network in Toronto were recruited (Nissim et al., 2014). This study used semi-structured interview to explore participants' experience of the illness and treatment during transition. The important findings included readjusting expectation, sudden shift of responsibility, understanding the long-term plan, and reconstructing a sense of identity (Nissim et al., 2014). As inpatients, participants focused on surviving their immediate inpatient treatment and getting to the point of discharge. Their expectation was that transitioning to follow-up care meant that the worst was behind them. Therefore, despite being provided with information about their post-discharge therapy, participants felt surprised by the intensity of consolidation therapy and the impact on them. The transition to outpatient management require participants to assume greater responsibility for their care, to monitor symptoms, and coordinate many aspects of their treatment on their own (Nissim et al., 2014).

2.12 Coordination of Healthcare Teams

Quality survivorship relies on coordination of cancer care between specialized oncology teams and primary care providers teams during treatment transition **(**Hebdon et al., 2018). Hebdon et al. (2018) explored the perspective of healthcare team members regarding cancer survivorship care in the USA. A qualitative phenomenological approach and semi-structured interviews was used for their study. Hebdon et al. (2018) interviewed cancer survivors, primary support individuals, oncology providers, primary care providers, and registered nurses. The healthcare provider’s roles focused primarily on primary care and oncology care. After completion of acute cancer treatment, cancer care provider’s team shifts from specialized oncology teams to primary care provider teams; the two teams need coordination to promote continuity of cancer care. Roles of oncology team providers were responsible for cancer diagnosis, treatment, and high-risk follow-up care while the roles of primary care provider teams were responsible for preventive care, comorbid illness management, and health promotion (Hebdon et al., 2018). Three gaps in cancer care were noted by participants including being unprepared for the survivorship phase of cancer care, gaps between perceived needs and care delivered, and failing through the cracks (Hebdon et al., 2018). Periods of transition from cancer treatment to follow-up care were noted as a time when survivors became lost. Not surprisingly, poor communication between the two teams was a barrier to coordination of survivorship care (Hebdon et al., 2018).

Roundtree, Giordano, Price, and Suarez-Almazor (2011) conducted a qualitative study to explore American breast cancer survivor’s perceptions and attitudes about their healthcare utilization, screening, and information needs. Roundtree et al. (2011) indicated that cancer survivors in their study were frustrated in their personal experience by interactions with physicians and had problems with communication with and between physicians.

Franco et al. (2016) conducted a qualitative research on the experiences of Canadian cancer survivors transitioning from tertiary to primary care in the Transition Care Clinic (TCC) in the Odette Cancer Centre in the Sunnybrook Health Sciences Centre. Their study identified eight categories regarding transition readiness: how the transition was introduced, perceived continuity of care, support from health care providers, clarity of the timeline throughout the transition, and desire for a “roadmap.” Participants claimed that their relationship with the primary care provider had more influence on their transition readiness than relationship with health care providers in tertiary and transition. This claims of the participants in Franco et al. (2016) may come from the special design of the TCC. The TCC were the nurse practitioner– operated clinic that was designed to receive cancer patients from inpatient department after completion of acute cancer treatment and promote their transition to primary care provider team. Patient participants in my study were transitioned directly from oncology team in outpatient department to primary care provider’s team clinic. They may have different points of view from those in TCC in Franco et al. (2016) about whose relationship patient participant worked with - oncology team or primary care provider’s team had more influence on their transition readiness in treatment transition. The type of cancer care provided and roles performed by oncology team and primary care provider’s team would decide their influence on cancer survivor’s treatment transition.

To sum up, the coordination of healthcare teams promotes cancer survivor’s readiness for transition while poor communication among cancer survivors, oncology team, and primary care provider team is a barrier for the coordination of cancer care in treatment transition.

2.13 Continuity of Cancer Care

Over the past 20 years, considerable healthcare resources have shifted from an inpatient to an outpatient setting. Bergkvist, Fossum, Johansson, Mattsson, and Larsen (2018) explored cancer survivor’s experience of different care settings (hospital or home) and a new life situation during the acute post-transplant phase after allogeneic hematopoietic stem cell transplantation (allo-HSCT). The study was carried out at a transplantation center in Sweden. Advantages for home care after HSCT included more opportunities for physical activities, a sense of freedom, being with family, the joy of being at home in their own environment, and the environment near home (Bergkvist et al., 2018). More importantly, some participants stated that being at home probably helped them to recover more quickly and to reduce the level of discomfort (Bergkvist et al., 2018). To be medically safe and beneficial to the participants' shift from inpatient unit to outpatient settings, management and preparation must be well done during treatment transition. Through education and counselling, participants gained knowledge and took control of self-care. They also obtained a supportive network. For example, home care nurse informed the participants and family members about hygiene routines at home; participants at home were visited and cared for once a day (1-2 hours) by experienced nurses from the transplant center; and a physician called each afternoon to check on the participants' wellbeing and to make appropriate modification regarding examination, treatment, medication and participants management (Bergkvist et al., 2018). If there were any signs of unstable vital parameters that could not be dealt with at home, the participant was re-admitted to the transplant center (Bergkvist et al., 2018). Preparation, education, and coordination during transition between different health care settings promote continuity of cancer care.

2.14 Experience of Oncology Nurses in Treatment Transition

Nurses are uniquely positioned to care for cancer survivors in transition and their .works are gaining recognition nationally and internationally (Boyle, 2009; McCabe &

Jacobs, 2012; Rowland, 2008; Warnock, Siddall, Freeman, & Greenfield, 2012). In the USA, the researchers investigating the experience of oncology nurses highlighted the significance of the nurses in promoting communication among healthcare providers, survivors, and caregivers (Grant, Economou, & Ferrell, 2010) and facilitating informed and independent decision-making to delay treatment for fertility preservation (Nobel-Murray, Chrisler, & Robbins, 2016). In addition, the oncology nurses reported that the greatest barriers to provide coordinated and continuous cancer care were the lack of time, funding, and knowledge about survivorship care (Irwin, Klemp, Glennon, & Frazier, 2011). In Korea, nurses played a key role in rehabilitation for cancer survivors by enhancing cancer survivors' strength and resilience in order to lead a healthy life (Chang & Park, 2013).

Chan, Button, Thomas, Gates, and Yates (2018) conducted a cross-sectional survey to explore attitude and practice of Australian cancer nurses about survivorship care provided for people living with a hematological cancer after completion of treatment. Survivorship defined and used in Chan et al. (2018) began with diagnosis and continued throughout the life span. Among 17 survivorship care items, three items that received the lowest confidence score were discussing fertility issues, employment and financial issues, and how to identify signs of cancer recurrence (Chan et al., 2018). The least performed survivorship care items were discussing fertility issues, communicating survivorship care with primary care provider’s team, and discussing sexuality issues (Chan et al., 2018). Chan et al. (2018) indicated that older age, more years of experience, having a post-graduate qualification, and working in non-metropolitan area were associated with high levels of perception of responsibility and confidence. The top ranked barriers transitioning to survivorship care were reported to be lack of end-of-treatment consultation dedicated to survivorship care, time, and appropriate physical space for delivering care (Chan et al., 2018). Although oncology nurses considered key aspects of survivorship care as their roles, their practice and confidence for implementation of survivorship care varied.

Karvinen, Bruner, and Truant (2015) did cross-sectional survey to investigate the perspective of nurses working in USA and Canada about the teachable moment for cancer survivors to receive health behavior guidance. The findings indicated that cancer survivors received guidance on health behaviors after diagnosis and during treatment. However, only some survivors asked for guidance and few made improvements to their health behaviors (Karvinen et al., 2015).

Yuille et al. (2016) conducted a qualitative research on oncology nurses that only focused on the role of registered nurses in working with cancer survivors on primary care teams in an Ontario primary care setting without the description of their experience.

2.15 Summary of Literature Gap

Researchers have explored experience of cancer survivors in other countries during treatment transition including personal transition (physical transition, emotional transition, and social transition) and care transition (from hospital to home, from oncology team to primary care provider’s team, and from acute cancer care to follow-up care). Their findings have been used to improve cancer care with expected outcomes.

In Canada, research on experience of cancer survivors during treatment transition is less than expected. A quantitative online survey identified that Canadian cancer survivors had physical, emotional and practical concerns. However, a qualitative research is needed to explore the experience of Canadian cancer survivors about physical, emotional and social transitions, how the physical, emotional and practical concerns affect their quality of life, what are their perspectives promoting or inhibiting the delivery of quality cancer care, and what are suggestion and recommendations that meet their needs and improve their quality of life during treatment transition. A qualitative study indicated that Canadian cancer survivors felt greater responsibility for following-up care than expected when they transitioned from hospital to home. However, the study only explored the cancer survivors diagnosed with acute myeloid leukemia (AML). Little is known about what cancer survivors diagnosed with other types of cancer experienced during treatment transition and how they regained control of their life. Another qualitative study identified eight categories about transition readiness for Canadian cancer survivors. However, the study did not explore the experience of cancer survivors about how they communicated with the oncology team and primary care providers' team, what challenges they faced when they communicated with the two teams, and how these two teams worked to promote continuity of cancer care during treatment transition. In addition, it seems that no qualitative Canadian research explore the experience of Canadian cancer survivors on social transition such as new identity, label of cancer survivors, meaning and priority of survivorship, getting back to normal life, return to work, and self-care management. Moreover, no qualitative Canadian research explore experience of oncology nurses providing cancer care for cancer survivors during treatment transition.

Nursing Theory of Transition is a useful framework to explore the experience of cancer survivors during treatment transition. It seems that no Canadian studies use the Nursing Theory of Transition to explore experience of oncology nurses and cancer survivors in treatment transition. In addition, care transitions in the study of Schulman-Green et al. (2012) referred to shift of cancer care since they aimed to explore the self-management experience of women participants with ovarian cancer. The researcher in this study will attempt to further develop the Nursing Theory of Transition by using this framework to explore experience of cancer survivors and oncology nurses on shift of health settings and shift of healthcare teams besides shift of cancer care. The researcher in this study will use the Nursing Theory of Transition to explore experience of cancer survivors and oncology nurses during treatment transition including personal transition (physical, emotional, and social transition) and care transition (transition from inpatient departments of hospital to outpatient departments/clinics/home, from oncology team to primary care providers' team, and from acute cancer care to follow-up care).

In order to add body of knowledge to the research gap, this research study is to explore the experience of Canadian oncology nurses and cancer survivors during treatment transition, their perspectives influencing the delivery of quality cancer care, and suggestion and/or recommendations for improving cancer care from perspectives of both oncology nurses and cancer survivors. The next Chapter 3 demonstrates research design, data collection, and data analysis method.

Chapter 3. Methods, Data Collections, and Analysis

This chapter outlines research methodology and procedures. It demonstrates detailed process and rationales of research methods, data collection, and data analysis to meet the research purpose and objectives. This chapter consists of ethical considerations, research design, setting and participants, data collection, and data analysis.

3.1 Ethical Considerations

Ethics approval was required for this research study because the study involved human beings as participants including nurse and patient participants. Ethics approvals help protect the participant's rights, safety, privacy, welfare, and dignity.

3.1.1 Research Ethics Board Approval

Ethical consideration for this study was met according to the Research Ethics Board (REB) from the University of Ontario Institute of Technology (UOIT) and Lakeridge Health. This study has been approved by the UOIT REB (File # 14995) (Appendix A) and Lakeridge Health REB (RI-ID#: 2018-013) (Appendix B).

3.1.2 Protecting Participants Confidentiality

All information and data collected was kept completely confidential. Participant's confidentiality was treated with respect and protected at all times. Their names and contact information did not appear on any forms or any type of publication. An ID code was used as an identifier, as well as to keep all the names disclosed. All the interview recordings, consent forms, and personal information collected were kept private in the faculty supervisor's (Dr. Manon Lemonde, RN, PhD at the University of Ontario Institute of Technology) office at UOIT, and only the investigators had access to the data. The participant’s privacy was respected. No information about their identity was shared or published without permission, unless required by law. Confidentiality was provided to the fullest extent possible by law, professional practice, and ethical codes of conduct. All recordings and transcriptions will be kept for five years after the completion of the research study. After the five years period, all data will be destroyed in a proper manner. Any confidential research data and records in paper format will be shredded. Confidential research data and records in electronic format will be destroyed by reforming, rewriting or deleting. All the information provided will remain confidential and will only be utilized for the purpose of this research.

3.1.3 Obtaining Consent

The participants in this study were provided with a consent form. The participants were informed that they would be tape-recorded during the interview, who would have access to the data, how the data would be stored, and who they could contact if they had concerns about risk of disclosing their personal information. The participants were also informed that they could answer only those questions that they were comfortable during the interview. Prior to the interview, the participants had opportunity to ask questions. The participants were asked to read the consent form and sign the written consent form to participate in this study. A copy of consent form was given to the participants for their record. The participation was voluntary and the participants may withdraw at any time without any consequences to the care they are entitled to receive at Durham Regional Cancer Center (DRCC) (for the patient participants) or the employment at DRCC (for the nurse participants).

3.2 Research Design

3.2.1 Rationale for Social Constructive Paradigm and Qualitative Methodology

Social constructivism is an approach to qualitative research. Social constructivists hold worldview that individuals seek understanding of the world around them and they develop subjective meaning of their experience towards objectives or situations. The goal of the researcher is to depend on the participant's view of the situation under study and explore the meaning of the situation. This study explored experience of oncology nurses and cancer survivors in treatment transition. Therefore, the research was guided by social constructive paradigm and the researcher used qualitative approach to explore and describe the experience of oncology nurses and cancer survivors in treatment transition.

3.2.2 Phenomenology

Phenomenological research is one type of qualitative approach that describe the lived experience of individuals about a phenomenon (Creswell, 2014; Creswell & Poth, 2018). The Interpretative Phenomenological Analysis (IPA) is a qualitative research analysis approach committed to interpreting the lived experience of participants and examining of how participants make sense of their life experience (Smith et al., 2009). This research applied phenomenological study and IPA analysis to explore the lived experience of oncology nurse and cancer survivors in treatment transition. Nurse participants have experience of providing cancer care for cancer survivors and patient participants have experience of receiving cancer care during treatment transition. The participants developed the subjective meaning of their experience in treatment transition. Through data collection and IPA analysis, this qualitative phenomenological study would promote understanding of what nurses and cancer survivors experience, how they experience it, what are similarities and difference of their experiences, what are their perspectives influencing their experience, and what are suggestions and recommendations from perspectives of both nurses and patient participants for quality cancer care in treatment transition. The findings would potentially provide important information and suggestions to improve cancer care for cancer survivors in treatment transition in order to meet their needs and improve their quality of life.

3.3 Setting and Participants

3.3.1 Research Setting

The research took place in the R.S. McLaughlin Durham Regional Cancer Centre (DRCC), a Cancer Care Ontario (CCO) partner, within Lakeridge Health Hospital in Oshawa (referred to as the hospital below). The nurse participants were recruited from the outpatient department of the DRCC who provided cancer care for cancer survivors in treatment transition. The patient participants were cancer survivors who received cancer care in treatment transition in DRCC. The DRCC offers a full range of cancer services including prevention and screening, diagnosis, acute cancer treatment, follow-up cancer care in treatment transition, and palliative care. The DRCC also offered After Cancer Group Teaching Class (referred as to the Class) to educate cancer survivors on what they can expect in treatment transition.

3.3.2 Participants Inclusion and Exclusion Criteria

To be eligible for the study, all participants in this study were required to meet criteria requirement. The inclusion and exclusion criteria for both nurse and patient participants are outlined below.

3.3.2.1 Patient Participants

3.3.2.1.1 Inclusion Criteria

Patient participants include those who (1) have completed their acute cancer treatment (cancer treatment in between from diagnosis to follow-up care); (2) are adults above age of 18 years and of either sex; (3) speak English; and (4) can provide informed consent (capacity to make the decision voluntary and comprehend the information).

3.3.2.1.2 Exclusion Criteria

Patient participants who (1) are receiving acute cancer treatment, palliative or hospice care; (2) do not speak, read, and write English; and (3) are excluded from this study if they are already participating in another research. The participants have been asked if they are already participating in another research before the start of interview.

3.3.2.2 Nurse Participants

3.3.2.2.1 Inclusion Criteria

Nurse participants in this study must meet the following criteria: (1) they are registered nurses (RNs); (2) they are oncology nurses in the outpatient department of the hospital (ether part time or full time); (3) the oncology nurses are currently providing cancer care for cancer survivors; and (4) the oncology nurses have one or more years of work experience.

All nurse participants have experience providing cancer care for cancer survivors in treatment transition. Some of them may also facilitate the After Cancer Group Teaching Class. Oncology nurses who facilitate the Class but did not provide cancer care for cancer survivors in treatment transition were excluded. Social workers were excluded from the study.

3.3.2.2.2 Exclusion Criteria

Nurses who (1) provide palliative or hospice care for cancer patients; or (2) have less than one year of work experience are excluded.

3.3.3 Recruitment Strategy

A guiding principle in recruitment strategy for this phenomenological study is that all participants must have experienced the phenomenon and saturation principle for sampling and data collection are achieved to the point at which no new key information is obtained (Polit & Beck, 2012). The sample size can be affected by research purpose and question, resources availability, and time constraints (Creswell & Poth, 2018; Polit & Beck, 2012). Duke as reported by Creswell and Poth (2018) recommends 3 to 10 participants and Polit and Beck (2012) claims that researchers tend to rely on small number of participants.

Phenomenological study is an approach to understanding people's life experience. The two categories of phenomenology are descriptive phenomenology and interpretative phenomenology (hermeneutics). Descriptive phenomenology emphasizes description of human experience and descriptive phenomenologists insist on the careful description of things that people experience (Polit & Beck, 2012). Interpretative phenomenology emphasizes interpreting and understanding human experience and interpretative phenomenologists enter another person's world and discover and understand the person's experience by interpretation (Polit & Beck, 2012). Interpretative phenomenological analysis (IPA) is an approach used to analyze and interpret the data (Polit & Beck, 2012). The IPA focus on the subjective experience of persons. Studying the person's experience requires interpretation on the part of the researcher and the persons because it is impossible to directly enter a person's lifeworld (Smith et al., 2009). The key principles of IPA are to investigate the phenomenon of experience of a person, require intense interpretation and engagement with the data collected form the person, and examine in details. The IPA studies usually benefit from a concentrated focus on and detailed engagement with a small number of participants. It is concerned with understanding particular phenomenon in particular contexts (Smith et al., 2009). Smith et al. (2009) suggest that between three and six participants of each group of nurse and/or patient participants can be a reasonable sample size for a student research project using IPA to explore the experience of the participants.

The gold standard for qualitative study is saturation. Data saturation refers to sampling and data collection to the point where no new information is obtained and redundancy is achieved (Polit & Beck, 2012). However, Low (2019) claimed that "saturation as the point at which no new information emerges is a logical impossibility" (p.135). When the researcher interviews every new cancer survivor about their experience in treatment transition in this study, there could be something new to discover because each of cancer survivors is individual and they have unique experience arising from their different cancer, treatment, history, environment, socioeconomic status and so on. Theoretical Saturation refers to the continuation of sampling and data collection until no new conceptual insights are generated and no new themes identified (Bowen, 2008). Therefore, this research used theoretical saturation and ensured sampling and data collection to the point where no new key themes were identified from nurse and patient participants.

3.3.4 Sampling Procedures and Recruitment

The recruitment process began in January, 2019 after the study has been approved by the two institutions of UOIT REB and Lakeridge Health REB. The purposive sampling strategy was used in this study. All participants must meet the inclusion criteria. I have obtained supports from my supervisor, clinic manager of the outpatient department, and education lead of the DRCC to recruit qualified participants to ensure for collection of diverse, rich, thick data (Creswell & Poth, 2018; Robinson, 2013). During the recruitment process, the researcher asked questions, checked qualification of participants, and ensured that both nurse participants working in DRCC had experience of providing cancer care for cancer survivors in treatment transition and patient participants had experience of receiving cancer care in treatment transition in DRCC.

3.3.4.1 Patient Participants

For the potential patient participants, a letter of invitation (Appendix C) was sent to cancer survivors attending the After Cancer Group Teaching Class by the facilitator (nurses or social workers) and to cancer survivors who volunteer as patient advisors by the education lead of the DRCC from January to May 2019. When the patient participants expressed their interests in the research study, the researcher screened them based on the inclusion criteria, answered their questions, and sent the consent form (Appendix D) to them. After the potential patient participants met the inclusion criteria and agreed to give consent, the researcher made an appointment for individual semi-structured interview with each of patient participants from March to May 2019. A total of five patient participants expressed their interest in this study and all of them were qualified participants based on inclusion criteria. The five patient participants were interviewed in March, April, and May 2019 respectively.

3.3.4.2 Nurse Participants

For nurse participants, the letter of invitation (Appendix E) and the consent form (Appendix F) were sent to all the registered nurses working in the outpatient department in DRCC by the administrative assistant of the Patient Care Manager (PCM), Chemotherapy in January 2019. The reminder invitation emails were sent to all the registered nurses every two weeks from January to May 2019. The registered nurses have also been informed by a reminder request email from the PCM that the researcher had been in the library in their hospital eight hours a day for total 8 days in three weeks in April 2019 to promote the recruitment process and data collection. When the potential nurse participants who were interested in the research study contacted the researcher, the researcher screened them based on the inclusion criteria and answered their questions. After the nurse participants met the inclusion and agreed to provide informed consent, the researcher scheduled an appointment in the library of the hospital for individual semi-structured interview with each of nurse participants for data collection from February to April 2019. Total of three nurse participants expressed interest in this study and all of the three nurses were qualified participants based on inclusion criteria. The three nurse participants were interviewed in February and April 2019 respectively.

3.4 Data Collection

3.4.1 In-depth Interview

The researcher used individual semi-structured interview method to collect data. The semi-structured, one-to-one interviews tend to be the preferred means for collecting such data because the semi-structured, one-to-one interviews also easily manage, facilitate rapport and empathy, protect privacy, give participants the space to think, speak, and be heard, permit great flexibility, and tend to produce rich and interesting data. Researcher using IPA need rich detailed data so that participants will be granted as more as possible opportunities to tell their stories, to speak freely and reflectively, develop their ideas, and express their concerns. Therefore, the semi-structured interview method is well suited to in-depth and personal discussion and is the most appropriate method for this study.

Unstructured interview and focus group interview were not appropriate for this study. Researchers usually use unstructured interview when they become more experienced and they may choose to conduct even less structured interviews research projects (Creswell & Poth, 2018; Polit & Beck, 2012). Focus group interview are not suitable for IPA researchers because multiple voices and interactional complexities during the interview (1) may create difficulties to develop phenomenological aspects required by IPA; (2) may make participants uncomfortable to tell their own lived experience; and (3) may affect attitude of participants and direct opinion for evaluation (Smith et al., 2009). The research did not use these two methods to collect data.

Purposeful individual in-depth semi-structured interviews was applied to facilitate participants to recall stories, thoughts, and feelings in their own words. The interview is open-ended, allowing new ideas to be brought up during the interview because of what the interviewees say (Newton, 2010; Opdenakker, 2006). The researcher would highly value the unanticipated and unexpected experience of the participants that will occur during interview and think that these experiences are particular importance to the participants and are often the most valuable aspects of interviewing.

The researcher had prepared for the interview with about nine open-ended questions that got approval from the two institution's REB; these questions were reviewed and approved by the supervisor and based on the Nursing Theory of Transition framework. The questions focused on understanding what actually happened in treatment transition from the perspectives of both oncology nurses and cancer survivors, what and how oncology nurses provided cancer care for the survivors, what type of cancer care and/or services the cancer survivors received, what are their perspectives promoting or inhibiting the experience of oncology nurses and cancer survivors, what were the barriers and facilitators for the coordinated and continuous cancer care for the survivors in treatment transition and what were their suggestion and recommendations to improve cancer care for the survivors in transition. According to Schulman-Green et al. (2012), there are two types of health-illness transitions: personal transition and care transition. The researcher categorized the interview questions into three sections for nurse participants and patient participants respectively to collect data and information for their experience during treatment transition including personal transition (physical transitions, emotional transitions, and social transitions), care transitions (shifts in cancer care, healthcare setting and health care teams), and their perspectives promoting or inhibiting delivery of quality cancer care during treatment transition. Interview questions approved by two institutional REBs were listed on Appendix G for nurse participants and Appendix H for patient participants.

3.4.2 Interview Process

There are several guidelines about how to conduct an interview (Creswell, 2014; Creswell & Poth, 2018; Polit & Beck, 2012). The purpose of the guidelines helps researchers to take steps to prepare the interview, provide comfortable environment, increase confidence, overcome communication barriers, promote free talking of participants, obtain rich data and information, and ensure the audibility and completeness of data. (Creswell, 2014; Creswell & Poth, 2018; Polit & Beck, 2012). Even if they are difference in detailed steps, these interview guidelines share common phases of interview including before the interview, during the interview, and after the interview.

Prior to the interview, the researcher interviewed the participants at a time that were convenient for their participation in the study to collect data. The researcher booked a single private room for the interview with assistance of the librarian. The researcher got to the library of the hospital early to make the room ready and comfortable for the interview, prepared consent form and socio-demographic form, and practiced interview questions.

At the beginning of the interview, the researcher reviewed the consent form (Appendix I) and socio-demographic form (Appendix J) with each participant and answered the questions. The participant signed the consent form and filled in the socio-demographic form. Each participant was named an anonymous code such as P1, P2 P3, P4 and P5 for each patient participant respectively and N1, N2, and N3 for each nurse participant respectively to protect their privacy and confidentiality. Only the anonymous

ID code was used as an identifier for each participant during data collection, analysis, and in potential future publications. The researcher prepared two different recorders to record the interview. The ID codebook, recording, transcript, and themes were kept in supervisor's office. The length of each interview varied and depended on the participant's answers until each participant did not have new or additional information and data to tell the researcher. Appendix K include all the narratives collected.

During the interview, the researcher played the role of facilitator to encourage oncology nurses and cancer survivors to talk freely and tell their lived experience in their own words (Polit & Beck, 2012). The participants were speakers and the researcher was a good listener during the interview (Polit & Beck, 2012). The researcher gave appropriate responses to facilitate the participant's talks and clarify issues when needed. The researcher was flexible about the sequence of questions based on the participant's responses, wishes and situation when interviewing them. The researcher would bracket off personal experience and minimize its effects on the interview (Creswell & Poth, 2018). The researcher was open to the experience of participants that would promote the depth and width of understanding the participant's experience. The researcher was respectful and courteous for the interview.

At the end of each interview, the researcher checked the quality of interview recording. The researcher would transcribe verbatim from the recorders immediately after each interview.

3.4.3 Data Storage and Management

The data and information collected was stored on the researcher's computer with a password protected, and was stored on an encrypted and password protected memory stick that was locked in supervisor's office. The researcher collected and analyzed the data and information for the research in a limited period. All data and information will be properly disposed of upon completion of the study. The timeframe to complete the study was approximately 10 months. Data and information will be properly disposed after five years by erasing the electronic files and shredding of all records in paper format.

3.4.4 Researcher Experience

The researcher has no affiliation with the research setting, oncology nurses, and cancer survivors prior to the research project. The researcher has no conflict of interest. The relationship between participants and the researcher is a professional interview relationship for this study: the researcher is the interviewer as instrument and the participants are interviewees as information providers. The participants did not have nursing care from the researcher.

The researcher is a nurse with many years of work experience in a hospital that is different from the research setting in this study. The researcher is open, flexible, passionate, organized, and self-motivated. The researcher has strong professional ethics. The researcher originally has an oriental culture background. The researcher is moderate in culture, politics, and religion. The researcher prefers rational analysis to emotional feeling. All these may consciously or subconsciously shape analysis and interpretation of the experience of oncology nurses and cancer survivors (Creswell & Poth, 2018; Polit & Beck, 2012). To reduce potential bias in the research study, the researcher bracketed personal experience and was open to the experience of oncology nurses and cancer survivors during the interview. The researcher also embedded reflexivity by reflecting on and considering intersubjective dynamics between data and the researcher.

3.5 Data Analysis

3.5.1 Interpretative Phenomenological Analysis (IPA)

Smith et al. (2009) have led the development of Interpretative Phenomenological Analysis (IPA) as a qualitative research framework originated in psychology and widely used in the human, social, and health science. IPA is a thorough and systematic approach to analyze and examine how a particular phenomenon has been understood from the perspective of particular people (participants) in particular context.

The IPA is mainly influenced by phenomenology, hermeneutics, and idiography. Firstly, phenomenology is a philosophical approach to the study of people's experience that provides us with concepts about how to examine and comprehend their lived experience. The philosopher Edmund Husserl famously urged phenomenologists to go back to the things themselves. The founding principle of phenomenological inquiry is that experience should be examined in the way that it occurs in its own terms. According to Husserl's work, researchers need to bracket off the taken-for-granted world in order to concentrate on the participant's world (Smith et al., 2009).

Secondly, hermeneutics is a theory of interpretation. Heidegger established hermeneutic phenomenology. Studying participant's experience require researcher's interpretation on them because it is impossible to directly access their lived experiences (Smith et al., 2009). Building upon Heidegger's work, researchers should re-evaluate the role of bracketing in the interpretative of qualitative data based on the relationship between interpretative work and the fore-structure of our understanding. Based on the Gadamer's work, Smith et al. (2009) further claimed that researcher's preconceptions and fore-structure are inevitably present. "The phenomenon, the thing itself, influences the interpretation, which in turn can influence the fore-structure, which can then itself influence the interpretation" (Smith et al., 2009, p.26). "Interpretation will focus on the meaning of the text and that meaning will be strongly influenced by the moment at which the interpretation is made of" (Smith et al., 2009, p.27). Researchers can hold many conceptions and interpret them by comparing, contrasting, and modifying them during the sense-making process.

Thirdly, IPA is idiographic. Idiography is concerned with the particular**.** IPA researchers want to know the experience of a participant in detail and what sense this particular participant is making of what is happening to him or her. IPA's commitment to the particular operates at two levels (Smith et al., 2009). On the first level, IPA is committed to the particular, in the sense of details with the depth of analysis. Consequently, analysis must be thorough and systematic. On the second level, IPA is committed to understanding particular experiential phenomenon from the perspective of a particular participant in a particular context. Therefore, IPA utilize small, purposively selective and careful-situated participants and may often make very effective use of analyses for each participant. IPA researchers usually prefer individual interview to focus group interview (Smith et al., 2009). The emphasis of IPA on the particular cannot be conflated with exactly with a focus on individual. The lived experience of a participant is uniquely embodied, situated, perspectival and it is a worldly and relational phenomenon.

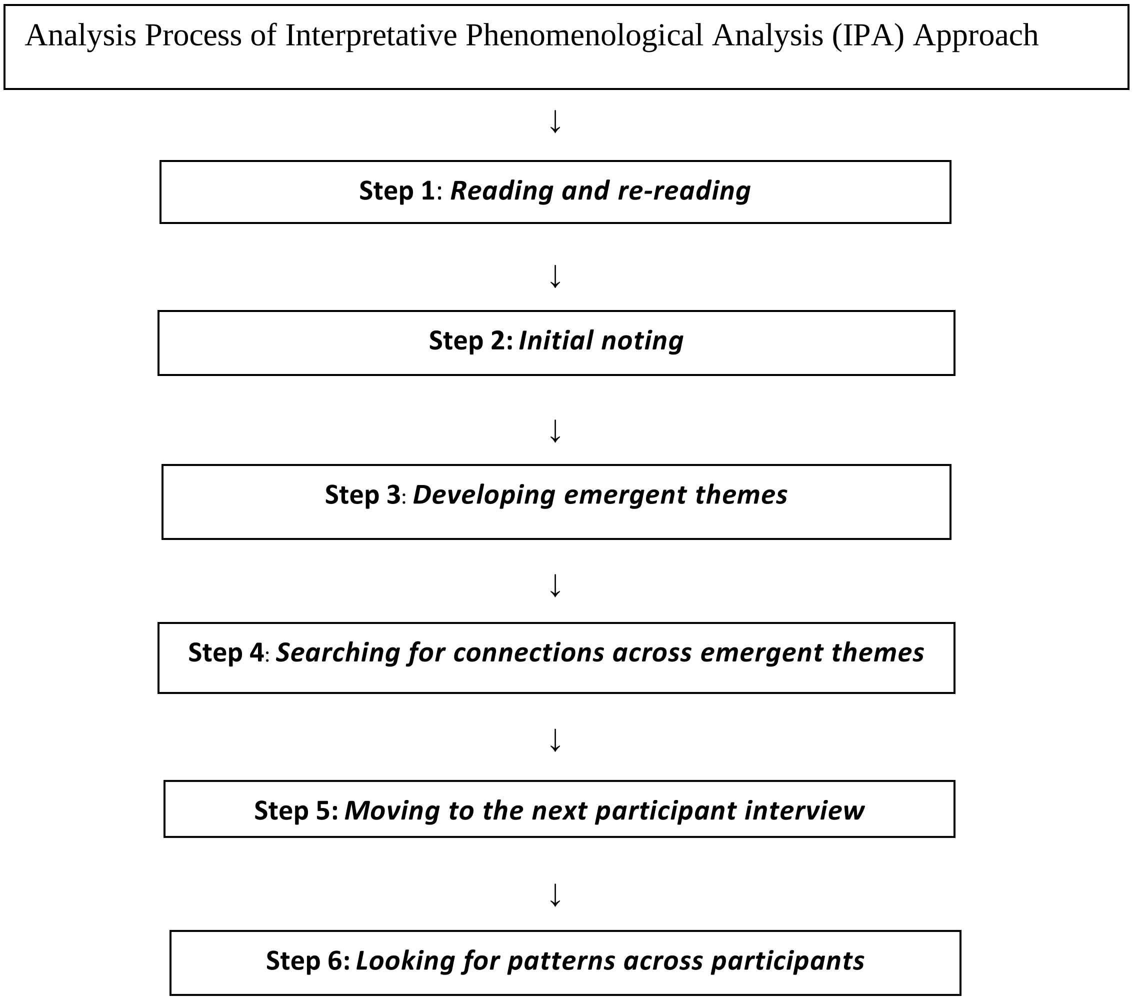
Similarities and differences across the participants demonstrate both subjective his or her particular experience and objective existential shared common experience related to the phenomenon. A good IPA research should insightfully analyze data and may take us into the universal based on lived experiences of participants (Smith et al., 2009).

Interpretative Phenomenological Analysis (IPA) is committed to exploration of participant's experience in its own terms and examination of how the participants make sense of their lived experience. The IPA guides researchers to investigate the phenomenon of experience of participants, interpret the data obtained from the participants, and exam their experiences in detail. Without the lived experience of participants, there would be nothing to interpret; without the interpretation, essence of lived experiences would not be seen. "The IPA can be characterized by a set of common processes (e.g. moving from the particular to the shared, and from the descriptive to the interpretative)" (Smith et al., 2009, p.79). IPA researchers are engaged in a double hermeneutic: participants make sense of their lived experience and the researchers attempt in understanding how the participants make sense of their lived experience (Smith et al., 2009). "The participants' meaning –making is first order, while the researchers' sense making is second-order" (Smith et al., 2009, p.36). Therefore, "the analysis inevitably is a joint product of the participant and the analyst" (Smith et al., 2009, p.80).

3.5.2 Data Analysis Procedure

The researcher applied the interpretative phenomenological analysis (IPA) approach for this study because the IPA is a thorough and systemic analysis approach that is used to examine how a phenomenon has been understood both from the participants' view in a particular context and through researcher's own, experientially-informed lens (Smith et al., 2009). The IPA is used in this study to exploring, describing, and interpreting what and how the participants make sense of their experiences. The researcher using IPA for the first time will need more principles. In order to make IPA process more manageable for those novice researchers to IPA, Smith et al. (2009) present a step-by-step unidirectional guide to conduct IPA analysis. The IPA approach uses specific, structured, and cyclical process for analysis where the researcher will proceed through six stages (Figure 3.1) (Smith et al., 2009). The researcher for this study followed the six stages to make analysis. Actually, the analysis was an iterative process, back and forth many times.

Figure 3.1 IPA analysis process



Step 1: Reading and Re-reading

The researcher will transcribe the transcript recording, read and re-read the transcription, describe the experience of oncology nurses and cancer survivors first. The researcher will bracket off own assumption and ensure that the participants become the focus of analysis.

Step 2: Initial Noting

The researcher will identify and develop a list of nonrepetitive and nonoverlapping significant statements from the participant's experience. The researcher will write a comprehensive and detailed set of notes and comments, identify specific ways by which that participant talks about, understand, and thinks about their experience in treatment transition, and describe experience that matter to them and the meaning of those experiences for the participants.

Step 3: Developing Emergent Themes

The researcher will generate themes by organizing and categorizing the significant statements into meaning units. The main tasks are to turn notes into themes to produce a concise statement of what was important in the comments. This process mainly involves analysis and interpretation of the initial notes rather than the transcript itself. "The themes will reflect not only the participant's original words and thoughts but also the analyst's interpretation. They reflect a synergistic process of description and interpretation" (Smith et al., 2009, p.92).

Step 4: Searching for Connections across Emergent Themes

The researcher will group the themes together as clusters or concepts and suggest relationship between them. The researcher will also go through some more specific ways of looking for patterns and connections between emergent themes

Step 5: Moving to the Next Participant Interview

The researcher will repeat the process of Step 1 to Step 4 to analyze the transcripts collected from another participant interview. The researcher will treat the transcript of next interview data on its own terms by keeping with IPA's idiographic commitment and bracketing the ideas emerging from the analysis of the previous interview data.

Step 6: Looking for Patterns across Participants

In this step, the researcher seeks patterns across participants. First, the researcher compares and contrasts themes among patient participants. The researcher identifies similarities and differences among patient participant's themes. Next, the researcher compares and contrasts themes among nurse participants. The researcher identifies similarities and differences among nurse participant's themes. Afterwards, the researcher compares and contrasts themes between nurse and patient participants. The researcher identifies similarities and differences between nurse and patient participant's themes. Finally, the researcher will move to a more theoretical level and develop the essence of the lived experience of oncology nurses and cancer survivors in treatment transition. The results are showed in Chapter 4.

3.5.3 Evaluating Authenticity and Trustworthiness

Lincoln and Guba as reported by Polit & Beck (2012) develop four quality criteria for trustworthiness of qualitative research, including credibility, dependability, confirmability, and transferability. They explain further that credibility refers to confidence in the truth of the data and interpretations of them. Dependability refers to reliability of data over time and conditions. Confirmability refers to objectivity that data represent the information participants provided and that the researchers do not invent the interpretations of the data. Transferability refers to the extent to which the findings can be transferred to other settings (Polit & Beck, 2012). The researcher applied the Lincoln and Guba's quality framework for this research inquiry to enhance its trustworthiness. The researcher ensured the credibility of data and interpretations of them by collecting rich in-depth information from both nurse and patient participants and sent recording, transcript, and themes analysis to supervisor for review. The dependability is demonstrated by recruiting nurse participants providing cancer care for cancer survivors and patient participants receiving cancer care in treatment transition; in addition, reporting in details about the process of participant recruitment and data collection and analysis for peer review to enable external researcher to repeat the inquiry and achieve similar results. The confirmability is through review and audit by supervisor and members of supervisory committee with expertise in health research until consensus; this is to reduce the researcher's bias and ensure that the research findings are supported by the data. The transferability is by reporting highly specific details of the research situation, participant's characteristic, methods of data collection and analysis for readers to compare these to a similar situation that they are more familiar with.

Chapter 4. Results

This chapter presents the results based on the data collected from the patient interviews and the nurse interviews. Section 4.1 provides a description of the patient participants and documents the results based on the patient interviews. The results from the nurse interviews and a description of the nurses who participated in the interview can be found in section 4.2. The chapter ends with an overall summary of the results.

4.1 Patient Interviews

This section consists of two sub-sections including patient participants and results of their interviews.

4.1.1 Patient Participants

Five cancer survivors participated in this study. They were recruited according to research inclusion criteria. The five patient participants were interviewed in March, April, and May 2019. They were named with an anonymous identifier P1, P2, P3, P4, and P5 respectively. The demographics of the patient participants were collected through a self-reported socio-demographics form (Appendix J). Socio-demographics of the patient participants are presented in Table 4.1. All of the patient participants are female. Male cancer survivors did not express their interest in this study. Researcher following requirements of Research Ethic Board of both UOIT and Lakeridge Health did not receive contact from male cancer survivors.

Table 4.1 Socio-demographics of patient participants

Participant ID	P1	P2	P3	P4	P5
Gender	F	F	F	F	F
Age	52	61	51	47	46
Highest level of education	College diploma	Baccalaureate degree	Doctorate degree	College diploma	Master degree
Marital status	Divorced	Married	Divorced	Married	Married
Ethnicity	European	Caucasian	Aboriginal	European	Latin, Central, & South American/ Caribbean
Employment status	Employed	Employed	Employed	Employed	Employed
Cancer diagnosis	Stage II breast cancer	Breast cancer	Rectal and breast cancer	Cervical cancer	Breast cancer
Treatment					
Chemotherapy	Chemo-therapy		Chemo-therapy	Chemo-therapy	Chemotherapy
Radiation	Radiation	Radiation	Radiation	Radiation	Radiation
Surgery	Surgery	Surgery	Surgery		Surgery
Other				Brachy therapy	Tamoxifen

4.1.2 Results of Patient Interviews

Data for experience of patient participants was collected and categorized according to the Nursing Theory of Transition framework and was analyzed by Interpretative Phenomenological Analysis (IPA) approach to identify themes. The experiences of patient participants offer concepts of cancer survivors and indicate universal and relational patterns for cancer survivors in treatment transition. The results demonstrate both subjective particular experience and objective existential shared common experience of cancer survivors. Results of patient interview reports in the following four sub-sections including experience of patient participants under the Nursing Theory of Transition, experience of nursing care received, experience influencing delivery of cancer care and quality of life, and suggestions and recommendations to improve them.

Sub - Section One Experience of Patient Participants Under Nursing Theory of Transition

Nursing Theory of Transition framework includes personal transition and care transition. Patient participants experienced personal transition including physical, emotional, and social transition and care transition including transitioning from inpatient department to outpatient department/clinic, from oncology team to primary care provider team, and from acute cancer treatment to follow-up cancer care. Results report under each component of the Nursing Theory of Transition framework. Sections 4.1.2.1 through 4.1.2.3 present the results related to personal transition.

4.1.2.1 Physical Transition

Physical transition focuses on physical changes for cancer survivors in treatment transition. Patient participants experienced physical concerns and the following key emerging themes were identified: physical symptom distress, loss of body functions, and changes in body image that were presented in Table 4.2 below.

Table 4.2 Key emerging themes of patient participants in physical transition

Key emerging themes in physical transition	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Physical symptom distress	Tiredness	“How to try to give myself some energy, my biggest complaint was that I was really tired, no energy”. (P2)
	Pain	“I still have residual pain on my right side that will never go away; it feels like you have been punched, like every day you feel you have been punched on the side. Those type of things, but they don’t really want to take ownership for that, they don’t want to say oh yeah, this caused this, the chemotherapy caused this or the radiation treatment caused this, they tend not to take ownership for that. They will have to do something about that right?” (P1)
Loss of body functions	Chemo brain	“I still have memory issue that I have to work on. Brain fog, you know, there are things that just happens and you just have to work with them. I forget where I’m going, I forget where I have put things, I was tired all the time. Uh, I forget names that I used to remember names a lot. Those kinds of things a lot”. (P5)
	Limited lifting ability	“In the gym, even to this day, I can’t like what I used to lift. So, I used to be able to lift 25 pounds in one arm, you know, to do repetitions. (P2)
	Sexual problems	“My husband and I want to resume sexual activities, uh, they said that it could happen over time, and there were certain products we could use. But it was not possible without going into much detail, so, it was more uh coping skills I found to help myself psychologically, not really anything from our clinical point of view”. (P2)
Changes in body image.	Hair loss	“My hair started to fall a little, and I panicked, and they told me it was ok, just come to the hospital, we will take a look. And when I got to the hospital, they told me that it was more over because of the stress instead of the chemotherapy because I only had half of a dose. (P4)
	Lymphedema	“You know, the only thing is, when I started to look like I had lymphedema, the nurses, there was one nurse that was able to say, lymphedema, you look like you are going to have lymphedema, you should have that checked”. (P5)
	Scar tissues	“I still have a lot of scar tissue that causes my mobility to be different. The scar tissue has done a lot; I don’t have much mobility. Uh, the nurses haven’t provided me with anything, but I do a lot of other treatment. I do a lot of massage, for the scar tissue, and I have to go to the chiropractor, I have to take medication so my feet don’t burn. I just return to work part time because I cannot do full time”. (P5)

4.1.2.2 Emotional Transition

Emotional transition focuses on psychological upheaval and adjustment for cancer survivors in treatment transition. Patient participants experienced emotional concerns and the following key emerging themes were identified: emotional symptom distress, indignity, and survivor guilt that were presented in Table 4.3.

Table 4.3 Key emerging themes of patient participants in emotional transition

Key emerging themes in emotional transition	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Emotional symptom distress	Fear of recurrence	“The mind is a very powerful thing in the entire medical field. The mind can play tricks on you. So, every little pain, every little thing, it feels like that now since you have had cancer, then cancer just keep coming back. You start to think on it’s coming back, you want to run back to the hospital” (P1).
	Worries	“It was 2015, so I had, how old were they now, they were like 14, 12? My son was quite young, so I worry that if I leave, he would not have his mother that played on me emotionally. The rest of my family, they would be ok, they would be all right, but I was more concerned with my son’s well-being than anybody else. That played a toll on you”. (P4)
	Confusion	“You have the big talk thing after your last treatment, and you went home and you are on your own, that’s about it. So, that was something that was bothering me that you just went home and they just go congratulations, see you later, because like you are just then sitting at home saying, then what?”. (P1)
Indignity	Embarrassment	“The pain was very difficult to deal with. I remember immediately after my surgery, uh, within days, because of that knife-like pain that could arrive anytime, I would be standing in line in a grocery store, and I would suddenly grip me, and people would start to look at me, and I would say I’m fine. So, it was a little bit embarrassing. I just have to learn to accept it”. (P2)
	Frustration	“Because I always wanted to do things that I used to do, you know, and so sometimes you get really frustrated and upset that you cannot do those anymore. So now you realized that you just have to do things differently or those things will eventually come back. I just work with what I have, right?” (P5)
	Helplessness	“But you know I’m struggling on a daily basis, so I kind of ask my family doctor about my side effects, could you help me out, like you got anything that could help me?” (P3)
	Stigma	“I guess my identity, there’s me, and there will always be the stigma of, you know, having cancer and beating cancer”. (P4)
Survivor guilt	Survivor guilt	“I think it’s survivor’s guilt. I have a lot of cancer coming back to me. Even in our group, we lost 3 or 4 people at the hospital. You sit around the table and it almost feel like what’s next, you know. By the way, I love our group, I think it’s great, but you know, I have 2 of my best friends passed away because of cancer, and they are younger than me, and that’s very hard. And also, there’s also the thing of survivor’s guilt. I’m alive. I’m still here, but you know I have a cousin that has brain cancer right now, it’s like, ok why her, why not me, why am I still here, why she has so many troubles that she could possibly not be here. I’m just here hoping that she is ok and she is getting treatment, but there’s that issue of she might not be here, so why her, not me. So, it’s that survivor’s guilt too”. (P1)

4.1.2.3 Social Transition

Social transition focuses on socioeconomic issues of cancer survivors in treatment transition. Patient participants experienced social concerns and the following key emerging themes were identified: re-establishment of self-identity, return to new normal life, return to work, and meaning of survivorship that were presented in Table 4.4.

Table 4.4 Key emerging themes of patient participants in social transition

Key emerging themes in social transition	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Re-establishment of self-identity	Whole persons changed	"You are not the same person before. You were a person without cancer, and now you are a person that did or does have cancer. It's a whole different lifestyle now, a whole different mindset." (P1)
	Label of cancer survivor not accepted	"At first, I don't mind it (the label of cancer survivor), but I don't think. You are ever a survivor of that, because there is a constant monkey on your back, because it's always gonna be, I'm here, I'm here, I'm here, knocking at you. We have 2 friends that passed away and 2 friends that are still here, and we prefer the work warrior, cancer warrior, because we are constantly fighting against it, versus a survivor, because you will never be free of it. Survivor means that it's done, it's over, you are free of it, I would prefer the term warrior or something like that". (P1).
	New self-identity (warriors, winners, and/or victors) established	"Uh, honestly, I would prefer to say that I beat it. I fought it and I beat it. Because I guess, you could use survivor, but it is not usually one of the terms I familiar myself with. I just uh, I like to say that, yes, I fought and I beat it, I'm the victor in the battle, I won that one. One for me, zero for cancer. Yeah, there's a lot of people that had a lot more vigorous battle with cancer, but it uh, survivor is a different term, survivor makes me think that, uh, when I think of survivor, well I don't want to describe what I have gone through, because it is traumatic. Well it is a big change in my life, it changed my view on my life, my advantage point in my life. But, survivor, when I think of survivor, I think of somebody that have gone through something that is a lot more difficult than I have. I would like to say I was victorious in my battle with cancer. I mean it's a hard thing. I never think of myself as a cancer survivor." (P4).
Return to new normal life	Recognizing never back to previous normal life	"I don't know if I would physically be able to go back to what I was before. It changes a person psychologically, emotionally; it changes a person's view of themselves, a view of everybody around them. I don't think that person exists anymore due to the transformation I have gone through because of cancer". (P4)
	Starting a new normal life	"I mean, cancer does a lot of things, not just physically affect you, but emotionally and mentally. And you never look at things the same way. You decide what are the important priorities. You make some changes that you need to make, and your body doesn't even respond the same way when you come out of it, and even when they say you done well. That's why they usually say, it's a new normal. And so, I'm more tired sometimes, and uh, there are things that I cannot do that I did before. Will I do them again? Maybe, but right now, it's a working progress. So, it is a new normal because it taken out somethings and you add somethings. And most things that you add are some stress, so you don't over add things that you used to stress over before. A new normal, it's not the same". (P5)
	Adjusting to the new normal life	"That's a good way to put it, a new normal. That's why I don't compare to what I was because that doesn't exist anymore. So, this is exactly what I call it, my new normal. My new normal is, I can't lift, I have to be very careful about my joints, but I do what I can. I rather than being upset, what I can do, I continue with trying to push, and do what I can. So, in the beginning, I had a lot of difficulty with many things. This week, there's one night, I had a good night sleep, but when I waked up, I was tired, so I went

		back to take a nap, right in the morning. So, I accept that, when there were days that I'm tired, then I just have a nap. There was no, it's not a question of shame, but I don't see it with having something wrong with me, that I can't make it through the day without a nap, I just accept it. If that's what I need that day, then I just have a nap". (P2)
Return to work	No accommodation plan	"Because people don't know, they just want you to jump right back in. There's no gradual coming back to work. Because here at HR (human resources) is either you are coming back full time or you are not coming back. They had no sympathy or understanding for me at all". (P1) "Well I would like a gradual coming back, but no. It was like coming back full time, you are in or you are out" (P1).
	Job change	"I went back to work, I went back part time, for a little bit, to ease myself in, then I went full time, I realized I just could not sustain the full time hours, I was physically exhausted, like to the point that I was nausea when I finished a seven or eight-hour shift, I just, I couldn't do it. So, I work only 4-5 hours a week now". (P4)
Meaning of survivorship	Hard life	"Well, they (family) definitely worried about you all the time. And they always asking how you doing. So, I just try to show them that I'm well, that I'm ok. I have 5 sons, and I try to not look sick for them. I try to look well, so they don't worry, right? but it's hard when I'm having trouble moving. They can see that I'm different. They can see that I'm struggling, and I can't hide that. I can't hide that my joints won't move. I can't hide that I'm stiff. I can't hide that I'm like an 80-year-old woman. I can't hide that. So, they have to come to accept the fact that mom is not the same. Mom is not the same anymore, maybe mom will never be the same anymore. And I'm just sitting here". (P3)
	Loss	"I did lose a few people of my life I thought were closer to me, than they turned out being. They just fell off the radar, sort of speak, and I let them go, because if you don't want to be in touch of me, when I'm experiencing probably the hardest journey of my life, I probably don't need you anymore". (P4)
	Fighting against cancer	"The fact that I was able to make it through, is, uh, you know, I fought because I have a husband I love. I fought because I have children I love. I fought because I have a family. So, for me, uh, my meaning was to live for them. Right? To be able to experience life with them". (P5)
	Living a new second life with hope.	"My meaning of life has changed. I take this as my second chance, and you know, the universe doesn't hand them out too often. So, I think that, with my perception and my perspective of changing, and me wanting to change, how I do things in my life, how I want to be for the later part of my life. I think I'm on the right road of making a difference for myself, and for the path I have chosen". (P4) "My life was completely turned around. I have decided to make better of my life. And, I uh, went back to school full time, this year, after a few years of humming and hiding, going from full time of my job to part time because my physical level wasn't, they weren't coming back as quickly as I hope it would, but I have decided to come back to school". (P4)

The following sections 4.1.2.4 through 4.1.2.6 present the results related to care transition

4.1.2.4 Transitioning from Inpatient Department to Outpatient Department/Clinic

Patient participants experienced transition from inpatient department to outpatient department/clinic and self-care management was a key emerging theme presented in Table 4.5. During this transition, the patient participants felt overwhelming responsibilities for self-care management.

Table 4.5 Key emerging theme of patient participants in transition from inpatient department to outpatient department/clinic

Key emerging theme in transition from inpatient department to outpatient department/clinic	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Self-care management	Self-care management	“I was hard because I was on my own. And I have a 13-year-old at the time. So, that was hard to manage. My parents loved you help but they lived 3 hours away, so they came to help after I have already got my treatment. And I remember the time I got myself off the couch, it was about a week. But I couldn’t drive or do anything like that because my brain was very foggy. So, I relied a lot on Uber (a company offering ride service) to come in. Community care would come in but that would be right after just to check on my PICC line (peripherally inserted central catheter) and things like that. After my PICC line come out, I suspected that I had a blood clot, so I have to start getting myself needles. I trained my daughter to give me needles because I don’t want to do it myself. Eventually I have to learn how to do that. So, a lot of the stuff was done on my own. There was a lot of selfcare on my own. Community care would come in, and they were great, whenever I had that. There were nurses from community care, but a lot of it was done by myself”. (P1)

4.1.2.5 Transitioning from Oncology Team to Primary Care Provider Team

Patient participants experienced transition from oncology team to primary care provider team and communication was a key emerging theme presented in Table 4.6. During this transition, there were no physical meeting among patient participants, oncology team, and primary care provider team. Patient participants had to communicate with either oncology team or primary care provider team according to their preference when they needed help.

Table 4.6 Key emerging theme of patient participants in transition from oncology team to primary care provider's team

Key emerging theme in transition from oncology team to primary care provider's team	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Communication	No physical meetings	"I don't know if there's any, I don't think there is communication. I think they send information because I think it's all on file or through the internet. But they don't talk. They just sent paper". (P5) "I know my oncologist from chemo and my oncologist from radiation treatment, I'm sure they talked, but they never talked to me as a group. My radiation oncologist was very fast, it took me within 5 minutes. I come in and do some stuff and that's it. My chemo oncologist, I saw him quite often, and I saw her a little bit more because they are finding more spots. But when I was released, I didn't even go see the family doctor, there was no, no connection. All I need to have done; I have done. But other than going into the groups, I have no other connection with the hospital". (P1)
Communication	Communicate with healthcare teams according to patient's preference	"I would tend to, if I had a question, I would call the oncologist's coordinator. It's not that I don't trust my GP, but they are more specialized, where my GP is more general". (P2) "So, if I feel that if anything is wrong, I could call any one of them (the radiologist, the oncologist, the specialist, and family doctor). Between the 4 of them I see any one of them, and I express my needs, and they do whatever they can to help and take care of me" (P5)

4.1.2.6 Transitioning from Acute Cancer Treatment to Follow-up Cancer Care

Patient participants experienced transition from acute cancer treatment to follow-up cancer care and recovery of body functions was a key emerging theme presented in Table 4.7. Patient participants needed supports to promote their maximal recovery of body functions. Only P1 and P4 obtained education to promote their recovery of body functions while other three patient participants got little or even no supports.

Table 4.7 Key emerging theme of patient participants in transition from acute cancer treatment to follow-up cancer care

Key emerging theme in transition from acute cancer treatment to follow-up cancer care	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Recovery of body functions	Recovery of body functions	"My main concern was my energy levels. They (nurses) have advised that I do something, like I mentioned before, the yoga, doing some physical exercise, doing something you know that make me, because in order to create energy, you have to spend energy. I believe that, with my best interest in their hearts, they have told me that the physical exercise, you know doing something that would promote me to looking forward to doing something like that". (P4)

Sub - Section Two Experience of Nursing Care Received

During treatment transition, patient participants obtained nursing care in each component of the Nursing Theory of Transition. Results report under two components of the Nursing Theory of Transition. Sections 4.1.2.7 through 4.1.2.10 present the key emerging themes of results related to personal transition and care transition: nursing assessment, patient education, symptoms management, and resources offered to address patient participant's concerns and improve their health. However, patient participant's concerns have not been addressed completely.

4.1.2.7 Nursing Assessment

Experience of patient participants indicated that they were assessed by nurses in treatment transition presented in Table 4.8. Nursing assessment is a process by which nurses gather data and information about a patient' physical, psychological, sociological, and spiritual status in order to decide and provide further nursing care.

Table 4.8 Key emerging theme of patient participants – nursing assessment

Key emerging theme of nursing care received	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Nursing Assessment	Information and data collected	"The nurses call me in and they ask, uh, they ask a few questions, just kind of like, how I'm doing, have noticed, has anything changed? You know, if I'm having any issues, that kinds of things. And uh, and then I think they check your weight, and they do blood pressure, and they sometimes they take my temperature. Uh, and that's about it. It's probably just about 5 minutes. There's always a lot of people waiting in the waiting room. A lot of people in the waiting room in the clinic each time I visit there". (P3)

4.1.2.8 Patient Education

Experience of patient participants indicated that they obtained education in treatment transition by which nurses provided them with information to prevent injury and complications and promoted their health presented in Table 4.9.

Table 4.9 Key emerging theme of patient participants – patient education

Key emerging theme of nursing care received	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Patient education	Information provided to prevent injury and promote their health	“There’s pain, and uh, pain at the site, I’m told that it was just scar tissue, I’m told that if I massage it, it could eventually cause it to be broken down, but sometimes breaking them down would cause more scar tissue, it’s like a vicious cycle, so I don’t do anything about it. After my cancer treatment, no shaving in the arm pit. Because mine is breast cancer, so I wouldn’t run the risk of cutting myself because of the nerve damage and some numbness. How to deal, how soon could I go back to the gym, because I was very active before cancer and before my treatment, so I was told that I could go back after 6 weeks, so I did follow that. I think that’s it”. (P2)

4.1.2.9 Symptoms Management

Patient participants received cancer care to address their symptoms distress in treatment transition presented in Table 4.10.

Table 4.10 Key emerging theme of patient participants – symptoms management

Key emerging theme of nursing care received	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Symptoms management	Electrical pain addressed	“In the beginning I had severe knife-like electrical pain, which I came to believe that it was nerve damage, or the nerves that try to re-group themselves. It was very painful. They said in some people it would pass. And thank god it did”. (P2)
	Phantom pain not addressed	However, P2’s phantom pain was not addressed. “I don’t know if there’s anything you can do. Everyone I have asked, from my GP (family doctor), from my surgeon. My surgeon said that some people have phantom pain, and it could just continue for many years. Well because phantom pain is not ongoing, it could happen any place any time. It’s intermittent”. (P2)

4.1.2.10 Resources Offered

The experience of patient participants indicated that nurses provided them with resources available presented in Table 4.11.

Table 4.11 Key emerging theme of patient participants – resources offered

Key emerging theme of nursing care received	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Resources offered	List of places to go and people to see for supports	“They (nurses) have a list of places you can go, people you can see. They have the social workers there. Before UV (Ultraviolet), you can get a list about how you get harmed with anything in your neighborhood and they can call and make that connection for you. They will make sure you get that connection first before you get started. And sometime work has it too, you know, the work place may have free counseling as well”. (P1)
	Hotline services to answer questions	“I think they provided was a life line. They assured me, if I had any questions, all I had to do was call. For a couple times I did call. They always got back to me during the same day or within 24 hours. I have always felt confident what they tell me. Usually I was asking about something and they say don’t worry about it. They were right, eventually, they did pass. Whatever the issue was, they said they would take it up with my oncologist”. (P2)

Sub - Section Three Experience Influencing Delivery of Cancer Care and Quality of Life

Three key emerging themes were identified including active self-care management, social supports, and limited hospital capacity that influenced delivery of cancer care and quality of life. Sections 4.1.2.11 and 4.1.2.12 present the results related to the positive experience.

4.1.2.11 Active Self-care Management

Patient participants believed that active self-care management was a positive experience promoting delivery of cancer care and improving quality of life presented in Table 4.12.

Table 4.12 Key emerging theme of patient participants – active self-care management

Key emerging theme influencing delivery of cancer care and quality of life	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Active self-care management	Actively did research for self-care	"I actually don't think I received a whole lot of information. I was able to do some research on my own, and I came prepared with what I thought would be good for me, and discuss it with them. I asked them about the information that I have found". (P5)
	Actively learned from sessions and lived a healthy lifestyle	"I think, for me again, it is the proactive nature that I have. I surrounded myself with my family, my staff, knowing that the hearth place is the second family for me, the hearth place cancer care center. I'm very involved in all that. When the hearth place has sessions on, you know, things that interest me, I go and I sit and I listen to those. Uh, I find that, again, it's the same, going to church was important to me, going out with my friends and my family, getting involved in the sports my boys are doing, being able to watch them, doing those things help me transition well into normal life, and eating well. So, for me, it's knowing the things that make me feel good, knowing the things that help to fight cancer, I keep eating those things and doing those things. So that, mentally and physically, I know I'm feeling better because I'm making some good choices about what I eat, what I rest, where I go, who I spend time with, those were all positive factors in helping me cope". (P5)

4.1.2.12 Social Supports

Patient participants believed that social supports had positive impact on delivery of cancer care and quality of life presented in Table 4.13.

Table 4.13 Key emerging theme of patient participants – social supports

Key emerging theme influencing delivery of cancer care and quality of life	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Social supports	Supports from friends, family, and social groups	"Personally, what I used that kind of helped me to get through everything is I had good friends, I stayed very connected to them. We actually had a set time each month that we all come together and uh that's been very good to me. I had great family supports as well. I also go to a support group at hospice, in Peterborough, because that's my closest city, and that's great, because those are people that are going through the same things. Your friends and your family are great, but they don't have the same experience you are having, right? But the women at hospice do. So that's great". (P3)

Section 4.1.2.13 presents the results related to the negative experience (barriers)

4.1.2.13 Limited Hospital Capacity

The current hospital capacity to meet the increasing number of cancer patients and their increasing cancer care demand may be in doubt presented in Table 4.14.

Table 4.14 Key emerging theme of patient participants – limited hospital capacity

Key emerging theme influencing delivery of cancer care and quality of life	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Limited hospital capacity	Hospital private rooms not enough	"Because it's an open space and you are doing treatment and there would someone literally right beside you. And we are come in staring at each other, and you are allowed one to two people with you. But it's kind of weird, it feels like a, I don't, I don't know how to describe it, it's just weird. But I know you can't do anything about it, there's just so many people that have cancer, so many people that need treatment, so of course it's going to be busy. You can't have everybody having a private room, that's almost impossible. I mean they do have curtains and stuff, but anyway". (P1)
	Time for cancer care not enough	"I know it's not fair to say because I can't control it, but it's just so busy. There so many people that have cancer, and it's a huge cost for treatment, and you just don't feel like you have enough time to ask your questions or it feels like here, here is your treatment and get out that kind of thing. They are not actually saying get out, but you see other people coming through, and hmm, I didn't really like these, and I know there's no other way of doing this. I feel back because I'm saying it but there's no other way of doing it". (P1)

Sub - Section Four Suggestions and Recommendations to Improve Cancer Care and Quality of Life

Patient participants made suggestions and/or recommendations and the following key emerging themes were identified: increasing the numbers of healthcare professionals, needing effective information with rationales, and treating them in a holistic way to improve delivery of cancer care and quality of life. Sections 4.1.2.14 through 4.1.2.16 present the results related to these suggestions and recommendations.

4.1.2.14 Increasing the Numbers of Healthcare Professionals

Patient participants suggested increasing the number of healthcare professionals presented in Table 4.15.

Table 4.15 Key emerging theme of patient participants – increasing the number of healthcare professionals

Key emerging theme of suggestions and recommendations	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Increasing the number of healthcare professionals	Increase the number of social workers and nurses	"Of course, I think it would, I mean they have more time to spend with people. It's definitely needed. Yeah, I don't mean doctors may increase, but increase the number of social workers, the nurses can increase. These 2 people spend more time. We have more time to talk to them; they are more of the key component, I think. I'm not saying the oncology doctors aren't important, but uh they have a specific job to do, where I think the nurses and the social workers are more of the social component. I guess I go to there to get treatment, but the emotional component if important as well, the emotional wellbeing". (P1)

4.1.2.15 Needing Effective Information with Rationales

Patient participants needed specific and effective information with rationales that could address their concerns in treatment transition presented in Table 4.16.

Table 4.16 Key emerging theme of patient participants – needing effective information with rationales

Key emerging theme of suggestions and recommendations	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Needing effective information with rationales	Information needed	“I think they, I think they did look, even at a conversation about after care, because that was my biggest concern a year ago was, what happens? Like do you just drop me like a hot potato? What if I have a question, where do I go, who do I call, do I call you, do I call my GP (family doctor), do I call my surgeon”. (P2)
	Rationales needed	“It was always don’t lift over that amount. So, whenever I draw blood, it was don’t life anything, of course I don’t do it on that side, but don’t lift anything heavy right afterwards, so yeah, and I don’t understand the physical reasons why”. (P2)

4.1.2.16 Treating Them in a Holistic Way

Patient participants suggested understanding them, treating them in a holistic way, and providing quality cancer care to address their concerns comprehensively presented in Table 4.17.

Table 4.17 Key emerging theme of patient participants – treating them in a holistic way

Key emerging theme of suggestions and recommendations	Meaning units of significant statements of patient participants	Significant statements of experience of patient participants
Treating them in a holistic way	Address physical, emotional, social, and spiritual concerns	"My suggestion would be to keep it well rounded, to look at it as a whole. I know everybody has their little piece, but we need to all come together and look at it as a holistic view. Yes, you get your treatment, but there's also emotional, financial, the care givers, I think we really do deserve good care givers, and looking at it as a whole" (P1).
	Manage side effects and also treat the roots of health problems	"I would like help managing my side effect that is going to be with me for a long time. And I would like to look at, you know, all of the possibilities that could help me. Just don't give me a drug to combat the side effects that's from another drug that I'm taking. You know, that's just like layering problem on top of problem. I want, kind of, let's get down to the root of the problem and deal with it. It's kinds of only what I need right because I have to be able to navigate the side effects to go back to work". (P3)
	Address health concerns by medical treatment and also consider alternatives and/or natural treatment	"I really do think that cancer care involves the integration of all aspects of care. So, not just medicinal, but adding the natural, you know, being there to allow integrative care it's not just fight the cancer, but it's also strengthening the body. So you need to strengthen the immune system, you need to strengthen the mental capacity, and you need to be able to say, you know what, everybody's body is different, the journey is not just this long, it could take 2 years, it could take 3 years, it could take, and given the integration, and the health care that is needed for that period of time". (P5)

4.2 Nurse Interviews

This section consists of two sub-sections including nurse participants and results of their interviews.

4.2.1 Nurse Participants

Three oncology nurses participated in this study. They were recruited according to research inclusion criteria. The three nurse participants were interviewed in March and April, 2019. They were named as anonymous identifier N1, N2, and N3 respectively. The demographics of nurse participants were collected through a self- reported socio-demographics form (Appendix I). Socio-demographics of the nurse participants are presented in Table 4.18. All of the nurse participants are female. Male oncology nurses did not express their interest in this study. Researcher following requirements of Research Ethics Board of both UOIT and Lakeridge Health did not receive contact from male oncology nurses.

Table 4.18 Socio-demographics of nurse participants

Participant ID	N1	N2	N3
Gender	F	F	F
Age	41	52	37
Highest level of education in nursing	College diploma	College diploma	Baccalaureate
Have you completed certification(s)?	Oncology	Oncology	
Years of working as an oncology nurse	20	13	1.5
Employment status	Part time	Full time	Part-time

4.2.2 Results of Nurse Interviews

Data for experience of nurse participants was collected and categorized according to the Nursing Theory of Transition framework and was analyzed by Interpretative Phenomenological Analysis (IPA) approach to identify themes. The experiences of nurse participants offer concepts of oncology nurses and indicate universal and relational patterns for oncology nurses providing cancer care for cancer survivors in treatment transition. The results demonstrate both subjective particular experience and objective existential shared common experience of oncology nurses. Results of nurse interview reports in the following three sub-sections including experience of nurse participants under the Nursing Theory of Transition, experience influencing delivery of quality cancer care, and suggestions and recommendations to improve cancer care.

Sub - Section One Experience of Nurse Participants under the Nursing Theory of Transition

Nurse participants provided nursing care for cancer survivors in treatment transition. Key themes of nurse participant’s experience emerged and reported under each component of the Nursing Theory of Transition framework. Sections 4.2.2.1 through 4.2.2.3 present the results related to personal transition.

4.2.2.1 Physical Transition

Nurse participants provided nursing care for cancer survivors in physical transition. The following key emerging themes were identified: patient education and physical symptoms management presented in Table 4.19 to address cancer survivor’s physical concerns.

Table 4.19 Key emerging themes of nurse participants in physical transition

Key emerging themes in physical transition	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse participants
Patient education	Provide information and educate patients to manage side effects	“So, there’s either written information we given, that we print off, or verbally, we discuss with them. And if they don’t understand, we have to get them an interpreter. For people that has a hearing deficit, we get a sign language interpreter, and if there’s a different language, we have different interpreters to do the languages. Ideally, we get an actually interpreter rather than a family member so thing don’t get distorted. So that’s yeah, in radiation specifically, it’s, it’s specific to body parts, whereas chemotherapy, it’s systemic of course, the side effects. We spend a lot of the time with them during consultation, I spend quite a lot of time teaching them verbally on potential side effects. And in chemotherapy, I spend a little bit of time talking with them, but the patient also goes to a class, where they learn everything. I do the classes as well, there are different nurses that do different classes, there’s also one nurse that do the general class, where we give a presentation on chemotherapy and how it affects you physically, and how to manage those side effects”. (N1)
Physical symptoms management	Tiredness management	“I work mainly in radiation, a lot of people say that they feel tired, and, then I just recommend to them, I just make sure are you getting a good diet, are you eating sufficient meal, are you eating good quality meals, are you getting enough fluids. And I always tell them, paradoxically, if you work your body with exercise and all that, you actually feel better. Because sometimes, when they are feeling so unwell, during their treatment, the physical activity goes down right? And they call and say I’m still feeling very tired. So, I always tell them try diet, fluids, exercise gradually, and see if that helps you. If not, then yeah definitely call us back because you probably need to be assessed, you need blood work checked. So, the fatigue”. (N3)
	Peripheral sensory neuropathy management	“People complain of peripheral sensory neuropathy, the numbness and the tingling they feel in their hands and their feet. And unfortunately, with that one, there isn’t a whole lot that could be done, like in terms of giving them a prescription or something like that. But I always try to give the patients hope. I know I have talked to a lot of patient that it has been going on for years and it still feels like fire in my fingers after years. I have talked to a lot of people for whom it got better as well. So, when they are complaining about it, I just make sure the circulation is ok. When the circulation is ok, I say I know it’s uncomfortable and unpleasant, but you know, this will likely get better with time. I can’t offer much more than that. And I just say, if it gets much worse, make sure to call us back, or see the family doctor, or go to the emergency. Then I say, you have to make sure that you get checked by a doctor. But for the tingling, I just say that make sure the circulation is good, make sure that you are moving your body and your limbs, and keeping a good diet, and as long as you are ok with your family doctor, make sure that your hemoglobin level is good, you have good blood volume, and good circulation”. (N3)

4.2.2.2 Emotional Transition

Nurse participants provided nursing care for cancer survivors in emotional transition. The following key emerging themes were identified: nursing assessment, emotional symptoms management, and resources offered presented in Table 4.20 to address emotional concerns of cancer survivors.

Table 4.20 Key emerging themes of nurse participants in emotional transition

Key emerging themes in emotional transition	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse participants
Nursing Assessment	Information and concerns collected by inquiring and with assessment tools	“First of all, I assess their emotional transition when I’m talking to them. So, one of the specific questions I ask them specifically is “do you have any mental health issues?”. Some people are very open with that; some people aren’t; Uh so that’s the first thing I do, and some people just simply start telling me these kinds of things. So, I take their lead usually, if they start telling me that they are having anxiety, you know, because they have done their blood pressure, it’s really high. So, I started talking with them, to see if they are having difficulties. Another tool I use is the ESAS system assessment scoring, you know 0 to 10. So, when our patient checks in at the cancer center, they have to give themselves the scoring on depression, anxiety, those kinds of things, there are other physical things on there too. So, when I’m assessing the patient, that score already shows up on the chart. So, if I notice if that score is becoming higher, I will come out and ask them about it” are you suffering from any depression?” So, that’s another resource I use. Another resource is that we have social workers too. So, if the social worker has reported to me that there is an issue, then I will talk to my patients. Uh so when I talk to my patients, I validate their feelings, and how they are feeling, and I go through what is common in a cancer patient, things they will typically experience and try not to let them feel like they are alienated or this is weird or anything like that. What they are feeling is very common. And we talk about things they can go to help, for instance, deep breathing exercises, stuff like that, if I have time, I will do a little bit of that’. (N1)
Emotional Symptoms Management	Refer to doctors, social workers, and psychiatrists to address concerns	“Sometimes I suggest that they go see their family doctor when they feel like a medication might be helpful. I also refer them to our counselors, we have social workers that are trained in cancer behavior therapy, they can do some of that with patients. We also have a what we call a better clinic. What it is that people can get referred to see a psychiatrist to initiate some mental health treatment. So, I talk to them about that, but there is a process before they can get referred, so I kind of open up the gate way if they feel they want to talk about it”. (N1)
Resources Offered	Offer hotline services, support groups, and follow-up appointments	“The emotional part is the huge part. I think it’s just as important as the physical part. With the emotional adjustment, there’s a lot of talking. There’s a place called the hearth place in Oshawa, and you are able to go, they have a lot of classes. And you can meet peers that have gone through the same thing, is currently going through the same thing, or will be going through the same thing. So, they get to be in a group of people that understand what they are going through. Because as nurse, I have seen, but I have not experienced. So, I can say things, but that does not have the same meaning as someone that have gone through it. So, hearth place is a wonderful resource that we recommend to a lot of people. And they have workshops on relationships, on going back to whatever your normal is, on perhaps returning to work. So that’s the major resource. And again, it’s the follow up appointments, it’s the talking until the patient is comfortable leaving. It’s like they have a little burden or nest or something. They are not comfortable yet, and then, both the patient and the nurse know, it’s time to move on”. (N2)

4.2.2.3 Social Transition

Nurse participants provided nursing care for cancer survivors in social transition. The following key emerging themes were identified: refusing label of cancer survivors, promoting adjustment to a new normal life, promoting return to work, and recognizing meaning of survivorship that presented in Table 4.21.

Table 4.21 Key emerging themes of nurse participants in social transition

Key emerging themes in social transition	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse participants
Refusing label of cancer survivors	Not label cancer patients as cancer survivors	"I do not label my patients that way. Uh, because at what point is a cancer survivor? Because you have gone to treatment? Because you lived a year? Because the cancer is not coming back? At what point do you label them as cancer survivor? I don't know. That's not really defined in my opinion. There are people that come with stage one or two diseases, they will get cured. And in my opinion, ok that's easy. People that come to us as stage 4 patients, they are not gonna get cured. Just because, does that mean they are not cancer survivor? They have gone through treatment; they have gone through surgery. They picked up and gone back home, and they are living life, they still have cancer than many others, does that mean they are not a cancer survivor? Because they are still enduring a life. I myself, I don't label them that way". (N1)
Promoting adjustment to a new normal life	Recognize not return to their previous life Educate to start a new normal life Adjust to new normal life with achievable and realistic goals	"We want everybody to return to their normal life. We are encouraging that because that's a major sign that everything is ok. People want to be ok. If they can't go back to their normal life, then something is wrong with them, and there's some fault and they are afraid that they will never be able to be what they were before. And so, if they can, that's wonderful. It's also teaching them, if they can't reach that level they were at before, that's ok too, there a new normal, a new way of doing things. It would just be a different way, but that would be ok, they would be ok. But it takes time, it takes time for any change and any acceptance. I have experienced and they are still having the side effect, and they are still trying to deal with that part. It's a step by step. So once when all the side effects are gone, then it's the trying to get back to normal". (N2) "I talk to them, and ask what they want to do, whether its achievable, whether it's realistic, just talk to them about, well I don't have a lot of time when I'm talking to them, so yeah, it's just a lot of talking, a lot of hearth place, it's just emotional support at this point that they need, it's the encouragement". (N2)
Promoting return to work	Patient education on return to work	"If they want to return to work, at what point in duration that they will still be experiencing side effects, if there some way they can work from home, if there's some way they can do work at the beginning of the week so they can take the end of the week off, if they can work in the morning and take the afternoon off. So, I talk to them about those kinds of things a head of times if they plan to return to work". (N1)
Recognizing meaning of survivorship	Shift of family jobs	"You can see, from what I have spoken with the patient, there was a shift whereas, a wife had cancer, she was the strong one and she was the one that managed things, and there's a whole shift of jobs in which the husband now needs to be the strong one, to look after things. And there's a little bit of transition there. But uh, there's the support there. There's a little bit of anger in the beginning, where the spouse that was in control and had everything in control now has the cancer, and she has to let that go, and that's the hardest part. But otherwise, the family has always been very supportive, which is very nice". (N2)

	Prioritize themselves	“Because likely most people are very giving and concerning about others, I say that I’m willing to bet, before you discovered this, you are probably doing a lot for other people. And of course, that’s important when you have responsibilities, you have your job, your kids, and all that. But find some way, some time, to prioritize yourself, with things you love that makes you happy. If the responsibilities you have are a lot and they make you stressful, then try to find a little bit of time to lower your stress down. That’s all good for you. So be healthy, stay alive, extend your life for your kids, and the way you are going to do that is by prioritizing yourself. That sounds weird, but you know, if you take more for yourself, you will have more left”. (N3)

Sections 4.2.2.4 through 4.2.2.6 present the results related to care transition

4.2.2.4 Transitioning from Inpatient Department to Outpatient Department/Clinic

Nurse participants promoted cancer survivor's transition from inpatient department to outpatient department/clinic. During this transition, promoting self-care management was a key emerging theme that presented in Table 4.22.

Table 4.22 Key emerging themes of nurse participants transitioning from inpatient department to outpatient department/clinic

Key emerging themes transitioning from inpatient department to outpatient department/clinic	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse participants
Promoting self-care management	Assess cancer survivors Order home care	"When I talk to them, you get to feel what their abilities are. Some people are just "I can't do this", "I can't do these". So, for these people, you just have to order home care for them to come in to help them. If they have family members, I ask them is there any family member that can help you. Uh there are a lot of people as I'm talking to them, tell me things that they have looked up on the internet or things that they have already done. So, I get a sense of what their abilities are, just with our discussion. When they are not able or they are facing challenges to do thing on their own, then we order home care. Uh at that point, depending what need to be done If it's needles that they have to do, home care will teach them to do their own needles over time". (N1)
	Patient education	"It there's something that they can do on their own, like saline soaks, I teach them everything, I go through with them. I give them written instructions they can read through, listing instructions and how to do it. And I reassess them again, and again, and again, and I keep asking them. If they need reinforcement, then I document that in their chart that they need educational reinforcement, you know every time you see them". (N1)
	Back to hospital for further cancer treatment	"Sometimes we would have patients brought in from their home, brought in to rapid response clinic from home to have certain treatment done if they are having difficulties, or assess if they are having difficulties, like if there's something they brought up during the telephone that did not make sense, then I would just bring them here and assess them". (N1)

4.2.2.5 Transitioning from Oncology Team to Primary Care Provider Team

Nurse participants promoted cancer survivor's transition from oncology team to primary care provider team. During this transition, promoting communication between cancer survivors and healthcare teams was a key emerging theme that presented in Table 4.23.

Table 4.23 Key emerging themes of nurse participants transitioning from oncology team to primary care provider team

Key emerging themes transitioning from oncology team to primary care provider team	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse participants
Promoting communication between cancer survivors and healthcare teams	No physical meeting among cancer survivors, oncology team, and primary care provider's team. Nurses bridged communication between cancer survivors and health care teams.	"So, with my experience, I find there's a lot of grayness. The doctor gives, they write letters saying that they have completed their treatment. If their doctor received it, they received it. I have a lot of patients calling saying that their doctors want to know what kind of screen do I need to know, what kind of medication do I need to be on. So, a lot of the communication between primary care givers and us is between the patient. Patient goes and see that doctor, and then come back to ask us or phone us. Usually I tell the patient themselves what it is, and explain it to them. Sometimes I would phone the GP or the doctor I'm working with will phone the GP, depending on the situation. Like if the patient is calling us saying that I'm having some serious pain in my leg, and it's not working properly, I'm going to see my GP and see what it is. But I would be concerned that they have a spinal cord compression. I will call the GP right away and say the patient is coming to see you. But if the patient is having a bladder infection or having bad bowl movement, I would not call their GP. I will just tell the patients, go see your GP, tell them what your symptoms are and get your infection of what other symptoms assessed. So, depending on the degree of seriousness of what they are explaining to me, that determines if I'm going to phone the GP or not. It's usually the patient that is communicating between the doctors". (N1)

4.2.2.6 Transitioning from Acute Cancer Treatment to Follow-up Cancer Care

Nurse participants promoted cancer survivor's transition from acute cancer treatment to follow-up cancer care. During this transition, promoting maximal recovery of body functions was a key emerging theme presented in Table 4.24.

Table 4.24 Key emerging themes of nurse participants transitioning from acute cancer treatment to follow-up cancer care

Key emerging themes transitioning from acute cancer treatment to follow-up cancer care	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse participants
Promoting maximal recovery of body functions	Patient education	"What I encourage them all the time is just to be active. Don't sit too long, do more exercise, even if it's just walking around the block, walking around the mall, just doing what they think normal would usually be. And in time, hope that it would improve. It they sit, nothing will get fixed. All the side effects will not be fixed. The nausea will get worse, the constipation will get worse, everything will get worse. But if they get your body moving, the heart start to pump and the blood start to move, and then they are just feeling better, they are getting stronger, lying around is not going to make them stronger. Being active, again even if it's just going to a walk in the mall. Or join a gym, so they can do minor gym thing, whatever it is, but just try to constantly get their body moving". (N2)
	Offer therapy programs Refer to registered dietitians, social workers, and doctors	"I refer my patients to dietitian, social workers. We have physiotherapy, message therapy. We do have physiotherapy program we could refer our patient to, and they would assess their physical condition and give them a 12-week walking program or exercise program according to abilities. So, I always offer that to patients, but if they are going to the gym already, they are not going to need that. So, for a lot of the patients when I offer this program to them, they say "oh nonono, I can walk on my own. I can walk half an hour each day". That's fine, I don't want to put more daily work to them. If they can walk on their own for half an hour per day, that's fine. So as long as we have that discussion, we don't need to use this service. Very rarely, I have people that actually take the offer of this service". (N1)

Sub - Section Two Experience of Nurse Participants Influencing Delivery of Quality Cancer Care

Nurse participants reported positive experience promoting delivery of quality cancer care and barriers inhibiting delivery of quality cancer care. Six key emerging themes were identified. Three themes including caring for cancer survivors, experience and knowledge, and advocate for cancer survivors were positive experience. Three themes including low socioeconomic status of cancer survivors, culture and language barriers, and limited time providing nursing care were barriers. Sections 4.2.2.7 through 4.2.2.9 present results related to the positive experience

4.2.2.7 Caring for Cancer Survivors

Nurse participants shared caring values and cared for cancer survivors to promote their health presented in Table 4.25.

Table 4.25 Key emerging themes of nurse participants - caring for cancer survivors

Key emerging theme influencing delivery of quality cancer care	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse
Caring for cancer survivors	Caring for cancer survivors	"I get very attached to my patients whether I have met them one day or years. I mean they are living beings; I want them to be happy, I want them to be able to achieve their goals, I want them to be well, I want them to, you know, it's like an internal motherly instinct you know? Like when you go "okok, is this ok, is that ok, is this what you need". (N2)

4.2.2.8 Knowledge and Experience

Nurse participants believed that their knowledge and experience laid a good foundation for delivery of quality cancer care for cancer survivors presented in Table 4.26.

Table 4.26 Key emerging themes of nurse participants - knowledge and experience

Key emerging theme influencing delivery of quality cancer care	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse
Knowledge and experience	Knowledge and experience	"Well, I'm a cancer nurse because of the experience I have with my patients, I have seen what they have gone through. If I figured out how to fix a certain problem, I could use it for my next patients. A lot of what I learned from each and every patient, I bring them forward to other patients and so on. When I start to see a very competitive complain from patients, or when I assess something over and over again, then I say ok we need to do something about this. There is, for instance, a cream I would like to recommend to a lot of my patients. A lot of the patients have never heard of it, so I reached out to the company and asked for samples. I told them I would like samples so I could give them to my patients, so they can try and go buy it. I think it works well." (N1)

4.2.2.9 Advocate for Cancer Survivors

Nurse participants worked as advocates for cancer survivors to promote delivery of quality cancer care presented in Table 4.27.

Table 4.27 Key emerging themes of nurse participants - advocates for cancer survivors

Key emerging theme influencing delivery of quality cancer care	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse
Advocates for cancer survivors	Advocates for cancer survivors	"I participated in meetings with patient advisors, so basically patient advisors have been patients. They tell us what's been wrong and what should we do about it to make it better. So, I have been to those meetings, and when we plan to develop programs at our cancer center, I give my inputs on behalf of my patients. They don't know, uh they want a paper telling them what they should do, they want a telephone call after the treatment. I bring all of this to my managers during meetings, and sometime it was heard and it developed into a practice that we should all be doing. Sometimes it does not get heard, or other staff don't value it as much as I do. So, I just have to practice it on my own". (N1)

Sections 4.2.2.10 through 4.2.2.12 present results related to the negative experience (barriers)

4.2.2.10 Low Socioeconomic Status of Cancer Survivors

Nurse participants believed that low socioeconomic status of cancer survivors especially low income was a key barrier for delivery of quality cancer care that presented in Table 4.28.

Table 4.28 Key emerging themes of nurse participants - low socioeconomic status of cancer survivors

Key emerging theme influencing delivery of quality cancer care	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse
Low socioeconomic status of cancer survivors	Low income Homeless Cannot afford healthy food Cannot afford medication Difficult access to cancer care	“Finances, that can be a big deal too. People don’t have the money to buy medication that help with their eating or swallowing. And there are patients that live on food banks, and now we are giving them advice on what they should be eating, drinking and consuming, but they are using food banks, they get what they get. And sometimes we have patients that are homeless, and they just usually find a friend’s couch to sleep with. So, in that case, they can’t afford cream, they can’t afford medication, and there’s barriers with that as well. You know, money is a big deal”. (N1) “Transportation is a huge barrier. It depends whether the patient has money or where do the patients live. We cover a huge area, so when people find out that they need to come here for their treatment, sometimes they just can’t do that. They can’t come every day for radiation. They just can’t drive, it’s too harsh. We do have a hotel that they can stay at, and I go through with them what is it like to stay there. But a lot of people don’t want to do that, they feel they are too distracted from their life. They want to stay at home they want to be with their pets, their family in their comfortable bed. So, transportation is a big deal. They might be not well enough to drive, it might be too far to drive, so sometimes they just choose not to get treatment, or they choose to get treatment not in a timely manner”. (N1)

4.2.2.11 Culture and Language Barriers

Different cultures and languages between nurse participants and cancer survivors became barriers for delivery of quality cancer care presented in Table 4.29.

Table 4.29 Key emerging themes of nurse participants - cultures and languages barriers

Key emerging theme influencing delivery of quality cancer care	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse
Cultures and languages barriers	Cultures barriers	"I found there's cultural barriers. It does drive me crazy. The one that drives me nuts is when family member says they don't know they have cancer. Don't tell them; if there's anything, tell me. Don't use that word. And I'm like, this is their life. Surely, they know there's something wrong, and who are you to make that decision for them? So, I do find that often is a cultural thing. There are certain people that comes from the world, there are people that really focus on that. And there are other cultural, I don't if they are barriers per se, we just have to all understand and get through that. It happens when a patient really can't understand treatment anymore, but the family feels like they need to have more treatment, but it's the treatment itself that is too harsh. So that's when, I found sometimes, there's a cultural barrier". (N1)
	Languages barriers	"Language barriers inhibits it because you don't perhaps not understand what the needs are the patients are asking". (N2)

4.2.2.12 Limited Time Providing Nursing Care

Nurse participants did not have sufficient time to provide quality cancer care for cancer survivors presented in Table 4.30.

Table 4.30 Key emerging themes of nurse participants - limited time providing nursing care

Key emerging theme influencing delivery of quality cancer care	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse
Limited time providing nursing care	Increasing number of cancer patients Short of staff	"There's lots. The one thing is simply time. We have so many patients, and I have an eight-hour shift, so I have to divide that time for each patient. So, I found that it was one of the barriers is that the time I was given to look after each patient. And that's unfortunate. And I think in some way it's also the resources. If we have more staff, I might be able to have more time with each patient. So that unfortunate". (N1)
	Heavy work load	"I'm in an out-patient department, a lot of the appointments are 10-minute appointment. That means, we are weighing the patient, we are doing their vital signs, we are assessing their ESAS information they put in, I'm checking all their medications, I'm asking all their symptoms and how they are feeling, and I have to respond to them, like say for instance, they don't know how to use their puffers properly, and I have to teach them how to use their puffers. You can't do all that in 10 minutes, you can't. And those are very simple appointments, and for someone that has jaundice, other complicated conditions, it's going to take way more than 10 minutes to address this patient's needs. So, uh we are not given enough time". (N1)
	Time not enough	"You can't really talk to them as much as you would like to. There's even less time to talk to people. So, you can't really get all the information to actually look after every issue they have or every need they have. There's no time, I have to see a patient every 10 minutes, and sometimes there's 2 people in that 10-minute slot they have given me, so there's like 25 people from 9 to 12. It's hard, it's frustrating. You want the patient to know that you care and you are listening, but there's very little time, and it's just keep adding more and more. It's frustrating, but again they can call, but again it's frustrating, and it does affect patient care big time". (N2)
	Time waste	"If we only have like 10 minutes or 15 minutes to spend with the patient, it's such a waste that during that time we are fumbling because things don't work. I need to take their blood pressure; the battery keeps dying. In order to keep it working I need to stop and plug it in. Or, uh the computer program, it won't accept what I'm typing because I didn't do it in capitals, and it wants it in capitals and I have to erase everything. It's those little things that I always tell them that time drains. So, if you can't give me more than 10 minutes, it's fine. But just make sure in those 10 minutes, I can efficiently work". (N3) It's just a few seconds here and there, but in a 10-minute window, those wasted seconds could be spend doing anything else. Like in that 10-minute window, I could direct that time more to the patient, whatever they need. But I'm wasting time, I'm plugging this in, I'm deleting this again, I'm copying it, I'm, ummm, you know, I need uh, they say can I have my blood work, but I'm in a room where there's no printer". (N3) "Why are these machines, they are either old or mal-functioning, that slows me down, or the computer program is not as ideal as it could be, that slows me down. It's lack of time, or the inability to maximize the time you have because of the other, you know, broken this". (N3)

Sub - Section Three Suggestions and Recommendations to Improve Cancer Care

Nurse participants made suggestions and/or recommendations to improve cancer care for cancer survivors. The following key emerging themes were identified: establishing a new position - one primary nurse, increasing the number of healthcare professionals, and improving knowledge, skills, and experience. Sections 4.2.2.13 through 4.2.2.15 present results related to the suggestions and recommendations by the nurse participants

4.2.2.13 Establishing a New Position - One Primary Nurse

Nurse participants believed that one primary nurse was needed to address fragmented cancer care for cancer survivors in their whole cancer journey presented in Table 4.31.

Table 4.31 Key emerging theme of nurse participants – establishing a new position - one primary nurse

Key emerging theme of suggestions and recommendations	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse participants
Establishing a new position - one primary nurse	Establishing a new position - one primary nurse	“So as far as nursing goes, I would like to see a nurse to be with the patient through the entire journey. Rather than right now, I feel very fragmented. You go to this doctor; this doctor has a nurse. You go to that doctor, that doctor has a nurse, you go to this center, you meet a different nurse, you have home care, you have a different case manager. I feel it’s very fragmented for the patient. When I hear them talking about, they have a case manager with home care, but they have to deal with this company, that company, and then when they come to the cancer center, they have more than one primary nurse, and they have a nurse navigator. When they are diagnosed with cancer, they should get a nurse, and that should be nurse for them through the entire journey. That’s their primary nurse. Of course, there will be other nurses, cancer centers, inpatient unit, outpatient unit, there will be other people and other nurses. But there should be one nurse that ensure that builds up the relationship with the patient. They need one person that understands their needs and understands the system at the same time. It’s good to have one nurse that can do the whole thing. With that said, I kind of understand why we have multiple people. We all have our strength and weaknesses along the way. But I feel like it would be a good thing to do, to have that one nurse whose always in connection with the patient. They don’t have to see the nurse every time they go to the cancer center. They can phone them; they can do a lot over the telephone with the patient. But I would like to see that”. (N1)

4.2.2.14 Increasing the Numbers of Healthcare Professionals

Nurse participants suggested increasing the numbers of healthcare professionals presented in Table 4.32.

Table 4.32 Key emerging theme of nurse participants – increasing the numbers of healthcare professionals

Key emerging theme of suggestions and recommendations	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse participants
Increasing the numbers of healthcare professionals	Increasing the numbers of healthcare professionals	"More nurses would be great, more doctors would be great, uh more facilities to help people would be great, uh it's just more of everything, less cancer would be wonderful". (N2) "I'm thinking the doctors would say the same thing. They need more doctors in order to provide a more quality of care because they are constantly working harder. And social workers would say the same thing. We need more social workers in order to provide a more quality care. You just need more of the right type of workers" (N2)

4.2.2.15 Improving Knowledge, Skills, and Experience

Nurse participants believed that nurses need to improve their knowledge, skills, and experience to provide quality cancer care presented in Table 4.33.

Table 4.33 Key emerging theme of nurse participants – improve knowledge, skills, and experience

Key emerging theme of suggestions and recommendations	Meaning units of significant statements of nurse participants	Significant statements of experience of nurse participants
Improve knowledge, skills, and experience	Improve knowledge, skills, and experience	"I would advise every nurse to take oncology courses and I think all nurses should try to do every part of the oncology program. So, I think they should have the experience in diagnostic assessment, they should have the experience of patients doing systemic treatment, they should definitely work in palliative care. I feel like the nurse should have the experience of the oncology nurse in all parts of the oncology journey to be the best oncology nurse they can be". (N1)

4.3 Summary of Results

This chapter presents results of experience of patient and nurse participants in treatment transition. Socio-demographics information of patient and nurse participants provided. The data collected from patient and nurse interviews was analyzed by Interpretative Phenomenological Analysis (IPA) approach. Themes were identified and reported under each component of the Nursing Theory of Transition framework in Patient Interviews section and Nurse Interviews Section respectively. The results of Chapter Four are summarized in the Table 4.34. The following Chapter 5 Discussion will explain results of participants interviews, compare and contrast the findings with those in other current literatures, and analyze similarities and differences of patient and nurse participant’s results.

Table 4.34 Summary of results of patient interviews and nurse interviews

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews
			Emerging themes	Emerging themes of nursing care received	Emerging themes
Nursing Theory of Transition	Personal transition	Physical transition	Physical symptom distress Loss of body functions Changes in body image	Nursing assessment Patient education Symptoms management Resources offered	Patient Education Physical symptoms management
		Emotional transition	Emotional symptom distress Indignity Survivor guilt		Nursing assessment Emotional symptoms management Resources offered
		Social transition	Re-establishment of self-identity Return to new normal life Return to work Meaning of survivorship		Refusing label of cancer survivors Promoting adjustment to a new normal life Promoting return to work Recognizing meaning of survivorship
	Care Transition	Transitioning from inpatient department to outpatient department/ clinic	Self-care management		Promoting self-care management
		Transitioning from oncology team to primary care provider team	Communication		Promoting communication between cancer survivors and healthcare teams
		Transitioning from acute cancer treatment to follow-up cancer car	Recovery of body functions		Promoting maximal recovery of body functions

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews
			Emerging themes	Emerging themes of nursing care received	Emerging themes
Experience influencing delivery of quality cancer care	Positive experience		Active self-care management Social supports		Caring for cancer survivors Experience and knowledge Advocate for cancer survivors
	Negative experience Barriers)		Limited hospital capacity		Limited time providing nursing care Low socio-economic status of cancer survivors Culture and language barriers

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews
			Emerging themes	Emerging themes of nursing care received	Emerging themes
Suggestions and recommendations to improve cancer care			Increasing the numbers of healthcare professionals Needing effective information with rationales Treating them in a holistic way		Increasing the numbers of healthcare professionals Establishing a new position - one primary nurse Improving knowledge, skills, and experience

Chapter 5. Discussion

The purpose of this study explored the lived experience of oncology nurses and cancer survivors in treatment transition. This chapter discusses results of patient and nurse participants' interviews respectively, compares and contrasts the findings with those in`` current literature, and analyzes similarities and differences of patient and nurse participants' results in the following sections.

5.1 Summary Table
5.2 Patient Participants
5.3 Nurse Participants
5.4 Similarities and Differences between Results of Patient and Nurse Interviews
5.5 Methodology
5.6 Issues to be Considered

5.1 Summary Table

The Summary Table 5.1 below summarizes the discussion of patient and nurse participants' interview results.

Table 5.1 Summary Table

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interview	Similarities	Differences	Issues to be considered
			Emerging themes	Emerging themes of nursing care received in treatment transition	Emerging themes			
Nursing Theory of Transition	Personal transition	Physical transition	Physical symptom distress Loss of body functions Changes in body image	Nursing assessment Patient education Symptoms management Resources offered	Patient education Physical symptoms management	Physical concerns Negative consequences Nursing care provided	Quality of cancer care	Insufficient knowledge and experience, Limited time providing cancer care, Not sole responsibility of nurses, Needs to establish and/or improve standardization of nursing care Raising primary care provider team’s capacity Call for a new model for coordinated continuous cancer care for cancer survivors

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews	Similarities	Differences	Issues to be considered
			Emerging themes	Emerging themes of nursing care received in treatment transition	Emerging themes			
Nursing Theory of Transition	Personal transition	Emotional transition	Emotional symptom distress Indignity Survivor guilt	Nursing assessment Patient education Symptoms management Resources offered	Nursing assessment Emotional symptoms management Resources offered	Emotional distress Negative consequences Nursing care provided	Indignity Quality of cancer care	Insufficient knowledge and experience, Limited time providing cancer care, Not sole responsibility of nurses, Needs to establish and/or improve standardization of nursing care Raising primary care provider team’s capacity Call for a new model for coordinated continuous cancer care for cancer survivors

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews	Similarities	Differences	Issues to be considered
			Emerging themes	Emerging themes of nursing care received in treatment transition	Emerging themes			
Nursing Theory of Transition	Personal transition	Social transition	Re-establishment of self-identity Return to new normal life Return to work Meaning of survivorship	Nursing assessment Patient education Symptoms management Resources offered	Refusing label of cancer survivors Promoting adjustment to a new normal life Promoting return to work Recognizing meaning of survivorship	Refusing label of cancer survivors New Self-identity as warriors Return to new normal life Return to work Fighting against cancer and hard life	New self-identity as winners and/or victors besides warriors Supports not sufficient Return to work Loss and living a better second life with hope	Insufficient knowledge and experience, Limited time providing cancer care, Not sole responsibility of nurses, Needs to establish and/or improve standardization of nursing care Raising primary care provider team’s capacity Call for a new model for coordinated continuous cancer care for cancer survivors

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews	Similarities	Differences	Issues to be considered
			Emerging themes	Emerging themes of nursing care received in treatment transition	Emerging themes			
Nursing Theory of Transition	Care Transition	Transitioning from inpatient department to outpatient department / clinic	Self-care management	Nursing assessment Patient education Symptoms management Resources offered	Promoting self-care management	Self-care support provided	Quality of self-care	Insufficient knowledge and experience, Limited time providing cancer care, Not sole responsibility of nurses, Needs to establish and/or improve standardization of nursing care Raising primary care provider team's capacity Call for a new model for coordinated continuous cancer care for cancer survivors

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews	Similarities	Differences	Issues to be considered
			Emerging themes	Emerging themes of nursing care received in treatment transition	Emerging themes			
Nursing Theory of Transition	Care Transition	Transitioning from oncology team to primary care provider team	Communication	Nursing assessment Patient education Symptoms management Resources offered	Promoting communication between cancer survivors and healthcare teams	Nurses bridged and promoted communication	Fragmented communication	Insufficient knowledge and experience, Limited time providing cancer care, Not sole responsibility of nurses, Needs to establish and/or improve standardization of nursing care Raising primary care provider team’s capacity Call for a new model for coordinated continuous cancer care for cancer survivors

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews	Similarities	Differences	Issues to be considered
			Emerging themes	Emerging themes of nursing care received in treatment transition	Emerging themes			
Nursing Theory of Transition	Care Transition	Transitioning from acute cancer treatment to follow-up cancer care	Recovery of body functions	Nursing assessment Patient education Symptoms management Resources offered	Promoting maximal recovery of body functions	Recovery of body functions promoted	Quality of recovery of body functions	Insufficient knowledge and experience, Limited time providing cancer care, Not sole responsibility of nurses, Needs to establish and/or improve standardization of nursing care Raising primary care provider team's capacity Call for a new model for coordinated continuous cancer care for cancer survivors

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews	Similarities	Differences	Issues to be considered
			Emerging themes	Emerging themes of nursing care received in treatment transition	Emerging themes			
Experience influencing delivery of quality cancer care	Positive experience		Active self-care management Social supports		Caring for cancer survivors Advocate for cancer survivors Experience and knowledge	Active self-care management Social supports Caring for cancer survivors Advocate for cancer survivors Experience and knowledge	Emphasis of patient and nurse participants was different	Insufficient knowledge and experience, Limited time providing cancer care, Not sole responsibility of nurses, Needs to establish and/or improve standardization of nursing care Raising primary care provider team's capacity Call for a new model for coordinated continuous cancer care for cancer survivors

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews	Similarities	Differences	Issues to be considered
			Emerging themes	Emerging themes of nursing care received in treatment transition	Emerging themes			
Experience influencing delivery of quality cancer care	Negative experience (Barriers)		Limited hospital capacity		Limited time providing cancer care Low socio-economic status of cancer survivors Culture and language barriers	Limited hospital capacity Limited time providing cancer are	Low socio-economic status of cancer survivors Culture and language barriers	Insufficient knowledge and experience, Limited time providing cancer care, Not sole responsibility of nurses, Needs to establish and/or improve standardization of nursing care Raising primary care provider team's capacity Call for a new model for coordinated continuous cancer care for cancer survivors

Main Sections	Sub-sections	Sub-sections	Results of patient interviews		Results of nurse interviews	Similarities	Differences	Issues to be considered
			Emerging themes	Emerging themes of nursing care received in treatment transition	Emerging themes			
Sugges-tions and recomme-ndations to improve cancer care			Increasing the numbers of healthcare professionals Needing effective information with rationales Treating cancer survivors in a holistic way		Increasing the number of healthcare professionals Establishing a new position-one primary nurse Improving knowledge, skills and experience	Increasing the numbers of healthcare professionals	Needing effective information with rationales Treating cancer survivors in a holistic way Establishing a new position - one primary nurse Improving knowledge, skills, and experience	Insufficient knowledge and experience, Limited time providing cancer are, Not sole responsibility of nurses, Needs to establish and/or improve standardization of nursing care Raising primary care provider team's capacity Call for a new model for coordinated continuous cancer care for cancer survivors

5.2 Patient Participants

The findings of key emerging themes of patient participants are discussed and compared to current research under each component of the Nursing Theory of Transition in the following sections. Nursing care received, experience influencing delivery of quality cancer care and quality of life, suggestions, and recommendations to improve cancer care are also discussed.

5.2.1 Physical Transition

Patient participants experienced physical transition under personal transition of the Nursing Theory of Transition. Three key emerging themes were identified from the experience of patient participants including physical symptoms distress, loss of body functions, and changes in body image.

Pain and tiredness were common physical symptoms distress that patient participants experienced even if they had different cancer diagnosis and treatment. The patient participants also lost some body functions such as impaired memory, sexual problems, and limited lifting ability. Fitch et al. (2018) conducted a national survey to identify unmet needs and experiences for Canadian post-treatment cancer survivors. The most common symptom of cancer survivors in their study was fatigue/tiredness, change in sexual function/activity, and change in memory/concentration followed by pain and lymphoedema (Fitch et al., 2018). Tan et al. (2019) conducted a survey to determine the health concerns of Australian post-primary treatment cancer survivors with breast, colorectal and haematological cancers. Fatigue and pain of cancer survivors in their study were common physical symptoms distress for them who also had moderate problems with sex (Tan et al., 2019). Changes in body image such as hair loss, scar tissues, and lymphedema negatively affected appearance and body functions of patient participants. Patient participants in this study emphasized that changes in body image negatively affected their body functions. However, cancer survivors in Fitch et al. (2018) and Cheng et al. (2016) emphasized negative impact on appearance. Fitch et al. (2018) indicated that changes in body image lowered confidence in appearance and caused emotional concerns for their cancer survivors. Cheng et al. (2016) conducted a qualitative study and explored negative and positive life changes for Chinese breast cancer survivors following treatment completion. They indicated that losing breast/breasts caused poor body images. Cancer survivors felt less feminine and unattractive so that they worried about being noticed as disfigured bodies (Cheng et al., 2016).

The three key emerging themes identified in this study negatively affected patient participant's memory, mobility, sexual activity, activities of daily living, and return to work. Accordingly, Cheng et al. (2016) indicated that physical symptoms (e.g. fatigue, lymphedema, and cognitive problems) imposed limitations on their participant's daily activities.

All patient participants in this study sought help. Some participants in Fitch et al. (2018) sought help while others did not. Both the findings in this study and those in Fitch et al. (2018) indicated that it was difficult to obtain help and/or help obtained did not address cancer survivor's physical concerns. Patient participants in this study further explained that they did not have enough time to ask questions, information obtained was too general, and they were not treated in holistic way.

5.2.2 Emotional Transition

Patient participants experienced emotional transition under personal transition of the Nursing Theory of Transition. Emotional transition focuses on psychological and emotional upheaval and adjustment (Schulman-Green et al., 2012). Three key emerging themes were identified from experience of patient participants including emotional symptoms distress, indignity, and survivor guilt.

Patient participants experienced emotional symptoms distress. Fear of cancer recurrence was common among patient participants. They had anxiety characterized by frequently intense, excessive and persistent worry about their situations. They also felt confused and were unsure what was next. The findings of emotional symptom distress such as fear of recurrence and anxiety coincided with those in Fitch et al. (2018) and Tan et al. (2019).

Patient participants felt indignity in emotional transition. They experienced embarrassment due to suddenly unexpected pain in public places, felt frustrated for loss of capacity that they could not carry previous activities anymore, became helpless and struggled day by day, and had stigma with identity of having cancer. The theme of indignity was a new finding for this study. Indignity impaired participant’s self-respect and self-worth and caused a deep sadness that interfered with activities of daily living for them.

Patient participants suffered survivor guilt in emotional transition. Survivor guilt is often associated with a reaction for cancer survivors surviving cancer while other cancer patients especially family, friends, colleagues, or fellow cancer patients have died. Another form of survivor’s guilt is that cancer survivors may feel guilty about disrupting the routines of family members such as becoming care givers and/or increasing burden for family (Grisham, 2016). Survivor guilt caused feelings of blame and regret for patient participants in this study. Glaser, Knowles, and Damaskos (2019) in their study of cancer survivor guilt in cancer survivorship indicated that cancer survivors compared their lives with lives of people with cancer who had died and they also struggled to justify that they were still living. Both this study and Glaser et al. (2019) also indicated that cancer survivors with survivor guilt felt overwhelming helpless, a deep sadness, and injustice. Consequently, it can overtake cancer survivor's thoughts to interfere with their activities of daily activities (Eldridge, 2019). Survivor's guilt was an under addressed emotion distress in survivorship care. Eldridge (2019) made some suggestions to help cancer survivors to cope their survivor's guilt including acknowledge survivor guilt, express your feelings, allow grieve, remember your friend through an act of kindness, accept that there are no answers, embrace your spirituality, practice stress relief, get help from support groups, and celebrate your survival. Eldridge (2019) also called for more future research to address cancer survivor's guilt since majority of cancer survivors experience it to some degree.

All patient participants sought help to address their emotional upheaval in emotional transition, which was not common practice in Fitch et al. (2018)'participants. Patient participants sought help but it was difficult to obtain help and/or supports obtained was not sufficient to address their concerns. They further explained that they were not well understood, consultation obtained was not specific, and they were not treated in holistic way.

5.2.3 Social Transition

Patient participants experienced social transition under personal transition of the Nursing Theory of Transition. Social transition focuses on shifts and/or changes in identities, life, and work as well as meaning of survivorship (Kim & Wiernikowski, 2011; Potter & Perry, 2010; Schulman-Green et al., 2012). Four key emerging themes were identified from experience of patient participants including re-establishment of self-identity, return to new normal life, return to work, and meaning of survivorship.

Patient participants experienced re-establishment of self-identity. Self-identity refers to recognition of participant's potentials and qualities in social context (Khan Academy.n.d.; LEXICO, 2019). Self-identity is important because it increases people's self-esteem, self-awareness, and awareness of the world where they live and work (Cooper, Smith, & Russell, 2017). The researcher analyzed the experience of patient participants and discovered that re-establishment of their new self-identity was a process over time along their cancer journey in which they changed previous self-identity, refused label of cancer survivors, and established new self-identity. Patient participants recognized that they could not resume their previous self-identity although they wanted it because cancer and treatment had changed them physically, emotionally, and socially; the consequence was that they had to change their previous self-identity. Self-identity is combination of individual and social needs. Erik Erikson, a developmental psychologist, emphasized people as a function of their biological and sociocultural forces and presumed a change in personal identity in his theory of eight stages life (Knight, 2017; Mcleod, 2018). Abraham Harold Maslow, a psychologist, created a theory of psychological health: hierarchy of needs. He emphasized importance of fulfilling human needs in priority (Hattangadi, 2014; Mcleod, 2020). Besides basic needs, people are deeply driven by their self-identity to achieve social, self-esteem, and self-actualization needs (Hattangadi, 2014; Mcleod, 2020). Self-identity of cancer survivors affect how and what they think, feel, and live their life in survivorship. After completion of acute cancer treatment, patient participants survived their cancer and had been labeled as cancer survivors. However, patient participants refused the label of cancer survivors. They believed that the label did not reflect their experience because their cancer journey was not over; they still faced high risk of cancer recurrence; they were surviving but they were not vibrancy; and their goals were not only surviving the cancer but more importantly they wanted to live a thriving life. Khan et al. (2012) in their qualitative study of British people at least 5 years post-diagnosis of breast, colorectal or prostate cancer indicated that majority of British participants did not accept the term ‘cancer survivors’ because they think the term implied a high risk of death that did not reflect their experience. On the contrary, Davis et al. (2016) in their qualitative study of African American breast cancer survivors, indicated that majority of their participants felt that they were cancer survivors; they accepted it as new identity for advocacy because the term ‘cancer survivor’ was first created in the USA and widely used as a term to encourage patients’ advocacy, which is a fundamental aspect of cancer survivorship in the USA.

The patient participants in this study established their new self-identity as warriors, winners, and/or victors rather than cancer survivors because the new self-identity reflected their experience and established their new life goals fighting against cancer and winning the battle.

The researcher analyzed experience of patient participants and found that they could never get back to their previous normal life. The patient participants wanted to get back to their previous normal life but they could not because they changed totally by cancer and treatment including physical, psychological, and mental changes as well as the changes of their view of people and life. Patient participants had to start a new normal life facing challenges from lasting side effects and adjusted themselves to the new normal life. Baker et al. (2016) conducted a qualitative study of ‘getting back to normal’ of British patients with breast, prostate or lung cancer attending pre-treatment, treatment or follow-up appointments. They indicated that cancer survivors, particularly those completing acute cancer treatment, described a new ‘normality’ discontinuous with their past because of their permanent changes by cancer and treatment (Baker et al., 2016).

Work is an essential part of life for patient participants. Both Bilodeau et al. (2017) in their scoping review study of cancer survivors with breast cancer and Brusletto et al. (2018) in their qualitative study of Norwegian cancer survivors with breast cancer and other type of cancers, supported the findings in this study that patient participants wanted to return to their work because it represented identity, normality, self-esteem, psychological well-being, financial security, and a contribution to the community. However, both patient participants and their work environment in this study were not well prepared for return to work. They experienced physical, emotional, and social challenges that impaired their capacity for return to work. Their employers had no accommodation plan that negatively further affected cancer survivor’s return to work. Moskowitz et al. (2014) conducted a multidimensional analysis of work outcomes in American cancer survivors with breast cancer and/or other type of cancer. Pransky et al.

(2016) summarized existing peer-review research on challenges for employers to manage cancer and mental illness in an aging workforce. All Brusletto et al. (2018), Moskowitz et al. (2014), and Pransky et al. (2016) supported these findings in this study. Consequently, failure or delay on their return to work caused loss of self-identity, low self-esteem, and financial insecurity. Patient participants in this study experienced three different issues: being not able return to work, much delayed return to work, or had to change to work part time jobs instead of their previous full-time jobs. The National Cancer Institute (NCI) (2019) confirms that cancer survivors are more likely to have financial burden than people without cancer that may lead to debt and even bankruptcy. Cancer survivor with financial burden also experienced severe physical, emotional, social, or family distress that lower their quality of life (NCI, 2019). Although there are differences in healthcare system around the world, cancer survivors without return to work would increase financial burden for them and/or their family that would cause distress on both cancer survivors and their family and negatively affected their quality of life.

Meaning of survivorship for patient participants included hard life, loss, fighting against cancer, and living a new second life with hope. The patient participants experienced hard life because they faced challenges from lasting side effects of cancer and treatment and the challenges caused concerns and worries for their families that in turn created stress for them. The patient participants also experienced various losses including loss of spouse, friends, previous full-time jobs, and even a house. They fought against cancer for themselves and for their significant ones. According to the patient participants, survivorship also meant living a new second life with hope. The patient participants were both grateful for and enjoyed their new second life. The meaning of hard life and loss were negative experiences brought from cancer and treatment. Patient participants recognized that fighting against cancer was their life goal in survivorship. Positively, they considered the survivorship as a new second life and wanted to live a better life with hope and through personal growth. Davis et al. (2016) indicated that survivorship meant creating a new thriving life, not just being alive such as eating balanced healthy foods and beginning the process of healing.

Patient participants hoped to get supports and promoted re-establishment of self-identity, return to work, and adjustment to their new normal life. Unfortunately, the supports obtained were limited to meet their needs.

5.2.4 Transitioning from Inpatient Department to Outpatient Department/Clinic

A key emerging theme of self-care management was identified in this transition. Self-care management emphasizes patient participant’s responsibilities and actions to address their concerns and improve their health and wellbeing (Hasanpour-Dehkordi, 2016). Patient participants happily went back home because they could stay with their family and empower themselves over what was happening to them.

Missel et al. (2018) conducted qualitative interviews exploring experience of Denmark cancer patients in an education and counselling nutritional intervention after surgery for oesophageal squamous-cell carcinoma to improve eating functions and nutritional needs. Schulman-Green et al. (2012) described experiences of self-management and transitioning among American women with ovarian cancer.

Both Missel et al. (2018) and Schulman-Green et al. (2012) supported that effective self-management of the cancer and its psychosocial consequence empowered their participants to regain some control of their own body and in their own lives so that it was critical to their quality of life. However, patient participants assumed more responsibilities for being outpatients than being inpatients. They were not well prepared and felt overwhelming responsibilities for self-care management because of challenges, role strains, and limited supports. Lack of coordinated cancer care between oncology team and primary care provider's team in treatment transition consequently raised burdens for cancer survivors. Cancer survivor's needs are unique and complex due to the different forms of cancer and treatments. "Even details that might seem insignificant or inconsequential can turn into monumental problems for patients, adding anxiety and stress to an already difficult situation" (Grunfeld, 2019, p.3180). Jepsen et al. (2016) conducted a qualitative study of Denmark cancer patients with acute leukemia in an outpatient setting and Nissim et al. (2014) conducted a qualitative study of Canadian cancer patients with acute myeloid leukemia (AML) in the transition from inpatient to ambulatory care. Both of them indicated that outpatients felt surprised about overwhelming responsibility for self-care without healthcare professionals around after they transitioned from inpatients to outpatients (Jepsen et al., 2016; Nissim et al., 2014). Patient participants needed continuous supports for their self-care management in treatment transition. They got some supports from community nurses. However, the supports obtained was too limited to meet patient participants' needs in their treatment transition.

5.2.5 Transitioning from Oncology Team to Primary Care Provider Team

A key emerging theme of communication was identified in this transition. Effective communication between patient participants and healthcare teams and between oncology team and primary care provider team can optimize health outcomes while poor communication can lead to disruptions in continuity and coordination of cancer care for patient participants in treatment transition (Frank & Brien, 2008). Patient participants believed that oncology team communicated with primary care provider team by paper or via internet. Patient participants did not obtain survivorship plan or they may not read or understand it. Physical meetings among cancer survivors, oncology team, and primary care provider's team would help establish a trusting relationship between cancer survivors and the healthcare teams in treatment transition, promote to share information with each other, encourage cancer survivors to express their concerns and needs, and empower them to make informed decision about following cancer care (NCI, 2015, 2018; Potter & Perry, 2010; Yip, 2017). However, there were no physical meetings among patient participants, oncology team, and primary care provider's team. The patient participants did not know what had happened and what would be next. Roundtree et al. (2011) indicated in their qualitative study exploring American breast cancer survivors' perceptions and attitudes about their cancer care in survivorship that cancer survivors were frustrated in their personal experience with physician's interactions and had communication problems with and between physicians.

Patient participants had to communicate with either the oncology team or the primary care provider's team according to their liking rather than their medical conditions and/or different roles of healthcare teams due to fragmented communication between the two healthcare teams. It may be overwhelming for them to determine whom to access and result in overuse or misuse of scarce resources. They would like to continuously communicate with and obtain cancer care from oncology teams because they believed that oncology teams were more specialized while primary care provider team were more general. Their relationships with the oncology teams have more influence on their treatment transition than primary care provider’s team. In contrast, Franco et al. (2016) in their qualitative study exploring the experiences of Canadian cancer survivors with gastrointestinal cancer or lymphoma transitioning from tertiary to primary care, indicated that primary care provider’s team had the most influence on cancer survivor’s transition readiness. Participants in this study were transitioned from oncology teams in the hospital to primary care provider’s team in community while those in the Franco et al. (2016) had been discharged after acute cancer treatment and they were being followed in nursing practitioner-operated transition care clinic (TCC) preparing for transition to primary care provider’s team. Importantly, these two studies indicated that effective communication between healthcare teams promoted cancer survivor’s readiness and preparation for treatment transition. Unfortunately, the experience of patient participants indicated that communication among oncology team, primary care provider’s team, and patient participants was fragmented that disrupted coordinated and continuous cancer care for them in treatment transition. Similarly, Hebdon et al. (2018) in their qualitative study of American cancer survivors, reported that primary support individuals, oncology providers, primary care providers, and registered nurses indicated that not surprisingly, poor communication between the two teams was a barrier to coordination of survivorship care.

5.2.6 Transitioning from Acute Cancer Treatment to Follow-up Cancer Care

A key emerging theme of recovery of body functions was identified in this transition. Recovery of body functions refers to partial or complete return to the normal or proper physiologic activity following acute cancer treatment. Patient participants wanted supports to promote recovery of body functions and improve their health. However, some patient participants obtained education on diet and exercise while others got little or even no supports. Bergkvist et al. (2018) conducted a qualitative study exploring experience of Swedish cancer survivors after allogeneic haematopoietic stem cell transplantation (allo-HSCT). They indicated that patient education, supports, and coordination of healthcare teams during transition between different health care settings (hospital to home) improved continuity of cancer care and promoted recovery of body functions for their cancer survivors.

5.2.7 Nursing Care Received

Patient participants obtained nursing care in each component of the Nursing Theory of Transition. Four key emerging themes were identified including nursing assessment, patient education, symptoms management, and resources offered. Nursing assessment is a process by which nurses gather data and information about a patient' physical, psychological, sociological, and spiritual status in order to decide and provide further patient-centered care. Patient participants were assessed by nurses when they visited outpatient department/clinic for follow-up cancer care. The patient participants also received nursing care including patient education, reference to doctors, and medication administration to address their physical and emotional symptoms. Patient participants obtained resources offered to make them well-informed including booklet material, social support places, therapy programs, and hotline services. Nursing care promoted understanding of patient participant's situation, conditions, and concerns, informed expected side effects, provided material, programs, and services available, helped prevent injury and complications, and managed symptoms. However, experience of patient participants indicated that time for interacting with nurses was not enough, cancer care received were not sufficient and/or not specific to manage symptoms effectively, and their concerns were not addressed comprehensively. Shen et al. (2016) conducted multimethod study (questionnaires, focus groups, and telephone interviews) and explored experiences of Canadian cancer patients with early-stage testicular cancer transitioning from acute cancer treatment to follow-up care. They indicated that cancer survivors felt unprepared to cope with the aftereffects of their cancers, lower continuity of care scores, and did not receive self-management tools and education or information about patient resources. Consequently, cancer survivors continued to be frustrated and worried about their health problems (Shen et al., 2016).

5.2.8 Experience Influencing Delivery of Quality Cancer Care and Quality of Life

Three key emerging themes were identified including active self-care management, social supports, and limited hospital capacity that influenced delivery of cancer care and quality of life. Active self-care management and social supports were positive experiences that promoted delivery of quality cancer care and expected health outcomes and improved quality of life. Patient participants actively asked questions, sought help, did “some research” to obtain information, and discussed with nurses. Nurses assessed the “proactive nature” of patient participants, supported their active self-care management, and encouraged them to obtain and manage information from professionals and other sources. Shay, Schmidt, Cornell, and Parsons (2018) conducted a cross-sectional survey with American cancer survivors. They indicated that active self-care management reduced anxiety, which was related to uncertainty and fear of negative outcomes (Shay et al., 2018). Chang and Park (2013) added that active self-care management could be effective in enhancing Korean cancer survivor's strength and resilience that helped lead a healthy life.

Patient participants obtained social supports through interactions with their family, friends, support groups, and healthcare professionals. The patient participants emphasized that social supports from cancer survivor's groups with similar experience were better that those from families and friends because the families and friends did not have the same experience while cancer survivors had. Growing evidence indicated that social supports promoted healthy life style, lowered risk of mortality, and benefited survival. Kroenke et al. (2013) conducted Life After Cancer Epidemiology (LACE) study cohort of American cancer survivors with early-stage primary breast cancer and completion of breast cancer treatment. They evaluated the association between larger social support networks and lower breast cancer mortality. Kroenke et al. (2013) specified that cancer survivors with larger social support networks increased physical activity, decreased alcohol intake, and more likely never became smokers. Therefore, they concluded that the larger social support networks helped reduce risk of recurrence and/or mortality (Kroenke et al., 2013).

The theme of limited hospital capacity was a negative experience (barrier). Patient participants did not receive all cancer care they expected leading to unmet needs. They believed that current hospital capacity would be limited to meet their increasing needs and managing their increasing cancer care demand. Dr. Sri Navaratnam, President and Chief Executive Officer, Cancer Care Manitoba, confirmed hospital capacity problems at the Cancer Care Manitoba building by saying that "Cancer is growing, one in two Canadians will develop cancer in their lifetime. We are going to see more volume pressures" (Pfeifer, October 25, 2018).

5.2.9 Suggestions and Recommendations to Improve Cancer Care and Quality of Life

Patient participants made suggestions and/or recommendations to improve cancer care and quality of life from their perspectives. Three key emerging themes were identified including increasing the number of healthcare professionals, needing effective information with rationales, and treating them in a holistic way. Increasing the number of healthcare professionals could improve the ratio of healthcare professionals and cancer survivors and increase time to provide cancer care for cancer survivors. This suggestion from patient participants is the same as the one provided by nurse participants and is discussed in the section of suggestions by nurse participants to avoid repeat.

Patient participants not only need information about what have happened, what is happening now, and what will happen next for their cancer, treatment, and follow-up care but also rationales for the information. Specific, effective education and information could help address cancer survivor's concerns. Rationales for information would promote cancer survivor to follow education, adhere to cancer care plan, and actively involve into self-care management to improve their health. Shay et al. (2018) emphasized that cancer survivors desired more information but Yoon, Sohn, Choi, and Jung (2017) reported that cancer survivors themselves might not be active in seeking health information. The latter is corroborated by Keegan et al. (2012) indicating that cancer survivors have substantial unmet information needs. Keegan et al. (2012) in their survey study of American cancer survivors with acute lymphocytic leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma, germ cell cancer or sarcoma indicated that less than excellent general health and/or fair/poor quality of care of cancer survivors were associated with unmet information needs. Therefore, healthcare professionals need to provide effective information with rationales for cancer survivors to promote their understanding and improve their health.

This study shows that patient participants need to be understood, hope to be treated in a holistic way, and want their concerns to be addressed comprehensively. Their needs not only manage side effects but also treat the roots of health problems; not only address health concerns by medical treatment but also consider alternatives and/or natural treatment; and not only treat physical concerns but also emotional, social, and spiritual concerns. Cancer survivors are human beings. Treating cancer survivors in holistic way involves considering physical, emotional, social, and spiritual aspects as well as cultural differences and preferences to create lasting healing and sustainable better life. The findings of themes in each component of the Nursing Theory of Transition would potentially provide information and help healthcare professionals to understand cancer survivor’s comprehensive concerns and needs and promote holistic cancer care. This concept coincides with core value of Academy of Integrative Health & Medicine (Academy of Integrative Health & Medicine (AIHM), 2020).

5.2.10 Summary

Patient participants experienced physical concerns, emotional concerns, and social concerns in personal transition under the Nursing Theory of Transition. These concerns negatively affected their activities of daily living, return to work, and relationship with family and friends. Consequently, their quality of life is impaired. The patient participants wanted help. They recognized importance and contribution of nursing care in treatment transition. However, cancer care obtained was not sufficient and/or specific to address their concerns. Patient participants also experienced challenges about self-care management, communication with healthcare teams, and recovery of body functions in care transition under the Nursing Theory of Transition. They did not well prepare for treatment transition. From the perspectives of patient participants, active self-care management and social supports were positive experience promoting delivery of quality cancer care and improving their quality of life while limited hospital capacity as a barrier could not meet the increasing demand of increasing number of cancer survivors. Patient participants suggested increasing the numbers of healthcare professionals, needing effective information with rationales, and treating them in a holistic way to improve their cancer care, promote their health, and achieve their better quality of life.

5.3 Nurse Participants

Nurse participants provided cancer care for cancer survivors in treatment transition. Experience of nurse participants in the Nursing Theory of Transition, experience influencing delivery of quality cancer care, and suggestions and recommendations to improve cancer care are discussed in the following sections.

5.3.1 Experience of Nurse Participants in the Nursing Theory of Transition

In physical transition, nurse participants provided cancer care for cancer survivors and two key emerging themes were identified including physical symptoms management and patient education to address cancer survivor's physical concerns. Lippincott Solutions (2017) and Potter and Perry (2010) supported the findings while the findings were different from those in Bouya et al. (2018) and Chan et al. (2018). The nurse participants recognized that cancer survivors experienced lasting signs and symptoms caused by cancer and treatment and helped manage their symptoms such as pain, peripheral sensory neuropathy, fatigue, and chemo brain by assessment, education, and reference to doctors. However, Bouya et al. (2018) conducted a systematic review of oncology nurse's knowledge, attitude, and related factors of cancer-related pain management and indicated that most oncology nurses had poor knowledge of pain management and one key barrier was deficit in nursing staff's knowledge of pain.

Patient education is the responsibility of nurses by which they provide information to cancer survivors, educate them, and help them to improve their health status (Lippincott Solutions, 2017). Patient education promoted cancer survivor's informed decision about their cancer care and lifestyle. Increasing number of cancer survivors and their increasing demand emphasize the importance of high-quality patient education because patient education helps ensure continuity of cancer care in treatment transition (Potter & Perry, 2010). Nurse participants educated cancer survivors by providing them with information on expected side effects and preventing injury and complications. Besides educating cancer survivors during their visits to the clinic, the nurse participants also encouraged cancer survivors to attend After Cancer Group Teaching Class (referred as to the Class) for education. Contrary to these findings, Chan et al. (2018) indicated in their online survey study of Australian cancer nurses' perceptions of responsibility, confidence levels and practice for survivorship care for cancer survivors that nurses had the lowest confidence in discussing how to identify signs of cancer recurrence.

In emotional transition, nurse participants provided cancer care for cancer survivors and three key emerging themes were identified including nursing assessment, emotional symptoms management, and resources offered to address emotional concerns of cancer survivors. Mazanec, Gallagher, Miano, Sattar, and Daly (2017) in their survey study of prioritizing American cancer survivors' concerns and assessing the perceived importance of their needs concluded the importance of assessment. They indicated "Health care professionals are caring for a growing number of diverse cancer survivors, often in an environment in which resources are limited. The identification of the most salient concerns of survivors is essential for targeted program planning and for providing quality care" (Mazanec et al., 2017, p. 1). Nurse participants assessed cancer survivors to collect information relevant to their cancer care including history of cancer and treatment, their impact on cancer survivors, signs and symptoms, concerns, and needs. The nurse participants used communication techniques to get information, asked specific questions for inquiry, and examined cancer survivors with assessment tools. According to the assessment, nurse participants recognized that cancer survivors experienced emotional distress including anxiety, fear of recurrence, frustration, and survivor's guilt. Hulbert-Williams (2016) stressed the importance and effect of psychosocial care for longer-term anxiety management.

Nurse participants managed emotional symptoms of cancer survivors by acknowledgement, patient education, and reference to other team members such as doctors, social workers, and psychiatrists. They also provided cancer survivors with resources available including hard copy material, support groups, follow-up appointments, hotlines, and interpreter services.

In social transition, nurse participants provided cancer care for cancer survivors and four key emerging themes were identified including refusing label of cancer survivors, promoting adjustment to a new normal life, promoting return to work, and recognizing meaning of survivorship. Cancer patients were labeled as cancer survivor after completion of acute cancer treatment. However, nurse participants did not like the label of cancer survivors for their cancer patients. They believed that cancer survivors were not well defined and the label of cancer survivors did not reflect their experience. Their cancer patients were not free of cancer in treatment transition or never free of it. Additionally, Susan Gubar, a distinguished emerita professor of English at Indiana University, explored her experience with ovarian cancer and wrote an article in The New York Times "I am not a cancer survivor, and neither are the women in my cancer support group" (Gubar, 2012, p. 1). Nurse participants also believed that label of cancer survivors created emotional distress such as fear, worries, and stress that had negative impact on their cancer patients. They identified cancer survivors as warriors fighting against their cancer.

Nurse participants recognized that cancer survivors could not return to their previous life. They helped cancer survivors to adjust to their new normal life by referring to cancer survivor's support groups, emphasizing adjustment step by step, and educating them to establish achievable and realistic goals for their new normal life. Hullmann, Robb, and Rand (2016) indicated in their systematic review of impact of cancer experience on life goals that people's life goals changed because of cancer experience and emphasized that "life goal attainment is related to better psychological outcomes, and inability to attain life goals is related to poorer outcomes" (p. 7).

Some nurse participants promoted cancer survivors' return to work through patient education about negative impact of lasting side effects on their capacity of return to work and return to work gradually while other nurse participants did not encounter the issue. However, it seems that there is neither formal return-to-work plan nor discussion with work place to justify accommodation plan. Irwin et al. (2011) indicated in an online survey of American oncology nurses about survivorship care that nurses performed least assistance for employment or legal issues. Chan et al. (2018) also indicated that discussing employment and financial issues was one of the two least performed survivorship care items. More importantly, this study, Chan et al. (2018), and Irwin et al. (2011) shared common findings that experience of nurses was important and the more years of experiences were associated with high level of knowledge, confidence, and awareness to discuss issues such as employment/return to work.

Nurse participants recognized that survivorship meant living with cancer and change of life especially family roles for cancer survivor. Fighting against cancer and free of cancer became life goals for cancer survivor in survivorship. Changes in family roles increased burdens for other family members and in return that created stress for cancer survivors themselves. ASCO (2018 B) supported the findings and indicated that family roles changed due to cancer and treatment. Both cancer survivors and family members may experience psychological distress. Stress of cancer may create new problems and worsen existing problems (ASCO, 2018 B).

The key emerging themes of nurse participants in personal transition were discussed above. The three key emerging themes of nurse participants in care transition are discussed below including promoting self-care management, promoting communication, and promoting maximal recovery of body functions.

Nurse participants promoted cancer survivor's transition from inpatient department to outpatient department/clinic in promoting self-care management. Frade, Lopes, Ramos, and Fonseca (2017) indicated that nurses played an important role to promote self-care for cancer patients and self-care increased their capacity to lead with the impact of cancer treatment and reduced their physical and psychological distress. "However, the level of self-care is influenced by the degree of information, motivation, self-confidence and the involvement of family or friends" (p. 2). Nurse participants assessed cancer survivors, ordered home care, provided patient education, and offered resources and services available. They assessed cancer survivors about what they could do and what they could not do. If cancer survivors were not able to do activities of daily livings based on assessment, nurse participants helped order home care for them. Nurse participants also provided education by teaching, demonstrating, and reinforcing cancer survivors for self-care management. In addition, nurse participants offered resources such as websites and hotline services to equip cancer survivors with knowledge and answer their questions to address their concerns.

Nurse participants promoted cancer survivor's transition from oncology team to primary care provider's team in promoting communication between cancer survivors and healthcare teams. The nurse participants played an important role to bridge communication between cancer survivors and health care teams. Grant et al. (2010) indicated that nurses were key in facilitating communication and coordinating information among healthcare providers, cancer survivors, and caregivers. Potter and Perry (2010) indicated that nurses usually became the main sources of information for cancer survivors and helped clarify information provided by doctors for them. The nurse participants recognized that there was no physical meeting among cancer survivors, oncology team, and primary care provider's team. Communication between oncology team and primary care provider's team was paper work and/or via Internet. Nurse participants bridged communication among cancer survivors, oncology team, and primary care provider's team to advocate for cancer survivors and address their concerns; if cancer survivor's situation was not serious, nurse participants would have cancer survivors call their family doctors. When cancer survivor's situation was serious, nurse participants would contact the oncology team. In addition, nurse participants also communicated with other hospital departments such as emergency team for cancer survivors when needed. Nurse participants emphasized that they were nurses of cancer survivors and cared for them. Communication with cancer survivors largely depended on nurse participant’s knowledge, skill, and experience. Kourkouta and Papathanasiou (2014) supported the finding. They also emphasized the importance of listening and understanding patients, demonstrate courtesy, kindness and sincerity, and devote enough time for communication in nursing practice (Kourkouta & Papathanasiou, 2014).

Nurse participants promoted cancer survivor’s transition from acute cancer treatment to follow-up cancer care in promoting maximal recovery of body functions. Dunberger and Bergmark (2012) and Chang and Park (2013) acknowledged that nurses were uniquely positioned in the care of cancer survivors such as in the rehabilitation of cancer patients, improving patients' quality of life, and psychosocial well-being. In fact, nurse participants educated cancer survivors on exercise and healthy diet to promote their recovery of body functions. The nurse participants also offered therapy programs and referred cancer survivors to registered dietitians, social workers, and doctors for consultation and treatments.

5.3.2 Experience Influencing Delivery of Quality Cancer Care

Nurse participants reported experience influencing delivery of quality cancer care in treatment transition and six key emerging themes were identified. Three themes of positive experience included caring for cancer survivors, experience and knowledge, and advocate for cancer survivors to promote delivery of quality cancer care while three themes of negative experience (barriers) were low socioeconomic status of cancer survivors (e.g. low income), culture and language barriers, and limited time providing cancer care (e.g. heavy workload, short of staff, time waste) that created challenges for delivery of quality cancer care.

Nurse participants shared caring values of displaying compassion, kindness, and concern for cancer survivors and cared for them to promote their health. “Caring reflects what matters to a person; it describes a wide range of involvement, from parental love to friendship, from caring for one’s work to caring for one’s pet, to caring for and about one’s clients” (Potter & Perry, 2010, p.266). The nurse participants believed that their caring for cancer survivors promoted delivery of quality cancer care and helped address their concerns. Liu, Mok, and Wong (2006) indicated in their qualitative study of Chinese cancer patients for understanding of caring in nursing that nurse’s caring attitudes and behavior, knowledge, and professional responsibilities promoted the provision of informational, emotional, and practical supports and help required by cancer patients. McCorkle (2012) shared her experience of cancer nurse as cancer survivors of breast cancer and her experience made her a better nurse. She emphasized the importance of caring for cancer survivors during diagnosis, treatment, and recovery in cancer journey (McCorkle, 2012).

Nurse participants believed that their knowledge and experience laid a good foundation for delivery of quality cancer care for cancer survivors. Utne, Smastuen, and Nyblin (2018) studied on pain knowledge and attitudes among nurses in cancer care in Norway, indicated that the nurses had relatively good pain knowledge. However, Wallace et al. (2015) conducted a survey study for nursing care practice for Australian cancer survivors. They indicated that nurse’s skills and knowledge were insufficient that negatively affected survivorship care provision. Bouya et al. (2018) also concluded that oncology nurse had a poor or moderate level of knowledge about cancer pain management. Pai and Ongole (2015) in their survey study of Indian oncology nurses’ knowledge and education about oral care in cancer patients undergoing chemotherapy and radiation therapy, indicated that majority of staff nurses had poor knowledge of oral care in cancer patients. Pai and Ongole (2015) further indicated that there was significant association between knowledge and variables such as designation, years of work experience, and years of experience in cancer wards. Irwin et al. (2011) explained that nurses with fewer than five years of oncology experience lacked sufficient knowledge compared to nurses with more than five years of oncology experience. Although nurse's knowledge varied, findings in these studies confirmed that knowledge and experience are positive experience to promote delivery of quality cancer care. Oncology nurses need continuously to improve their knowledge and experience.

Cancer advocates helped provide supports to cancer survivors and improve quality of cancer care (ASCO, 2019A). Nurse participants believed that advocates for cancer survivors was positive experience and the nurse participants advocated for them to promote quality cancer care. Vaartio-Rajalin and Leino-Kilpi, (2011) in their literature review about oncology nurses' patient advocacy activities found that oncology nurses advocated for cancer patients by analyzing patients' psychosocial and physical distress and care plans, educating patient about cancer management, presenting and raising awareness of patients' needs and preferences.

Low socioeconomic status of cancer survivors (especially low income), culture and language barriers, and limited time providing nursing care were three themes of negative experience (barriers) that negatively affected delivery of quality cancer care.

Cancer is one of leading cause of death and disability in Ontario (Public Health Ontario (PHO), 2020). Lung, breast, colorectal and prostate cancer are the most commonly diagnosed types of cancer in Canada (Canadian Cancer Society (CCS), 2020A). Cancer survivor's economic burden would be worse when they faced challenges from both lasting side effects and low income in treatment transition. "When dealing with a cancer diagnosis or coping with treatment and recovery, patients and their families often worry about finances and benefits" (CCS, 2020B). Wang et al. (2015) found in their survey study of the relationship between socioeconomic status (SES) and esophageal cancer in China that low socioeconomic status delayed access of cancer patients to health care. Nurse participants indicate in this study that cancer survivor could not afford for medication, healthy food, house, and transportation for access to healthcare when they face increasing financial burden.

Different cultures and languages between nurse participants and cancer survivors caused misunderstanding that negatively affected delivery of quality cancer care. Lopez-Class et al. (2011) conducted a qualitative study of impact of social, cultural, and health care system factors on quality of life and survivorship experiences of Latina immigrant breast cancer survivors in USA. They indicated that Latina breast cancer survivors adhered to certain cultural values and language and health literacy barriers made medical information difficult to navigate. Consequently, it negatively influenced communication between healthcare teams and cancer patients, delivery of health care interactions, and their overall quality of life.

Nurse participants believed that they did not have sufficient time to provide cancer survivor-centered care and address their concerns individually and comprehensively. The nurse participants believed that their heavy workload, shortages of staff, and time waste were the key reasons for limited time providing cancer care.

Oncology nurses in the study of Wallace et al. (2015) identified lack of time as one of key barriers to delivery of quality survivorship care. Chan et al. (2017,2018) and Irwin et al. (2011) also indicated that lack of time was one of key barriers to delivering survivorship care identified by nurses in their studies. A lack of time inhibited the provision of nursing care because patient education and meaningful discussion on their concerns and needs required significant time with the cancer patients (Irwin et al., 2011).

5.3.3 Suggestions and Recommendations to Improve Cancer Care

Nurse participants recommended establishing a new position-one primary nurse, increasing the number of healthcare professionals, and improving knowledge, skills and experience to enhance quality cancer care for cancer survivors. The nurse participants believed that one primary nurse was needed to address fragmented cancer care for cancer survivors in their whole cancer journey. Primary Nursing is a model of nursing care delivery, which maintains continuity of care and responsibility acceptance (Potter & Perry, 2010). Potter and Perry (2010) indicate that a primary nurse is responsible for assessing patient's needs, developing care plan, and enduring delivery of quality care as well as coordinating all aspects of their care. "It can be applied in any health care setting" (Potter & Perry, 2010, p. 136). In their whole cancer journey, cancer survivors would experience many phases and transitions in-between. They received cancer care from various healthcare teams. Nurse participants recommended applying concepts of primary nursing and adding a registered nurse as the primary nurse. Mcfarlane and Bennett (2006) defined primary nurse roles in oncology care, Smolowitz et al. (2015) explored their roles in primary health care, and Garcia-Vivar, Elizondo, and Ambrosio (2019) emphasized essential roles of primary nurse to implement survivorship care plans for cancer survivors. By summarizing the findings of all these three studies and applying the concept of primary nursing for cancer survivors in their whole cancer journey, the roles of one primary nurse should: a) participate in making cancer care plan for cancer patients/survivors in each phase of cancer treatment and transition in between, b) monitor and promote implementation of the cancer plan, c) update cancer survivor's concerns, needs and progress, d) advocate for cancer survivors, and e) bridge cancer survivors and healthcare teams and between healthcare teams to promote coordinated and continuous cancer care. To sum up, goals of the one primary nurse is to coordinate with all aspects for cancer survivors in their whole cancer journey including healthcare teams, employers, community, government, and other stakeholders to maximally promote attentive, coordinated, and continuous cancer care to increase cancer survivor's satisfaction and improve their health outcomes. However, the one primary nurse is a new suggestion for cancer survivors. Roles of the one primary nurse for cancer survivors need further research to enrich and clarify besides this study.

Nurse participants recommended increasing the number of healthcare professionals to improve quality of cancer care. The appropriate patient–nurse ratio staffing is essential for expected outcomes for both patients and nurses. Wynendaele, Willems, and Trybou (2019) conducted a systematic review on relationship between the patient–nurse ratio staffing method and nurse employee outcomes. Wynendaele et al. (2019) indicated that a large majority of the studies showed a significant association between higher patient to nurse ratios and adverse nurse outcomes. The shortage of nursing staff caused increased burden, created high levels of job stress, resulted in emotion exhaustion, lowered job satisfaction, increased sickness absence, caused a vicious circle of absenteeism, and placed pressure on the remaining nurses. Wynendaele et al. (2019) further indicated that the higher patient to nurse ratios ratio result in negative nurses' perception on quality of care while lower patient to nurse ratios indicated more favorable perceptions of patient safety. Increasing the number of healthcare professionals is a suggestion to meet the increasing demand for the increasing number of cancer survivors from the perspectives of nurse participants. However, implementation of this suggestion would face challenges in the present context of healthcare systems in crisis with limited resources. It is further discussed in 5.6 under Issues to be considered.

Nurse participants believed that improving knowledge, skills, and experience promoted delivery of quality cancer care. Knowledge to guide nursing practice include both theoretical and evidence-based knowledge (Potter & Perry, 2010). Oncology nurses use their knowledge and experience to assess, plan, implement, and evaluate cancer care. However, Bouya et al. (2018) indicated that knowledge of oncology nurses varied. Many nurses had poor knowledge that impaired quality of cancer care (Bouya et al., 2018). Cancer survivor’s needs have been changing and cancer care have been complexing with advance in cancer treatment (Grunfeld, 2019). Nurse participants suggested that oncology nurses should continuously increase knowledge and experience for cancer survivors in each phase of their whole cancer journey. “Knowledge acquired will promote the integration of concepts and theories of cancer survivorship, thereby facilitating a high quality of care delivery to patient and families during survivorship (Chapman & Wiernikowsi, 2011, p. 4).

5.3.4 Summary

Nurse participants provided cancer care for cancer survivors in each component of the Nursing Theory of Transition. Nursing care contributed to address cancer survivor’s physical, emotional, and social concerns in personal transition and provided supports to address their challenges in care transition. Nursing care had strengths on clinical patient-care but had weakness on sensitive issues such as sexual problems, employment issues such as inability for return to work and no accommodation plan, and financial issues such as low income or insurance-uncovered therapy. From the perspectives of nurse participants, caring for cancer survivors, advocate for them, and nurses’ experience and knowledge were positive experience promoting delivery of quality cancer care and expected health outcomes; however, nurse’s knowledge and experience varied.

Low income of cancer survivors, culture and language barriers, and limited time providing cancer care negatively affected delivery of quality cancer care. Therefore, nurse participants suggested establishing a new position-one primary nurse, increasing the number of healthcare professionals, and improving nurse’ knowledge, skills and experience to ensure delivery and continuity of quality cancer care for cancer survivors.

5.4 Similarities and Differences between Results of Patient and Nurse Interviews

Experience of patient participants and nurse participants indicates that there are similarities and differences between their results. The similarities and differences are discussed in the following three sections including similarities and differences under the Nursing Theory of Transition, similarities and differences for experience influencing delivery of quality cancer care, and similarities and differences for suggestions and recommendations to improve cancer care.

5.4.1 Similarities and Differences under the Nursing Theory of Transition

In physical transition, both patient and nurse participants understood that cancer survivors experienced physical concerns such as physical symptom distress, loss of body functions, and changes in body images supported by Fitch et al. (2018) and Tan et al. (2019). They believed that physical concerns had negative impact on cancer survivor's activities of daily living, return to work, and family relations supported by Cheng et al. (2016). Both patient and nurse participants recognized that nurses provided cancer care including assessment, patient education, and physical symptoms management for cancer survivors to address their physical concerns. Key difference of experience of patient and nurse participants was quality of cancer care. Nurse participants provided cancer care for cancer survivors. However, patient participants were not satisfied about cancer care received to some degree. For example, information obtained for resuming sexual activities was not specific to address their concerns. Symptoms such as pain and fatigue were not managed completed. Body functions such as lifting ability did not restore as expected. These concerns and unmet needs negatively affect the quality of life for cancer survivors. Roberge, Tremblay, Turgeon, and Berbiche (2013) conducted a survey to compare cancer patients' and health care professionals (including physicians, nurses and others)' evaluations of the quality of care in Quebec's oncology outpatient clinics. The findings in both this study and Roberge et al. (2013) recognized positive perception of cancer care provided to address cancer survivors' concerns and meet their needs. Unlikely, cancer patients and professionals in Roberge et al. (2013) believed positive perceptions of continuity and patient-centered cancer care. For example, professionals provided cancer patients with the information they needed and address all their needs that was different from the findings in this study.

In emotional transition, both patient and nurse participants understood that cancer survivors experienced emotional distress such as fear of recurrence, anxiety, and survivor guilt supported by Fitch et al. (2018), Glaser et al. (2019), and Tan et al. (2019). They believed that emotional distress had negative impact on cancer survivor's health supported by Eldridge (2019). Both of them recognized that nurses provided cancer care including assessment, emotional symptoms management, and resources offered for cancer survivors to address their emotional concerns. However, there were two key differences. One is indignity of cancer survivors and the other is quality of cancer care. Patient participants felt indignity in emotional transition and their value and self-worth compromised while nurse participants seemed not to identify and understand it. Fear of recurrence, survivor's guilt, and indignity of patient participants were not well addressed.

In social transition, both patient and nurse participants shared experience that cancer survivors experienced re-establishment of self-identity, return to new normal life, and return to work and they also recognized meaning of survivorship.

In the process of re-establishment of self-identity, both patient and nurse participants refused the label of cancer survivors because the label did not reflect experience of cancer survivors supported by Khan et al. (2012) but contrary to the finding in Davis et al. (2016).

In return to normal life, both of them recognized that cancer survivors could not return to their previous normal life supported by Baker et al. (2016). Patient participants adjusted to their new normal life and nurse participants promoted their adjustment to the new normal life.

In return to work, both patient participants and nurse participants recognized the importance of cancer survivor's return to work supported by Bilodeau et al. (2017) and Brusletto et al. (2018). Nursing care focused on patient education for expected side effects influencing return to work and emphasized steps for gradually return to work.

In meaning of survivorship, both patient and nurse participants understood that cancer survivors faced challenges in survivorship. They believed that hard life and fighting against cancer were meaning of survivorship.

However, there were three key differences including new identity, return to work, and meaning of survivorship.

Regarding new identity, nurse participants believed that cancer survivors fought against cancer as warriors while patient participants preferred to be winners and/or victors against cancer beyond warriors. This is a new finding.

Regarding return to work, patient participants were not satisfied about cancer care obtained for their return to work. Supports needed for their return to work were beyond patient education supported by Brusletto et al. (2018), Moskowitz et al. (2014), and Pransky et al. (2016).

Regarding meaning of survivorship, patient participants believed that their meaning of survivorship included loss and living a better second life with hope besides hard life and fighting against cancer supported by Davis et al. (2016). Cancer care were not sufficient to meet cancer survivor’s needs for return to work and their new identity and meaning of survivorship were not well understood.

In transition from inpatient department to outpatient department/clinic, both patient and nurse participants believed that cancer survivors assumed more self-care responsibility than expected and cancer survivors needed more supports for their self-care management in treatment transition supported by Jepsen et al. (2016) and Nissim et al. (2014). Both of them recognized that nurses provided cancer care to promote self-care management but it was not sufficient.

In transition from oncology team to primary care provider’s team, both patient and nurse participants believed that communication was fragmented among cancer survivors, oncology team, and primary care provider’s team supported by Roundtree et al. (2011). They recognized that nurses contributed to bridge communication between cancer survivors and the two healthcare teams. However, Roberge et al. (2013) indicated that both cancer patients and professionals specified positive perception of communication between them. Both this study and Roundtree et al. (2011) indicate that cancer survivors had problems with physician’s interactions and had communication problems with and between physicians. The health care professionals in Roberge et al. (2013) included physicians, oncology nurses, and others.

In transition from acute cancer treatment to follow-up cancer care, both patient participants and nurse participants recognized that nurses provided cancer care to promote recovery of body functions for cancer survivors but the patient participants were not satisfied about it and believed that it was not sufficient.

To sum up, experiences of patient and nurse participants indicated that cancer survivors had concerns in each component of the Nursing Theory of Transition and oncology nurses were well positioned and provided cancer care to address cancer survivor’s concerns and promote their health and wellbeing in treatment transition. However, cancer survivors were not satisfied about cancer care received. They felt not well understood. Cancer survivors faced challenges in personal transition since their concerns were not well addressed and they also faced increasing burdens in care transition since supports were not sufficient.

5.4.2 Similarities and Differences for Experience Influencing Delivery of Quality Cancer Care

There were similarities and differences for experience of patient and nurse participants influencing delivery of quality cancer care in treatment transition.

5.4.2.1 Positive Experience

Patient participants believed that active self-care management and social supports were positive experience promoting delivery of quality cancer care while nurse participants believed that caring for cancer survivors, experience and knowledge, and advocate for cancer survivors were positive experience. It seemed that there were no similarities. However, nurse participants promoted cancer survivor’s self-care management and offered social support groups. Patient participants also understood the importance of nurse’ caring value, knowledge and experience, and advocate for them for quality cancer care. Therefore, both patient and nurse participants believed that active self-care management, social supports, caring for cancer survivors, experience and knowledge, and advocate for cancer survivors were positive experience promoting delivery of quality cancer care for cancer survivors in treatment transition. The difference was that patient participants emphasized their positive experience from what they could do to receive quality cancer care and nurse participants emphasized their positive experience from what nurses could do to provide quality cancer care.

5.4.2.2 Barriers (Negative Experience)

Both patient and nurse participants believed that limited hospital capacity and limited time for nurses to provide cancer are were barriers. Limited hospital capacity could not meet the increasing demand for quality cancer care due to increasing number of cancer survivors and their increasing needs. Nurses could not provide quality cancer care to address cancer survivor’s concerns and meet their needs comprehensively due to limited time. Roberge et al. (2013) also indicated that timeliness was evaluated least positively by both patients and professionals. However, they were critical of the amount of time spent in the waiting room before consultations and patients' inability to reach a professional by telephone outside the clinic's open hours (Roberge et al., 2013). In this study, patient participants felt did not have enough time to ask questions and nurse participants felt time limited to provide cancer care. Both patient and nurse participants recognized contributions of hotline services and positive feedback from nurses to address cancer survivor’s concerns.

Compared with patient participants, nurse participants emphasized that low socio-economic status and different culture and languages were barriers. Low socio-economic status especially low income negatively affected cancer survivor's accessing healthcare, affording therapy, eating healthy food, and living in safe and healthy environment. Different cultures and languages may cause misunderstandings between cancer survivors and nurses that negatively affected delivery of quality cancer care.

5.4.3 Similarities and Differences for Suggestions and Recommendations to Improve Cancer Care

There were similarities and differences for suggestions and recommendations to improve cancer care in treatment transition. Both patient and nurse participants suggested increasing the numbers of healthcare professionals since the number of cancer survivors and demands for cancer care have been increasing. The suggestion would improve ratio of cancer survivors and healthcare professionals and increase time to provide cancer care for cancer survivors.

There are differences in suggestions and recommendations between patient and nurse participants. Patient participants suggested needing effective information with rationales and treating them in a holistic way to improve cancer care while nurse participants suggested establishing a new position - one primary nurse and improving knowledge, skills, and experience.

Obtaining effective information with rationales would promote cancer survivor's understanding and application of information and adherence to cancer care plan to reduce their concerns and improve their health.

Cancer survivors had concerns in each component transition of the Nursing Theory of Transition. The cancer survivors not only need to manage side effects but also treat the roots of health problems; not only address health concerns by medical treatment but also consider alternatives and/or natural treatment; and not only treat physical concerns but also emotional, social, and spiritual concerns. Their whole persons' needs and all of resources not just "tumor treatment' should be taken into consideration. Therefore, patient participants suggested to be understood and treated in a holistic way.

From the perspectives of nurse participants, establishing a new position - one primary nurse would improve fragmented cancer care in the whole cancer journey for cancer survivors and improving knowledge, skills, and experience would lay a solid foundation to provide quality cancer care. To sum up, all suggestions and recommendations from both patient and nurse participants would potentially improve cancer care for cancer survivors.

5.5 Methodology

This study recruited patient and nurse participants with experience and applied Nursing Theory of Transition framework and Interpretative Phenomenological Analysis (IPA) approach as a guide to collect and analyze rich and detailed data and identify themes to build pattern of cancer survivors receiving cancer care and oncology nurse providing cancer care in treatment transition.

5.5.1 Patient and Nurse Participants

Patient participants have wide age range from 40 to 70 years old, various level of education from college diploma to doctorate degree, married or divorced, a variety of culture and ethnicity background, different return to work status with either full-time job, part-time job, or unable return to work, different type of cancer such as breast, rectal, and cervical cancer with various treatment such as surgery, radiation, chemical therapy and/or others. Nurse participants have wide age range from 30 to 60 years old, different level of education in nursing from college diploma to baccalaureate with either oncology certificate or not, different work status with either full-time job or part-time job, and various years working as oncology nurses from 1 to 20 years. Even if there are many differences in socio-demographics information, both patient and nurse participants share much more common experience receiving cancer care and providing cancer care. Importantly, both of them had experience, would like to share their experience, and provide rich data about their experience in treatment transition.

However, all patient and nurse participants are female. Both male cancer survivors and oncology nurse did not express their interest in this study. Researcher following requirements of the Research Ethics Board of both UOIT and Lakeridge Health did not receive contact from male cancer survivors and oncology nurse. Fitch et al. (2018), Tan et al. (2019), Brusletto et al. (2018), Khan et al. (2012), Missel et al. (2018), and Jepsen et al. (2016) recruited both male and female patient participants in their studies. Their findings supported the themes identified from this study and their findings were not associated with sex of patient participants.

In addition, according to Canadian Nurses Association (CNA) (2020), male nurses were 9.5% of total regulated nurses in 2018. More than 90 percent of regulated nurses were female. Both Bouya et al. (2018) and Chan et al. (2018) have different findings from this study. The conclusion of Grant et al. (2010) and Irwin et al. (2011) supported the findings of this study. The findings of Bouya et al. (2018), Chan et al.

(2018), Grant et al. (2010), and Irwin et al. (2011) were not associated with sex of their nurse participants.

Experiences of patient participants in this study and their themes identified, reflected cancer care that they received from both male and female nurses. Likely, experiences of nurse participants and their themes identified, reflected cancer care that nurses provided for both male and female cancer survivors. Researcher endeavored to minimize the variation due to all female patient and nurse participants by recruiting patient and nurse participants with various social demographic information who had valued experience and provided rich information. More research to explore experience of Canadian male cancer survivors and male oncology nurses might be helpful to compare their findings with those in this study.

Nurses acquired knowledge and experience on nursing theory of transition and cancer care from education in university/college and hospital/clinic. However, their knowledge and experience varied. Cancer survivors understood treatment transition from patient education and their own experience. Common goals of patient and nurse participants are to promote cancer survivor's health while their focuses are different. Cancer survivors emphasized what and how they obtained cancer care to address their concerns and meet their needs while nurse emphasized what and how to provide cancer care. Experience of patient and nurse participants were unique and different. Bias might exist. However, themes identified from their experience indicated common patterns of cancer survivors receiving cancer care and oncology nurse providing cancer care in treatment transition.

5.5.2 Use of the Term “Cancer Survivors”

Researcher still uses the term “cancer survivors” in this study because cancer survivors in this study are defined as adults and/or elders who are diagnosed with cancer, complete acute cancer treatment, and are in a follow-up cancer care phase. Using the term “cancer survivors” would promote consistence of terminology in this study and understand its results and analysis. People survived after cancer diagnosis and acute cancer treatment but the lasting side effects of cancer and treatment did not suddenly stop and they also face high risk of cancer recurrence. Both patient and nurse participants refused the label of cancer survivors because the label did not reflect their experience. The appropriate term might be people living with and beyond cancer (ASCO, 2019B; Walter, Usher-Smith, Yadlapalli, & Watson, 2015) that needs to be further explored.

5.5.3 Application of Nursing Theory of Transition Framework and Interpretative Phenomenological Analysis (IPA) Approach

Nursing Theory of Transition guided researcher to comprehensively collect rich and detailed experience of nurse and patient participants that lay a solid base to develop themes and identify patterns of oncology nurse and cancer survivors in cancer treatment transition. Researcher developed open-ended questions according to the key themes and research gap identified through literature review. Under guide of the Nursing Theory of Transition, researcher categorized the open questions into each component transition for participant interviews. Researcher collected rich and detailed data for patient participant’s concerns, challenges, and burdens and nurse participant’s cancer care for cancer survivors. Further, researcher analyzed the data and developed themes of experience of both oncology nurses and cancer survivors in treatment transition.

To my knowledge, it is the first Canadian study to apply the Nursing Theory of Transition framework (Schulman-Green et al., 2012; Schumacher & Meleis, 1994) to explore the experience of cancer survivor and oncology nurse in treatment transition. This study built patterns for the lived experience of cancer survivors in physical, emotional, and social transition under personal transition. More importantly, researcher developed care transition of the Nursing Theory of Transition and subcategorized the care transition into three new sub-transition including transition from inpatient department to outpatient department/ clinic, from oncology team to primary care provider's team, and from acute cancer treatment to follow-up cancer care. Application and development of the Nursing Theory of Transition for this study comprehensively and systemically help collect and categorize experience of cancer survivor and oncology nurse in treatment transition.

Researcher applied Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) to help guide in-depth interviews, collect detailed rich data, and promote intense engagement with the data. The IPA helped analyze and identify emerging themes of participant's experiences in each component of the Nursing Theory of Transition and interpret how they make sense of their lived experience in treatment transition.

The application of both Nursing Theory of Transition framework and IPA approach helped identify pattern and essence of lived experience of cancer survivors and oncology nurses. The findings would potentially provide information to (1) have cancer survivors themselves know their situation and concerns comprehensively and promote their communication with healthcare professionals; (2) help healthcare professionals understand cancer survivors and identify and address their concerns and needs systemically; and (3) understand oncology nurses' important roles in the delivery of continuous and coordinated cancer care and establish/improve standardization of nursing care.

5.6 Issues to be Considered

Nurse participants provided cancer care to address cancer survivor's concerns and promote their health in treatment transition. However, patient participants believed that cancer care was not sufficient to address their concerns and/or not meet their needs comprehensively. It may be associated with the following issues and their potential solutions that are discussed: insufficient knowledge and experience, limited time providing cancer care, not sole responsibility of nurses, needs to establish and/or improve standardization of nursing care, raising primary care provider team's capacity, and call for a new model for coordinated continuous cancer care for cancer survivors.

5.6.1 Insufficient Knowledge and Experience

Experience of patient and nurse participants indicated that some nurses did not have enough knowledge and experience to address concerns and meet needs of cancer survivors. For example, nurses did not provide specific education and/or supports on sensitive issues such as recovery of sexuality activity. Nurses were not aware of emotional concerns of indignity and its negative impact on cancer survivors. Nurses recognized cancer survivor's new identity as warriors but they did not identify their new identity as winners/victors. Cancer survivors not only wanted to fight their cancer but also win the battle. Nurses knew that cancer survivors needed to start a new normal life but they did not recognize that cancer survivors not only wanted to survive the cancer and live a new normal life but also wanted to live a better life. If nurses did not know cancer survivor’s new identity, meaning of survivorship, individual goals of life, and unique needs, cancer care provided to address cancer survivor’s concerns and meet their needs would be difficult. Therefore, insufficient knowledge and experience of nurses negatively affected delivery of quality cancer care.

5.6.2 Limited Time Providing Cancer Care

Nurse participants emphasized that they did not have enough time to provide quality cancer care to address cancer survivor’s concerns and meet their needs. Facing the increasing number of cancer survivors, shortage of nursing staff, heavy workload, and time waste, the time for providing cancer care were limited. The patient participants also felt that the time providing cancer care for them was too limited. Nurse participants suggest that the patient to nurse ratios improve to increase nursing time to provide cancer care. Nurse participants also hope that hospital/clinics provide supportive work environment to reduce time waste.

5.6.3 Not Sole Responsibility of Nurses

Addressing cancer survivor’s concerns and meeting their needs were responsibility of nurses but not sole responsibility of nurses. It needs supports and coordination from many aspects. For example, symptoms management and recovery of body functions need healthcare team work, coordination between healthcare teams, and advance in treatment. Pain and fatigue are two key physical symptoms that negatively affect activities of daily living and return to work for cancer survivors. Nurses are responsible for assessing cancer survivor’s pain and fatigue and their needs, communicating with healthcare teams, promoting pain and fatigue management plans, implementing the management plans, and evaluating responses and/or results. It needs coordination of healthcare team members to address pain and fatigue and achieve expected outcomes. In addition, return to work need employer's coordination for accommodation plan. Decrease in financial burden for cancer survivors may need financial aid from government, supports from bank to delay repayment of mortgage loan, and/or supports from insurance company to cover long-term disability. Nurses themselves could not solve all of these issues. Further research is needed to establish return to work accommodation plan for cancer survivors and to explore roles of healthcare teams, employers, government, and other stakeholders.

5.6.4 Needs to Establish and/or Improve Standardization of Nursing Care

Nurses provided cancer care to address cancer survivor's concerns, meet their needs, and improve their health. However, quality of cancer care depends on nurse's knowledge and experience. Researcher calls on standardizations of nursing care for cancer survivors rather than only depending on individual nurse's knowledge and experience. The standardizations of nursing care could help identify cancer survivor's concerns and address these concerns. It could also guide nurses to promote healthcare team work and optimize application of resources available. For example, nurses should know how to identify and address cancer survivor's concerns about return to work besides managing lasting side effects, discuss with work place to justify accommodation plan, refer to doctors, social workers, and others, and help formalize return to work plan.

This study explored the experience of both oncology nurses and cancer survivors in treatment transition and identified key emerging themes in each component of the Nursing Theory of Transition. The findings would potentially provide helpful information to establish and/or improve standardizations of nursing care and promote coordination of healthcare teams and continuity of cancer care for cancer survivors.

5.6.5 Raising Primary Care Provider Team's Capacity

Both patient and nurse participants believed that limited hospital capacity and limited time to provide cancer were barriers. Both of them suggested increasing the number of healthcare professionals to lower ratio of cancer survivors and healthcare professionals and to increase time for cancer care. However, in the current context of a healthcare system in crisis with limited resources, cancer care re-organization to optimize current health resources should be considered as competing priorities. Balancing the demand of cancer survivors and responses of cancer care providers is an important issue. Walter, Usher-Smith, Yadlapalli, & Watson (2015) conducted a survey of general practitioner (GP) in England regarding cancer survivorship care. They concluded that GPs played potentially important role caring for cancer survivors after completion of acute cancer treatment and highlighted to optimize their role in cancer survivorship care. Chan et al. (2018) also indicated that the role of primary care provider's team should be enhanced for sustainable survivorship care for cancer survivors. Raising primary care provider team's capacity may be a potential option to address cancer survivor's concerns with limited hospital capacity.

5.6.6 Call for a New Model for Coordinated Continuous Cancer Care for Cancer Survivors.

Many researchers and healthcare providers have been working on establishing new cancer care model to promote coordination and continuity of cancer care for cancer survivors. However, "there is no one best model for survivorship care" (Grunfeld, 2019, p.3181). Actually, both patient and nurse participants indicated that current cancer care is fragmented; coordination between healthcare teams and between cancer survivors and healthcare teams face challenges; and cancer survivor's concerns were not well addressed and their needs were unmet. The findings in this study support further research to establish a new model for continuous and coordinated cancer care for cancer survivors in treatment transition. The findings would also provide helpful information and suggestions for practice improvement: clarifying roles of healthcare professionals, updating knowledge and experience, improving communication among cancer survivors and health cancer teams, understanding cancer survivor's concerns timely, accurately, specifically, and comprehensively, making individualized cancer survivor-centered care plan, encouraging involvement of cancer survivor in cancer care decision-making, reinforcing coordination between oncology team and primary care provider's team and between cancer survivors and healthcare teams, and calling for supports from all levels of social aspects such as governments, employers, insurance company, and other stakeholders.

The previous Chapter 4 presented results of experience of patient and nurse participants in treatment transition. This Chapter 5 analyzed the results, compared and contrasted the findings with those in other current literatures, explained similarities and differences of patient and nurse participant's results, and discussed methodology and issues to be considered. The following Chapter 6 will conclude this study by summarizing the findings, analyzing strengths and limitations, and making implications and recommendations for practice, education, research, and policy to further improve cancer care for cancer survivors, meet their needs, and improve their quality of life in treatment transition.

Chapter 6. Conclusion

This chapter summarizes the study, identifies its strengths and limitations, and indicates implications and recommendations for practice, education, research, and policy in the following sections.

6.1 Summary

Cancer survivors experience lasting side effects after completion of acute cancer treatment. They are not well prepared for treatment transition. They have physical, emotional, and social concerns under personal transition and face challenges on care transition from inpatient department to outpatient department, from oncology team to primary care provider's team, and from acute care to follow-up care. They need continuous and coordinated supports from healthcare professionals. Cancer survivors receive cancer care but the cancer care obtained are not sufficient and/or specific to address their concerns and meet their needs comprehensively.

Oncology nurses are well positioned to play key role in treatment transition. Their knowledge and experience lay a good foundation for quality cancer care and contribute to cancer survivor's health and wellbeing. Oncology nurses demonstrate caring value, advocate for cancer survivors, bridge communication between cancer survivor and healthcare teams and between oncology team and primary care provider's team, and provide quality cancer care to address their concerns. However, their knowledge and experience vary. Addressing cancer survivor's concerns, meeting their needs, and improving their quality of life are not solely the responsibility for nurses and/or any one of the health professionals. It needs coordination and supports from all aspects including cancer survivors, healthcare teams, hospitals, employers, community, government, and other stakeholders such as insurance companies and financial institutes.

Both patient and nurse participants specify positive experience promoting delivery of quality cancer care. They also recognized barriers that negatively affect delivery of quality cancer care. They made suggestions and recommendations to improve cancer care from their perspectives respectively.

In current context of healthcare system, effectively and efficiently allocating, using, and developing available health resource is a priority. Considering increasing number of cancer survivors and their demand, current healthcare system capacity, and suggestions and recommendations from cancer survivors and oncology nurses in this study, researcher calls for a new model for continuous and coordinated cancer care for cancer survivors in treatment transition. Researcher recommends that the new model focuses on equipping cancer survivors with knowledge and ability of self-care management for treatment transition, establishing and/or improving standards and guidelines for nursing practice, promoting coordination between healthcare teams, raising capacity of primary care provider’s team, treating cancer survivors in holistic way, establishing community supports networks, and strengthening coordination among cancer survivors, healthcare teams, employers, community, government, and other stakeholders such as insurance company and financial institutions.

6.2 Strengths

This study explored experience of both patient participants receiving cancer care and nurse participants providing cancer care and also compared and contrasted their experiences in treatment transition. The researcher applied the Nursing Theory of Transition framework and IPA approach to comprehensively and systemically collected data and identified themes of experience of patient and nurse participants in each component transition. This study further discussed the findings by analyzing, interpreting the themes identified, comparing, and contrasting them with current literature.

This study applied the Lincoln and Guba's quality framework to enhance trustworthiness: credibility, dependability, confirmability, and transferability. The researcher demonstrated credibility of data and its interpretations by collecting rich information through semi-structured in-depth interview and sending recordings, transcripts, and themes analysis to research supervisor for review. The researcher showed dependability by recruiting patient and nurse participants according to criteria, having willingness to share their experience, and reporting in details about the process of participant's recruitment and data collection and analysis. The researcher illustrated confirmability by presenting narratives of participants (Appendix K) and undertaking review and audit by the supervisor and members of supervisory committee with expertise in health research to reduce the researcher's bias and ensure that the findings are supported by the data. Regarding potential transferability of the findings of this study, the researcher reported specific details of the research situation, participant's characteristics, and methods of data collection and analysis for readers to compare these details to their similar situation.

This study added body of knowledge by identifying patterns and culminating essence of experience of both Canadian cancer survivors and oncology nurses in treatment transition. The study made suggestions and recommendations to optimize current health resources to improve cancer care, address cancer survivor's concerns, meet their needs, and improve their quality of life. The findings from this study can inform the establishment of a new model for continuous and coordinated cancer care for cancer survivors in treatment transition.

6.3 Limitations

Limitations exist in this study. Recognizing the limitations promotes understanding the findings of this study with cautions. There were five patient participants and three nurse participants and they were all female as the researcher followed the requirements of the Research Ethics Board from both institutions, respected participant's wishes, willingness, and interests, and experienced time constraints with data collections. This limitation was compensated by the in-depth and richness of data collection, the rigor of analysis, and trustworthiness enhanced by application of the Nursing Theory of Transition framework, IPA approach, and Lincoln and Guba's quality framework in this study. The researcher used purposively sampling strategy to select patient participants who had experience receiving cancer care in treatment transition and nurse participants who had experience providing cancer care for cancer survivors in treatment transition. Both of them would like to share their valued experience. The researcher collected rich and detailed data listed as narratives in Appendix K. If the researcher recruited more patient and nurse participants, there might be something new to discover. This study used theoretical saturation and ensured sampling and data collection to the point where no new key emerging themes were identified from nurse and patient participants. Though every participant gave substantial amount of information, there were a large proportion of redundancy of themes within each person's input. Each participant's interview input was thoroughly analyzed to develop themes before interviewing the next participant. It was found that there was a gradual reduction in the uniqueness of input from participants along the process of interview. By the end, both of patient and nurse participants did not provide new key emerging themes. The process of data collection and analysis to develop themes was reported clearly and transparently and themes were reviewed by members of supervisory committee.

6.4 Implications and Recommendations

The researcher successfully applied the Nursing Theory of Transition framework and IPA approach to guide this study, identify pattern, and culminate essence of experience of cancer survivors and oncology nurses in treatment transition. The Nursing Theory of Transition framework might potentially bias the researcher to mainly focus on exploring experiences of cancer survivors and oncology nurses under personal transition and care transition, rather than other potential transition that is unknown to the researcher.

The study recognizes cancer survivor's concerns and needs in each component transition and indicate oncology nurse's key roles and contributions to deliver quality cancer care and improve cancer survivor's health. The findings would potentially provide helpful information to support the following recommendations for practice, education, research, and policy.

6.4.1 Practice

Themes identified in this study would potentially help both health care professionals and cancer survivors to comprehensively recognize and address their concerns and needs in each component transition.

Cancer survivors hope that they have more time and supportive environment to express their concerns and needs and to address them. Health care professionals should educate cancer survivors on treatment transition, encourage their involvement in their cancer care, improve their ability for self-care management, provide effective supports and information with rationales, and treat cancer survivors in holistic ways.

Oncology nurses hope that they have more time and supportive environment to provide cancer care for cancer survivors. Improving oncology nurse’s knowledge and experiences can promote delivery of quality cancer care efficiently and effectively on the one hand. On the other hand, hospitals/clinics should provide supportive environment to reduce time waste during delivery of cancer care such as ensuring machine and/or devices working well and supplies available if they may not increase the number of healthcare professionals and/or reduce staff workload.

Under currently limited health resources compared to increasing number of cancer survivors, improving coordination between and/or within healthcare teams and increasing primary care provider’s capacity should be considered. Completion and discussion of survivor care plan among cancer survivors, oncology team, and primary care provider’s team together would improve communication, facilitate transfer of information and care collaboration, and provide cancer survivors with a road map for treatment transition. Survivorship care plan for cancer survivors is different from usual discharge planning. Cancer survivors face high risk of cancer recurrence and mortality, have lasting side effects for months to years, and experience other medical complications caused by cancer and treatment. Survivorship care plan summarizes their acute cancer treatment and potential consequences, provides guidance for follow-up care to monitor and prevent cancer recurrence, manage lasting side effects and promote healthy life style. Oncology team and primary care provider's team should integrate cancer survivor's preference and goals into the survivorship care plan to comprehensively address their concerns and improve their quality of life.

6.4.2 Education

The study indicates the importance of education for both oncology nurses providing cancer care and cancer survivors receiving cancer care. Healthcare professionals should equip cancer survivors with knowledge to recognize and report their concerns and needs in each component transition to be addressed comprehensively. Cancer survivors should obtain education to improve their abilities for self-care management.

Improving oncology nurse's knowledge and experiences ensure delivery of quality cancer care. Hospitals and/or clinics should establish and/or improve standardizations and guidelines to educate and train oncology nurses to identify and address cancer survivor's concerns and needs in each component transition beyond depending on individual nurse's knowledge and experience. Oncology nurses need to participate in continuous education to perform evidence-based practice for cancer survivors. Oncology nurses not only equip with knowledge of nursing care for the phase of treatment transition but also knowledge in all parts of the oncology journey. Oncology nurses should coordinate with oncology team and primary care provider's team to complete survivorship care plan for cancer survivors. The findings of this study such as themes in each component transition would potentially provide oncology nurses with helpful information to comprehensively and actively identify, assess, and address concerns and needs of cancer survivors in treatment transition besides depending on what cancer survivors mention.

6.4.3 Research

The findings of this study add knowledge for research gap by identifying themes of experience of Canadian cancer survivors and oncology nurses in treatment transition, exploring positive experience and barriers, analyzing, and discussing potential suggestions and recommendations to improve cancer care for cancer survivors.

This study indicates the importance of the following potential research.

- Research to establish and/or optimize community support networks including professional supports from healthcare teams and social supports from volunteers, community support centers such as the Hearth Place, and patient-to-patient support groups
- Research to promote coordination between oncology team and primary care provider's team and raise capacity of primary care provider's team for cancer survivors in treatment transition
- Research to establish one primary nurse to bridge cancer survivors with all aspect in their entire cancer journey.
- Research to establish a new model of continuous and coordinated cancer care for cancer survivors in treatment transition.

6.4.4 Policy

Policy is a system of principles and/or regulations to guide decisions and actions and achieve expected outcomes. Researcher recommends to revise current policy and/or establish new policy below to address cancer survivor’s concerns and needs in treatment transition.

- Policy for patient education to equip their knowledge of potential concerns and needs in each component of treatment transition and self-care management
- Policy for supporting oncology nurse’s continuous education to improve knowledge and experience about identifying and addressing cancer survivor’s concerns and needs in each component transition
- Policy for discussion and completion of survivorship cancer plan by oncology team, primary care provider’s team, and cancer survivors together
- Policy for discussion and completion of return to work with accommodation plan among cancer survivors, employers, and healthcare teams
- Policy for offering community support resources available for cancer survivors

The researcher makes the above recommendations for practice, education, research, and policy according to the findings of this study. Further research needs to evaluate feasibility for these recommendations and develop strategies to implement them. The findings of this study would potentially provide helpful information for improving current cancer care, creating a new model for coordinated and continuous cancer care for cancer survivors, and establishing and/or revising policy to address cancer survivor’s concerns, meet their needs, and improve their quality of life.

REFERENCES

Academy of Integrative Health & Medicine (AIHM) (2020). *AIHM Core Values*. Retrieved from https://aihm.org/page/vision/

Agency for Healthcare Research and Quality (AHRQ). (2014). *What is Care Coordination*? Retrieved from https://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/chapter2.html

American Cancer Society (ACS). (2016). *Managing Cancer as a Chronic Illness*. Retrieved from https://www.cancer.org/treatment/survivorship-during-and-after-treatment/when-cancer-doesnt-go-away.html

American Society of Clinical Oncology (ASCO) (2018 A). *The Oncology Team*. Cancer.Net Retrieved from https://www.cancer.net/navigating-cancer-care/cancer-basics/cancer-care-team/oncology-team.

American Society of Clinical Oncology (ASCO) (2018 B). *How Cancer Affects Family Life*. Cancer.Net. Retrieved from https://www.cancer.net/coping-with-cancer/talking-with-family-and-friends/how-cancer-affects-family-life

American Society of Clinical Oncology (ASCO) (2018C). The Oncology Team. Cancer.Net. Retrieved from https://www.cancer.net/navigating-cancer-care/cancer-basics/cancer-care-team/oncology-team

American Society of Clinical Oncology (ASCO) (2019A). *Being a Cancer Advocate*. Cancer.Net. Retrieved from https://www.cancer.net/research-and-advocacy/patient-advocates/being-cancer-advocate

American Society of Clinical Oncology (ASCO) (2019B). *What is Survivorship?* Cancer.Net. Retrieved from https://www.cancer.net/survivorship/what-survivorship

Ang, W., Lang, S., Ang, E., & Lopez, V. (2016). Transition Journey from Hospital to Home in Patients with Cancer and their Caregivers: A Qualitative Study. *Supportive Care in Cancer, 24*(10), 4319–4326. https://doi.org/10.1007/s00520-016-3269-0

Aubin, M., Vézina, L., Verreault, R., Fillion, L., Hudon, E., Lehmann, F., … Morin, D. (2012). Patient, Primary Care Physician and Specialist Expectations of Primary Care Physician Involvement in Cancer Care. *Journal of General Internal Medicine, 27*(1), 8–15. doi:10.1007/s11606-011-1777-7

Baker, P., Beesley, H., Fletcher, I., Ablett, J., Holcombe, C., & Salmon, P. (2016). ‘Getting Back to Normal’ or ‘A New Type of Normal’? A qualitative Study of Patients' Responses to the Existential Threat of Cancer. *European Journal of Cancer Care, 25*(1), 180-189. doi:10.1111/ecc.12274

Barnard, A., Clur, L., & Joubert, Y. (2016). Returning to Work: The Cancer Survivor's Transformational Journey of Adjustment and Coping. *International Journal of Qualitative Studies on Health and Well-being, 11*(1), 1-12. doi:10.3402/qhw.v11.32488

Belansky H., & Mahon, S.M. (2012). Using Care Plans to Enhance Care throughout the Cancer Survivorship Trajectory. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/22297013

Bergkvist, K., Fossum, B., Johansson, U.-B., Mattsson, J., & Larsen, J., (2018). Patients' Experiences of Different Care Settings and a New Life Situation after Allogeneic Hematopoietic Stem Cell Transplantation. *European Journal of Cancer Care, 27*(1), n/a. doi:10.1111/ecc.12672

Berg, L., Nolbris, M.J., Koinberg, I., Melin-Johansson, C., Möller, A., & Öhlén, J. (2014). Characterisation of Cancer Support and Rehabilitation Programmes: A Swedish Multiple Case Study. Retrieved from http://europepmc.org/articles/PMC3905349

Bilodeau, K., Tremblay, D., & Durand, M.J. (2017). Exploration of Return-to-work Interventions for Breast Cancer Patients: A Scoping Review. *Support Care Cancer (2017) 25*: 1993 - 2007. https://doi.org/10.1007/s00520-016-3526-2

Boehmke, M., & Dickerson, S. (2006). The Diagnosis of Breast Cancer: Transition from Health to Illness. Retrieved from https://search-proquest-com.uproxy.library.dc-uoit.ca/docview/223107045?pq-origsite=summon

Boland, L., Bennett, L., & Connolly, D. (2018). Self-management Interventions for Cancer Survivors: A Systematic Review. *Supportive Care in Cancer*. Retrieved from http://link.galegroup.com.uproxy.library.dc-uoit.ca/apps/doc/A533934594/AONE?u=ko_acd_uoo&sid=AONE&xid=0714abff

Bouya, S., Balouchi, A., Maleknejad, A., Koochakzai, M., AlKhasawneh, E., & Abdollahimohammad, A. (2018). Cancer Pain Management Among Oncology Nurses: Knowledge, Attitude, Related Factors, and Clinical Recommendations: A Systematic Review. *Journal of Cancer Education. 34*(5), pp 839–846. Retrieved from https://link-springer-com.uproxy.library.dc-uoit.ca/article/10.1007%2Fs13187-018-1433-6

Bowen, G.A. (2008). Naturalistic Inquiry and the Saturation Concept: A Research Note. *Sociological Focus, 52*(2), 131-139. Retrieved from https://journals-sagepub-com.uproxy.library.dc-uoit.ca/doi/abs/10.1177/1468794107085301

Boyle, D. A. (2009). Nursing Leadership in Survivor Care. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/19860044

Brennan, J. (2001). Adjustment to Cancer—Coping or Personal transition? *Psycho-oncology, 10*(1), 1-18. doi:10.1002/1099-1611(200101/02)10:1<1::AID-PON484>3.0.CO;2-T

Brusletto, B., Torp, S., Ihlebæk, C. M., & Vinje, H. F. (2018). A Five-phase Process Model Describing the Return to Sustainable Work of Persons Who Survived Cancer: A Qualitative Study. *European Journal of Oncology Nursing, 34*, 21-27. doi:10.1016/j.ejon.2018.03.003

Bryant, R., Porter, J., & Sobota, A. (2015). APHON/ASPHO Policy Statement for the Transition of Patients with Sickle Cell Disease from Pediatric to Adult Health Care. *Journal of Pediatric Oncology Nursing*. *32*(6), 355–359. https://doi.org/10.1177/1043454215591954

Butt, C.M. (2012). Hope in Patients with Cancer Transitioning to Survivorship: The Mid-life Direction Workshop as a Supportive Intervention. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/22543398

Canadian Cancer Society (CCS). (2018). *Cancer Statistics at a Glance*. Retrieved from http://www.cancer.ca/en/cancer-information/cancer-101/cancer-statistics-at-a-glance/?region=on#ixzz58Vtohp00

Canadian Cancer Society (CCS) (2020A). *Cancer Statistics at a Glance*. Retrieved from https://www.cancer.ca/en/cancer-information/cancer-101/cancer-statistics-at-a-glance/?region=on

Canadian Cancer Society (CCS) (2020B). *Financial Help*. Retrieved from https://www.cancer.ca/en/support-and-services/support-services/financial-help-on/?region=on

Canadian Nurses Association (CNA). (2020). *Nursing Statistics*. Retrieved from https://www.cna-aiic.ca/en/nursing-practice/the-practice-of-nursing/health-human-resources/nursing-statistics

Canada Population Growth Rate. (2019). Retrieved from https://www.macrotrends.net/countries/CAN/canada/population-growth-rate

Canadian Nurses Association (CNA). (2015). *Framework for the Practice of Registered Nurses in Canada.* Retrieved from https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/framework-for-the-pracice-of-registered-nurses-in-canada.pdf?la=en

Canadian Partnership Against Cancer (CPAC). (2016). *Pan-Canadian Study Aims to Improve Transitions in Care: Experiences of Cancer Patients in Transition*. Retrieved from

http://www.partnershipagainstcancer.ca/pan-canadian-study-aims-improve-transitions-in-care/

Cancer Care Ontario (CCO). (2018). *Ontario Cancer Statistics 2018*. Retrieved from https://www.cancercareontario.ca/sites/ccocancercare/files/assets/OCS2018_2.pdf

Chan, R. J., Button, E., Thomas, A., Gates, P., & Yates, P. (2018). Nurses Attitudes and Practices towards Provision of Survivorship Care for People with a Hematological Cancer on Completion of Treatment. *Supportive Care in Cancer, 26*(5), 1401-1409. doi:10.1007/s00520-017-3972-5

Chan, R.J., Yates, P., Li, Q., Komatsu, H., Lopez, V., Thandar, M., Chacko, S., So, W., Pongthavornkamol, K., Yi, M., Pittayapan, P., Butcon, J., Wyld, D., & Molassiotis, A. (2017). Oncology Practitioners' Perspectives and Practice Patterns of Post-treatment Cancer Survivorship Care in the Asia-Pacific Region: Results from the STEP Study. *BMC Cancer, 17*(1), 715–715. https://doi.org/10.1186/s12885-017-3733-3

Chang, H., & Park, Y.H. (2013). Cancer Rehabilitation from the Perspectives of Oncology Nurses in Korea. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/23107511

Chapman, K., & Wiernikowski, J. (2011). Adult Cancer Survivorship: A Self-Learning Resource for Nurse. *Canadian Association of Nurses in Oncology*. Retrieved from http://www.cano-acio.ca/page/survivorship_module

Cheng, H., Sit, J. W. H., & Cheng, K. K. F. (2016). Negative and Positive Life Changes Following Treatment Completion: Chinese Breast Cancer Survivors' Perspectives. *Supportive Care in Cancer, 24*(2), 791-798. doi:10.1007/s00520-015-2845-z

Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social Identity, Self-esteem, and Mental Health in Autism. Retrieved from https://onlinelibrary-wiley-com.uproxy.library.dc-uoit.ca/doi/full/10.1002/ejsp.2297

Corbin, J.M., & Strauss, A., (1988). *Unending Work and Care: Managing Chronic Illness at Home*. San Francisco, Ca: Jossey-Bass.

Creswell, J.W. (2014). *Research Design: Qualitative, Quantitative, and Mixed methods Approaches* (*4th Ed.*). Los Angeles: SAGA Publications, Inc.

Creswell, J.W., & Poth, C. (2018). *Qualitative Inquiry & Research Design: Choosing among Five Approaches* (4th edition). Los Angeles: SAGA Publications, Inc.

Davis, C. M., Myers, H. F., Nyamathi, A. M., Lewis, M., & Brecht, M. (2016). The Meaning of Survivorship as Defined by African American Breast Cancer Survivors. *Journal of Transcultural Nursing, 27*(3), 277-285. doi:10.1177/1043659614561678

Dudley, W. N., Brant, J. M., Gray, E., Aders, K., Oliver, D., & Blaseg, K. (2016). Navigating the Transition from Cancer Care to Primary Care: Assistance of a Survivorship Care lan. *Oncology Nursing Forum, 43*(6), 710. doi:10.1188/16.ONF.710-719

Dunberger, G., & Bergmark, K. (2012). Nurse-led Care for the Management of Side Effects of Pelvic Radiotherapy: What Does It Achieve? doi: 10.1097/SPC.0b013e32834f6a95. Retrieved from https://www.researchgate.net/publication/221748338_Nurse-led_care_for_the_management_of_side_effects_of_pelvic_radiotherapy_What_does_it_achieve

Eldridge, L. (2019). Survivor's Guilt in People with Cancer. Retrieved from https://www.verywellhealth.com/cancer-survivors-guilt-2249275

Feuerstein, M. (2007). Defining Cancer Survivorship. Retrieved from https://link-springer-com.uproxy.library.dc-uoit.ca/article/10.1007%2Fs11764-006-0002-x

Fitch, M., Zomer, S., Lockwood, G., Louzado, C., Moxam, R.S., Rahal, R., & Green., E. (2018). Experiences of Adult Cancer Survivors in Transitions. Retrieved from http://fr7cx7ua3s.search.serialssolutions.com/?ctx_ver=Z39.88-2004&ctx_enc=info%3Aofi%2Fenc%3AUTF-8&rfr_id=info%3Asid%2Fsummon.serialssolutions.com&rft_val_fmt=info%3Aofi%2Ffmt%3Akev%3Amtx%3Ajournal&rft.genre=article&rft.atitle=Experiences+of+adult+cancer+survivors+in+transitions&rft.jtitle=Supportive+Care+in+Cancer&rft.au=Margaret+Fitch&rft.au=Sarah+Zomer&rft.au=Gina+Lockwood&rft.au=Cheryl+Louzado&rft.date=2018-12-01&rft.pub=Springer+Science+%26+Business+Media&rft.issn=0941-4355&rft.eissn=1433-7339&rft.spage=1&rft_id=info:doi/10.1007%2Fs00520-018-4605-3&paramdict=en-US

Foster, C., Breckons, M., Cotterell, P., Barbosa, D., Calman, L., Corner, J., . . . Smith, P. W. (2015). Cancer Survivors' Self-efficacy to Self-manage in the Year Following Primary Treatment. *Journal of Cancer Survivorship, 9*(1), 11-19. doi:http://dx.doi.org.uproxy.library.dc-uoit.ca/10.1007/s11764-014-0384-0

Frade, A., Lopes, M., Ramos, A.F., & Fonseca, C. (2017). Self-Care and Promotion of Patient's Health in Chemotherapy: Contribution to the Practice of Nurses. Retrieved from https://www.elynsgroup.com/journal/article/self-care-and-promotion-of-patients-health-in-chemotherapy-contribution-to-the-practice-of-nurses

Franco, B. B., Dharmakulaseelan, L., McAndrew, A., Bae, S., Cheung, M. C., & Singh, S. (2016). The experiences of cancer survivors while transitioning from tertiary to primary care. *Current Oncology*, *23*(6), 378–385. http://doi.org/10.3747/co.23.3140

Frank, J.R., & Brien, S. (2008). The Safety Competencies: Enhancing Patient Safety across the Health Professions. Safety Competencies Steering Committee of the Canadian Patient Safety Institute. Retrieved from https://www.patientsafetyinstitute.ca/en/toolsResources/safetyCompetencies/Documents/Safety%20Competencies.pdf

Galbraith, M.E., Hays, L., & Tanner, T. (2012). What Men Say about Surviving Prostate Cancer: Complexities Represented in a Decade of Comments. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/22297009

Garcia-Vivar, C., Elizondo, N., & Ambrosio, L. (2019). Primary Care Nursing Is Essential to Fully Implement Survivorship Care Plans for Long-term Cancer Survivors and Their Families. *Cancer Nursing*, *42*(3), 177–178. https://doi.org/10.1097/NCC.0000000000000704

Gavin, D. (2016). Using Theoretical or Conceptual Frameworks in a Scholarly Study. Retrieved from https://research.phoenix.edu/blog/using-theoretical-or-conceptual-frameworks-scholarly-study

Glaser, S., Knowles, K., & Damaskos, P. (2019). Survivor Guilt in Cancer Survivorship. Retrieved from https://www-tandfonline-com.uproxy.library.dc-uoit.ca/doi/full/10.1080/00981389.2019.1640337?scroll=top&needAccess=true.

Goldberg, J., Hinchey, J., Feder, S., & Schulman-Green, D. (2016). Developing and Evaluating a Self-Management Intervention for Women with Breast Cancer. *Western Journal of Nursing Research, 38*(10), 1243–1263. https://doi.org/10.1177/0193945916650675

Gorin, S.S., Haggstrom, D., Han, P.K.J., Fairfield, K.M., Krebs, P., & Clauser, S.B. (2017). Cancer Care Coordination: A Systematic Review and Meta-Analysis of Over 30 Years of Empirical Studies. Retrieved from https://link.springer.com/article/10.1007/s12160-017-9876-2

Government of Canada (2015). *Executive Summary: Cancer Incidence in Canada: Trends and Projections (1983-2032) – HPCDP. 35*(1). Retrieved from https://www.canada.ca/en/public-health/services/reports-publications/health-promotion-chronic-disease-prevention-canada-research-policy-practice/vol-35-no-1-2015/supplement/page-31.html

Grant, M., Economou, D., & Ferrell, B. (2010). Oncology Nurse Participation in Survivorship Care. *Clinical Journal of Oncology Nursing, 14*(6), 709–715. http://doi.org/10.1188/10.CJON.709-715

Grant, M., Economou, D., Ferrell, B., & Uman, G. (2012). Educating Health Care Professionals to Provide Institutional Changes in Cancer Survivorship Care. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education, 27*(2), 226–232. http://doi.org/10.1007/s13187-012-0314-7

Grisham, J. (2016). Guilt: A Lasting Side Effect for Cancer Survivors. *Memorial Sloan Kettering Cancer Center*. Retrieved from https://www.mskcc.org/blog/guilt-lasting-side-effect-cancer-survivors.

Grunfeld, E. (2019). Survivorship 2.0. *Journal of Clinical Oncology*. Retrieved from https://ascopubs.org/doi/full/10.1200/JCO.19.01098

Grunfeld, E., & Earle, C. C. (2010). The Interface Between Primary and Oncology Specialty Care: Treatment Through Survivorship. *Journal of the National Cancer Institute. Monographs, 2010*(40), 25–30. Http://doi.org/10.1093/jncimonographs/lgq002

Gubar, S. (September 6, 2012). Not a Cancer Survivor. *The New York Time*. Retrieved from https://well.blogs.nytimes.com/2012/09/06/not-a-cancer-survivor/

Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of Care: A Multidisciplinary Review. *BMJ (Clinical research ed.)*, *327*(7425), 1219–1221. doi:10.1136/bmj.327.7425.1219

Halcomb, E., & Davidson, P. (2005). Using the Illness Trajectory Framework to Describe Recovery from Traumatic Injury. *Contemporary Nurse. 19*.1-2, p232. Retrieved from http://go.galegroup.com.uproxy.library.dc-uoit.ca/ps/i.do?p=AONE&u=ko_acd_uoo&id=GALE|A158525878&v=2.1&it=r&sid=summon

Hallowell, S. C. (2014). Setting the Stage for Development of a Program for Adolescent Heart Transplant Recipients to Transition to Adult Providers: An Integrative Review of the Literature *Journal for Specialists in Pediatric Nursing*, , n/a. doi:10.1111/jspn.12084

Hallowell, S., Boitnott, A., Epstein, B., & Schneider, D. (2013). Transitioning from Adolescent to Adult Providers: Bridging the Gap in Pediatric Heart Transplant Care Through the Development of a Transition Program (ProQuest Dissertations Publishing). Retrieved from http://search.proquest.com/docview/1433853425/

Harrison, S.E., Watson, E.K., Ward, A.M., Khan, N.F., Turner, D., Adams, E., Forman, D., Roche, M.F., & Rose, P.W. (2012). Cancer Survivors' Experiences of Discharge from Hospital Follow-up. *European Journal of Cancer Care* 21, 390–397. Retrieved from http://onlinelibrary.wiley.com/wol1/doi/10.1111/j.1365-2354.2011.01312.x/full

Hasanpour-Dehkordi, A. (2016). Self-care Concept Analysis in Cancer Patients: An Evolutionary Concept Analysis. *Indian Journal of Palliative Care, 22*(4), 388–394. doi:10.4103/0973-1075.191753

Hattangadi, V. (2014). Maslow's Hierarchy of Needs. Retrieved from http://drvidyahattangadi.com/maslows-hierarchy-of-needs/

Hauken, A., Larsen, B., & Holsen, B. (2013). Meeting Reality: Young Adult Cancer Survivors' Experiences of Reentering Everyday Life After Cancer Treatment. *Cancer Nursing, 36*(5), E17–E26. https://doi.org/10.1097/NCC.0b013e318278d4fc

Hebdon, M. C., Abrahamson, K., Griggs, R. R., & McComb, S. A. (2018). Shared Mental Models of Cancer Survivorship Care. *European Journal of Cancer Care, 27*(2), n/a. doi:10.1111/ecc.12831

Hebdon, M., Foli, K., & McComb, S. (2015). Survivor in the Cancer Context: A Concept Analysis. *Journal of Advanced Nursing, 71*(8), 1774–1786. https://doi.org/10.1111/jan.12646

Hewitt, M., Greenfield, S., & Stoval, E. (2005). From Cancer Patient to Cancer Survivor: Lost in Transition. *Institute of Medicine and National Research Council of the National Academics*. Retrieved from http://georgiacore.org/articleImages/articlePDF_396.pdf

Hsueh, M., & Dorcy, K. (2016). Improving Transitions of Care with an Advanced Practice Nurse: A Pilot Study. *Clinical Journal of Oncology Nursing*, *20*(3), 240–243. https://doi.org/10.1188/16.CJON.240-243

Hulbert-Williams, N.J. (2016). Supporting Cancer Patients with Anxiety. *Nursing in Practice*. Retrieved from https://www.nursinginpractice.com/supporting-cancer-patients-anxiety

Hullmann, S. E., Robb, S. L., & Rand, K. L. (2016). Life Goals in Patients with Cancer: A Systematic Review of the Literature. *Psycho-oncology*, *25*(4), 387–399. https://doi.org/10.1002/pon.3852

Irwin, M., Klemp, J.R., Glennon, C. & Frazier, L. (2011). Oncology Nurses' Perspectives on the State of Cancer Survivorship Care: Current Practice and Barriers to Implementation. *Oncology Nursing Forum, 38*(1), E11-9. Retrieved from http://search.proquest.com.uproxy.library.dc-uoit.ca/docview/822931398?accountid=14694

Jepsen, L. Ø., Høybye, M. T., Hansen, D. G., Marcher, C. W., & Friis, L. S. (2016). Outpatient Management of Intensively Treated Acute Leukemia Patients—The Patients' Perspective. *Supportive Care in Cancer*, *24*(5), 2111-2118. doi:10.1007/s00520-015-3012-2

Johnson, W., & Cadogan, M. P. (2013). Clinical Considerations for Care of Older Adult Cancer Survivors. *Journal of Gerontological Nursing, 39*(9), 8. doi:10.3928/00989134-20130808-01

Karvinen, K., Bruner, B., & Truant, T. (2015). The Teachable Moment After Cancer Diagnosis: Perceptions from Oncology Nurses. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/26488830

Keegan, T. H., Lichtensztajn, D. Y., Kato, I., Kent, E. E., Wu, X. C., West, M. M., … AYA HOPE Study Collaborative Group (2012). Unmet Adolescent and Young Adult Cancer Survivors Information and Service Needs: A Population-based Cancer Registry Study. *Journal of Cancer Survivorship: Research and Practice, 6*(3), 239–250. doi:10.1007/s11764-012-0219-9

Keesing. S., McNamara, B., & Rosenwax, L. (2014). Cancer Survivors' Experiences of Using Survivorship Care Plans: A Systematic Review of Qualitative Studies. Retrieved from http://europepmc.org/articles/PMC4441735

Khan Academy (n.d.). *What is self identity?* Retrieved from https://socialmediapsych.weebly.com/self-identity.html

Khan, N. F., Harrison, S., Rose, P. W., Ward, A., & Evans, J. (2012). Interpretation and Acceptance of the Term 'Cancer Survivor': A United Kingdom-based Qualitative Study. *European Journal of Cancer Care, 21*(2), 177-186. doi:10.1111/j.1365-2354.2011.01277.x

Kim, C., & Wiernikowski, J. (2011). Adult Cancer Survivorship— A Self - Learning Resource for Nurses. *Canadian Association of Nurses in Ontario*. Retrieved from https://www.cano-acio.ca/page/survivorship_module

King, M., Jones, L., Richardson, A., Murad, S., Irving, A., Aslett, H., . . . Nazareth, I. (2008). The Relationship between Patients' Experiences of Continuity of Cancer Care and Health Outcomes: A Mixed Methods Study. *British Journal of Cancer, 98*(3), 529-536. doi:10.1038/sj.bjc.6604164

Klemp, J.R. (2015). Survivorship Care Planning: One Size Does Not Fit All. *Seminars in Oncology Nursing*. *31*(1):67-72. https://doi.org/10.1016/j.soncn.2014.11.008.

Klimmek, R., & Wenzel, J. (2012). Adaptation of the Illness Trajectory Framework to Describe the Work of Transitional Cancer Survivorship. *Oncology Nursing Forum*, *39*(6), E499-E510. doi:10.1188/12.ONF.E499-E510

Knight, Z. (2017). A Proposed Model of Psychodynamic Psychotherapy Linked to Erik Erikson's Eight Stages of Psychosocial Development. *Clinical Psychology & Psychotherapy, 24*(5), 1047–1058. https://doi.org/10.1002/cpp.2066

Kourkouta, L., & Papathanasiou, I. V. (2014). Communication in Nursing Practice. *Materia Socio-medica*, *26*(1), 65–67. https://doi.org/10.5455/msm.2014.26.65-67

Kroenke, C. H., Quesenberry, C., Kwan, M. L., Sweeney, C., Castillo, A., & Caan, B. J. (2013). Social Networks, Social Support, and Burden in Relationships, and Mortality after Breast Cancer Diagnosis in the Life After Breast Cancer Epidemiology (LACE) study. *Breast Cancer Research and Treatment, 137*(1), 261–271. doi:10.1007/s10549-012-2253-8

Lauria, M.M. (1991). Continuity of Cancer Care. *Wiley Online Library*. Retrieved from https://onlinelibrary.wiley.com/doi/abs/10.1002/cncr.2820671812#references-section

Lauver, D.R., Connolly-Nelson, K., & Vang, P. (2007). Stressors and Coping Strategies among Female Cancer Survivors after Treatments. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/17413775

LEXICO (2019). *Dictionary*. Retrieved from https://www.lexico.com/en/definition/self-identity

Lester, J. L., Wessels, A. L., & Jung, Y. (2014). Oncology Nurses' Knowledge of Survivorship Care Planning: The Need for Education. *Oncology Nursing Forum, 41*(2), E35. doi:10.1188/14.ONF.E35-E43

Lippincott Solutions (2017). Five Strategies for Providing Effective Patient Education Retrieved from http://lippincottsolutions.lww.com/blog.entry.html/2017/08/22/5_strategies_forpro-kDDq.html

Liu, J.E., Mok, E., & Wong, T. (2006). Caring in Nursing: Investigating the Meaning of Caring from the Perspective of Cancer Patients in Beijing, China. *Journal of Clinical Nursing*. *15*(2):188-96. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/16422736

Low, J. (2019). A Pragmatic Definition of the Concept of Theoretical Saturation. *Sociological Focus, 52*(2). https://doi.org/10.1080/00380237.2018.1544514

Lopez-Class, M., Perret-Gentil, M., Kreling, B., Caicedo, L., Mandelblatt, J., & Graves, K. D. (2011). Quality of Life among Immigrant Latina Breast Cancer Survivors: Realities of Culture and Enhancing Cancer Care. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education, 26*(4), 724–733. doi:10.1007/s13187-011-0249-4

Masterton, K., & Tariman, J. (2016). Effective Transitional Therapy for Adolescent and Young Adult Patients with Cancer: An Integrative Literature Review (Report). *Clinical Journal of Oncology Nursing, 20*(4), 391–396. https://doi.org/10.1188/16.CJON.391-396

Matheson, L., Boulton, M., Lavender, V., Collins, G., Mitchell-Floyd, T., Watson, E., & Matheson, L. (2016). The Experiences of Young Adults with Hodgkin Lymphoma Transitioning to Survivorship: A Grounded Theory Study. *Oncology Nursing Forum, 43*(5), E195–E2014. https://doi.org/10.1188/16.ONF.E195-E2014

Maxwell, J. A. (2013). *Qualitative Research Design: An Interactive Approach* (3rd ed.). Thousand Oaks, Calif: SAGE Publications.

Mazanec, S.R., Gallagher, P., Miano, W.R., Sattar, A., & Daly, B.J. (2017). Comprehensive Assessment of Cancer Ssurvivors' Concerns to Inform Program Development. *The Journal of Community and Supportive Oncology (JCSO), 15*(3): e155-e162. Retrieved from https://www.mdedge.com/hematology-oncology/article/141529/patient-survivor-care/comprehensive-assessment-cancer-survivors

McCabe, M.S., & Jacobs, L. (2008). Survivorship Care: Models and Programs. *Seminars in Oncology Nursing. 24*(3):202-7. https://doi: 10.1016/j.soncn.2008.05.008

McCabe, M.S., & Jacobs, L. (2012). Clinical Update: Survivorship Care--models and Programs Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/22846488

McCabe, M.S., Partridge, A.H., Grunfeld, E., & Melissa, M.H. (2013). Risk-Based Health Care, the Cancer Survivor, the Oncologist, and the Primary Care Physician. *Seminars in Oncolog*: *40*(6), 804-812. Retrieved from https://doi.org/10.1053/j.seminoncol.2013.09.004

McCorkle, R. (2012). Cancer Nurse as Cancer Survivor. *Cancer Nursing*. doi: 10.1097/NCC.0b013e31824d2b71. Retrieved from https://journals.lww.com/cancernursingonline/pages/articleviewer.aspx?year=2012&issue=05000&article=00011&type=Fulltext

Mcfarlane, S., & Bennett, C. (2006). Redefining the Primary Nurse Role in Oncology Care: A 21st Century Perspective. *Canadian Oncology Nursing Journal*, *16*(2), 99–103. https://doi.org/10.5737/1181912x16299103

Mcleod, S. (2018). Erik Erikson's Stages of Psychosocial Development. *Simply Psychology*. Retrieved from https://www.simplypsychology.org/Erik-Erikson.html

Mcleod, S. (2020). Maslow's Hierarchy of Needs. *Simply Psychology*. Retrieved from https://www.simplypsychology.org/maslow.html

Meade, E., McIlfatrick, S., Groarke, A.M., Butler, E., & Dowling, M. (2017). Survivorship Care for Postmenopausal Breast Cancer Patients in Ireland: What Do Women Want? Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/28478858

Mehnert, A., de Boer, A., & Feuerstein, M. (2013). Employment Challenges for Cancer Survivors: Employment Challenges. Cancer, 119, 2151-2159. doi:10.1002/cncr.28067

Miles, M.B. & Huberman, M.A. (1994). *Qualitative Data Analysis: An Expanded Sourcebook.* (2nd ed). Thousand Oaks, CA: SAGE.

Missel, M., Hansen, M., Jackson, R., Siemsen, M., & Schønau, M. (2018). Re-embodying Eating after Surgery for Oesophageal Cancer: Patients' Lived Experiences of Participating in an Education and Counselling Nutritional Intervention. *Journal of Clinical Nursing, 27*(7-8), 1420–1430. https://doi.org/10.1111/jocn.14297

Miyashita, M., Ohno, S., Kataoka, A., Tokunaga, E., Masuda, N., Shien, T., … Takahashi, M. (2015). Unmet Information Needs and Quality of Life in Young Breast Cancer Survivors in Japan. *Cancer Nursing, 38*(6), E1–E11. http://doi.org/10.1097/NCC.0000000000000201

Mollica, M., & Nemeth, L. (2015). Transition from Patient to Survivor in African American Breast Cancer Survivors. *Cancer Nursing, 38*(1), 16-22. doi:10.1097/NCC.0000000000000120

Mollica, M., & Newman, S. D. (2014). Breast Cancer in African Americans: From Patient to Survivor. *Journal of Transcultural Nursing, 25*(4), 334-340. doi:10.1177/1043659614524248

Moskowitz, M. C., Todd, B. L., Chen, R., & Feuerstein, M. (2014). Function and Friction at Work: A Multidimensional Analysis of Work Outcomes in Cancer Survivors. *Journal of Cancer Survivorship, 8*(2), 173-82. doi:http://dx.doi.org.uproxy.library.dc-uoit.ca/10.1007/s11764-013-0340-4

Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. The New England Journal of Medicine, 313(4), 270-273. Retrieved from http://search.proquest.com.uproxy.library.dc-uoit.ca/docview/76188052?accountid=14694

Nachreiner, N.M., Dagher, R.K., McGovern, P.M., Baker, B.A., Alexander, B.H. & Gerberich, S. G. (2007). Successful Return to Work for Cancer Survivors. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/17665826

National Cancer Institute (NCI) (2018). Communication in Cancer Care (PDQ®)–Health Professional Version. Retrieved from https://www.cancer.gov/about-cancer/coping/adjusting-to-cancer/communication-hp-pdq

National Cancer Institute (NCI) (2015). *Communication in Cancer Care (PDQ®)–Patient Version*. Retrieved from https://www.cancer.gov/about-cancer/coping/adjusting-to-cancer/communication-pdq

National Cancer Institute (NCI) (2019). *Financial Toxicity (Financial Distress) and Cancer Treatment (PDQ®)–Patient Version*. Retrieved from https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-pdq#_273.

Naylor, M., & Keating, S. A. (2008). Transitional care. *The American journal of nursing, 108*(9Suppl), 58–63. doi:10.1097/01.NAJ.0000336420.34946.3a

Nekhlyudov, L., O'Malley, D. M., & Hudson, S. V. (2017). Integrating Primary Care Providers in the Care of Cancer Survivors: Gaps in Evidence and Future Opportunities. *The Lancet. Oncology, 18*(1), e30–e38. http://doi.org/10.1016/S1470-2045(16)30570-8

Newton, N. (2010). The Use of Semi-Structured Interviews in Qualitative Research: Strengths and Weaknesses. Retrieved from http://www.academia.edu/1561689/The_use_of_semi-structured_interviews_in_qualitative_research_strengths_and_weaknesses

Nissim, R., Rodin, G., Schimmer, A., Minden, M., Rydall, A., Yuen, D., . . . Zimmermann, C. (2014). Finding New bBarings: A Qualitative Study on the Transition from Inpatient to Ambulatory Care of Patients with Acute Myeloid Leukemia. *Supportive Care in Cancer, 22*(9), 2435-2443. doi:10.1007/s00520-014-2230-3

Nobel-Murray, A., Chrisler, J.C., & Robbins, M.L. (2016). Adolescents and Young Adults with Cancer: Oncology Nurses Report Attitudes and Barriers to Discussing Fertility Preservation. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/27441525

Oliveira, R. A. A., Conceição, V. M., Araujo, J. S., & Zago, M. M. F. (2018). Concept Analysis of Cancer Survivorship and Contributions to Oncological Nursing. *International Journal of Nursing Practice, 24*(1), n/a. doi:10.1111/ijn.12608

Opdenakker, R. (2006). Advantages and Disadvantages of Four Interview Techniques in Qualitative Research. Retrieved from http://www.qualitative-research.net/index.php/fqs/article/viewArticle/175/391&sa=U&ei=FdsJTdDCGYOnrAer0YjVDg&ved=0CP4BEBYwXg&usg=AFQjCNEsC2J0wILvNuH7LEhQaA2znBkKvw

Pai, R. R., & Ongole, R. (2015). Nurses' Knowledge and Education about Oral Care of Cancer Patients Undergoing Chemotherapy and Radiation Therapy. *Indian Journal of Palliative Care, 21*(2), 225–230. doi:10.4103/0973-1075.156507

Pfeifer, S. (October 25, 2018). Limited Capacity at Cancer Clinic is Hurting Patients, Says Winnipeg Client. *Global News*. Retrieved from https://globalnews.ca/news/4591306/limited-capacity-at-cancer-clinic-harmful-to-patients-says-winnipeg-client/

Polit, D.F.,& Beck, C.T. (2012). *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. (9th edition). New York: Wolter Kluwer Health

Potter, P.A., & Perry, A.G. (2010). *Canadian Fundamentals of Nursing*. (4th edition). Toronto, Canada: Mosby Elsevier.

Pransky, G. S., Fassier, J. B., Besen, E., Blanck, P., Ekberg, K., Feuerstein, M., … Hopkinton Conference Working Group on Workplace Disability Prevention (2016). Sustaining Work Participation Across the Life Course. *Journal of Occupational Rehabilitation, 26*(4), 465–479. doi:10.1007/s10926-016-9670-1

Public Health Ontario (PHO) (2020). *Chronic Diseases and Conditions*. Retrieved from https://www.publichealthontario.ca/en/diseases-and-conditions/chronic-diseases-and-conditions

Ravitch, S.M. & Riggan, M. (2012). *Reason & Rigor: How Conceptual Frameworks Guide Research*. Thousand Oaks, CA: SAGE.

Reed, E., & Corner, J. (2015). Defining the Illness Trajectory of Metastatic Breast Cancer. *BMJ Supportive & Palliative care, 5*(4), 358–365. doi:10.1136/bmjspcare-2012-000415

Roberge, D., Tremblay, D., Turgeon, M., & Berbiche, D. (2013). Patients’ and Professionals’ Evaluations of Quality of Care in Oncology Outpatient Clinics. *Supportive Care in Cancer, 21*(11), 2983–2990. https://doi.org/10.1007/s00520-013-1872-x

Robinson, K.M., Piacentine, L.B., Waltke L.J., Ng, A.V., & Tjoe, J.A. (2016). Survivors speak: a qualitative analysis of motivational factors influencing breast cancer survivors’ participation in a sprint distance triathlon. Retrieved from http://onlinelibrary.wiley.com/doi/10.1111/jocn.13067/abstract

Robinson, O.C. (2013). Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide. Retrieved from https://uoit.blackboard.com/webapps/blackboard/execute/content/file?cmd=view&content_id=_1040895_1&course_id=_32671_1

Roundtree, A. K., Giordano, S. H., Price, A., & Suarez-Almazor, M. E. (2011). Problems in Transition and Quality of Care: Perspectives of Breast Cancer Survivors. *Supportive Care in Cancer, 19*(12), 1921-1929. doi:10.1007/s00520-010-1031-6

Rowland, J.H. (2008). Cancer Survivorship: Rethinking the Cancer Control Continuum. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/18687260

Savin-Baden, M. & Major, C.H. (2012). *Qualitative Research: The Essential Guide to Theory and Practice*. New York: Routledge.

Schulman-Green, D., Bradley, E. H., Nicholson, J., Nicholas R, George, E., Indeck, A., & McCorkle, R. (2012). One Step at a Time: Self-management and Transitions among Women with Ovarian Cancer. *Oncology Nursing Forum, 39*(4), 354. doi:10.1188/12.ONF.354-360)

Schumacher, K. L., & Meleis, A. I. (1994). Transitions: A Central Concept in Nursing. *Journal of Nursing Scholarship, 26*(2), 119-127. doi:10.1111/j.1547-5069.1994.tb00929.x

Segall, A. & Fries, C.J. (2017). *Pursuing Health and Wellness: Healthy Societies, Healthy People*. (2nd Ed.) Don Mills: Oxford University Press

Shay, L.A., Schmidt, S., Cornell, S.D., & Parsons, H.M. (2018). "Making My Own Decisions Sometimes": A Pilot Study of Young Adult Cancer Survivors' Perspectives on Medical Decision-Making. Retrieved from https://link-springer-com.uproxy.library.dc-uoit.ca/article/10.1007%2Fs13187-017-1256-x

Shen, A.H, Howell, D, Edwards, E., Warde, P., Matthew, A., & Jones, J.M. (2016) The Experience of Patients with Early-stage Testicular Cancer during the Transition from Active Treatment to Follow-up Surveillance. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/26707612

Sheppard, C. (2007). Breast Cancer Follow-up: Literature Review and Discussion. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/17709299

Sisler, J.J., Brown, J.B., & Stewart, M. (2004). Family Physicians' Roles in Cancer Care. Survey of Patients on a Provincial Cancer Registry. *Canadian Family Physician (CFP).* Retrieved from https://www.cfp.ca/content/50/6/889Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis - Theory, Method and Research (3rd edition)*. London: SAGE Publications Ltd.

Smith, J., Larkin, M., & Flowers, P. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. Los Angeles: SAGE.

Smith, Y. (2018). Multidisciplinary Primary Care Teams. Retrieved from https://www.news-medical.net/health/Multidisciplinary-Primary-Care-Teams.aspx

Smolowitz, J., Speakman, E., Wojnar, D., Whelan, E., Ulrich, S., Hayes, C., & Wood, L. (2015). Role of the Registered Nurse in Primary Health Care: Meeting Health Care Needs in the 21st Century. *Nursing Outlook*, *63*(2), 130–136. https://doi.org/10.1016/j.outlook.2014.08.004

So, W.K., Chow, K.M., Chan, H.Y.,, Choi, K.C., Wan, R.W., Mak, S.S., Chair, S.Y., & Chan, C.W. (2014). Quality of Life and Most Prevalent Unmet Needs of Chinese Breast Cancer Survivors at One Year after Cancer Treatment. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/24703094

Svedberg, P., Einberg, E., Wärnestål, P., Stigmar, J., Castor, A., Enskär, K., & Nygren, J. (2016). Support from Healthcare Services during Transition to Adulthood: Experiences of Young Adult Survivors of Pediatric Cancer. *European Journal of Oncology Nursing, 21*, 105.

Tan, S. Y., Turner,J., Kerin-Ayres, K., Butler, s., Deguchi, C. Khatri, S., Mo, C., Warby, A., Cunningham, I., Malalasekera, A., Dhillon, H.M., & Vardy, J.L. (2019). Health Concerns of Cancer Survivors after Primary Anti-cancer Treatment. Retrieved from https://link-springer-com.uproxy.library.dc-uoit.ca/article/10.1007%2Fs00520-019-04664-w

Taylor, G.H., Todman, J., & Broomfield, N.M. (2011). Post-stroke Emotional Adjustment: A Modified Social Cognitive Transition model. *Neuropsychological Rehabilitation 21*(6):808-24. DOI: 10.1080/09602011.2011.598403

Thomson, B., Gorospe, G., Cooke, L., Giesie, P., & Johnson, S. (2015). Transitions of Care: A Hematopoietic Stem Cell Transplantation Nursing Education Project across the Trajectory. *Clinical Journal of Oncology Nursing, 19*(4), E74.

Tomasone, J.R., Brouwers, M.C., Vukmirovic, M., Grunfeld, E., O'Brien, M.A., Urquhart, R., Walker, M., Webster, F., & Fitch, M. (2016). Interventions to Improve Care Coordination between Primary Healthcare and Oncology Care Providers: A Systematic Review. *ESMO Opens, 1*(5). E000077. doi:10.1136/esmoopen-2016-000077

Torp, S., Nielsen, R. A., Gudbergsson, S. B., & Dahl, A. A. (2012). Worksite Adjustments and Work Ability among Employed Cancer Survivors. *Supportive Care in Cancer, 20*(9), 2149-2156. doi:10.1007/s00520-011-1325-3

Towsley, G. L., Beck, S. L., & Watkins, J. F. (2007). "Learning to Live with It": Coping with the Transition to Cancer Survivorship in Older Adults. *Journal of Aging Studies, 21*(2), 93-106. doi:10.1016/j.Jaging.2006.08.003

Tremblay, D., Latreille, J., Bilodeau, K., Samson, A., Roy, L., L'Italien, M., & Mimeault, C. (2016). Improving the Transition from Oncology to Primary Care Teams: A Case for Shared Leadership. *Journal of Oncology Practice*. https://ascopubs.org/doi/pdf/10.1200/JOP.2016.013771

Tremblay, D., Prady, C., Bilodeau, K., Nassera, T., Chouinard, M., Fortin, M., Gaboury, I., Rodrigue, J., & Litalien, M. (2017). Optimizing Clinical and Organizational Practice in Cancer Survivor Transitions between Specialized Oncology and Primary Care Teams: A Realist Evaluation of Multiple Case Studies. *BMC Health Services Research*. https://doi.org/10.1186/s12913-017-2785-z

Ullgren, H., Kirkpatrick, L., Kilpeläinen, S., & Sharp, L. (2017). Working in Silos? – Head & Neck Cancer Patients during and after Treatment with or without Early Palliative Care Referral. *European Journal of Oncology Nursing, 26,* 56-62. doi:10.1016/j.ejon.2016.12.003

Utne, I., Smastuen, M.C., & Nyblin, U. (2018). Pain Knowledge and Attitudes among Nurses in Cancer Care in Norway. *Journal of Cancer Education*. Retrieved from https://link-springer-com.uproxy.library.dc-uoit.ca/article/10.1007%2Fs13187-018-1355-3https://doi-org.uproxy.library.dc-uoit.ca/10.1007/s13187-018-1355-3

Vaartio-Rajalin, H., & Leino-Kilpi, H. (2011). Nurses as Patient Advocates in Oncology Care: Activities Based on Literature. Retrieved from https://go-gale-com.uproxy.library.dc-uoit.ca/ps/i.do?p=AONE&u=ko_acd_uoo&id=GALE|A270618497&v=2.1&it=r&sid=summon

Vachon, M. L. (2008). Meaning, Spirituality, and wellness in Cancer Survivors. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/18687268

Walker, R., Szanton, S. L., & Wenzel, J. (2015). Working Toward Normalcy Post-Treatment: A Qualitative Study of Older Adult Breast and Prostate Cancer Survivors. Oncology nursing forum, 42(6), E358–E367. doi:10.1188/15.ONF.E358-E367

Wallace, A., Downs, E., Gates, P., Thomas, A., Yates, P., & Chan, R. (2015). Provision of Survivorship Care for Patients with Haematological Malignancy at Completion of Treatment: A Cancer Nursing Practice Survey Study. *European Journal of Oncology Nursing*, *19*(5), 516–522. https://doi.org/10.1016/j.ejon.2015.02.012

Walter, F. M., Usher-Smith, J. A., Yadlapalli, S., & Watson, E. (2015). Caring for People Living with, and beyond, Cancer: An Online Survey of GPs in England. *The British Journal of General Practice: The Journal of the Royal College of General Practitioners*, *65*(640), e761–e768. https://doi.org/10.3399/bjgp15X687409

Wang, N.N., Cao, F.L., Liu, F., Jia, Y.B., Wang,L., Bao, C.H., Wang X.T., Song, Q.X., Tan, B.X., & Cheng, Y.F. (2015). The Effect of Socioeconomic Status on Health-care Delay and Treatment of Esophageal Cancer. *Journal of Translational Medicine*. Retrieved from https://go-gale-com.uproxy.library.dc-uoit.ca/ps/i.do?p=AONE&u=ko_acd_uoo&id=GALE|A542050991&v=2.1&it=r&sid=summon

Wang, S., Aldridge, M. D., Gross, C. P., Canavan, M., Cherlin, E., & Bradley, E. (2017). End-of-Life Care Transition Patterns of Medicare Beneficiaries. *Journal of the American Geriatrics Society*, *65*(7), 1406-1413. doi:10.1111/jgs.14891

Warnock, C., Siddall, J., Freeman, J., & Greenfield, D. (2012). Emerging Nursing Roles for Late Effects Care for Children and Young Adults with Cancer. *European Journal of Oncology Nursing, 17*(2), 242-249. doi:10.1016/j.ejon.2012.07.009

White, N., & Newman, E. (2016). Shared Recovery: Couples' Experiences after Treatment for Colorectal Cancer. *European Journal of Oncology Nursing, 21*, 223-231. doi:10.1016/j.ejon.2015.10.008

Wood, S. K. (2017). Transition to Cancer Survivorship: A Concept Analysis. *Advances in Nursing Science*, doi:10.1097/ANS.0000000000000190

Wynendaele, H., Willems, R., & Trybou, J. (2019). Systematic Review: Association between the Patient–nurse Ratio and Nurse Outcomes in Acute Aare Hospitals. *Journal of Nursing Management*. Retrieved from https://onlinelibrary-wiley-com.uproxy.library.dc-uoit.ca/doi/full/10.1111/jonm.12764

Yip, D. (2017). How Doctors Can Communicate Better with Patients. Retrived from https://greatergood.berkeley.edu/article/item/how_doctors_can_communicate_better_with_patients.

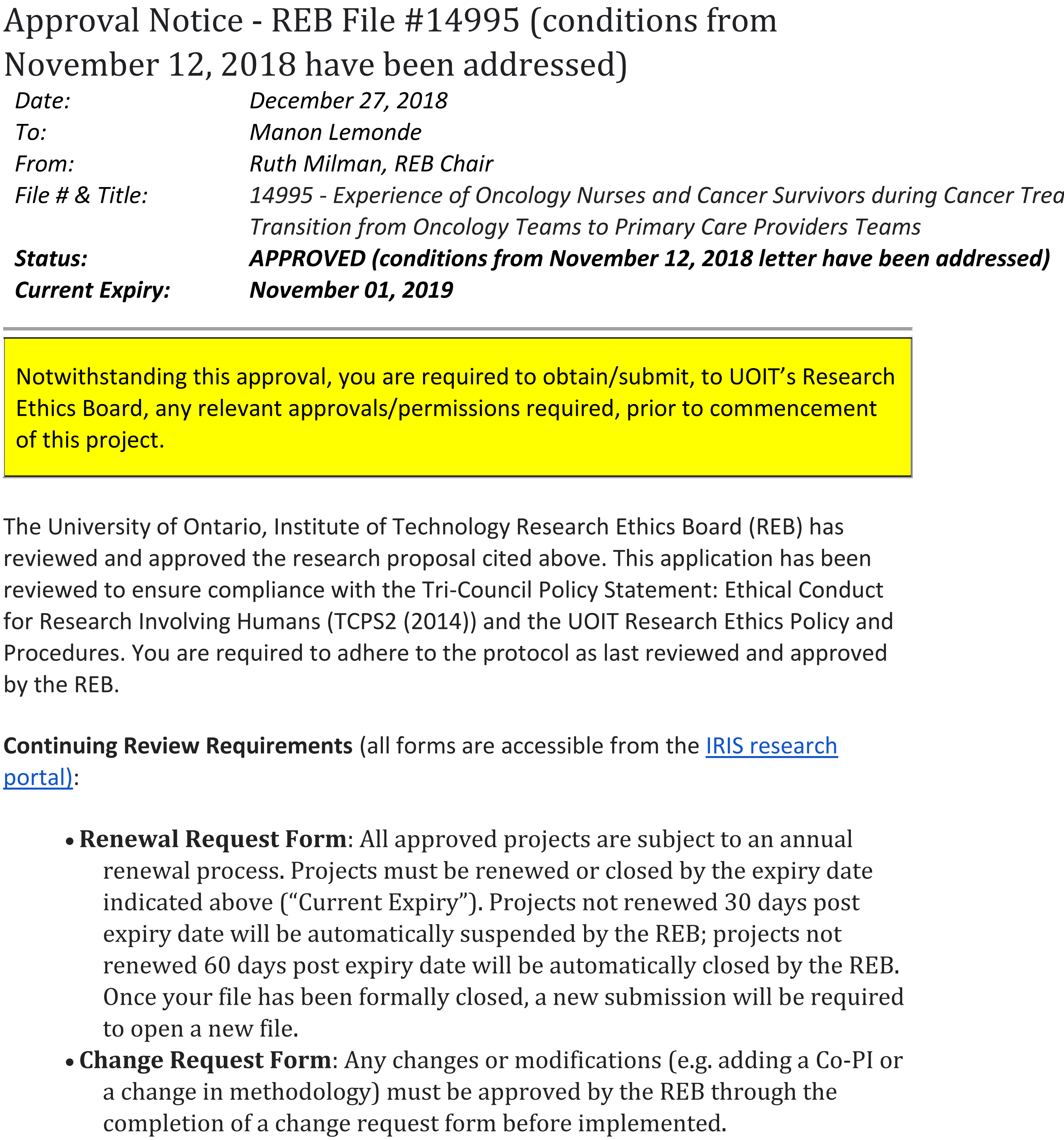
Yoon, H., Sohn, M., Choi, M., & Jung, M. (2017). Conflicting Online Health Information and Rational Decision Making. Retrieved from https://journals.lww.com/healthcaremanagerjournal/Abstract/2017/04000/Conflicting_Online_Health_Information_and_Rational.11.aspx

Yuille, L., Bryant-Lukosius, D., Valaitis, R., & Dolovich, L. (2016). Optimizing Registered Nurse Roles in the Delivery of Cancer Survivorship Care within Primary Care Settings. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/28281450

Appendices

Appendix A. UOIT REB Approval

A1. UOIT REB Approval December 2018



Approval Notice - REB File #14995 (conditions from November 12, 2018 have been addressed)

Date:	*December 27, 2018*
To:	*Manon Lemonde*
From:	*Ruth Milman, REB Chair*
File # & Title:	*14995 - Experience of Oncology Nurses and Cancer Survivors during Cancer Trea Transition from Oncology Teams to Primary Care Providers Teams*
Status:	***APPROVED (conditions from November 12, 2018 letter have been addressed)***
Current Expiry:	***November 01, 2019***

Notwithstanding this approval, you are required to obtain/submit, to UOIT's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the research proposal cited above. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 (2014)) and the UOIT Research Ethics Policy and Procedures. You are required to adhere to the protocol as last reviewed and approved by the REB.

Continuing Review Requirements (all forms are accessible from the IRIS research portal):

- **Renewal Request Form**: All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed 30 days post expiry date will be automatically suspended by the REB; projects not renewed 60 days post expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
- **Change Request Form**: Any changes or modifications (e.g. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.

- **Adverse or Unexpected Events Form**: Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form**: This form must be completed when the research study is concluded.

Always quote your REB file number (**14995**) on future correspondence. We wish you success with your study.

Dr. Ruth Milman	Janice Moseley
REB Chair	Research Ethics Officer
ruth.milman@uoit.ca	researchethics@uoit.ca

A2. UOIT REB Change Request Approval Notice February 2019

Date:	*February 19, 2019*
To:	*Manon Lemonde*
From:	*Ruth Milman, REB Chair*
File # & Title:	*14995 - Experience of Oncology Nurses and Cancer Survivors during Cancer Treatment Transition from Oncology Teams to Primary Care Providers Teams*
Status:	***CHANGE REQUEST APPROVED (received January 27th, 2019)***
Current Expiry:	***November 01, 2019***

Notwithstanding this approval, you are required to obtain/submit, to UOIT's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The University of Ontario, Institute of Technology (UOIT) Research Ethics Board (REB) has reviewed and approved the change request related to the research study named above. This request has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 2014), the UOIT Research Ethics Policy and Procedures, and associated regulations. As the Principal Investigator (PI), you are required to adhere to the research protocol described in the REB application as last reviewed and approved by the REB.

Under the Tri-Council Policy Statement 2, the PI is responsible for complying with the continuing research ethics reviews requirements listed below.

Renewal Request Form: All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed 30 days post expiry date will be automatically suspended by the REB; projects not renewed 60 days post expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.

Change Request Form: If the research plan, methods, and/or recruitment methods should change, please submit a change request application to the REB for review and approval prior to implementing the changes.

Adverse or Unexpected Events Form: Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).

Research Project Completion Form: This form must be completed when the research study is concluded.

Always quote your REB file number (**14995**) on future correspondence. We wish you success with your study.

Sincerely,

Dr. Ruth Milman	Emma Markoff
REB Chair	Research Ethics Assistant
ruth.milman@uoit.ca	researchethics@uoit.ca

A3. UOIT REB Renewal Approval October 2019

Date: *October 07, 2019*
To: *Manon Lemonde*
From: *Emma Markoff, Research Ethics Assistant*
File # & Title: *14995 - Experience of Oncology Nurses and Cancer Survivors during Cancer Treatment Transition from Oncology Teams to Primary Care Providers Teams*
Status: *RENEWAL APPROVED*
Current Expiry: ***November 01, 2020***

The above-noted research ethics file has been renewed. You are required to continue to adhere to the protocol as last reviewed and approved by the Research Ethics Board (REB) at the Ontario Tech.

This research is subject to continuing review requirements. This research file must be renewed or closed by the current expiry date (November 01, 2020) by using the following forms from the IRIS research portal.

- **Renewal Request Form**: All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed 30 days post expiry date will be automatically suspended by the REB; projects not renewed 60 days post expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
- **Change Request Form**: Any changes or modifications (e.g. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or Unexpected Events Form**: Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form**: This form must be completed when the research study is concluded.

Always quote your REB file number (**14995**) on future correspondence. We wish you continued success with your study.

Appendix B. Lakeridge Health REB Approval

B1. Lakeridge Health REB Approval December 2018

Lakeridge
Health

1 Hospital Court
Oshawa, ON
L1G 2B9

NOTIFICATION OF RESEARCH STUDY TO COMMENCE

To the Principal Investigator:
Manon Lemonde
Lakeridge Health

cc: Natascha Kozlowski, Director, Research
Lakeridge Health

attach: Research Team Form

From: Vice President, Research
Lakeridge Health
(for Administrative Approval)

Chair, Lakeridge Health Research Ethics Board
(for Research Ethics Board Approval)

RI-ID#: 2018-013
Study Title: Experience of Oncology Nurses and Cancer Survivors during Cancer Treatment Transition from Oncology Teams to Primary Care Providers Teams
Funding Source: N/A

All research studies must receive both Administrative Approval and Research Ethics Board Approval prior to commencement. Administrative Approval requires approval of the department impact, resource utilization (including sufficient funds to cover all expenses related to the study), and execution of a research Contract/Agreement. The above named study has been approved for administrative and resource utilization merit by Lakeridge Health under the current funding agreement. Any changes to the agreed funding, or protocol revisions that have an impact on resources, will require re-approval.

Please feel free to contact the Research Liaison if there are any questions.

Sincerely,

21.12.18

George Buldo, MD, FRCPC
Vice President, Research

Date

Lakeridge
Health
Lakeridge Health

1 Hospital Court
Oshawa, ON
L1G 2B9

In addition to Administrative Approval, the above named study has been approved for ethical and scientific merit by the Research Ethics Board (REB). This research study may now commence, contingent upon the following:

(i) As a reminder, the REB and LH operate in compliance with applicable laws and regulations including, but not limited to, the International Conference on Harmonization for Good Clinical Practice (ICH/GCP) Guidelines as set forth in Part C Division 5 under the Canadian Food and Drugs Act and the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans Version 2 (TCPS). Lakeridge Health is registered with the U.S. Department of Health & Human Service under IRB registration number IRB00003507. As the Principal Investigator, you are responsible for the ethical conduct of all research team members during the course of the study, and for cooperating with monitoring activities determined by the REB. As such, you and your Research Team (see attached) agree to undertake the study in conformity with the approved protocol, and to immediately report to the REB:

- any revisions, additions, deletions or other amendments via the *Amendment/Revised Consent Form;*
- any local, and specifically relevant external serious adverse events via the *Internal Serious Adverse Event (SAE)Report Form;* and
- any deviation or new information with respect to the protocol via the *Protocol Deviation Form*

(ii) In the event of confidentiality concerns or privacy breach, such as inappropriate and/or unauthorized use of information, you are to immediately report these to both the REB and to the LH Privacy Officer (in accordance with Ontario health privacy legislation – *Personal Health Information Protection Act, 2004*) via the *Privacy Breach Report Form.*

(iii) As the Principal Investigator, you are further expected to submit:

- an annual progress report and annual re-approval via the *Annual Report/Re-Approval Form* if the study is expected to continue beyond the Expiry Date; and
- a *Study Closure Form* along with a copy of the final report when the study has been completed.

Contact Information:

CONTACT	NAME	PHONE
Principal Investigator	Manon Lemonde	mlemonde@lakeridgehealth.on.ca
LH Research Department	Research Liaison	905.576.8711 x2745
Research Ethics Board	Chair	905.576.8711

Lakeridge
Health

1 Hospital Court
Oshawa, ON
L1G 2B9

REB Meeting Date: September 10, 2018

REB Review Type:
☒ A Full Board Meeting
☐ The Chair with Notification to All Board Members

REB Approval Date: September 10, 2018

REB Approval Expiry Date: September 10, 2019

The Research Ethics Board has received the following documentation for study entitled:

"Experience of Oncology Nurses and Cancer Survivors during Cancer Treatment Transition from Oncology Teams to Primary Care Providers Teams"

Documents approved until the expiry date noted above:

- Proposal v4 dated October 5th 2018
- Nurse ICF v3 dated October 5th 2018
- Patient ICF v3 dated October 5th 2018
- Nurse Letter of Invitation v6 dated October 5th 2018
- Patient Letter of Invitation v6 dated October 5th 2018
- Nurse Socio-demographics Form v3 dated October 5th 2018
- Patient Socio-demographics Form v3 dated October 5th 2018
- Nurse Interview Questions v3 dated October 5th 2018
- Patient Interview Questions v3 dated October 5th 2018
- Script for Administrative Assistant of Patient Care Manager for Recruiting Nurse Participants from Outpatient Department v3 dated October 5th 2018
- Thank you letter v1 dated 14Aug2018

Documents Acknowledged:

- LH REB Application

Lakeridge
Health

1 Hospital Court
Oshawa, ON
L1G 2B9

Signed: ______________________________

John Montgomery, BA, LLB
Chair, LH-REB

Please quote your file number (RID#2018-013) on all future correspondence.

Notification of Research Study to Commence Release Date: December 28, 2018

B2. Lakeridge Health Amendment Approval February 2019

Lakeridge Health

1 Hospital Court
Oshawa, ON
L1G 2B9

RID#	2018-013

AMENDMENT / REVISED CONSENT FORM

All revisions, additions or deletions to approved studies are considered amendments, and must be submitted by the PI to the Research Ethics Board for review and approval that the research remains scientifically and ethically sound. Refer to *Guidelines for Submitting Amendments/Revised Consent.*

Full Study Title: Experience of Oncology Nurses and Cancer Survivors during Cancer Treatment Transition from Oncology Teams to Primary Care Providers Teams			
Principal Investigator: Manon Lemonde			
Telephone #: (905)721-8668 (2706)	Cell/Pager #: ( ) -	Fax #: ( ) -	Email: mlemonde@lakeridgehealth.on.ca

DOCUMENTS ATTACHED:
☒ Amendment **(Amended Protocol)** Date and Version #: Guang Sun-LH-REB-Application – January 28 2019 5th-Guang Sun-Research Proposal
☐ **Revised Consent** Date:
☐ **Study Participant Material** (eg. patient wallet card, poster):

REB Initial Approval Date of Study: December 28, 2018
# of patients enrolled since REB approval: 0
Study Status (Open to Accrual or Closed to Accrual):
Amendments since REB approval:

Amendments involve changes to (***check all that apply***):

GENERAL INFORMATION	**BENEFITS/RISKS**
☐ Study	☐ Potential Benefits of the Study
☐ Principal Investigator	☐ Known/Anticipated Risks of the Study
☐ Research Team Members	☐ Procedures for Risks in Place
☐ Conflict of Interest	**INFORMATION/CONSENT PROCESS**
☐ Budget	☐ Informed Consent/Absence of Consent
☐ Impact Assessment (programs/fees)	☐ Process for Parental/Guardian Consent
STUDY SUMMARY	☐ Process for Withdrawal of Consent
☐ Purpose/Rationale/Objectives	**CONFIDENTIALITY**
☐ Methodology/Design	☐ Procedures to Ensure Confidentiality

☐ Dosage/Procedures	**OTHER (specify)**
☐ Sample Size	☐
☐ Inclusion/Exclusion Criteria	☐
☒ Recruitment Process	☐

1. For each amendment and/or revised consent and/or study participant material:

(a) briefly explain the rationale:

Based on recommendations from Patient Education Lead to promote patients' understanding of the research study, research student will take 3-5 minutes to briefly introduce the research study to the group of potential patient participants at the beginning of After Cancer Treatment Group Teaching Class.

This recruitment addition will not change the fact that a copy of the invitation will be part of the package that the attendees are getting.

(b) how the amendment and/or revised consent and/or study participant material will affect the study:

The patients will have the opportunity to meet (briefly) with the researcher and get an initial idea about the process of data collection for the research study.

(c) attach the revised consent form document with tracked changes ☐

(d) attach a clean copy of the revised consent on LH letterhead ☐

2. If study subjects need to be informed of changes related to the amendment and/or revised consent and/or study participant material, describe how and when study subjects will be informed:

N/A

3. Does this study involve investigational drugs or devices:

✓☐ No

☐ Yes. Complete questions below.

(a) Does this study involve any of the following (check all that apply):

☐ Investigational new drugs
☐ Investigational biologics
☐ Investigational natural health products
☐ Investigational medical devices
☐ Approved drug for a new indication (e.g., new age group, disease entity)

(b) If the amendment involves any of the above, is a "No Objection Letter" or authorization letter from Health Canada attached?

LAKERIDGE HEALTH – RESEARCH ETHICS BOARD

☐ YES: Health Canada "No Objection Letter" is attached.

☐ N/A

(c) Provide FDA IND number (drug studies):
or PMA number (device studies):

Principal Investigator Declaration:

I accept the amendments as submitted. I have assessed the safety implications of the amendments and the impact on study procedures, and am prepared to take all necessary steps to implement the changes.

Manon Lemonde January 28, 2019
Signature of Principal Investigator or Designate Date

*************** FOR RESEARCH ETHICS BOARD USE **************

This Research Ethics Board is organized and operates in compliance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans Version 2* (TCPS), ICH/GCP Guidelines and Pact C, Division 5 of the Food and Drug Regulations of Health Canada.

The above-noted amendment and/or revised consent were reviewed and approved by the Research Ethics Board at/by:

☐ A Full Board Meeting ☒ The Chair with Notification to All Board Members

Date: February 08, 2019

Signed:
John Montgomery, BA, LLB
Chair, LH-REB

OR

Andy Benson, BSc, AEMC, ACP
Vice-Chair, LH-REB

LAKERIDGE HEALTH – RESEARCH ETHICS BOARD

LHREB approval released on: February 08, 2019

B3. Lakeridge Health Renewal Approval September 2019

Lakeridge
Health

1 Hospital Court
Oshawa, ON
L1G 2B9

RID# 2018-013

ANNUAL REPORT / RE-APPROVAL FORM

The Lakeridge Health Research Ethics Board (REB) exists to ensure that all research involving human participants conducted at LH meets the highest ethical and acceptable scientific and safety standards. These guidelines are in compliance with the requirements for continuing ethical review as set out in the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans Version 2 (TCPS),* the *International Conference on Harmonization Good Clinical Practice (ICH/GCP)*, and *Health Canada Clinical Trial Regulations.*

The intent of this form is to update the REB on the progress of the study. It is the responsibility of the PI to submit this form to the REB a month prior to the REB expiry date for review and approval before the study can continue at LH. This form notifies the REB of the status of the study to date, and any potential amendments to the protocol. If there are changes, then the *Amendment Form* must be submitted. If the study is closed (study completed as scheduled or prematurely terminated), this is the wrong form – submit the *Study Closure Form.*

Full Study Title: Experience of Oncology Nurses and Cancer Survivors during Cancer Treatment Transition from Oncology Teams to Primary Care Providers Teams

Version Code / Date of current protocol:
January 28,2019 5th version

Version Code / Date of current informed consent form(s):
October 05, 2018 3rd Version

Lakeridge Health Principal Investigator: Manon Lemonde, PhD

Date of Initial REB Approval:	**Start Date of Study:**	**Estimated End Date:**
December 28, 2018	December 28, 2018	December 31, 2019

Expiry Date of REB Approval:
September 10, 2019

Please specify the nature of the study. Check all that apply:

☐ Interventional
☐ Prospective
☐ Clinical Trial
☒ Qualitative
☐ Case Study
☐ Educational

☐ Observational
☐ Retrospective
☐ Chart Review
☐ Human Tissue and Biological Specimens
☐ Epidemiological
☐ Quality Improvement/ Program Evaluation

☐ Other (specify):

1. **Please provide a lay summary of the study:**

The number of cancer survivors has been growing. After completion of acute cancer treatment, the cancer survivors continue to experience lasting side effects for months to years from both the cancer and the treatment including high risks of morbidity, reduced quality of life, and premature mortality. Coordinated and continuous cancer care for cancer survivors transitioning from oncology to primary care is considered to improve quality of life for cancer survivors. Unfortunately, coordination and continuity of cancer care for the cancer survivors in treatment transition is fragmented. Among healthcare professionals for cancer survivors, oncology nurses deliver direct cancer care, coordinate healthcare providers, and support cancer survivors and families in treatment transition. A comprehensive search of the literature found no Canadian studies examining experience of oncology nurses working for cancer survivors in treatment transition. This phenomenological study explored the experience of oncology nurses and cancer survivors in the R.S. McLaughlin Durham Regional Cancer Centre. The Nursing Theory of Transition was used to guide the study. A total of five cancer survivors and three oncology nurses were recruited. Data collection completed. Interpretative phenomenological analysis (IPA) was applied for data analysis. The researcher is writing the final report. The research will promote better understanding of what oncology nurses' practice for and their contributions to cancer survivors in treatment transition. The study will identify what influence the delivery of quality cancer care from the perspectives of both oncology nurses and cancer survivors in treatment transition. These would potentially be utilized to expand involvement of oncology nurses and improve nurse practice. The research findings would provide information to improve quality survivorship care provision, meet cancer survivors' needs, and improve their quality of life.

2. **In less than 200 words, please provide a brief summary of the study activity, progress or any interim findings over the past 12 months** (i.e., data is being analyzed, change in sponsor, recruitment is slower than expected globally)**?**

A total of five cancer survivors and three oncology nurses were recruited. Data collection completed and data analyzed. The researcher is writing the final thesis.

3. **Was there a lapse in REB approval?** ☐ YES ☒ NO

If YES:

a. When was the last date of REB approval?

b. Has any research activity transpired (including data collection) during the lapsed approval?

☐ NO

☐ YES:

If YES, please justify the continuation of data collection or treatment:

c. Provide the reason for the lapse and identify the steps taken to prevent future lapses:

4. Is this study Closed to Accrual? ☒ YES ☐ NO
(When the study is completed, submit the Study Closure Form)

5. Summary of Study Participants [at this site]:

1	Number of participants originally planned	8 to 16	
2	Number of participants currently receiving study intervention/ observation to date		☒ N/A
3	Number of participants in post-intervention follow-up to date		☒ N/A
4	Number of participants signed consent and screen failed before randomization		☒ N/A
5	Number of participants completed the study	8	☐ N/A
6	Number of participants withdrew consent	0	☐ N/A
7	Number of participants expired	0	☐ N/A
8	Number of participants planned for inclusion in a chart review (retrospective or prospective)		☒ N/A
9	Number of participants included in a chart review (retrospective or prospective)		☒ N/A
10	Number of participants enrolled to date (lines 2-7 or 9 alone should equal line 10)	8	

Additional notes/ comments: This is a qualitative study that explored the experience of oncology nurses and cancer survivors. There were no interventions in this study. The researcher planned to recruit 4 to 8 nurse participants and 4 to 8 cancer survivor participants. The researcher recruited 3 nurse participants and 5 cancer survivor participants based on their interests. The data was saturated. Data collection was completed.

6. Since the last renewal, check if there have been any change(s) to the:

Changes:	*Attach:*
☐ PI / Research Team	*Research Team Form attached*
☐ Impact on LH Programs	*DIA Forms submitted*
☐ Conflict of Interest	

7. Have all reportable Serious Adverse Events (SAEs) and protocol deviations/violations experienced by a Lakeridge Health participant been reported to the REB?

☐ YES
☒ NO reportable SAEs have occurred
☒ NO significant deviations/violations to report
☐ NO, will submit immediately. *If selected, please provide a reason below for the delay in reporting and identify the steps taken to prevent future delays*:

8. Please indicate the number of SAEs that were submitted to the LH REB within the last year?

N/A

9. In the opinion of the PI, are there any safety concerns (local or global) or trends in the SAEs that could pose a risk to Lakeridge Health patients?

☐ YES

If YES, please provide details and action taken:

☒ NO

☒ NO safety concerns or SAEs have occurred

I confirm that during the course of the study, I have reviewed and reported any adverse events and/or any revisions to the study protocol, consent form, and impact on LH programs to the Research Ethics Board in a timely fashion. At this time, I am not aware of any new information that may affect the continuation of the study or require changes to the protocol. I will continue to report any future amendments, adverse events, protocol deviations, and privacy breach.

August 18, 2019

Signature of Principal Investigator or Designate Date

*************** **FOR RESEARCH ETHICS BOARD USE** **************

This Research Ethics Board is organized and operates in compliance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans Version 2* (TCPS), ICH/GCP Guidelines and Pact C, Division 5 of the Food and Drug Regulations of Health Canada.

LAKERIDGE HEALTH – RESEARCH ETHICS BOARD

The Research Ethics Board has reviewed and approved the above-noted study for annual renewal at/by:

☒ A Full Board Meeting ☐ The Chair with Notification to All Board Members

Date: September 9, 2019

Signed:
John Montgomery, BA, LLB
Chair, LH-REB

OR

Andy Benson, BSc, AEMC, ACP
Vice-Chair, LH-REB

Expiry Date: September 9, 2020

Appendix C. Patient Letter of Invitation

Patient Letter of Invitation

Dear Sir or Madam,

I am writing to invite you to participate in a study approved by the UOIT Research Ethics Board (REB file number 14995 on December 27, 2018) and Lakeridge Health's Research Ethics Board (RI-ID#: 2018-013 on December 28, 2018) to explore your experience after completion of your cancer treatment. The findings can contribute to improving quality survivorship care provision and meeting cancer survivors' needs. If you decide to participate, I would like to schedule a meeting with you.

- I will schedule a one-to-one face-to-face meeting with you at your convenience. Only you and I will attend the meeting.
- You need to sign a consent form
- You need to fill in a socio-demographics form including gender, age, level of education, marital status, ethnicity, employment status, cancer diagnosis and treatment.
- The meeting will take place in a meeting room in one of the library room and should last about between 30-45 minutes.
- I will ask several questions to understand your experience after completion of your cancer treatment.
- The meeting will be audio recorded with your permission to accurately capture your experience.
- Your name and contact information will not appear on any forms or any types of publications. All information and data collected will be kept completely confidential.
- Participation is voluntary, which means that you may decide to quit the study at any time or decide not to answer any questions you are not comfortable answering. If you decide to withdraw, there will be no consequences to you. In case of withdrawal, any data you provided will be destroyed unless you indicate otherwise.

In appreciation of your time commitment, you will be given a $10 gift card for compensation. You will also receive money to reimburse for your parking expenses on the day of your scheduled meeting with me. You will be reimbursed for parking regardless of whether you complete the study.

Thank you very much for your consideration. If you would like to participate or have any questions about the research study, please feel free to call me 416-887-3722.

Best regards,

Guang (Peter) Sun

Registered Nurse, a UOIT graduate student

Appendix D. Patient Consent Form

Patient Consent Form

Title of Research Study: Experience of Oncology Nurses and Cancer Survivors during Cancer Treatment Transition from Oncology Teams to Primary Care Providers Teams

Principal Investigator, Faculty Supervisor, University of Ontario Institute of Technology (UOIT): Dr. Manon Lemonde, Registered Nurse (RN), PhD.

(Associate Professor/Research Associate) at 905-721-8668 (x2706)

Co-investigator: Guang Sun, Registered Nurse (RN), Bachelor of Science in Nursing (BScN)

(A graduate student of Master of Health Sciences (MHS), UOIT) at 416-887-3722

Department and Institutional Affiliation: Faculty of Health Science, UOIT

External Funder/Sponsor: None

A research study to explore the experience of oncology nurses and cancer survivors during cancer treatment transition from oncology teams to primary care providers teams is being conducted by Guang Sun, BScN, RN, under the supervision of Manon Lemonde, RN, PhD, at the University of Ontario Institute of Technology (UOIT). This research aims to study the lived experience of oncology nurse and cancer survivors. It is partnered with the Durham Regional Cancer Center (DRCC) at Lakeridge Health in Oshawa, Ontario**.** This study has been approved by the UOIT Research Ethics Board (REB file number 14995) on December 27, 2018 and Lakeridge Health's Research Ethics Board (RI-ID#: 2018-013) on December 28, 2018

The purpose of the research study is to explore the experience of oncology nurses providing cancer care for cancer survivors in treatment transition and also the experience of the cancer survivors who receive cancer care from oncology nurses. At the end of this study, the lived experience from the perspective of both oncology nurses and cancer survivors will be better understood by focusing on the treatment transition including what oncology nurses practice for and their contribution to cancer survivors, issues that cancer survivors face, factors that promote or hinder the coordinated and continuous cancer care, and what the context is and how the context affect the experience. The findings of the study would most likely be utilized to expand involvement of oncology nurses, identify needs for education, and improve nursing practice. The study would have the potential to improve quality survivorship care provision, meet survivors' needs, and improve quality of life for cancer survivors.

You are being invited to participate in this research study because you are a cancer patient who has completed active cancer treatment and become a cancer survivor. Your participation involves completing a socio demographic form and taking part in an individual semi-structured interview that consists of open-ended questions to discuss your lived experience during cancer treatment transition from completion of active cancer treatment to follow-up care. The interview will proceed after you have signed the written consent form. The interview will be audio-recorded and would last between 30 to 45 minutes. The completion of these interviews will be held in the meeting rooms within Lakeridge Health hospital.

Potential Benefits:

You will not benefit directly from participating in this study. However, your participation will contribute to better understanding of the lived experience for the cancer survivors during treatment transition.

Potential Risk or Discomforts:

There is minimal risk associated with the research study. Participants may have concerns about risk of disclosing your personal information. If you feel discomfort during the interview, please feel free to talk to the researcher or contact the social worker at Lakeridge Health with your concerns.

Storage of Data:

The data and information collected will be stored on the researcher's computer, will be a password protected, and will also be stored on an encrypted and password protected memory stick that is locked in supervisor's office. The researcher collects and analyzes the data and information for the research in a limited time frame. All data and information will be properly disposed of upon completion of the study. The timeframe to complete the study will be approximately 10 months. Data and information will be properly disposed after 5 years by erasing the electronic files and shredding of all records in paper format.

Confidentiality:

All information and data collected will be kept completely confidential. Your anonymity and confidentiality are treated with respect and will be protected at all times. Your names and contact information will not appear on any forms or any type of publication. An anonymous ID code will be used as an identifier for each participant. Only this anonymous ID code will be used during data collection, analysis and in potential future publications**.** All the interview recordings, consent forms, and personal information collected will be kept private in the faculty supervisor’s (Dr. Manon Lemonde, RN, PhD at the University of Ontario Institute of Technology) office at UOIT, and only the investigators will have access to the data. Your privacy shall be respected. No information about your identity will be shared or published without your permission, unless required by law. Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct. The data will only be transferred between research team members via UOIT emails. The data will be saved in a research team member’s computer protected by a password. In order to ensure confidentiality, data shared with the research team at UOIT will be de-identified and transferred to a password-protected computer. All recordings and transcriptions will be kept for 5 years after the completion of the research study. After the 5 years period, all data will be destroyed in a proper manner. Any confidential research data and records in paper format will be shredded. Confidential research data and records in electronic format will be irreversibly destroyed. All the information provided by you will remain confidential and will only be utilized for the purpose of this research.

Voluntary Participation

Your participation is voluntary, and you may only answer questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research team.

Right to Withdraw:

You may withdraw at any time and the decision to withdraw will not affect your medical care and access to health services. If you withdraw from the research project at any time, any data that you have contributed will be removed from the study and you need not offer any reason for making this request. It is not possible to withdraw from the research once the results have been published**.**

Access of the results of the study

Participants can contact the researcher to access the results of the study after its completion.

Conflict of Interest

Researchers have no conflict of interest.

Compensation:

There is no cost to participate in this study, except for the time engaging in the interview. You will receive money to reimburse for your parking expenses for your scheduled interview on the day of the interview. Participants will be reimbursed for parking regardless of whether they complete the study.

Each participant will get a $10 gift card for compensation.

Debriefing and Dissemination of Results

The results of the study may be published or presented at professional meetings.

Participant concerns and Reporting:

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the researcher, Guang Sun at 416-887-3722 or the faculty supervisor Dr. Manon Lemonde at 905-721-8668 (x2706). Should you have any questions or concerns regarding your rights as a participant in this research study, or if you wish to speak with someone who is not related to the study, you may contact the

Research Ethics Board Coordinator at 905-721-8668 (x3693) at UOIT and/or contact the Chair of the Research Ethics Board of Lakeridge Health at 905- 576-8711.By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Consent to Participate:

I ____________________________, acknowledge by signing this consent form that (1) I have read the consent from and understand the study being described; (2) I have had an opportunity to ask questions and my questions have been answered. I am free to ask questions about the study in the future; and (3) I freely consent to participate in the research study, understanding that I may discontinue participation at any time without penalty. A copy of this Consent Form has been made available to me.

___________________	____________________	_______________
Name of Participant	Signature of Participant	Date

Person Obtaining Informed Consent

_____________________	______________________	________________
Name of Researcher	Signature of Researcher	Date
Guang Sun		

Appendix E. Nurse Letter of Invitation

Nurse Letter of Invitation

Dear Sir or Madam,

You are invited to participate in a study approved by the UOIT Research Ethics Board (REB file number 14995 on December 27, 2018) and Lakeridge Health's Research Ethics Board (RI-ID#: 2018-013 on December 28, 2018) to explore the experiences of oncology nurses providing cancer care for cancer survivors in treatment transition. You are invited because you have had valuable experience providing cancer care for cancer survivors transitioning from oncology care to follow up care after cancer treatment. Particularly, we want to gain an in-depth understanding about oncology nurses' practice and their contributions to cancer survivors, issues that cancer survivors face, and what and how the contexts affect your experience.

Your participation involves signing a consent form, completing a socio-demographic form, and answering open-ended questions about your experiences. The interview will take place at Lakeridge Health and may take approximately 30-45 minutes to complete. The interviews are audio-recorded and the recording will only be reviewed by the research team. Your name and contact information will not appear on any forms or any types of publications. All information and data collected will be kept completely confidential. An anonymous ID code will be used as an identifier for you. Only this anonymous ID code will be used during data collection, analysis, and in potential future publications. You may only answer questions that you are comfortable with.

Participation is voluntary, which means that you may decide to quit the research study at any time or decide not to answer any questions you are not comfortable answering. If you decide to withdraw, there will be no consequences to you. In case of withdrawal, any data you provided will be destroyed unless you indicate otherwise.

In appreciation of your time commitment, you will be given a $10 gift card for compensation. You will be reimbursed for parking regardless of whether they complete the study.

Thank you very much for your consideration. If you would like to participate or have any questions about the research study, please feel free to contact me at 416-887-3722.

Best regards,

Guang (Peter) Sun

Registered Nurse, a UOIT graduate student

Appendix F. Nurse Consent Form

Nurse Consent Form

Title of Research Study: Experience of Oncology Nurses and Cancer Survivors during Cancer Treatment Transition from Oncology Teams to Primary Care Providers Teams

Principal Investigator, Faculty Supervisor, UOIT: Dr. Manon Lemonde, RN, PhD.

(Associate Professor/Research Associate) at 905-721-8668 (x2706)

Co-investigator: Guang Sun, RN, BScN

(A graduate student of Master of Health Science (MHS), UOIT) at 416-887-3722

Department and Institutional Affiliation: Faculty of Health Science, UOIT

External Funder/Sponsor: None

Purpose and Procedure:

A research study to explore the experience of oncology nurses and cancer survivors during cancer treatment transition from oncology teams to primary care providers teams is being conducted by Guang Sun, BScN, RN, under the supervision of Manon Lemonde, RN, PhD, at the University of Ontario Institute of Technology (UOIT). This research aims to study the lived experiences of oncology nurse and cancer survivors. It is partnered with the Durham Regional Cancer Center (DRCC) at Lakeridge Health in Oshawa, Ontario. This study has been approved by the UOIT Research Ethics Board (REB file number 14995) on December 27, 2018 and Lakeridge Health's Research Ethics Board (RI-ID#: 2018-013) on December 28, 2018.

The purpose of the research study is to explore the experience of oncology nurses providing cancer care for cancer survivors in treatment transition and also the experience of the cancer survivors who receive cancer care from oncology nurses. At the end of this study, the lived experience from the perspective of both oncology nurses and cancer survivors will be better understood by focusing on the treatment transition including what oncology nurses practice for and their contribution to cancer survivors, issues that cancer survivors face, factors that promote or hinder the coordinated and continuous cancer care, and what the context is and how the context affect the experience. The findings of the study would most likely be utilized to expand involvement of oncology nurses, identify needs for education, and improve nursing practice. The study would have the potential to improve quality survivorship care provision, meet survivors' needs, and improve quality of life for cancer survivors.

You are being invited to participate in this research study because you are an oncology nurse (RN) working in ensuring the treatment transition of cancer survivors. Your participation involves completing a socio demographic form and taking part in an individual semi-structured interview that consists of open-ended questions to discuss your lived experience about cancer care for cancer survivors during cancer treatment transition. The interview will proceed after you have signed the written consent form. The interview will be audio-recorded and would last between 30 to 45 minutes. The completion of these interviews will be held in the meeting rooms within Lakeridge Health hospital.

Potential Benefits:

You will not benefit directly from participating in this study. However, your participation will contribute to better understanding of the lived experience for the registered nurses providing cancer care during treatment transition.

Potential Risk or Discomforts:

There is minimal risk associated with the research study. Participants may have concerns about risk of disclosing your personal information. If you feel discomfort during the interview, please feel free to talk to the researcher or seek assistance through the use of the Employee Assistance Program.

Storage of Data:

The data and information collected will be stored on the researcher's computer, will be a password protected, and will also be stored on an encrypted and password protected memory stick that is locked in supervisor's office. The researcher collects and analyzes the data and information for the research in a limited time frame. All data and information will be properly disposed of upon completion of the study. The timeframe to complete the study will be approximately 10 months. Data and information will be properly disposed after 5 years by erasing the electronic files and shredding of all records in paper format.

Confidentiality:

All information and data collected will be kept completely confidential. Your anonymity and confidentiality are treated with respect and will be protected at all times. Your names and contact information will not appear on any forms or any type of publication. An anonymous ID code will be used as an identifier for each participant. Only this anonymous ID code will be used during data collection, analysis, and in potential future publications. All the interview recordings, consent forms, and personal information collected will be kept private in the faculty supervisor’s (Dr. Manon Lemonde, RN, PhD at the University of Ontario Institute of Technology) office at UOIT, and only the investigators will have access to the data. Your privacy shall be respected. No information about your identity will be shared or published without your permission, unless required by law. Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct. The data will only be transferred between research team members via UOIT emails. The data will be saved in a research team member’s computer protected by a password. In order to ensure confidentiality, data shared within the research team at UOIT will be de-identified and transferred to a password-protected computer. All recordings and transcriptions will be kept for 5 years after the completion of the research study. After the 5 years period, all data will be destroyed in a proper manner. Any confidential research data and records in paper format will be shredded. Confidential research data and records in electronic format will be irreversibly destroyed. All the information provided by you will remain confidential and will only be utilized for the purpose of this research.

Voluntary Participation

Your participation is voluntary, and you may only answer questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research team.

Right to Withdraw:

You may withdraw at any time and the decision to withdraw will not affect your employment status. If you withdraw from the research project at any time, any data that you have contributed will be removed from the study and you need not offer any reason for making this request. It is not possible to withdraw from the research once the results have been published.

Access of the results of the study

Participants can contact the researcher to access the results of the study after its completion.

Conflict of Interest

Researchers have no conflict of interest.

Compensation:

There is no cost to participate in this study, except for the time engaging in the interview. Each participant will get a $10 gift card for compensation. Participants will be reimbursed for parking regardless of whether they complete the study.

Debriefing and Dissemination of Results

The results of the study may be published or presented at professional m**e**etings.

Participant Concerns and Reporting:

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the researcher, Guang Sun at 416-887-3722 or the faculty supervisor Dr. Manon Lemonde at 905-721-8668 (x2706). Should you have any questions or concerns regarding your rights as a participant in this research study, or if you wish to speak with someone who is not related to the study, you may contact the Research Ethics Board Coordinator at 905-721-8668 (x3693) at UOIT and/or contact the Chair of the Research Ethics Board of Lakeridge Health at 905- 576-8711.

By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

Consent to Participate:

I ____________________________, acknowledge by signing this consent form that (1) I have read the consent from and understand the study being described; (2) I have had an opportunity to ask questions and my questions have been answered. I am free to ask questions about the study in the future; and (3) I freely consent to participate in the research study, understanding that I may discontinue participation at any time without penalty. A copy of this Consent Form has been made available to me.

________________	____________________	_______________
Name of Participant	Signature of Participant	Date

Person Obtaining Informed Consent

_____________________	______________________	________________
Name of Researcher	Signature of Researcher	Date

Guang Sun

Appendix G. Nurse Interview Questions

Nurse Interview Questions

Nurse ID #: ___________

1. Personal Transition

(1) Physical issues

Question #1:

What information and resources on symptoms and/or loss of body functions are you providing cancer survivors during treatment transition?

(2) Emotional issues - psychological upheaval and adjustment

Question #2:

How do you facilitate cancer survivors' emotional adjustment? What coping strategies and support do you provide to promote their emotional transition?

(3) Social transition – meaning of life, identity, relationship, return to normal life, and return to work

Question #3:

What is your experience to support cancer survivors to identify and adjust their identities, meanings of survivorship, and relationships to significant others during treatment transition?

Question #4:

What is your experience in promoting cancer survivors' return to "normal" life and/or return to sustainable work?

2. Treatment Transition

(1) Healthcare setting from hospital to home

Question #5

How do you assess cancer survivors' abilities and responsibilities of self-care management during treatment transition? What types of care and/or services do you provide and/or suggest to promote their self-care management?

(2) Healthcare teams from oncology team to primary care provider team

Question #6

What is your experience about cancer survivors transitioning from oncology teams to primary care providers teams?

(3) Transition of cancer care from acute treatment to follow-up care

Question #7

What types of care/services do you provide and/or suggest to promote maximal recovery of body functions during treatment transition?

3. Factors that positively and negatively affect cancer care during treatment transition

Question #8

How do you meet cancer survivors’ needs and improve their quality of life during treatment transition?

Question #9

What are the barriers that affect the delivery of quality cancer care to meet cancer survivors’ needs and improve their quality of life during treatment transition? What measures should be taken to limit these barriers?

Appendix H. Patient Interview Questions

Patient Interview Questions

Patient ID #: _____________

1. Personal Transition

(1) Physical issues

Question #1:

What types of information and/or resources about physical care did you receive from the oncology nurses during treatment transition?

(2) Emotionally - psychological upheaval and adjustment

Question #2:

What coping strategies do you use during treatment transition? What coping strategies and support do oncology nurses provide for you?

(3)Social transition – meaning of life, identity, relationship, return to normal life, and return to work

Question #3:

What are the meanings of survivorship or cancer survivor for you?

Question #4:

(a) What is your experience about return to "normal" life and/or return to sustainable work?
(b) What types of information and/or resources about return to "normal" life and/or sustainable work did you receive from the oncology nurses during treatment transition?

2. Treatment Transition

(1) Healthcare setting from hospital to home

Question #5:

What is your experience about self-care management during treatment transition?

(2) Healthcare teams from oncology team to primary care provider team

Question #6:

What is your experience during treatment transition between the oncology team and the primary care providers team?

(3) Transition of cancer care from acute treatment to follow-up care or home care

Question #7:

What is your experience with care and/or services provided by oncology nurses to promote maximal recovery during treatment transition?

3. Factors that affect cancer survivors' quality of life during treatment transition

Question #8:

What kinds of factors help to meet your needs and improve your quality of life during treatment transition?

Question #9:

What kinds of barriers do you face when trying to meet your needs and quality of life during treatment transition? What measures should be taken to limit these barriers?

Appendix I. Nurse Socio-demographics Form

Nurse Socio-demographics Form

Participant ID: _______________

Gender:

- ○ Female
- ○ Male
- ○ Not to say

Age: __________

Highest Level of Education in Nursing

- ○ College Diploma
- ○ Baccalaureate Degree
- ○ Master degree
- ○ Doctorate Degree
- ○ Others (please specify): _______________

Have you completed certification(s)? (check all that apply)

- ○ Oncology
- ○ Palliative care
- ○ Others (please specify): _______________

My years of working as an oncology nurse are _____________ years

Employment Status:

- ○ Full-Time
- ○ Part-time

Appendix J. Patient Socio-demographics Form

Patient Socio-demographics Form

Participant ID: _______________

Gender:

- Female
- Male
- Not to say

Age: __________

Highest Level of Education

- High School
- College Diploma
- Baccalaureate Degree
- Master Degree
- Doctorate Degree
- Others (please specify): _______________

Marital Status:

- Married
- Single
- Divorced
- Widow
- Others (please specify): _______________

Ethnicity:

- Aboriginal
- African
- Asian (East & Southeast)
- Asian (South)
- Caribbean
- European
- Latin, Central, & South American
- Middle Eastern
- Pacific islander
- Others (please specify): _______________

Employment Status:

- Employed
- Retired
- Not employed
- Others (please specify): _______________

Please briefly explain your diagnosis and treatment.

Cancer Diagnosis: ____________________

Treatment:

- Chemotherapy
- Radiation
- Surgery
- Others (please specify): _______________

Appendix K. Narratives

K1. Nurse Participant (N1) Narrative

Nurse Participant (N1) Narrative

Nurse's experience for cancer survivor's physical concerns and cancer care provided during treatment transition

- Listening to cancer survivors

"So, first, listening to the patient is the key. That help me to know what to do and how to respond to my patients".

- Patient education and resources offered

"We use patient information that is site specific for radiation specifically. I do radiation right now. So site specific patient education, there are a take home hard copy of the potential side effects, and it will describe nausea, vomiting diarrhea, skin symptoms and it will say on there what they can do to help themselves, what should they avoid, and I also discuss with them verbally as well, during consultation as well as when they see us in what we call review clinics. And when they are on treatment, they see us once a week, and I go through any potential side effects with them and how to manage it. At that point they don't have the resources with them, but I can give them more if they lost them. They are all written in English. I do have, uh the doctors also give them their consent, so it has their potential side effects on there. So the patients have that for reference. If I'm teaching a person that has chemotherapy, we also have resources that I print off of our own education, the potential side effects are also medication specific, and it come from cancer care Ontario, so we print off those potential side effects and how the medication are given in the computer. And that is either only French and English, maybe some other languages, but I could also use another service on our computer, I think it's called lexicom, and you can print off medications, there's around 20 different languages so I can print it off to people so that they have the written form they can resort to. So there's either written information we given, that we print off, or verbally, we discuss with them. And if they don't understand, we have to get them an interpreter. For people that has a hearing deficit, we get a sign language interpreter, and if there's a different language, we have different interpreters to do the languages. Ideally, we get an actually interpreter rather than a family member so thing don't get distorted. So that's yeah, in radiation specifically, it's, it's specific to body parts, whereas chemotherapy, it's systemic of course, the side effects. We spend a lot of the time with them during consultation, I spend quite a lot of time teaching them verbally on potential side effects. And in chemotherapy, I spend a little bit of time talking with them, but the patient also goes to a class, where they learn everything. I do the classes as well, there are different nurses that do different classes, there's also one nurse that do the general class, so it's, you know, 30 people, in one class, where we give a presentation on chemotherapy and how it affects you physically, and how to manage those side effects".

Nurse's experience for cancer survivor's emotional concerns and cancer care provided during treatment transition

- Assessment

"First of all, I assess their emotional transition when I'm talking to them. So, one of the specific questions I ask them specifically is "do you have any mental health issues?". Some people are very open with that, some people aren't. uh so that's the first thing I do, and some people just simply start telling me these kinds of things. So, I take their lead usually, if they start telling me that they are having anxiety, you know, because they have done their blood pressure, it's really high. So, I started talking with them, to see if they are having difficulties. Another tool I use is the ESAS system assessment scoring, you know 0 to 10. So, when our patient checks in at the cancer center, they have to give themselves the scoring on depression, anxiety, those kinds of things, there are other physical things on there too. So, when I'm assessing the patient, that score already shows up on the chart, so if I notice if that score is becoming higher, I will come out and ask them about it" are you suffering from any depression?" So that's another resource I use. Another resource is that we have social workers too. So, If the social worker has reported to me that there is an issue, then I will talk to my patients. Uh so when I talk to my patients, I validate their feelings, and how they are feeling, and I go through what is common in a cancer patient, things they will typically experience and try not to let them feel like they are alienated or this is weird or anything like that. What they are feeling is very common. And we talk about things they can go to help, for instance, deep breathing exercises, stuff like that, if I have time, I will do a little bit of that'.

- Refer to doctors, counselors and social workers

"Sometimes I suggest that they go see their family doctor when they feel like a medication might be helpful. I also refer them to our counselors, we have social workers that are trained in cancer behavior therapy, they can do some of that with patients.

- Programs offered and refer to psychiatrists

"We also have a what we call a better clinic. What it is that people can get referred to see a psychiatrist to initiate some mental health treatment. So I talk to them about that, but there is a process before they can get referred, so I kind of open up the gate way if they feel they want to talk about it”.

- Patient education

“When we are getting toward the end of treatment, I start talking to them about they will continue to see us, so a lot of patients are terrified that they are finishing treatment and now what’s next. It is frightening for them. So, we start talking how there will continue follow up, what things they are going to be worrying about, I talk to them about things they are going to experience, feeling tired, how long is it going to take to get over the side effects. I actually developed a program of class that the patients are supposed to attend, but not all of them do, it’s not appropriate for all of them. It’s actually called “what’s next”. When they are finished their treatment, to come close to finishing treatment, they are supposed to go to this class. It is a presentation about potential side effects, they may have long term chronic side effects, what the new norm feels like, and coping mechanisms, and in that class, there’s also a few recorded interview with patients that have experienced it themselves, and somethings they sat themselves, they transitioning back to work and what their difficulties are, and in this class, a lot of patients start to open up. It’s different than other classes other formats where when we teach them the patients just sit their quietly. In this class, the patients are a little bit more engaged, they want us to talk to them with their own experience, and with other patients. That’s been developed. I actually helped to develop that for patients so they can transition, so they kind of understand what’s happening to themselves. A lot of this is just during, a lot of what I talk to my patients is just in clinic, after appointment. Sometimes they have our phone number, they can call us and ask questions and tell us their problems and we can call them back. I find that a lot of patients that I have, you see where we are doing, we have cancer site specific, one doctor would work with lung, another GI cancer, another doctor would do breast. Depends on what doctors I'm working with; I find that there's very different response of patients. When I have a lot of women, I have a lot of breast cancer patient that would phone me with emotional difficulties, trying to deal with the family, breaking down when their kids are fighting because of the hormones and stuff. So, I have a lot of women calling me with these issues, so we talk about how it is the medication that make you feel that way. And that it is not unusual, it's not something you are doing wrong, and I try it off with coping mechanism and social workers. And when I get a lot of patient working with the doctor that is doing lung, or people like stage four and they have met the brain and stuff like that. I found that sometimes when I talk to people when they are reaching end of life stages, if they have made these, they have thoughts about what is next, are you going to talk to your children about the plans, have you talked to your care doctor. I get a lot of these patients to be completely closed. They don't want to talk about anything, they don't want to hear about anything. So, I'm like, ok you have my number, if you need me for anything, call me. I invite them to call me. And it's a different reaction from different people. Some people want me to help, some people don't want any interaction from me and I don't hear from them again".

Nurse's experience for cancer survivor's social concerns and cancer care provided during treatment transition

- Label of cancer survivors

"I do not label my patients that way. Uh, because at what point is a cancer survivor? Because you have gone to treatment? Because you lived a year? Because the cancer is not coming back? At what point do you label them as cancer survivor? I don't know. That's not really defined in my opinion. There are people that come with stage one or two diseases, they will get cured. And in my opinion, ok that's easy. People that come to us as stage 4 patients, they are not gonna get cured. Just because, does that mean they are not cancer survivor? They have gone through treatment; they have gone through surgery. They picked up and gone back home, and they are living life, they still have cancer than many others, does that mean they are not a cancer survivor? Because they are still enduring a life. I myself, I don't label them that way. I feel that everyone is a cancer survivor to some degree, because they all have had cancer, whether they got rid of it or not. I get really upset because a lot of my patients are stage 4, and I get really upset when I see in the newspaper stating that they have lost a battle against cancer. That drive me nuts. No on they didn't. You should have seen the fight they put on. And they got diagnosed with stage four at the very beginning, they couldn't get completely cured. But the fight they put in, and when they get to that point where they, ok, I'm going to die from this, that's not normal for us to acceptance. It is not easy for us to accept. They accepting it, that to myself is winning battle, to accept that you are dying from cancer. So, I don't like that, you know, some of those says right? Stage 1, stage 2, yeah you are going to win that battle, yeah you are going to be a survivor. But stage 3, stage 4, those little ones are dealing with a lot. To me, they are as much as a survivor. And winning the battle is a much higher bargain because it is a higher stage, right?"

- Return to new normal life

"Right, so uh, it is very different for different patient. We don't ever tell patient, that they are returning to normal life again. I will talk to them about their new normal. When 'm talking to my patient, I will tell them what the side effects are gonna be like and how long they can expect them to last for. I always explain to them that you are not going to figure out where you are at, probably until 3 years after your treatment is done. Because it is a long transition, through being having cancer treatment to getting back to a new normal".

- Return to work

"If they want to return to work, at what point in duration that they will still be experiencing side effects, if there some way they can work from home, if there's some way they can do work at the beginning of the week so they can take the end of the week off, if they can work in the morning and take the afternoon off. So, I talk to them about those kinds of things a head of times if they plan to return to work".

Nurse's experience during cancer survivor's transition from acute care hospital to home

- Promote self-care management
    - Home care

"When I talk to them, you get to feel what their abilities are when you are talking with them. Some people are "I can't do this", "I can't do these". So, for these people, you just have to order home care for them to come in to help them. If they have family members, I ask them is there any family member that can help you. Uh there are a lot of people as I'm talking to them, tell me things that they have looked up on the internet or things that they have already done. So, I get a sense of what their abilities are, just with our discussion. When they are not able or they are facing challenges to do thing on their own, then we order home care. Uh at that point, depending what need to be done If it's needles that they have to do, home care will teach them to do their own needles over time. If it's dressing, well, it's an awkward place, home care has to do, it's just an awkward place".

  - Patient education

"It there's something that they can do on their own, like saline soaks, I teach them everything, I go through with them. I give them written instructions they can read through, listing instructions and how to do it. And I reassess them again, and again, and again, and I keep asking them. If they need reinforcement, then I document that in their chart that they need educational reinforcement, you know every time you see them".

  - Back to hospital

"Sometimes we would have patients brought in from their home, brought in to rapid response clinic from home to have certain treatment done if they are having difficulties, or assess if they are having difficulties, like if there's something they brought up during the telephone that did not make sense, then I would just bring them here and assess them".

Nurse's experience during cancer survivor's transition from oncology team to primary care provider team

- Bridge communication among cancer survivor, oncology team, and primary care provider team

"So, with my experience, I find there's a lot of grayness. The doctor gives, they write letters saying that they have completed their treatment. If their doctor received it, they received it. I have a lot of patients calling saying that their doctors want to know what kind of screen do I need to know, what kind of medication do I need to be on. So, a lot of the communication between primary care givers and us is between the patient, patient goes and see that doctor, and then come back to ask us or phone us. Usually I tell the patient themselves what it is, and explain it to them. Sometimes I would phone the GP or the doctor I'm working with will phone the GP, depending on the situation. Like if the patient is calling us saying that I'm having some serious pain in my leg, and it's not working properly, I'm going to see my GP and see what it is. But I would be concerned that they have a spinal cord compression. I will call the GP right away and say the patient is coming to see you. But if the patient is having a bladder infection or having bad bowl movement, I would not call their GP. I will just tell the patients, go see your GP, tell them what your symptoms are and get your infection of what other symptoms assessed. So, depending on the degree of seriousness of what they are explaining to me, that determines if I'm going to phone the GP or not. It's usually the patient that is communicating between the doctors".

- Patient's advocate

"Yeah, I do, and that's what you are, you are patient's advocate. Whatever the patient is asking you, you are going to ask the doctor. I will tell the doctor what he will understand, and it's the same the other way around. The doctor is going to tell the patient the same thing he tells me, but that would be confusing for the patient because of all those medical terms, and I will re-interpret to patient in an easy to understand manner".

Nurse's experience during cancer survivor's transition from acute cancer treatment to follow-up care

- Promote maximal recovery of body functions
    - Patient education

“I always tell my patients, I want them to exercise while they are on treatment, so that they can recover better after treatment. If they are not being mobile or doing light exercise, like a daily walk, I always want them to do that because they will become deconditioned in time and it would be harder to recover, it would be much harder. Exercise, I will always ask them, because that will help them recover. Besides that, a diet that is balanced, I do encourage them to continue to eat, and not go on any extreme diets right now because that’s not helpful, it messes with your mind too if you go for these things.”.

“So, I also tell them about all the acute side effects they are going to have, and how long the other side effects will take to go away, so they can expect that. So usually they don’t hear from me right at the very beginning, like when they first finish treatment, so when I see them during their follow up, I review these things with them again. So still, they may not remember what we say, so when I see them again after 6 months, I remind them again. So they have the paper, they have the hard copy or everything we say that will happen to them, we talk to them, but we do have to reinforce all the way long, we continue to see them, we continue to see them for 3 to 5 years for follow up. We just reinforcing, and like I said, it usually takes at least 2-3 years for everything to settle down”.

- Resources offered

“We do have physiotherapy program we could refer our patient to, and they would assess their physical condition and give them a 12-week walking program or exercise program according to abilities. So, I always offer that to patients, but if they are going to the gym already, they are not going to need that. So, for a lot of the patients when I offer this program to them, they say “oh nonono, I can walk on my own. I can walk half an hour each day”. That’s fine, I don’t want to put more daily work to them. If they can walk on their own for half an hour per day, that’s fine. So as long as we have that discussion, we don’t need to use this service. Very rarely, I have people that actually take the offer of this service, that’s fine”.

  - Refer to doctors, dietitian, social workers, therapists...

“I refer my patients to dietitian, social workers. We have physiotherapy, message therapy. Physiotherapy would be out or center. Massage therapy, I would refer them to a massage therapy in another cancer center nearby that has so many other programs that we don’t have at our center, they have group therapy, they have wellness programs, I encourage patient to use those ones, the things like feel-better programs. I try to find resources in the community to refer them to. But my time is limited. If there’s something I don’t know where to refer the patients to, I refer them to hearth place cancer center, they have all those programs we don’t have here at the cancer center. So yeah, and other specialties that the doctor feels like the patient may need”.

“We are like the person to go to. Everyone talks to us to arrange, organize, communicate. I could be sitting right next to the doctor, and having social worker come in speaking to me that this patient needs home care, we need to order this for the patient. And then I would turn to the doctor and say doctor, we need to order this and that for this patient and blah blah blah.

  - Work as coordinator

“So, everybody comes to the nurse. Whether there’s a problem with a patient, like the dietitian has seen a patient and they have discovered an issue with nausea that we did not know before. She will send an email to me, as well as the doctor that the patient needs a prescription. So, we are like the center. I will tell my patients that I'm your nurse because the patient often thinks that I'm what doctor's nurse. No no no no, I will tell the patient that I'm your nurse. I don't look after the doctor; I look after you. So, we are like the center, they all phone us, they all email us, so we are like the coordinator".

Experience influencing delivery of cancer care and quality of life

- Positive experiences promoting delivery of cancer care and quality of life
    - Valued experience

"Well, I'm a cancer nurse because of the experience I have with my patients, I have seen what they have gone through. If I figured out how to fix a certain problem, I could use it for my next patients. A lot of what I learned from each and every patient, I bring them forward to other patients and so on and so on. When I start to see a very competitive complain from patients, or when I assess something over and over again, then I say ok we need to do something about this. There is, for instance, a cream I would like to recommend to a lot of my patients. A lot of the patients have never heard of it, so I reached out to the company and asked for samples. I told them I would like samples so I could give them to my patients, so they can try and go buy it. I think it works well".

- Patient's advocate

"I participated in meetings with patient advisors, so basically patient advisors have been patients. They tell us what's been wrong and what should we do about it to make it better. So, I have been to those meetings, and when we plan to develop programs at our cancer center, I give my input on behalf of my patients. They don't know, uh they want a paper telling them what they should do, they want a telephone call after the treatment. I bring all of this to my managers during meetings, and sometime it was heard and it developed into a practice that we should all be doing. Sometimes it does not get heard, or other staff don't value it as much as I do. So, I just have to practice it on my own".

- Barrier inhibiting delivery of cancer care and quality of life
    - Time not enough providing cancer care

"There's lots. The one thing is simply time. We have so many patients, and I have an eight-hour shift, so I have to divide that time for each patient. So, I found that it was one of the barriers is that the time I was given to look after each patient. And that's unfortunate. And I think in some way it's also the resources. If we have more staff, I might be able to have more time with each patient. So that unfortunate".

"I'm in an out-patient department, a lot of the appointments are 10-minute appointment. That means, we are weighing the patient, we are doing their vital signs, we are assessing their ESAS information they put in, I'm checking all their medications, I'm asking all their symptoms and how they are feeling, and I have to respond to them, like say for instance, they don't know how to use their puffers properly, and I have to teach them how to use their puffers. You can't do all that in 10 minutes, you can't. And those are very simple appointments, and for someone that has jaundice, other complicated conditions, it's going to take way more than 10 minutes to address this patient's needs. So, uh we are not given enough time".

- Shortage of staff

"There's other barriers as well. Like the patients themselves might feel intimidated, some of the patient's own emotional behavior as well or something like that can be big time barriers. And to develop a relationship with that patient is really important to provide good care for that patient. I want to see the same patient over and over and over again, I don’t want to be switched around because I don’t have the same relationship with me, they are not as open with me, so you are not able to give them the same care. And I noticed when I phone nurses in the inpatient unit, that’s the first thing so many nurses say to me, they haven’t been with this patient or this is their first day with this patient, so they haven’t built up that relationship. Once you have that relationship, you know, you understand the look on their face, you understand what they are saying to you, you know what they like what they dislike. You have the relationship with them; therefore, you can provide better care for them, you know what their needs their wants are. So once again that is the staff issue. When we don’t have that many staff, we have to spread over and look after other patients that we do not have a relationship”.

“I think there’s room for improvement and I think we really need to. I have all kinds of ideas that I told my managers. However, there’s a lot of the staff that think that other disciplines will address this, will address that, so when they finish their little 10-minutes appointment, they will be referred to all different people that should address these issues as well. Uh in some cases, that work perfectly fine. For special people, it doesn’t, they need more care”.

- Finance barriers

“Transportation is a huge barrier. It depends whether the patient has money or where do the patients live. We cover a huge area, so when people find out that they need to come here for their treatment, sometimes they just can’t do that. They can’t come every day for radiation. They just can’t drive, it’s too harsh. We do have a hotel that they can stay at, and I go through with them what is it like to stay there. But a lot of people don’t want to do that, they feel they are too distracted from their life. They want to stay at home they want to be with their pets, their family in their comfortable bed. So, transportation is a big deal. They might be not well enough to drive, it might be too far to drive, so sometimes they just choose not to get treatment, or they choose to get treatment not in a timely manner”.

“And finances, that can be a big deal too. People don’t have the money to buy medication that help with their eating or swallowing. And there are patients that live on food banks, and now we are giving them advice on what they should be eating, drinking and consuming, but they are using food banks, they get what they get. And sometimes we have patients that are homeless, and they just usually find a friend’s couch to sleep with. So, in that case, they can’t afford cream, they can’t afford medication, and there’s barriers with that as well. You know, money is a big deal”.

- Culture and language barriers

“I found there’s cultural barriers. It does drive me crazy. The one that drives me nuts is when family member says they don’t know they have cancer. Don’t tell them, if there’s anything, tell me. Don’t use that word. And I’m like, this is their life. Surely, they know there’s something wrong, and who are you to make that decision for them? So, I do find that often is a cultural thing. There are certain people that comes from the world, there are people that really focus on that. And there are other cultural, I don’t if they are barriers per se, we just have to all understand and get through that. It happens when a patient really can’t understand treatment anymore, but the family feels like they need to have more treatment, but it’s the treatment itself that is too harsh. So that’s when, I found sometimes, there’s a cultural barrier”.

  - Substance abuse

“Substance use is a big one. Patients that are alcoholic, they drink while they are having treatment, so they don’t remember the stuff we told them to do. So right away, the treatment we are giving them, the alcohol is interfering with that. And not only that, the things we told them to do when they get home, they are doing any of that as well, so I found substance use is a big barrier as well”.

Suggestions and recommendations to improve delivery of cancer care and quality of life

- One primary nurse to be with cancer survivors through their entire journey

“So as far as nursing goes, I would like to see a nurse to be with the patient through the entire journey. Rather than right now, I feel very fragmented. You go to this doctor; this doctor has a nurse. You go to that doctor, that doctor has a nurse, you go to this center, you meet a different nurse, you have home care, you have a different case manager. I feel it’s very fragmented for the patient. When I hear them talking about, they have a case manager with home care, but they have to deal with this company, that company, and then when they come to the cancer center, they have more than one primary nurse, and they have a nurse navigator. When they are diagnosed with cancer, they should get a nurse, and that should be nurse for them through the entire journey. That’s their primary nurse. Of course, there will be other nurses, cancer centers, inpatient unit, outpatient unit, there will be other people and other nurses. But there should be one nurse that ensure that builds up the relationship with the patient. They need one person that understands their needs and understands the system at the same time. It’s good to have one nurse that can do the whole thing. With that said, I kind of understand why we have multiple people. We all have our strength and weaknesses along the way. But I feel like it would be a good thing to do, to have that one nurse whose always in connection with the patient. They don’t have to see the nurse every time they go to the cancer center. They can phone them; they can do a lot over the telephone with the patient. But I would like to see that”.

- **Cancer care coordinator**

“I feel right now, there isn’t a coordinator. And I feel like the nurse is the best one, because we have our knowledge about the hospitals, and we have the education about their physical needs, their emotional needs and their disease as well. If it’s non-medical personnel, like an administrator or some sort, I think there would be things that would be messed. I think the nurses do put the patients first, we don’t put money first, we don’t care about what the money are, we just care about the patients’ needs. That’s why I think the nurse is the best person to do that”.

- **Improve knowledge, skill and experience**

“I would advise every nurse to take oncology courses and I think all nurses should try to do every part of the oncology program. So, I think they should have the experience in diagnostic assessment, they should have the experience of patients doing systemic treatment, they should definitely work in palliative care. I feel like the nurse should have the experience of the oncology nurse in all parts of the oncology journey to be the best oncology nurse they can be”.

K2. Nurse Participant (N2) Narrative

<u>Nurse Participant (N2) Narrative</u>

Nurse's experience for cancer survivor's physical concerns and cancer care provided during treatment transition

- Low energy

"Their energy level is going to be lower perhaps, their lung function might not be as good, and just that constant fear that the symptoms will return, the cancer will return. So that, it talks about all of that".

"Patients are mostly concerned about their lungs, their respiratory parts, their energy levels, making sure that they are breezing ok, there are some issues with that, because during chemotherapy, toxicity really affects the lungs. So those are the things I really look for. Also, their oxygen, their energy level, need to make sure their blood work is ok. It's just, it's really just little things. And as time progresses, those gets better hopefully? If they don't get better, then we talk about what else that needs to be done".

- Patient education

"So right after chemotherapy, what we give all the patients is what that says life after cancer, which describes some feelings or symptoms that some patients may experience, after their treatment, so we give them that. We also do follow up appointments, but that's something different. But this resource, the major one we give, is life after cancer, it talks about not being able to do what they used to do before treatment, because they still have the side effects from the treatment for quite a long time, well not quite long, but sometime after. And also, the feeling, it talks about the feeling of not being monitored constantly with all the doctor appointments and it frightens the patients because they feel like they are on their own. So, there’s that side. Just trying to learn what a new normal is going to be. So, what they were like before the treatment is not going to be the same”.

- Resources offered

“If there’s a specific symptom they want, we do have pamphlets as well. It’s mostly just a lot of pamphlets and booklets that we give and of course when they come up with a follow up appointment, we talk about those. And also, there are phone calls too, to clarify, they are free to call anytime”.

Nurse’s experience for cancer survivor’s emotional concerns and cancer care provided during treatment transition

- Fear of recurrence

“From all the patients I have seen that are not coming back, cancer reoccurrence is on the back of their mind. A cold “oh no, does that mean I have cancer again.” It’s like having post-traumatic stress, they never forget, every little thing is very scary because they are always afraid that they are going to come back to cancer again”.

- Became angry and upset

“Sometimes they are very upset, they are very sad, it’s not fair, and they get angry, and you need to be able to help them understand that life is not all this fair”.

- Survivor’s guilt

“They feel a little guilty, because they feel that they have already opposed that on the family, and since cancer might return, they have to oppose that again”.

- Resources offered

“The emotional part is the huge part. I think it’s just as important as the physical part. With the emotional adjustment, there’s a lot of talking. There’s a place called the hearth place in Oshawa, and you are able to go, they have a lot of classes. And you can meet peers that have gone through the same thing, is currently going through the same thing, or will be going through the same thing. So, they get to be in a group of people that understand what they are going through. Because as nurse, I have seen, but I have not experienced. So, I can say things, but that does not have the same meaning as someone that have gone through it. So, hearth place is a wonderful resource that we recommend to a lot of people. And they have workshops on relationships, on going back to whatever your normal is, on perhaps returning to work. So that’s the major resource. And again, it’s the follow up appointments, it’s the talking until the patient is comfortable leaving. It’s like they have a little burden or nest or something. They are not comfortable yet, they are not comfortable yet, and then, both the patient and the nurse know, it’s time to move on”.

Nurse’s experience for cancer survivor’s social concerns and cancer care provided during treatment transition

- Label of cancer survivors

“I don’t know if I like the term cancer survivor, because there are people that haven’t survived the cancer, they are in remission, or that they will never be totally cancer free. And it’s just as important to try to help those individuals to get back to normal. So, cancer survivors, I guess, I guess that’s what they are. I don’t know what other words to use, yeah a cancer survivor, I don’t know what else to use”.

- Return to work

“Everyone has their own little things. For some people, what is really important to get back to is their jobs, so their job kind of identify what they are at times. So just talk to them about what steps need to be taken to reach that goal, perhaps going back to work”.

- Return to new normal life
    - New normal life

“We want everybody to return to their normal life. We are encouraging that because that’s a major sign that everything is ok. People want to be ok. If they can’t go back to their normal life, then something is wrong with them, and there’s some fault and they are afraid that they will never be able to be what they were before. And so, if they can, that’s wonderful, it’s also teaching them, if they can’t reach that level they were at before, that’s ok too, there a new normal, a new way of doing things. It would just be a different way, but that would be ok, they would be ok. But it takes time, it takes time for any change and any acceptance. I have experienced and they are still having the side effect, and they are still trying to deal with that part. It’s a step by step. So once when all the side effects are gone, then it’s the trying to get back to normal”.

-
    - Resources offered

“It’s the hearth place I would suggest because they have a very good program on how to get back to normal life. With me, it’s just talking to them, wondering what their goals are, seeing what if those goals, talking to them to see if those goals are achievable, if they are realistic. Because sometimes, if it’s affecting their lungs, and they want to be a marathon runner, it’s not possible. Perhaps, it could, but the chances are. So, you have to work a little harder on it”.

  - Education

"I just talk to them, talk to them and ask what they want to do, whether its achievable, whether it's realistic, just talk to them about, well I don't have a lot of time when I'm talking to them, so yeah, it's just a lot of talking, a lot of hearth place, it's just emotional support at this point that they need, it's the encouragement".

- Meaning of survivorship
  - Shift of family job

"You can see, from what I have spoken with the patient, there was a shift whereas, a wife had cancer, she was the strong one and she was the one that managed things, and there's a whole shift of jobs in which the husband now needs to be the strong one, to look after things. And there's a little bit of transition there. But uh, there's the support there. There's a little bit of anger in the beginning, where the spouse that was in control and had everything in control now has the cancer, and she has to let that go, and that's the hardest part. But otherwise, the family has always been very supportive, which is very nice".

  - Support

"They do get a lot of support, majority of them do. But there are a lot that are on their own, there are a lot of older population that their spouse has passed away, so they are on their own really. So, support is hard to find at times. But those that do have support, it's a little easier. From what I have seen, family members have always been very supportive of the patients".

Nurse's experience during cancer survivor's transition from acute care hospital to home

- Promote self-care management
    - Home care

"Umm, mostly this is a home care thing that I'm thinking about. So, they would tell me what type that they need as home care. For self-care management, it would be having homecare referred to them, so they could go into their home and assess what need to be done. But this would have happened before they become a cancer survivor. Yeah, I don't know. That's all I can think of for that question.

"When they are in the hospital, when they are discharged, there's usually a discharge coordinator that will talk to the patient and the family and talk to them about what are some of the needs of the homes are. For self-care, they will talk about getting the home care and all of that stuff organized, so when they get home, that would be looked after. In regards to when the next appointments are and medications, so if you are with a certain doctor, and you will be if you are a cancer survivor, there would a scheduler that will call the patients and tell them when the next appointments are. The patients are much welcomed to call the primary nurses and leave a message and the nurses will call back within 24 hours to help and kind of see what else need to be put in place. So, if it's anything that we can do, but there's the discharge transition people that would look after the home care part".

- Follow-up appointment

"They have appointments to come every so often, so they will have that, and there's also another appointment to come say 2 weeks after their discharge, they come back, they do their blood work, and we talk. After that, whether it's 2 weeks or whatever the protocol it I to bring them back, they come back every 2 weeks, every month, every 3 months, and we just monitor them for quite a long time, until we know that they are ok. If they are discharged, they are at home, after 2 weeks, we see them, and if they are like you know what, self-care is too hard, I can't make any dinner for myself, I'm just so exhausted and I don't know what to do. Then we would refer home care to go there and see why can't they do it, what's needed. Perhaps they need someone to come to their home to make meals, perhaps they need meals on wheels, perhaps, who knows. So, we would help, like we would push to the right direction, which is home care".

Nurse's experience during cancer survivor's transition from oncology team to primary care provider team

"Because as soon as their acute treatment is done, they are aware of it, but they still have their next appointment to see the doctor as a follow up. From my experience, it's seamless, it's, yeah. I have not noticed any barriers; I have not noticed any confusion".

Nurse's experience during cancer survivor's transition from acute cancer treatment to follow-up care

- Promote maximal recovery of body functions

"What I encourage them all the time is just to be active. Don't sit too long, do more exercise, even if it's just walking around the block, walking around the mall, just doing what they think normal would usually be. And in time, hope that it would improve. It they sit, nothing will get fixed. All the side effects will not be fixed. The nausea will get worse, the constipation will get worse, everything will get worse. But if they get your body moving, the heart start to pump and the blood start to move, and then they are just feeling better, they are getting stronger, lying around is not going to make them stronger. Being active, again even if it's just going to a walk in the mall. Or join a gym, so they can do minor gym thing, whatever it is, but just try to constantly get their body moving".

Experience influencing delivery of cancer care and quality of life

- Positive experiences promoting delivery of cancer care and quality of life
    - Core value-Caring for cancer survivors

"I get very attached to my patients whether I have met them one day or years. I mean they are living beings; I want them to be happy, I want them to be able to achieve their goals, I want them to be well, I want them to, you know, it's like an internal motherly instinct you know? Like when you go "okok, is this ok, is that ok, is this what you need".

- Healthcare team

"Social worker goes into this as well, you can talk about the social workers who provide the extra support. If it has to do with employment and other stuff, they usually have all the papers for it. Unemployment or disability so they look at all the little things in order to be able to afford food or whatever. So of course, you talk with the social workers, you talk with the pharmacists because if you don't have private insurance, some medications are not covered so they find ways to subsidize that medication so it's more affordable. Uh, the volunteers are amazing. The drivers, I think you have to pay 100 dollars to the home a year and you have to call a few days in advance so they can bring you to your appointments and bring you home, so that's all wonderful. I mean there are so many, so many programs and uh, things that are available to patients that they are not aware of that I wish they would be. Again, when we give out the books for care after treatment after chemo, at the back there are a lot of ads for everything that are available, but nobody really looks at them".

  - Family support

"From a budgetary point of view, having the family looking after you so you don't have to have home care come over, well then that's their happy. The hospital would be happy because they don't have to worry about that. Well, it's great that the family would look after that, but not all families can, and I don't think it's right to assume all families can".

  - Resources are helpful but not enough

"I would like that there could be more resources that we could use, uh, I'm happy with what there is, I like the hearth place, I like the home care, and all that stuff. But there are a lot of people that fall through the cracks, there are a lot of people that could not go to hearth place, there are a lot of people that could not get home care because, I don't know, maybe they don't really understand it, maybe they don't really know about it. So, there's good things, I would like there to be more resources, but many of them wasn't there or the resources, depending on where they live, like the patients that live up in the north, it is not feasible for them to drive all the way to Oshawa. So, it would be nice for them to have a meeting place up there. So, what we have is good, but there should be more".

- Barrier inhibiting delivery of cancer care and quality of life
  - Transportation

"It's like, sometimes transportation inhibits it."

  - Culture, religion and language barriers

"Language barriers inhibits it because you don't perhaps not understand what the needs are the patients are asking. And at time I might not understand because culture is a big barrier. For some cultures, family looks after themselves, so “don’t give me home care, my family will look after me”, which puts a big burden on the family, and then you have other issues., in fact all factors would be a barrier, yeah. Culture is a big one, religion is as well. There are people that does not want the blood transfusion thing. Many years ago, I had a patient who is almost dying because he wasn’t getting any blood”.

  - Socioeconomic status

“Uh barriers like monetary So you have to face, the socioeconomic. If you are wealthier, well not wealthier but when you have more means, it is easier to buy all the boost you need because you need meal replacements and those can be expensive. So, if you are wealthier, you can purchase these little snacks and boosts and stuffs. But if you are not, well then you can’t really afford, and you are not going to be as able to look after yourself. So, there are all sorts of barriers they have to end. Again, hope the transition from discharge would hopefully help a little bit. And with them coming and talking to the nurses or calling them could help them a little bit. But that really depends on what they allow us to do”.

  - Limited time providing cancer care

“The time that, there’s actually no time to sit with every person and say “so you know you have this issue, you have this issue and you have this issue, there are all the things that are available to you”. You can go like “nice meeting you, here’s all your issue, and here’s some information you can look at” and not everybody is gonna look at that because they are not all gonna understand what it means”.

“Well it’s a huge factor. It’s a huge factor, you don’t have any time, most you do is through pills, well not throwing pills, but handing over pills and hope you will feel well and just leave them. In the chemo suite, it was constant, and you can't really talk to them as much as you would like to. And as where I'm at now, there's even less time to talk to people. So, you can't really get all the information to actually look after every issue they have or every need they have. There's no time, I have to see a patient every 10 minutes, and sometimes there's 2 people in that 10-minute slot they have given me, so there's like 25 people from 9 to 12. It's hard, it's frustrating. You want the patient to know that you care and you are listening, but there's very little time, and it's just keep adding more and more. It's frustrating, but again they can call, but again it's frustrating, and it does affect patient care big time".

Suggestions and recommendations to improve delivery of cancer care and quality of life

- Increasing the number of nurses…

"Oh, in a perfect world, there would be more nurses, less management and more nurses hahahaha. Uh in a perfect world, there would be more nurses, things would be less expensive. It's not gonna happen, I don't think it could ever happen, I don't know what to tell you. More nurses would be great, more doctors would be great, uh more facilities to help people would be great, uh it's just more of everything, less cancer would be wonderful. Just finding cures for different type of cancer would alleviate all of the other issues. So, I mean, access, access to get whatever needs you have is wonderful, but I mean, it's not gonna happen".

"Having more nurses, so you can kind of spread that, so you have less patients, so therefore more time to look after the needs. Having a coordinator telling the nurse who are already booked, not only they have to do all that, now I also want you to look into this thing to make this patient's life a little bit better at home, that's a lot of stress on the nurse herself. That's not realistic, and that's what's happening all the time. Like "here, you can do more, do more" and you can't. and its' the same one that when the nurses have all the workloads on them, and then of course they go the others, the doctors, the social workers, and they having the same heavy workload, that's when things fall through the crack, so giving me a coordinator that tells me I need to do more things is not going to be helpful. Give me a nurse that can kind of take one or two patients from me so I can do what I'm supposed to do works a little bit better".

"We need more nurses; we don't need more management. We don't need more people telling us what we need to do. We know what we need to do, we just need more people in order to do it".

"I'm thinking the doctors would say the same thing. They need more doctors in order to provide a more quality of care because they are constantly working harder. And social workers would say the same thing. We need more social workers in order to provide a more quality care. You just need more of the right type of workers, and less of the managerial individuals. It's great to have managers, I have nothing against them, but getting more of them is not helping me being able to do my job. Having somebody getting hired so that they can tell me how I can better use my time is not very helpful. How about you use that money for more nurses, more healthcare, more anything else. But don't come in and tell me how I can do my job better when you are not a nurse, you don't know what you are taking about, you don't know the ins and outs. Just more right type of the workers, whether be nurses, social workers, home care, doctors, with me, it doesn't matter, just more".

K3. Nurse Participant (N3) Narrative

Nurse Participant (N3) Narrative

Nurse's experience for cancer survivor's physical concerns and cancer care provided during treatment transition

- Tiredness and cancer care

"I work mainly in radiation, a lot of people say that they feel tired, and, then I just recommend to them, I just make sure are you getting a good diet, are you eating sufficient meal, are you eating good quality meals, are you getting enough fluids. And I always tell them, paradoxically, if you work your body with exercise and all that, you actually feel better. Because sometimes, when they are feeling so unwell, during their treatment, the physical activity goes down right? And they call and say I'm still feeling very tired. So, I always tell them try diet, fluids, exercise gradually, and see if that helps you. If not, then yeah definitely call us back because you probably need to be assessed, you need blood work checked. So, the fatigue".

- Peripheral neuropathy and cancer care

"People complain of peripheral sensory neuropathy, the numbness and the tingling they feel in their hands and their feet. And unfortunately, with that one, there isn't a whole lot that could be done, like in terms of giving them a prescription or something like that. That's just, the, the tingling goes away when it goes away. The feeling sensation just comes back when it does. But I always try to give the patients hope. I know I have talked to a lot of patient that it has been going on for years and it still feels like fire in my fingers after years. Uh, but I have talked to a lot of people for whom it got better as well. So, when they are complaining about it, I just make sure the circulation is ok. When the circulation is ok, I say I know it’s uncomfortable and unpleasant, but you know, this will likely get better with time. I can’t offer much more than that. There is no prescription to deal with that, but hopefully, it will get better with time. And I just say, if it gets much worse, make sure to call us back, or see the family doctor, or go to the emergency, because after your treatment is all done, and it’s a long time after your treatment, it shouldn’t get more tingling, more numbness. Then I say, then you have to make sure that you get checked by a doctor. But for the tingling, I just say that make sure the circulation is good, make sure that you are moving your body and your limbs, and keeping a good diet, and as long as you are ok with your family doctor, make sure that your hemoglobin level is good, you have good blood volume, and good circulation and all that. Cause otherwise, there’s not much you can do with neuropathy.

- Chemo brain and cancer care

“After chemo, people complain about the brain fog, uh, and same thing I tell them that, this will likely lift with time because for most people, it does. And then it’s the same recommendation, make sure you are eating well, make sure that you are resting well. If you are not resting well enough, if you need a prescription to help with sleep, and then I say, drink your fluids and exercise and all that, which will improve your sleeping when you rest, and hope it will translate into improved focus during the day to combat the brain fog. But you know what I tell them if you feel like your cognitive decline if really declining, or your losing consciousness or something like that, you need to see the doctor.

“So, brain fog, uh, peripheral sensory neuropathy, and fatigue are usually the lasting ones. Any other symptoms are shorter term, and depends on what was treated, usually”.

- Patient education and resources offered

“We usually try to let them know in advance about those symptoms that they might experience down the road. So, we have physical paper handouts. Umm, we also have little information booklets, and I believe somewhere in the booklets it says that it lists some of the symptoms they might experience. For example, muscle loss or something, but uh, declined muscle strength, uh because of the, fatigue, decreased activities or something. So physical handouts, we have a booklet. Uh, and also, the nurses would go over the booklet with the patients in conversation. This is what I do, I believe most of the nurses would do as well, uh but everyone’s practice is different. And a big reason for that is that we don’t want them to experience the side effects after the treatment and think that something has gone wrong. So, we usually tell them you might experience, uh, this, this and this. I work a lot in radiation, so, for example, we usually tell them radiation associated side effects, you can often expect them to last at least 2 weeks after, so don’t be surprised they continue after treatment stops, but also, they get a little worse. But usually after 2 weeks, 2 and a half weeks, they will turn a corner, and you will notice that you get better”.

“We know what symptoms or side effects we are looking for; we might hear back from the patients about. So, we usually tell them to, for example, they are getting lung treatment, the esophagus might be affected, you might find that it become painful to swallow, it might be difficult to swallow. So, if you notice this, please call us back and then we can prescribe for you a medicated rinse to help with swallowing. Or you might find that the pain might increase, so call us and we can give you prescription for pain meds or more pain meds”.

- Refer to doctor

“We usually just inform the doctor, because we work, uh, we often work with the same doctor who treat the same sites”.

Nurse’s experience for cancer survivor’s emotional concerns and cancer care provided during treatment transition

- Anxiety

“I think the concern is, a lot of patient have when they finish the acute treatment, you know when they are coming very regularly for their treatment. But after the last treatment, there were nothing. No more, or it’s not as frequent appointment. So they will feel a little bit anxious. they don’t know what. They don’t know if they will be ok on their own”.

- Patient education

“So, the DRCC here have an after-cancer group teaching session, where they come in like a classroom setting, there’s a lot of people, and they tell them about general symptoms they can have, they can expect to last. Some at least moderately lasting. Side effects like fatigue, pain, or uh whatever. So, they bring them in, just so that they don’t feel like everything just stops very abruptly. The only unfortunate part of that is they patients are often too excited to be done with their treatment that they don’t want to come back to the hospital. I have had a lot of people climb to come back. Uh, I, I always remind the patients that we have social worker in the cancer center. Like before they finished their treatment, they have the doctor’s contact information, and I just say that if at any point you are not copping, if you have questions you can call myself or the doctor, medical related questions. But if you are not coping, or you just want to talk about something, this is also, it is available for you, the patient, but also if you have care givers, or you have problems at home, something that affect your survival, you can also call the social workers too, or you can call me if you are not already connected with a social worker, I will make sure that a social worker will contact you. So, as I always say, you can call anyone in the cancer center at any time".

- Follow-up care plan

"I think our hospital and our cancer center is better for this. So this complain I hear is more related to other hospitals, other cancer centers, and that is that uh, the follow up plan is not clear, like uh you know like, when are my follow ups, I haven't heard, do I need follow up imaging, do I need a CT or a mammogram, how often do I need them. So, after the treatment finishes, I have heard a lot from other hospitals, just everything stops. And like, maybe they will get a one year follow up, and even then, it's not really, it's not clear that they are going to be followed after the treatment stopped. They are always wondering that, uh, because they are also not told either way. Like our policy, like, ok, there's not explicit statement, ok, our policy, not that you had your breast treatment, we do a 6 month follow up for 2 years, and it starts in one year, and you will get a CT every year or a mammogram every year, and we will schedule that. It's just, there's no, communication stops, they are left to wonder, I'm coming up to a year, and I have not been called to a CT or a mammogram yet, does that mean I don't need one? Or does someone forget? They don't know. Here, it seems to be a lot better. Like I haven't had many patients contact me confused about what was going on, and also when I do, I'm part time and I work with a lot of doctors, when I do my research and when I read the doctor's notes, it's usually very clear that it says like this patient was well today and they finished their treatment at this time, next follow up should occur after 3 months, at this time, the patient should have blood work, they will have a CT done, it's very clear. So, and then they put those orders in, and it triggers the scheduling department to schedule the patient and they get contacted, so, uh, for their appointment. So yeah, it seems like our hospital seems to do that a little better, there's a clearer follow up plan and the communication of that follow up plan to the patients. And like what I said, I have heard else that the patents say I just don't know, and it adds to the anxiety, right, of their survival. Yeah, because it's like, you know, have my cancer come back? I don't know, I haven't had a CT in 2 years, is that appropriate? And there's also the concern of, uh, hearing back from either the doctor or the nurses from the other hospital. Here at our hospital, our policy is that we aim as least a call back within 24 hours. Um, so because of that, patients can count on getting an answer anyway. If the patient ask that I haven't had a CT in 6 months, is that ok? We will at least call them back and say, there's no CT schedules because you don't need one. That's why we did not schedule one. So, you don't need one, not to worry about it. Whereas I heard other people you know they say I called, and like is that right? Am I supposed to have one? And they don't get a call back at least saying no. cause the answer is no, and they don't call to let you know. But they don't call to let you know it's that way.

Nurse's experience for cancer survivor's social concerns and cancer care provided during treatment transition

- Label of cancer survivors

"So, I personally don't like it. I'm fine with however people want to identity. So, when they say it, I certainly will not try to diminish it. So, I say ok, good".

"I think it's a weird expression. Because I don't necessarily view it as uh, well it depends on the individual circumstances. But in a lot of cases, it's not an acute upfront to health. So, for example, like uh, some people come to the center sometimes they have diseases for a while. And they ignored it, or they denied it, or they, you know they did not seek assistance. I actually met someone the other day who says she had, I think, mass for over a year that she hides from her family. So, when she finally came to us, the tumor is much larger. However, there's still not imminent risk of death, and had she come when she first noticed it, the risk of death or emergency happening, would have been even lower is she haven't come a year later. So, when I hear survive, I'm usually thinking like surviving something catastrophic, like death. Uh, so, but I understand a lot of people feel empowered by that, they are excited by, you know, avoided this imminent death. I'm a bit concerned about that, because the reason why I wanted to get into oncology was because there was a lot of fear around cancer, so I would like to work in cancer and try to decrease some people's fear. So, when I think, when I hear cancer survivor, the people were thinking that I could have died, but now I got treatment and I'm alive, I didn't die. You know, as long as they are happy, I would leave them with that. But I think it there was too much stress, it would leave them thinking that cancer was this monster that they survived".

- Return to new normal life

"I hear it being said a lot. I mean, I always try to think of it in terms of, or help the patients to think of it in terms of, again, how they can prioritize themselves. Because even people who think they are eating a good diet or they are physically active enough, the potential is that maybe they weren't. We don't really know what brought on the cancer, caused the cancer, but I think it’s related to my personal believe, it is usually the stress. Stress plays a big part, diet plays whatever part that it does, stress and happiness and all that. So, I usually tell them that after everything is done, our objective here, so we are pretty confident, when we do scans and all that, there’s nothing we can see. You had chemo, you had radiation, and you had surgery, we are pretty confident that we get it out of there. But if you strip down cancer to the most basic level, it’s just cells that grew and they did not clear as they were supposed to. Whatever event that caused it to go in this disordered fashion. So, I always say that, I don’t think of it as the diseases that is imminent to come back, but I’m like, really what is blocking that process of happening again. I know we removed the cells, but what’s to say if this cell over don’t just start to grew, all of a sudden, in a disordered fashion. So, what I always tell them I believe that it is stress will cause that, cigarettes will cause that, ummm drinking in excess will cause that, bad foods, who knows how much it causes that. But I’m just thinking, you know, remember to prioritize yourself, and try to not promote the disordered growth in your body. You got to keep your body balanced, you got to keep it happy and loose and stress-free, so uh, if we were talking about this concept of normal for a cancer patient versus someone who didn’t have cancer or who didn’t have treatment, well, you got that wake up call, something triggered this disordered growth in your body, we don’t know what it was, but maybe we could look at it as a wake-up call that try to balance things out, maybe your work was very stressful. That doesn’t mean to quit your job, but that means how are we gonna figure out try to bring the stress level down. Whether we take little breaks during the day, take little walks, uh, have 5 minutes where you just close your eyes or meditate or something like that. I just, I usually see cancer as a way, like as a kind of signal to people to prioritize themselves and their health and well-being. So that’s their new normal, it’s not like they are going to always on guard because this disease is going to come back. It’s no. It’s really just anything could be triggered at any point. For you, it manifested as a tumor, and we have cleared that, but remember don’t let that tumor or some other tumor come back, you have to, yeah”.

- Return to work

“Ummm. No, I haven’t really encountered that, yeah”.

- Meaning of survivorship
    - Focus on health and prioritize yourselves

“So, the meaning, I, I always just tell people now so, when you are doing your treatment, as much as you can, and it’s often, I found it different for parent, but really any individual, especially during treatment time, this is your time, you should really focus on you and your physical health. But even after your treatment, the physical and your emotional health. But even after treatment, remember that, you know, you should consider yourself more in your life. Yourself and your well-being, because I always say to them that, I believe that, lowering your stress as much as you can will do a lot for your survival. Your so-called survival. Being as happy in your life as you can will do a lot for your survival. To ensure that you don’t have a re-occurrence or to extend the time for a re-occurrence. Ummm, so the meaning, like uh, I just try to tell people to prioritize themselves in their life. Because likely, most people are very giving and concerning about others, I say that I’m willing to bet, before you discovered this, you are probably doing a lot for other people. And of course, that’s important when you have responsibilities, you have your job your kids and all that. But find some way, some time, to prioritize yourself, with things you love that makes you happy. If the responsibilities you have are a lot and they make you stressful, then try to find a little bit of time to lower your stress down. That's all good for you. So, be healthy, stay alive, extend your life for your kids, and the way you are going to do that is by prioritizing yourself. That sounds weird, but you know, if you take more for yourself, you will have more left".

Nurse's experience during cancer survivor's transition from acute care hospital to home

- Promote self-care management
    - Education and resources offered

"I think there's a lot on the internet, and it largely it depends on what the patient likes. I usually tell people that, if you have, because often people discover, they do a lot of research and they discover new activities, new foods, new diets, new supplements or something while they are going through treatment because they are looking for anything right? So then I'm like so if there's anything that you learned about, umm that you like, that you enjoyed that you want to keep going, then yeah, there's a lot of, uh, let's say like they took up meditation, there's tons of internet resources on direction, on instructions on how to do those things. Uh, I haven't had the opportunity to do it, I guess if someone ask me, I would just refer them to the internet, may be not the specific site or anything, but if they said, what's good, uh, exercises to promote circulation, I would be, just to check out, just google it. Not in a dismissive way, but they will be able to find out, they would be able to find things they specifically like, where as I could only tell them.

Nurse's experience during cancer survivor's transition from oncology team to primary care provider team

- No physical meeting among cancer survivors, oncology team, and primary care provider's team

"There's no physical meeting. It is usually like if the person is ok, yeah, like, you will be returning to your family doctor for care. And when the doctor dictates that note, that of the meeting they have with patient, then the copy is sent to the family doctor, and the doctor knows what kind of care".

"Ummm. I think they copy or they say, when they dictate their notes, send it to family doctor".

- Bridge communication among cancer survivor, oncology team, and primary care provider team

"Yeah, so if it's very soon after treatment, and it is clear that it is treatment related, then we would like the oncology doctor know and they might bring them back for a follow up. If it was separated by a significant time, for example, if somebody got radiation, uh, and their symptoms is getting worse, we would tell the doctor. And say if their symptoms are getting better and 6 months after, they are having trouble swallowing again. We usually make sure that there's no emergency like, swallowing like, it's closing off your breathing or something like that, then you would need to go to emergency. But say they did have throat treatment, but then 6 months later, then they developed diarrhea, then we say you need to see your family doctor about that, because we treated your throat, it shouldn't affect your vowels".

Nurse's experience during cancer survivor's transition from acute cancer treatment to follow-up care

- Promote maximal recovery of body functions
  - Patient education

"I will make sure their food intake is good, the food intake is good. And there's minimal to moderate physical activities. We don't want them to get progressively weaker, we don't want their muscle to get weaker. Even though we treated you with what so ever, when you feel comfortable, make sure your activities level goes back to your normal, activities among these. Make sure you are getting quality diet, make sure you have your proteins, to keep your muscles strong, sufficient fuel to"

  - Refer to doctors

"If there was a concern about functions, then we would say that refer to your family doctor, go see your family doctor. They are the ones that refer you to physiotherapy. Uh maximal bodily function, it's mainly diets, exercise, and fluids".

Experience influencing delivery of cancer care and quality of life

- Positive experiences promoting delivery of cancer care and quality of life
  - Working environment

"uh, like I think we have a good physical space, the rooms are good size, the hall ways are always kept clean and all that. So, I think it does a lot to have a good physical environment for people to come to, to be checked. So, if it's very tiny, it's very dirty, it's very congested because we are usually busy. If it was just really overwhelming, it might be misfunctioning for the survivors".

- Barrier inhibiting delivery of cancer care and quality of life
    - Time not enough providing cancer care

“I know people say this all the time, but more time to give to the patients. They feel like we are rushing them, because sometimes we do need to push through the appointments faster. If we had more time, we could listen to them more, and talk to them on a more personal level. Whereas sometimes we don’t have time for that, we just need to know physically what is happening, if anything, and we just have to keep on”.

“Mainly is not enough time, or the inability to maximize the time you do have. So, I have been mentioning to a lot of management individuals, like I say ok fine. If we only have like 10 minutes or 15 minutes to spend with the patient, it’s such a waste that during that time we are fumbling because things don’t work. I need to take their blood pressure; the battery keeps dying. In order to keep it working I need to stop and plug it in. Or, uh the computer program, it won’t accept what I’m typing because I didn’t do it in capitals, and it wants it in capitals and I have to erase everything. It’s those little things that I always tell them that time drains. So, if you can’t give me more than 10 minutes, it’s fine. But just make sure in those 10 minutes, I can efficiently work. I feel like we can’t. the room is a good size, but the set-up is weird. It’s just a few seconds here and there, but in a 10-minute window, those wasted seconds could be spend doing anything else. Hmmm, talking with them, or yeah, umm, yeah, being able, like in that 10-minute window, I could direct that time more to the patient, whatever they need. But I’m wasting time, I’m plugging this in, I’m deleting this again, I’m copying it, I’m, ummm, you know, I need uh, they say can I have my blood work, but I’m in a room where there’s no printer, I got to leave them, you know, or they need to go to the bathroom, and I tell them the bathroom is 3 halls that way, umm, I mean, there's only so much we can do with the physical room we have, we have the bathroom we have. It's little things like why it's the room set up so weird it's slowing what I do, or why are these machines, they are either old or mall-functioning, that slows me down, or the computer program is not as ideal as it could be, that slows me down. It's lack of time, or the inability to maximize the time you have because of the other, you know, broken this"

Suggestions and recommendations to improve delivery of cancer care and quality of life

- Need more time with patients

"So then there's the constant frustration from the nurses, and we say we need more time to spend with patient, instead of 10 minute, please give us 15 minute, and I, like I always, and I have said to some management that, like, if we can't have the extra five, just please let us use that 10 efficiently. And we are not, either do that, fix those things, or give us the extra five, because we are wasting time doing the extra stuff".

- Reduce time waste

"So, if you couldn't give us 15 minutes instead of 10 minutes, please make sure the batteries and the, the vital machine, it's a new one, it's not an old one that it will die or the machine will turn off. Or when we are typing things, like when in our documentation program, meditech, why sometimes it allows you to put in lower case letters, but sometimes it won't let you go on unless it's capitals. Why it is all different, why it can't be fixed so that it's all one thing, or no requirement for capitals or lower case or something like this".

- Room layout

“Can we re-visit the lay out of the room, because this really doesn’t make any sense, you know, those were little things that cause little money here and there, and they are not willing to make the investment”.

K4. Patient Participant (P1) Narrative

Patient Participant (P1) Narrative

Patient participant experienced physical concerns and received cancer care during treatment transition

- Lymphedema

"I know the oncology nurses talked about lymphedema that could kick in any time, because I did have lymph nodes removed, and they spoke about putting fingers on the wall to keep the side that had the treatment, for me it was the right side, moving".

- Pain
    - Residual pain was not addressed.

"The hospitals and the doctors, I mean I love the care I got, but they try not to take ownership to anything that happened to you because they don't want to be responsible for it. Because I did have a lot of side effects, my eye sight is a problem, and still to this day. I still have residual pain on my right side that will never go away; it feels like you have been punched, like every day you feel you have been punched on the side. Those type of things, but they don't really want to take ownership for that, they don't want to say oh yeah, this caused this, the chemotherapy caused this or the radiation treatment caused this, they tend not to take ownership for that. They will have to do something about that right?"

- Pain management by medication

"They (nurses) usually just say take a Tylenol or something. I don't usually, I mean that was what I was told to do, but I don't because I don't want to continuously take Tylenol, I just deal with that sort of things".

- Chemo brain

“Because you know chemo right, it’s frying your brains out, you are cooking from the inside out. It’s not a nice feeling. Sometimes I just can’t remember things. You know the term chemo brain? It’s a true thing. Your eye sights are terrible, to read you know”.

Patient participant experienced emotional concerns and received cancer care during treatment transition

- Emotional concerns
    - Confusion about what is next

“You have the big talk thing after your last treatment, and you went home and you are on your own, that’s about it. So that was something that was bothering me that you just went home and they just go congratulations, see you later, because like you are just then sitting at home saying, then what”.

    - Fear of cancer recurrence

“The mind is a very powerful thing in the entire medical field, the mind can play tricks on you, you know, so every little pain, every little things, you start to think on no it’s coming back, you want to run back to the hospital you know. You tend to take things to more extreme; it feels like that now since you have had cancer, then cancer just keep coming back”.

“A lot of my close friends have passed away from cancer, just in this one and a half year, and it kind of hits you hard, it takes you straight back to that place. Every time somebody passed away or get diagnosed, it takes you right back to that place”.

- Survivor’s guilt

“I think it’s survivor’s guilt, I have a lot of cancer coming back to me, even in our group, we lost 3 or 4 people at the hospital, you sit around the table and it almost feel like what’s next, you know. By the way, I love our group, I think it’s great, but you know, I have 2 of my best friends passed away because of cancer, and they are younger than me, and that’s very hard. And another thing that bugs me is that, not that I want everybody to have cancer, but for the people that don’t have cancer, they don’t understand how you feel. It’s very hard to tell them how you feeling or what are you experiencing or having in your mind. You get phrases like “you should be happy that you are alive”. Well I’m not saying that I’m not happy that I’m alive, it’s just that there are other things that comes with that. I think that’s the part that’s the worst, the emotional struggle. People that do not have cancer would not understand, and I understand that, because you know, I would certainly not understand someone with another illness. I would try to be sympathetic, but you can’t be empathetic. When you have been through that, then you can be empathetic”.

“And also, there’s also the thing of survivor’s guilt. I’m alive, I’m still here, but you know I have a cousin that has brain cancer right now, it’s like, ok why her, why not me, why am I still here, why she has so many trouble that she could possibly not be here. I’m just here hoping that she is ok and she I getting treatment, but there’s that issue of she might not be here, so why her not me. So it’s that survivor’s guilt too. There’s a lot of pieces emotionally after treatment, it’s a huge topic I would say”.

- Cancer care received
    - Programs offered (Psychiatrists and the better clinic)

“Well, as a group, I did. We had it set up in a specific are in the oncology department, for mental issues with oncology patients, it’s called the better clinic. If anyone wants to drop by and have a look at it, it would be amazing. It’s especially for when the patient is in bad mood or has a bad day, they can go to this room and visit the psychiatrist in that room to look after that patient. Before this, we have to go down stairs, go through the emergency like everybody else. But now we have this little room, just for us right there. We have put that into place, and it has been running for maybe a year now.

- Education (Transition course)

“So, we now have kind like a transition course, so you can come back”

- Refer to healthcare team

“We have amazing social workers that are always there, you can have an appointment with them, but they are usually quite booked up. So, we have those 2 areas for us that we can access”.

“We are really trying to encourage the social worker aspect. So, people can connect with social workers that are very important. So, they do that, they will have a lot to talk about, because we are experiencing things like, it’s almost like that we are experiencing PTSD. Your cousin, your aunt, your brother, your sister, your mother, you father, it comes in a way you know, suddenly everyone you know is dealing with cancer, or is dying to cancer, so it’s very hard to keep yourself calm and subtle, so it’s very good to connect with social worker because you are going to be like this for a while, and even if you don’t need it now, you will need them in the future. Because I’m kind of dealing with it right now”.

  - Nurse registration

“And the nurse registration is pretty good too. Because we have check ins, and when you check in, there are certain questions on the computer that you have to answer. 2 of those are based on your emotional stability, are you feeling depressed those kinds of questions. The rating is from 1 to 10, so if you say an 8, 9, or 10, there are going to ask you about it. They are going to say, what happening there, do you need to talk to somebody”.

Patient participant experienced social concerns and received cancer care during treatment transition

- Self-identity

“You are not the same person before. You were a person without cancer, and now you are a person that did or does have cancer. It’s a whole different lifestyle now, a whole different mindset.”

“Cancer warrior, I think that would be a term that describes us, yeah, yeah. The more and more I go on, the term survivor doesn’t really stick with me. I know that’s a big thing, and within the whole scheme of things. I like cancer warriors, and I would like they to come up with another name, I do agree with that. Yeah. Cancer warrior would be good”.

- Label of cancer survivors

“At first, I don’t mind it, but I don’t think. You are ever a survivor of that, because there is a constant monkey on your back, because it’s always gonna be, I’m here, I’m here, I’m here, knocking at you. We have 2 friends that passed away and 2 friends that are still here, and we prefer the work warrior, cancer warrior, because we are constantly fighting against it, versus a survivor, because you will never be free of it. Survivor means that it's done, it's over, you are free of it, I would prefer the term warrior or something like that".

- Return to new normal life
    - Whole person changed

"I'm still suffering from the side effects. I can't just hope back in and do everything like you did before, because I wasn't that same person, emotionally, physically, mentally, all those things change. I did a video for the hospital for after care, and I said on the video that your before and after change so much that you need to have a funeral for the before person, because you are gone, that person is gone. You are somebody else once you have gone through that experience. Whether it's good or bad, I can't really label it good or bad, it's just different. You see things differently. It's going back to, if you haven't been through it, you don't understand it".

- Start a new normal life

"Yeah, yeah, you can phrase like that, a new normal life, that's a good way to put it. I'm still having trouble with it".

- Need supports

"I'm not asking people to be like "are you ok, are you ok" all day. I just want them to understand that it's going to be different, and try to help me instead of getting mad at me because I forgot something. Be like "yeah, remember we have to do this?" instead of "you missed a meeting? Where were you?" Instead of people being judgmental, I would rather people be more supportive."

- Adjust to the new normal life

“I think you have to take it day by day. I think the problem is that when I finished my treatment, I put all my energy into making sure my daughter was ok, and I left myself behind, and that’s not a good thing. My daughter right now is pretty self-sufficient. She’s 21, she’s finishing up her university, and she’s living away from home. Uh so the time that I have spent with myself is going to come back to me.”

“I would take one day at a time, that’s for sure. Have that person that you can talk you, you really someone that you can talk to. And the care givers also, because we don’t talk to each other. My daughter and my mother don’t talk to me about me, they talk to other, because it would be too hard, too emotionally attached. The survivor, the warrior needs that person that they can talk to. They have different issues. And the care givers, they need some person to talk to. The social workers, the psychologist, the psychiatrist. They feel the need, you feel the need, everybody feel the need that they need to talk to someone. You can’t spin at home by yourself, because you don’t get the answer you need”.

- Get supports from oncology nurses.

“Yes. They (nurses) have a list of places you can go, people you can see. They have the social workers there. Before UV, you can get a list about how you get harmed with anything in your neighborhood and they can call and make that connection for you. They will make sure you get that connection first before you get started. And sometime work has it too, you know, the work place may have free counseling as well.

- Return to work
    - No understanding

“ It would be great to have some kind of workshop for when you are working in an area where someone is coming back to work from cancer, just have a little bit of more understanding of what that would look like, that would be a good thing, because people don’t know, they just want you to jump right back in, there’s no gradual coming back to work. Because here at HR is either you are coming back full time or you are not coming back. They had no sympathy or understanding for me at all.

-
    - No accommodation plans

“It changes a little bit, when you are away, like I was away for almost 2 years, and my job has a 2 year rotation for students, so all bran new students I have never seen before, well I would like a gradual coming back, but no, it was like coming back full time, you are in or you are out.

-
    - Information and/or resources about return to work

“Nothing at the time, it was just like bye. But we are working on it, and it was getting better”.

- Meanings of survivorship or cancer survivor

“I think the biggest meaning to me is awareness, I want people to know all of the things we talked about, how we are feeling after, how we are feeling during, uh, what things can you help with, I think open communication is the best thing, just letting people know and support. And I think a lot of the times, people forget about the care givers, I’m a big fan of the care givers. Because they are the people behind the scenes, and they are helping the people they love, they tend to get forget about, and for that there’s a lot of emotional attachment to it as far as it goes to, because they felt hopeless. I know my mom and my dad they just don't know what to do, and my daughter was only like 13 at the time, she had a really hard time, because it was a big bomb for her too. It's that whole, I would like the people to become more aware of the care givers too. They tend to get lost in the shuffle, and they need help as well.

Patient participant experienced self-care management transitioning from acute care hospital to home

- Self-care management

"I was hard because I was on my own. And I have a 13-year-old at the time. So, that was hard to manage. My parents loved you help but they lived 3 hours away, so they came to help after I have already got my treatment. And I remember the time I got myself off the couch, it was about a week. But I couldn't drive or do anything like that because my brain was very foggy. So, I relied a lot on uber to come in. Community care would come in but that would be right after just to check on my PICC line and things like that. After my PICC line come out, I suspected that I had a blood clot, so I have to start getting myself needles. I trained my daughter to give me needles because I don't want to do it myself. Eventually I have to learn how to do that. So, a lot of the stuff was done on my own. There was a lot of selfcare on my own. Community care would come in, and they were great, whenever I had that. There were nurses from community care, but a lot of it was done by myself.

Patient participant experienced communication transitioning from oncology team to primary care provider team

- Communication among patient participants, oncology team, and primary care provider team

“See so much has changed with my experience, if I had to talk about my experience only, it was very vague”.

“I know my oncologist from chemo and my oncologist from radiation treatment, I’m sure they talked, but they never talked to me as a group. My radiation oncologist was very fast, it took me within 5 minutes. I come in and do some stuff and that’s it. My chemo oncologist, I saw him quite often, and I saw her a little bit more because they are finding more spots. But when I was released, I didn’t even go see the family doctor, there was no, no connection. All I need to have done; I have done. But other than going into the groups, I have no other connection with the hospital”.

Patient participant experienced recovery of body function transitioning from acute cancer treatment to follow up care

- Recovery of body function
    - Cancer care and/or service obtained to promote recovery of body functions

“No, no. I mean I had community care during it, but after, after there was nothing.

- Education on diet and exercise

“After I finished, you know, someone like, you know, somebody in the fitness area saying maybe you should start to do this, or somebody in the nutrition department saying that now this is the food or this is the diet you should be trying to eating. Because as a cancer patient, you know, we should be having less sugar, and like no alcohol, you know those type of things. I would like to see that versus nothing.

Experience influencing delivery of cancer care and quality of life

- Positive experiences promoting delivery of cancer care and quality of life
  - Talk to someone

“I mean, having someone to talk to? That would have been, it’s helpful. I did not that, I should have, but I didn’t. We can also connect with the social workers that are there, for a period of time”.

  - Diet and exercise

“I mean like I said before having some kind of regimen, like exercise and diet, those kinds of things. I would like to see that, I should have done that as well. I mean I should have pointed the fingers to myself, I should have been.

  - Family supports

“I was so busy with being a mom, I was trying to get my kids through all that, I kind of took the ownership on myself and tried to get her through all these stuff that she kind of all left behind while I was getting better. I have found that I have left her in the background. But I think just trying to get back to routine helped as well, those kinds of things. So, having family around really helped, that’s a big deal. Yeah trying to get back into a normal routine, those type of things, I think are the things you need, just to get back into, you know, from treatment back to daily life”.

“Having family, family was the biggest thing. Having family, family support”.

- Oncology nurses supports

“The oncology nurses have always been very good at looking, I mean you have the time with them before the oncology doctors come in. They are very uh, they ask all the questions. They look at all your answers and make sure that you are ok. And you have more time talking to the nurses than the doctors, because they are usually in and out. But the nurses are always just a phone call away. There’s a special like, there’s a direct line in case you need to call them. When you have a question, they are usually pretty food at answering your question, yeah. I think they have that, you have to be a special kind of person to work in that field, to be the oncology nurse, because uh you see a lot of that stuff, right?

- Healthcare supports

“Social worker. She really helped me. My biggest pet peeve was uh the age of my daughter. So I went to hearth place, trying to get some help for her, but they had little kids, like toddlers, and they had helping your spouse, or whatever, she is like a tween, which is not really a teenager, not really a kid. She was like 12, 13, 4 kind of thing. They didn’t have any services for her. Nothing to help her. So, my social worker took her one. She wasn’t supposed to, she didn’t have to, but she did it anyway. Rachel (her kid) couldn’t come into the chemo area because she was too young. You have to be 18 to come in because it affects your reproductive organs, the cold chemical stuff. So, the door is wide open, I would go through, my mom would go through, buy she had to sit in the waiting area, she doesn’t what was going on behind there. There is this weird kind of place that mom would go in and when she come out, she feels like crap after. She would be in there for 3 hours and she would come out a different person. So, it was kind of like a weird place. I don't know how to describe it, because she's 21 now, and still haven't dived down deep how she felt about that. And that's very said.

"So, this is an interesting thing that happens, that I'm encouraging more hospitals to do. My social worker Kelly got attached to me when I first started. We just chatted briefly, we just introduced ourselves. She would come to my chemo treatments.

"She would just walk through the chemo area, and when she sees me, she knows I would be there because she saw the list right? So, I would be there for 3 hours. So, she would come by and say hey, how you doing, how you feeling. So many people found this stigma that oh you have to talk to somebody, oh you have no idea what are the times that she's going to be right. But she would do it so gradually and get that relationship going, so when you know you do need to talk, she was there and you felt comfortable talking to her. And it was not the first meeting you know? You and I just met today and we would sit down and talk about our feelings and we don't know each other. But my social worker did it like oh, I have seen you before, we talked several times, and now we feel comfortable about each other, and there's an issue I want to talk about. I could just go say, hey, this has been going on, and I'm really upset about it. So that was really good.

- Barrier inhibiting delivery of cancer care and quality of life
    - Financial issue

"Financial was the biggest one, yeah that's a huge one, I lost my house, because I wasn't working, so that's a big problem for me.

-
    - Role strains-Parenting

"Parenting is a big barrier for me, like trying to get your kids stable, and still going to school and make her life as normal as possible".

- Return to work

“Coming back to work was a huge barrier. There are quite a few huge barriers you don’t realize until you had treatment and were trying to be yourself again. Uh yeah, big barriers”.

- Limited time for cancer care

“I know it’s not fair to say because I can’t control it, but it’s just so busy. There so many people that have cancer, and it’s a huge cost for treatment, and you just don’t feel like you have enough time to ask your questions or it feels like here, here is your treatment and get out that kind of thing. They are not actually saying get out, but you see other people coming through, and hmm, I didn’t really like these, and I know there’s no other way of doing this. I feel back because I’m saying it but there’s no other way of doing it”.

- No private room for cancer care

“Because it’s an open space and you are doing treatment and there would someone literally right beside you. And we are come in staring at each other, and you are allowed one to two people with you. But it’s kind of weird, it feels like a, I don’t, I don’t know how to describe it, it’s just weird. But I know you can’t do anything about it, there’s just so many people that have cancer, so many people that need treatment, so of course it’s going to be busy. You can’t have everybody having a private room, that’s almost impossible. I mean they do have curtains and stuff, but anyway”.

Suggestions and recommendations to improve delivery of cancer care and quality of life

- Return to work

“I just think that we need to do a better job in transitioning people back to work, I think we are at lost that as well. Having an understanding and transitioning people back to their daily life. I know treatment is very important, I know surviving it is very important. I know we are working on that, but that’s a whole new world we need to get used to. And we are a different person, a whole new different person, and I think you need good service to that, I think we need to work on that. That’s a whole area that needs a lot more attention to it.

- To be treated in a holistic way

“My suggestion would be to keep it well rounded, to look at it as a whole. I know everybody has their little piece, but we need to all come together and look at it as a holistic view. Yes, you get your treatment, but there’s also emotional, financial, the care givers, I think we really do deserve good care givers, and looking at it as a whole”.

- Increase the number of healthcare professionals

“Of course, I think it would, I mean they have more time to spend with people. It’s definitely needed. Yeah, I don’t mean doctors may increase, but increase the number of social workers, the nurses can increase. These 2 people spend more time. We have more time to talk to them; they are more of the key component, I think. I’m not saying the oncology doctors aren’t important, but uh they have a specific job to do, where I think the nurses and the social workers are more of the social component. I guess I go to there to get treatment, but the emotional component if important as well, the emotional wellbeing".

K5. Patient Participant (P2) Narrative

Patient Participant (P2) Narrative

Patient participant experienced physical concerns and received cancer care during treatment transition

- Tired

“How to try to give myself some energy, my biggest complaint was that I was really tired, no energy”.

- Pain
    - Knife-like electrical pain

“In the beginning I had severe knife-like electrical pain, which I came to believe that it was nerve damage, or the nerves that try to re-group themselves. It was very very painful. They said in some people it would pass. And thank god it did”.

- Phantom pain

“uh I don’t know if there’s anything you can do. Everyone I have asked, from my GP from my surgeon. My surgeon said that yeah, some people have phantom pain, and it could just continue for many years. Well because phantom pain is not ongoing, it could happen any place any time. It’s intermittent. I just accept it. Psychologically I have found that whenever I don’t accept something, I just make it worse. So, I just try to reason through, I didn’t say I will just accept anything, I try to reason through. If there’s nothing that is in my control besides deep breezing while it’s happening and let it pass, luckily, it’s short lived, I just found that, that helps”.

- Edema

“I did wonder if I had some edema, because it was swelling. But I talked to them, to my doctors. He didn’t think so, he didn’t think it warranted wearing a sleeve. Lucky for me, overtime, it just passed”

- Limited lifting ability

“In the gym, even to this day, I can’t like what I used to lift. So, I used to be able to lift 25 pounds in one arm, you know, to do repetitions

“Well, uh I have to be careful, I’m sure that I life more than 25 pounds, because I have a physical job that I have to lift things, push things. So, I work out at the gym to try to keep my muscle. But I have to be very careful. If I moved the wrong way, I would feel it. And not just in my joints that I suffer with, but also in the muscle. Uh I never asked that question that what would happen to the muscle if I did too much, and I’m sure I do, but whatever I am, I can live with this.

- Sexual problems

“Some of the things they suggested weren’t really, well, uh, weren’t really practical. For example, if my husband and I want to resume sexual activities, uh, they said that it could happen over time, and there were certain products we could use. But it was not possible without going into much detail, so, it was more uh coping skills I found to help myself psychologically, not really anything from our clinical point of view”.

- Assessment for pain and tiredness

“Well they asked me about the pain, and they asked me about the tiredness. The pain sometimes is a 10, tiredness, I would, even today, I would put tiredness as a 5, it is very difficult. Whereas before, even a year ago, it might have been at 7.”

- Patient education
    - on scar issues

“There’s pain, and uh, pain at the site, I’m told that it was just scar tissue, I’m told that if I massage it, it could eventually cause it to be broken down, but sometimes breaking them down would cause more scar tissue, it’s like a vicious cycle, so I don’t do anything about it”.

-
    - Redness on radiation site

“Just the, just the redness. So, I have to be careful with any lotion or cream that they don’t contain perfume in it so it won’t aggravate the, the burn actually, the sun burn”.

“Well they did tell me that if the redness got more serious, if it started to blister, let them know. But I have never experienced that”.

-
    - Shoulder and arm near surgery

“They told me to be careful for is that whenever I give blood, to never gave that arm, the arm that had the surgery, that side, and to, don’t lift over 25 pounds”.

“They told me how to care for my incision site, what exercise to do, so I won’t have a frozen shoulder. Uh, what uh not to use any creams that could impact”.

“After my cancer treatment, no shaving in the arm pit. Because mine is breast cancer, so I wouldn’t run the risk of cutting myself because of the nerve damage and some numbness. How to deal, how soon could I go back to the gym, because I was very active before cancer and before my treatment, so I was told that I could go back after 6 weeks, so I did follow that. I think that’s it”.

- Education on lifting without rationales

“Yeah, no, it was always don’t lift over that amount. So, whenever I draw blood, it was don’t life anything, of course I don’t do it on that side, but don’t lift anything heavy right afterwards, so yeah, and I don’t understand the physical reasons why”.

Patient participant experienced emotional concerns and received cancer care during treatment transition

- Embarrassment

“The pain was very difficult to deal with. I remember immediately after my surgery, uh, within days, because of that knife-like pain that could arrive anytime, I would be standing in line in a grocery store, and I would suddenly grip me, and people would start to look at me, and I would say I’m fine. So, it was a little bit embarrassing. I just have to learn to accept it”.

- Hotline service offered

“I think they provided was a life line. They assured me, if I had any questions, all I had to do was call. For a couple times I did call. They always got back to me during the same day or within 24 hours. I have always felt confident what they tell me. Usually I was asking about something and they say don’t worry about it. They were right, eventually, they did pass. Whatever the issue was, they said they would take it up with my oncologist.”

Patient participant experienced social concerns and received cancer care during treatment transition

- Self-identity changed

“You are never the same person that you were after you have had cancer. No matter how well you recover, cancer to me, it isn’t the like the flu or the cold. You got permanent scars, I live with uh pain in my joints, I don’t know it’s because of the drug. I don’t have full motion in that side, in that arm. The physicality isn’t the same. I also praise on the mental, you are never the same after cancer, my experience was very good, so I’m not bittered. But yes, it definitely changed your identity”.

- Label of cancer survivors

“I did not like that term, survivor”.

“No, no. I don’t identify, I don’t relate to that word survivor, because my experience doesn’t compare with other people in my family who either didn’t survive, or who their quality of life was so poor that, surviving to me means that uh you have a, uh, element of vibrancy. But in one bad case in my family, the quality of life was so poor, that to you or I, if you compare, you would think that person is just existing. Their challenges are just so great. So to me, I just don’t relate to that word survivor. Uh, and as much as I was given the all clear, anybody I know who have had cancer, there’s always on the back of their mind that the cancer has a chance of coming back, or it’s there, but it’s just not showing up yet. It has not manifested themselves, and let’s not to say that I’m inviting it to come back, but from my understanding of cancer, it’s about how well you keep your body in terms of health, your mental state. Your immune system has had what it needs to fight the diseases, cancer can be any type of diseases. It was not just breast cancer that I had. So that’s another question I don’t relate to that word because I think people, the media, they use cancer and thinking that it was one disease. It is many diseases. It is an umbrella word. Again, I might have come out of this ok, in fact, my oncology said that my risk now of having breast cancer again is the same as other women who have never had it. But it was 74%, that’s still pretty high. To me, the threat is still very high, but I don’t let that, that idea to go over my day to day life now”.

- Return to new normal life

“That’s a good way to put it, a new normal. That’s why I don’t compare to what I was because that doesn’t exist anymore. So this is exactly what I call it, my new normal. My new normal is, I can’t lift, I have to be very careful about my joints, but I do what I can. I rather than being upset, what I can do, I continue with trying to push, and do what I can. So in the beginning, I had a lot of difficulty with many things. This week, there’s one night, I had a good night sleep, but when I wake up, I was tired, so I went back to take a nap, right in the morning. So, I accept that, when there were days that I’m tired, then I just have a nap. There was no, it’s not a question of shame, but I don’t see it with having something wrong with me, that I can’t make it through the day without a nap, I just accept it. If that’s what I need that day, then I just have a nap”.

- Return to work

“That was very difficult. I only work part-time, and that’s for a couple of reasons. First, I’m still not back 100%, I never will be. I do get tired easily. So, the part time work the best for me. I’m also at the age that I can consider myself semi-retired, so that also works well in my favor, so uh, and see I don’t know if I could blame my inability to live the way I would like to on my cancer or my age, because it happened at the same time. I had cancer when I was 55, and now I was 61, so how much of that is the cancer, and how much of that was age, I can’t tell”.

- Meanings of survivorship or cancer survivor

“I lost a husband, the love of my life, to cancer. That was the end of my life. So now, I compare anything to that, it was nothing. So, umm, when he died, I didn’t want to live. It’s not like I want to die, but I didn’t know how to live. I don’t know how to continue without. I was not the same person that I was before I met him, now I was not the same person I was with him, so going forward, I just went day by day, and I often wondered, when I was faced with a life threatening disease, would I fight? Or would I just say I accept it, and now I know, I would fight. Because in the beginning, you have your surgery, but you have to wait for your pathology report, so you don’t know how lethal your cancer was. So during that time, I realized that yes I want to fight, I want to live, life was important to me. And even today, with the physical issue I deal with, uh, I find work arounds. I can’t do yoga anymore, which I used to love to do, because my joints can’t support any weight, and I really missed that, it was very grounding, and mentally stabilizing practice. But I can do other things. So I try to stay very positive. But not just positive that everything is wonderful. But I learned to be appreciative of everything I can do, as opposed to what I couldn’t do, because I can’t change that. But I can change how I feel today. Thank you very much”.

- Patient education

“In the beginning, yes, that was certainly true. I was told not to go back to the gym until 6 weeks, and even then, I was told to start slowly. Uh, and, ummm, yeah, nothing else in terms of concrete”.

Patient participant experienced self-care management transitioning from acute care hospital to home

- Self-care management
    - Self-care

“I did, I did buy, I did but like a pad that nursing mothers use to put inside my bra, because I found it was very uncomfortable. Ummm but other than that, perhaps, I’m just trying to think when I started them, but I took vitamin supplements, to try to help with my cognitive. Yeah, that’s about it”.

-
    - Patient education

“They told me certain soaps and lotions to use, uh, not to use a manual razer, but an electronic razer for shaving under the arm, so I have to sort out those things. Uh, it was helpful, they even told which pharmacies carry those brands, so it was helpful”.

Patient participant experienced communication transitioning from oncology team to primary care provider team

- Communication among patient participants, oncology team, and primary care provider team

“They didn’t always, my surgeon, who I saw more often than the GP, he didn’t always get the reports. Uh, so that was probably the only thing.”

“My surgeon did not get the pathology reports back and my blood work result, so they just coordinated among themselves.

“I would tend to, if I had a question, I would call the oncologist’s coordinator. It’s not that I don’t trust my GP, but they are more specialized, where my GP is more general.

And believe me, I trusted my GP because I found my own lump. I went to him the very next day, I had an appointment the very next day. Before he even set me for a CT scan, and before we even got the results back from the CT scan, he told me that he thought it was cancer that very day. So I trusted him, uh, however, when I did have a question about my treatment, I called the oncology coordinator".

"The nurses. If I persisted, he would take it up with him and get back at me. Uh in fact, a week ago, Friday, I had my appointment, and the question is almost the same as the year before. And from her notes, I think she remember that, and she was joking with me. And uh, I never felt that I couldn't approach with him. Even when I was having my one on one with him, I never felt that he was shooting me out of the door, he would talk to me at length, sometimes my appointment could be an hour or a half hour just with him, which is amazing, uh but on the phone, if I had a question, it was her that would answer back. So, I assume that on the phone it was not something that were detailed enough that she would need to ask him. It was probably general enough that she was able to answer it. And I accepted that".

Patient participant experienced recovery of body function transitioning from acute cancer treatment to follow up care

- Recovery of body function

"No, haha. And I think sometimes, also become a patient advisor as a result of this experience. And that seems to be common when a patient only received radiation as opposed to chemotherapy and/or radiation, it doesn't seem to be, the information the resources doesn't seem to be as uh I want to say extensive, there seemed to be a little bit of gap there".

Experience influencing delivery of cancer care and quality of life

- Positive experiences promoting delivery of cancer care and quality of life
    - Doctors

"I think all my team, my oncology team here, in with the radiation, the, my GP and my surgeon, they all seemed to have the same mind, so I always felt that I have been looked very well after. Uh, I never felt that I was an out member, I didn't even feel that I was a patient. I always felt that I was part of the team, that we are all working toward a common goal, which is to get me healthy".

- Radiation specialists

"You know, you know, you know the one that stands out in my mind is uh it was a radiation treatment, because you know, I did not have chemo. And it was a Friday morning, the radiation tech was setting me up for my treatment, and he was just chatting away, you know, making small talk. He was asking what I was doing on the weekend. So on Monday, he remembers, to ask me specifically, about that occasion. So, I thought that level of, that gesture of friendship, was astounding to me".

"The tech, the radiation tech. that to me, is a level of commitment to his craft, to his care of patient, to patient first that he would bother to talk to me on such a personal level, that meant the world to me. Yeah.

- Oncology nurses

"I think yeah, all of the coordinators that I have met with were always very, very friendly, very smiley, and that makes a big difference every time you come in, you expect good news or bad news. It was just a normal check-up in my place. It's not a pleasant place to be, you don't want to be there. You are reminded of so many things just by looking at so many other faces. So, uh, I even told the gal at my last appointment that I really appreciate that, that she's so upbeat, she's always so smiley. Because it makes a big difference, it puts me at ease, and it takes away the gravity of the appointment.

- Barrier inhibiting delivery of cancer care and quality of life
    - Physical concerns

"I think, it wasn't so much psychology, because I was so strong. Uh, mentally, as I said, after I lost my husband due to cancer, I know what a strong person I was. I know what my limitations are, uh so, for me it wasn't so much the mental, it was the physical. And, uh, that's been the most difficult thing throughout the, I hate that word, the whole journey, through the whole experience is having to accept that I have such delicate joints, I can't do all the things I used to do.

- Difference between chemo-treatment patient and radiation-treatment treatment

"I think for me particularly, it's the different between the chemo patient and the radiation treatment patient. I don't think there's as intense a, like you said, do they offer me any resources, no. but that would have been nice.

"So, you, perhaps because you don't look ill, as someone that received chemo. Whatever the reason is, there's definitely a gap. Now, I told you that my conversation with the coordinator and indeed my oncologist was almost the same as it was a year ago because I was worried about at the end of treatment, what happens. Even at the end of my radiation, I ask what happens now, what happens next, so I asked enough question that I'm comfortable the decision they reached. But I have noticed that other radiation patient I have spoken to. I don't know how to put this, you are not treated the same if you have chemo. In people’s minds, perhaps you don’t need as much help as a chemo patient. But from what I have heard from friends who have had chemo and radiation, it was radiation that worse in terms of quality of life. Because the chemo, yes you are losing your hair and stuff, but it was temporary to a point. I mean there’s lasting effect form that as well. But the biggest complaint I would have for radiation is the stamina. Is the fact that you are so tired. It stops you from doing so many things. And that would be my biggest complaint, and I don’t know if there’s a solution for it, there was nothing that was offered to me. So, to me, there was a difference between patient with chemo and radiation, and patients that have just radiation. It was perhaps not thought as severe, but to me, the effects, I don’t want to say they are worse, because I didn’t lose my hair, I didn’t lose my nails, but that inability to perform simple tasks in a day is different from lying in bed so sick that you are not able to move, because it plays on your mind psychologically because lying in bed you are just too tired to do anything. You are just too tired to do even be engaged in going to the movies or watching TV or do anything that you might like to do before like read, because you just don’t have the energy, and to me, that’s worse.

Suggestions and recommendations to improve delivery of cancer care and quality of life

- Effective communication and information

“I think they, I think they did look, even at a conversation about after care, because that was my biggest concern a year ago was, what happens? Like do you just drop me like a hot potato? What if I have a question, where do I go, who do I call, do I call you, do I call my GP, do I call my surgeon. So, for a conversation, even if it’s initiated by the medical team, as opposed to the patient. Because I’m very confident in asking questions, but someone else may not be. I wouldn't want them to live with that, not that fear, but that niggling feeling of going through all these all by themselves. And I was assured that I was not being, it's not necessarily being dropped, and I know patient that have called up after a year so they could stay in contact whether there's anything wrong or not. I don't feel the need to do that, but I feel a conversation initiated by the oncology team, and usually it's the nurse, because a doctor does not have the time to sit as much as the nurse does. Not that their time is not precious as well. I think that would help to allay the patients, and help them with better recovery, because they don't have to always worry, they don't always have to think that they are alone. And in fact, that's what they said, they say you are not alone. That's what they use, that terminology. I think, again I have noticed that for patients within my group, when there's only patients that had radiation instead of chemo, and for radiation, they did not have that same feeling, that uh there's an after care. Even if it's a name only, it's not that we don't care about you, even though we are not going to see you anymore, that would go a long way to helping patient's psychology.

K6. Patient Participant (P3) Narrative

Patient Participant (P3) Narrative

Patient participant experienced physical concerns and received cancer care during treatment transition

- Bad burning on radiation sites

"I did my breast radiation in Peterborough; I did my rectal radiation here (DRCC)".

"For the rectal cancer, I engage with oncology nurses during radiation treatment. So, at the end of radiation treatment, yeah, this is hard. I engaged very little with oncology nurses. It was the doctors that I usually worked with"

"For the breast cancer, I run into complications after radiation. I had very bad burning, I remember calling in and asking the nurses. And they asked me to come in so they could have a look at me. So, I did that. They were, they kind of have to, scramble to find things to help me. Because my burn was so bad that they didn't have anything for me. So, they were kind of scrambling to find something that they could put on me that wouldn't stick, because I was trying to grow new skin. And uh so they were really, they were really stuck with hat to help me with. And I felt stuck because I couldn't put on any clothes, I couldn't go anywhere to do anything because I couldn't put anything on me because it would stick to me, and it was kind of like ripping it off me. So, I remember engaging with a nurse, and that was post-radiation, I was at home recovering from radiation, and I encountered these very bad burns. And I found it very weird that there were so very little resources for me to access".

"Yeah, so then I came in. she (nurse) knew I was coming, and she knew why was I coming. So, before I got there, she was looking for some pads or something that I could put on it, because she knew that was my issue. But she went to other parts of the hospital and try and find something that I could use. She really couldn't find very much. So that was very odd to me".

- Referred to radiologist

"When I called, they said come in, and they had a radiologist to look at me, to make sure that it was not infected or something, or is this ok or something like this. You know, the radiologist said, yeah you got a really bad burn. I guess they don't see it getting this bad with most patients, I had it pretty bad. So yeah. But the nurses were kind of left to try and scramble to find, uh, resources, like physical bandaging resources so that I could live with this at home until it healed, up until that right? I have personal gone to the local drug store to try and find bandages or whatever. What I needed was a non-stick absorbent pad. They have it in the pharmacy, but they have it like this size, they are like little things. But my area was like this big, right? And even in the hospital, they didn't have anything to give me. So, I'm thinking that, I must not be the only women who had breast cancer that had burns, and it struggling to find something to take care of it. You know what I mean? It just seemed really weird to me. So, I remember the nurses like".

Patient participant experienced emotional concerns and received cancer care during treatment transition

- Challenges from two cancers and confused for treatment

"Uh, emmm, I remember finishing my radiation here for my rectal cancer because it was the one that was first diagnoses, and 6 weeks after I was diagnosed with the breast. So, my very first block of treatment was radiation for the rectal cancer. I was just, I remember feeling that, step one was done. Because I know there would be a whole bunch of other stuff that were coming. So, I was like, ok, we are on this journey, and it was being proven that it would be rather complex because the doctors found 2 separate cancers that they have to treat. And these are 2 primary cancers, they are completely different, they are not related. So, and they were really very challenged with how do we treat this woman with 2 cancers going on at the same time? Because that's very rare, so, my treatment plan kind of changed all the time because we are doing this for the rectal, ok that's done. We really want to do this next, but we need to deal with the breast. And it was very confusing. And I just remember at the end of my rectal radiation, I'm feeling like step one is done. Now, you know then I had a little bit of breathing room, until we are going to do the next thing. So, it is like this up and down, roller coaster that you go on. Yeah, that's all I can remembers".

- Supports from family, friends, and people with similar experiences

"Personally, what I used that kind of helped me to get through everything is I had good friends, I stayed very connected to them. We actually had a set time each month that we all come together and uh that's been very good to me. I had great family support as well. I also go to a support group at hospice, in Peterborough, because that's my closest city, and that's great, because those are people that are going through the same things. Your friends and your family are great, but they don't have the same experience you are having, right? But the women at hospice do. So that's great".

- Supports from nurses

"Uh, oncology nurses, uh, I uh, I do recall being told a couple times that there's social workers I could access, I do remember being told that. I found the nurses, like during my treatment, and at the end of my treatment, being very supportive, and treated my very well. I made a point personally uh writing them a thank you letter and giving them a gift, at the end, because, you know for their care, I thought their care was very good. And I wanted them to know that they are appreciated because in the work, I know in the work I do, I often question whether I'm making a difference or not. And I wanted them to know that they are making a difference. They are making a difference in my world, right? So, relationships are always good. I particularly liked how uh I kind of had the same team. So, you kind of build the relationship with these nurses because it wasn't different people all the time. Like you are coming for 25 treatments right, and, it seems to me that you are assigned to a unit, and people in that unit are the same people, and I found that it was very helpful. By the time I was done with the treatment, and I was leaving to recover form that treatment, uh, I felt like I had some kind to relationship with these nurses, And I felt comfortable enough that I could, I could ask questions if I had them. So, I found that very helpful. Yeah.

- Nursing assessment

"The nurses call me in and they ask, uh, they ask a few questions, just kind of like, how I'm doing, have noticed, has anything changed? You know, if I'm having any issues, that kinds of things. And uh, and then I think they check your weight, and they do blood pressure, and they sometimes they take my temperature. Uh, and that's about it. It's probably just about 5 minutes. There's always a lot of people waiting in the waiting room. A lot of people in the waiting room in the clinic each time I visit there".

- Schedule follow-up care appointment

"It's the booking department. So, in Peterborough, in cancer care, there's bookings people right at the front desk, and they are the ones that send me the paper work that tells me.

Patient participant experienced social concerns and received cancer care during treatment transition

- Self-identity
    - Accepted cancer as part of her

"I have a strong identity before. And I still do, but one of the things I have come to learn is, the identity of, uh, a cancer patient or a cancer survivor, I kind of gotten a bit, I guess I challenged the labels or the narratives of someone who had cancer, because, when I first I was told that I have cancer, friends and family and all, coworkers, they all, they all say things like you are going to beat this fight, you are going to kick cancer's butt. You know. And I think it's not just the, but I think in general, send this message that cancer is some kind of this war that everybody wants to win. I mean, even on the funeral, someone would say that someone that lost their battle to cancer, right? So, I really questioned that kind of terminology, and it did not sit right with me. It doesn't feel right with that I'm at war with my own body. That didn't feel good. So, you know, or, there's even these like F cancer you know, that just felt so weird to me. So what I ended up doing, as I was going through treatment, and as I have done since treatment, was, changed my think about that, and chose not to take on that kind of persona as a cancer patient, and to me, instead of it being a fight or a war or a battle or somethings I was going to lose versus win, I take it as cancer was a part of me, and it was part of me that needs some attention or some help.

Instead of hating it or fighting it, I accepting it, and I'm going to love that part of me too. As I'm doing my own type of meditation, my own healing work on the side, I imagine in my own mind, the cancer of the tumor that we are trying to get rid of, is something that, is something that is not well. And I imagine my body embracing it with love, and healing light, to love that part of me back to life. So, you know there's loving to death, but instead of loving it to death, I want to love that part of me back to the good life that it should be in in the first place. Something has gone wrong with it to it had gone bad, but I'm going to love it back to life. And so, so my thinking about how we, as a society, perceive cancer, and the messages we send about it, I challenged that, and I don't like that".

- Challenge the label of cancer survivor

"I question we could never call ourselves cancer survivor because cancer keeps coming back right? So, it's like, my doctor could tell me right now that, uh, the cancer has been eliminated. In the case of my breast cancer, it was physically removed. And in the case of the rectal cancer, they believe that they completely eliminated the tumor. They can tell me today that they can tell me, xxx (patient name), there's no cancer in your body. But for tomorrow, they cannot be sure. And it's like, years down the road, it could pop up somewhere else in me, or the tumor could grow back again, and so, I'm reluctant to say that I'm a cancer survivor, because I think It could never be over. There's always a risk, and the women in my hospital group, they have had multiple cancers. You know, they have the breast cancer that had been dealt with, and a few years later, it has gone to their brain, now they are dealing with brain cancer. It doesn't seem to ever go away. So, I have a feel that".

- Return to new normal life
    - New normal life

“Well it has to be a new normal life for me because of the drug I’m on. That drug, I’m supposed to be on for 10 to 15 years. So, life is going to be different during that time. So it is a new normal. I’m enjoying life, I’m going to enjoy my life”.

“Well I have experienced it with other people that I know, who have gone through cancer, and now are going through it all over again. And now, they have a type of cancer that they cannot really help with, brain cancer or bone cancer. Uh, so I know from their experience that, it can be very different. And then, uh, and then with my oncologist telling me that, I’m the, I have to be on this drug for 10 to 15 years, and I will be feeling like this for that long, and I have to find a way to live like that.

- Adjust to new normal life

“My oncologist had only told me very little. She did give me this sheet, with all the information about the drug that I’m currently on, yes. And it tells you these are the common side effects, if these happen, this is what you can do. These are the less common side effects, these are severe side effects, if you have these, go to the hospital. She gave me that, and this is helpful, it helps me, because when I start to experience the change in my body, and I go refer to that sheet and go like oh yeah, this is one of the side effects that is happening, right? So that’s helpful. But, but, it doesn’t really tell me, strategies that I can use to navigate life with these things. It’s like, if you have muscle, bone, or joint pain, stiffness or cramping, take Tylenol. It’s like, well, I’m not going to live on Tylenol, that’s not good for you, you know what I mean? So, I have been trying to find out things on my own, mostly. Like the CBD oil, right? I was hearing that it helps a lot of old people that had arthritis or something like that. So, I go to the clinics in my town, and I meet with a doctor, and I say that this is something that could help me, and I tell her what I'm experiencing, and she goes yeah, definitely, and CBD oil could definitely help you with that. So, she gave it to me, and say try it. And it helps. You know, before that, I was double dosing on Alieve, just so I can move. And, uh, when I start taking the CBD oil, t was as effective as double doing on Alieve. So, and it was better for your body than taking double dosing alieve every day. So, there are things that I do on my own that helps me to manage, right? But yeah, the oncology department have done very little to help me with that".

- Return to work

"Because the last I was at cancer care in Peterborough was in November, and I still, I still had the, I was technically still in treatment, so going back to work was not even a topic at that time. Now it's starting to be a topic. it was some type of treatment or check-up in January, So I was just finishing the recovery from that. And technically as of right now, there's no other treatment planned. But I have made it through all my steps. There's no other future treatment planned, unless something raises its ugly hand. Like for my rectal surgery, we have decided, not to do surgery, because we believe we have eliminated the tumor with radiation and oral chemo. And so, there's a new, I don't know if you are familiar with this. There's a new approach. The standard care for colorectal cancer is usually radiation to reduce the size, and oral chemo with radiation to reduce the size, then they do surgery to remove it. And then, they do intravenous chemo. That's the standard care. But now, they start to realize that the radiation and the oral chemo sometimes completely eliminates the chemo. And so, then they said why would we do surgery, if there’s nothing there to take out. And this is called, uh, this is called uh, elective non-operative management, or what they coined as watchful waiting. And because they think my tumor was completely eliminated, me and my surgeon at St. Mikes, have decided not to do surgery, we are going to watch it very closely and make sure that it is gone. Because she said, if I’m going to do surgery, I’m taking a huge chunk of you out, that’s going to affect your quality of life for the rest of life, and why would I do that if there’s nothing there that really need to be taken out. So, I see her every 3 months, because she’s watching me very closely. And uh, so, you know, at any given moment, she sees any indication that it’s coming back, she’s putting me in a surgery right away. So, you know, I’m still walking on egg shells a little bit. And again, that affect my work, because at any given moment, things could change, and I can’t work again. So, it’s all up in the air right now”.

- Meaning of survivorship
    - Hard life

“It means to be grateful, it means life is going to be different, because, I was like, I was trying to learn how to live my life differently, it’s not going to be the same. And that’s because of the drug that ‘m on, that messes me up, so it’s hard to live with the body that does not perform or act the same way. So, sorry, thank you. So, I have I found that very hard, very hard. I have gotten not very much support for that. Because my oncologist said, uh, she said the drug you are on is the best drug for you, so she wants you to stay on that drug. I understand that I need to stay on this drug for it to do what it need to do for me, I understand that. But at the same time, how do I live with, you know, it’s like I’m 51 years old. But my body is like 80 years old, because of what this drug does to me. So, I’m questioning if I could ever go back to work. I don't know if I can work, because of my body is not the same. So that's hard, you know. Of course, you get all these money people on your back. I got my work insurance; you know they want me to get back to work so they could stop paying me. My bank wants me to get back to work, so they don't have to keep paying my payment. They are pressuring you to go back to work. But it's like, I couldn't work like this, you know. So that's very hard".

"Well, they (family) definitely worried about you all the time. And they always asking how you doing, uh, so, I just try to show them that I'm well, that I'm ok. I have 5 sons, and I, uh, I try to not look sick for them. I try to look well, so they don't worry, right? So, but it's hard, when uh, it's hard when, when I'm having trouble moving. They can see that I'm different. They can see that I'm struggling, and I can't hide that. I can't hide that my joints won't move. I can't hide that I'm stiff. I can't hide that I'm like an 80-year-old woman. I can't hide that. So, so they have to come to accept the fact that mom is not the same. Mom is not the same anymore, maybe mom will never be the same anymore. And I'm just sitting here, this is when I'm doing good, you know".

"I found it particularly suppressing that the nurses and the doctors have always seen me show up to all of my appointment, all of my treatments, alone. There is never anybody with me. And I'm surprised that nobody ever said that we have noticed that you always come to your appointments, you always come to your treatment, alone. Do you have some supports? You know you can rely on or whatever. You know nobody ever checked upon me to make sure that I have somebody around me. Because they weren't seen any people around me. I mean I do have people around. I'm not like alone, alone in this. I just found this surprising that nobody noticed this and said anything about this. And, you know check in with me. I would hope they would do that to other patients that are showing up alone all the time because they may be alone, you know? I would want them to have some support. So, I just, I found that a bit surprising.

- Supports

P: uh, support, from the hospital group I usually go to, I have friends that I can talk to. But medically, I, uh, I go to physio. I'm trying to use physio therapy to help me. So that's good. I also, uh, use, uh a doctor who prescribe me CBB oil. That helps me, so that helps. But nothing takes it away, it just makes it more manageable. But it does not take away what I'm experiencing within my body. So that's what I get for support, I guess.

- Services and programs offered

"This is interesting because, I think my very first visit to cancer care Peterborough. There's a lot that went on during that first meeting. They brought in a drug person to make sure that the drug would be covered through my work, they had me talk to a dietitian, and I think they mentioned that they have social worker. But in that moment, I don't think I needed anything like that. So I never talked to a social worker at all. It's not like it's never been mentioned, or anything like that. I think, I think it might be good to have check points throughout, because, at the very beginning I did not need any of those type of service. But later on, I might, so I think it might be good to have someone that checked in within, and say hi XXX (patient participant name), how is X, Y, Z going on for you, do you need anything with respect to other stuff. That might have been helpful. Because anybody could be like yeah, I don't need it before, but I need it now. Uh, so that, that might work".

Patient participant experienced self-care management transitioning from acute care hospital to home

- Self-care management

“I was managing my burn at home. I was surprised that when I go to the hospital to ask them to have a look at my burn after my radiation was done, I’m surprised that they didn’t order home care. I was having a hard time trying to manage the care for that on my own. I have had home care, post vasectomy surgeries, and they been, they have been, because I have drains and, they come in and keep an eye on you until your drains come out. After your drains come out, then you are pretty much on your own, and for the most part, I was fine. My surgery was in January, and I was not healing well, and my incision opened. And I went back to see my surgeon and he ordered home care to come back in to patch me up, trying to get that to heal up. You know, I have had post-treatment complications that I have gotten some help with”.

Patient participant experienced communication transitioning from oncology team to primary care provider team

- Communication among cancer survivors, oncology team and primary care provider team

“I don’t really know if they communicate. My doctor gets all the paper work, she’s aware of everything. I don’t know if they talk. I know my oncologist has taken my case to the tumor board a couple of times, because again, my treatment plan is complicated. So, I know she has communicated with the tumor board, which are people that have more expertise than her, and who puts their mind together and decide or recommend what is best for my treatment. That’s why my treatment plan has changed as time has gone on right? So, I know she communicates with that. I know she's not making all these decisions all herself, she has consulted with the tumor board. Uh, but I'm not gone back to the oncology departments between my appointments, I just uh, I just go to my appointments. I kind of manage everything else either on my own or with my family doctor.

"I don't know if she (family doctor) ever called the oncologist, when I have gotten to see her, uh, I kind of give her a quick update on what's happened recently, and I have been going in to see her about side effects that I have from the drug that my oncologist had me on. Because I last time, I saw my oncologist was in November, and my blood work and hair work were fine, and she said I don't have to see you for 6 months. So that's coming up in May, but you know I'm struggling on a daily basis, so I kind of ask my family doctor about my side effects, could you help me out, like you got anything that could help me? And you know she does the best she can that kind of thing. But I don't really see oncology nurses, uh, since my treatment has been done, you know what I mean?".

Patient participant experienced recovery of body function transitioning from acute cancer treatment to follow up care

- Recovery of body function

"I don't remember them saying very much, uh."

"No, I went, not post treatment, no. Before I had treatment, they set me for an education with a nurse to talk to me about the oral chemo. And, and they give you all the details on taking oral chemo. But that was pre-treatment. But post-treatment, no".

Experience influencing delivery of cancer care and quality of life

- Positive experiences promoting delivery of cancer care and quality of life
    - Supports (see emotional transition section)
    - Oncologists and nurses are positive

“P: yeah, well, my doctor (oncologists) has been very positive. Uh, so, that’s good, uh, you know like they say, like you are doing very well, you are tolerating the treatment very well, like things like that, that helps. But I don’t know, what else there is.

“I remember that, the uh, the oncology nurses during treatment, were always very positive. And when I was done treatment, they would wish me well, you know all that staff, like I said, the people I have encountered have been very good. Uh, I just think there’s just been some gaps, uh, in, in my care, you know, that’s all”.

“I guess one of the things I really liked is how informative is pre-treatment and during treatment, like how informative everybody was. My oncologist I found is very good at explaining things, she’s very good at answering my question, you know, she’s very thorough that way. But you are talking about the transition period, you know, it’s just, uh, about, you know, what I can do to kind of, uh, like recovery, in that recovery time. It’s like, uh, the burn is an example, like how they weren’t be there for me, to provide me what I needed. Uh, and then, there’s the side effects issue, I just want to, I want you to manage it, how do I do that, hahaha, you know”.

- Barrier inhibiting delivery of cancer care and quality of life
    - Finance

“Certainly financial, I don’t know, I mean, I have a great job, I have a great benefit plan. I honestly don’t know about people that do not have the things that I have. Honestly, I don't know how they do it. Because I struggled. So, finances just put a stress on you that you don't need. I mean, you are supposed to feel better, and you are not supposed to feel stress. I do believe that the number one killer in the world is stress, right? But when you get financial stress on you, it's really hard. So, finance is a huge, huge issue, a huge barrier to trying to get well. Uh, other than that".

"No. I have not gotten anything from the government. I have long term disability coverage from my work".

- Education and/or information not address concerns

"Well I think the problem with me is that they don't even know why I had it in the first place, because I don't fit the profile of either 2 cancers I had. I'm young for the 2 cancers I had, and so, and then when they found out that I had 2 going on at the same time, they were like, what the heck is wrong with this woman. And they send me to genetics, for genetic testing. The genetic testing came back saying that there's absolutely nothing wrong with this woman, her genetics are fine. So now, when I go to see my oncologist in May, she's going to receive the report saying that there's nothing wrong, there's no genetic problem with this woman. So, so my question is, why in the heck did this woman had it in the first place. So, since they don't even know why I had it in the first place, so how can they help me to know how to prevent it. You know what I mean? Like, it doesn't make sense because, I don't live the life style. It's not a life style issue. I never smoke, I never drink. I'm abstinence from drinking. No alcohol what so ever. I eat fairly well, I never touched drugs, never touched them. And for breast cancer, I birthed my babies, I nursed my babies, I nursed my babies for 2 years each, like, like there's no reason for me to have these 2 cancers. So, they are baffled. So how could you tell somebody how to prevent it, when you don't even know what caused it. You know what I mean?

- Not treated in a holistic way

"I guess one of the things I have found difficult is, the people at the hospital, and I understand this, they are medical doctors and they are medical people, so they are very medical perspective. And, so they, they treatment cancer as a medical condition, right? It's all about treating the cancer, and kind of the isolation of everything else. I'm a more, I'm a more holistic perspective. I look at, uh, I'm interested in knowing, what are some alternative therapies, that I can use that can help me. I'm not saying that I'm not going to do the medical, like, I have, it's actually that is the people on my family that is shocked that I would do the treatment that I did, because I'm a holistic kind of person. Naturalistic too, and uh. I'm like no no no, I'm going to take what modern medicine has to offer, but I'm also interested in other approaches that might help me too. And none of those were every being introduced or talked to be about. I even have to know some of them before going in myself, or search it up myself. Uh, and so, uh you know I did meet with a dietitian, who did talk to me what a good cancer care diet is, so that's a supportive piece. And uh, but at the same time, you know, there were questions that I couldn't answer. She starts by telling me the diet that contribute to the colorectal cancer. And I was like, that's not me. I don't eat red meat, I don't eat meat that's cooked at a high temperature, I don't eat processed meat, I don't eat like that. So, so, when she was telling me a good diet, and she says like, very little to no red meat, uh, does that include wild meat, because we are first nation people and we hunt for our food. And the meat in my freezer is red meat, but it's deer, it's moose, right? It's not cow, it's not a pig. I buy chicken, I buy chicken for something different. Holy heck, because you don’t want red meat. So, when I asked her, can I have wild meat, and she was like, oh geez I don’t know, I would have to look into that for you and get back to you. And when she got back to me, she said no, when we said red meat, we don’t mean wild meat. So, you can eat wild meat. So, oh my goodness, I don’t know what I could do if I couldn’t eat red meat. So, so, you know, side by side with the dietitian, we talked about what to eat, and that was kind of an alternative therapy. But, you know, there’s still questions like if there may vitamins that I should be taking? Are there any natural supplements that might help me? Is there any kind of physio, things like massage, things like meditation, you know? I wasn’t provided anything like that. And I don’t, I don’t look at cancer as something isolated by itself. I do look at cancer and other stuff all being connected. And, and I, the medical people just treated as a medical thing”.

Suggestions and recommendations to improve delivery of cancer care and quality of life

- Effectively manage side effects

“I would like help managing my side effect that is going to be with me for a long time. And I would like to look at, you know, the, all of the possibilities that could help me. Just don’t give me a drug to combat the side effects that’s from another drug that I’m taking. You know, that’s just like layering problem on top of problem. I want, kind of, let’s get down to the root of the problem and deal with it. It’s kinds of only what I need right because I have to be able to navigate the side effects to go back to work”.

- Supports for return to work

“My work is very supportive, and I know that they would accommodate me in whatever way I would need so that I could do my work. I know that, I’m confident with that. Somebody else who perhaps who can’t ever work again, or somebody else who can never do the kind of work they do before, that would be really hard. But I’m not there yet. I have got a wonderful letter form my bank telling me that I need to write them a letter to tell them what I have been doing for retraining, and what I have been doing to find work. I did not take that very well. And I have written them 3 sentences that says, I have a PHD, I have done 14 years at university, I’m not doing any retraining, thank you very much, and I have a job to go to so I’m not looking for another job. It’s like, don’t even go there with me, because that’s not happening, you know?”.

- Monitor cancer survivors more closely

“Yeah, I think the transition period that you are really focusing on, I think there really need to have more work done, to make sure that the patient is being supported. Because like I said, during my treatment, I got excellent care, it was excellent. But once the treatment is done, you are good to go now. We are done with your cancer; you are good to go now. And I was like I’m not good to go because I’m dealing with side effects now, or I’m dealing with major burns right now that I don’t know what to do. I’m not a nurse, I don’t know what to do about this. Or, you know, they leave you go for 6 months, well anything could happen in 6 months, I mean, both of the cancers I have popped up and grew quite significantly because I had a colonoscopy 4 years prior to my diagnosis, and it was crystal clear, not a mark on it. Well how did you go from crystal clear to stage 3 cancer in a five-year window, when my next colonoscopy was supposed to be. My breast cancer, I have mammogram every year, every year, how do I go from a clear mammogram and within that year, go to a stage 3, 11.3cm tumor? Within a year! I know things can change pretty quickly. So, one of the things I worry about right now, is how close are they even gonna watch me after all this. So, my surgeon, she reaches out to me every 3 months. I think that's great. But when is it to a point that she's going to say, XXX (patient name), from now on, I will see you after 2 years. I'm gonna be like, oh no, because that's too long for me. I'm worried about that, I'm worried about how close they are going to watch me, when they think everything is going to be ok. I think we need to be more watched more closely than that'.

K7. Patient Participant (P4) Narrative

Patient Participant (P4) Narrative

Patient participant experienced physical concerns and received cancer care during treatment transition

- Exhaustion

“The most challenging physical problem I had was the energy level. It was completely, completely alleviated. It felt that it does not exist anymore”.

“Always, always. And I still do, I still do, there’s not a lot I can do now that I could do before, without taking a break. Sometimes your body can take up to 10 years, 5-10 years to come back if it ever does, and I truly think that, that was the worst part of it, the physical. The emotional I could work through it by talking to my family and my doctor and such. But it was the physical, the feeling that I just could not do anything anymore, you know. I was sleeping all the time, I had no energy, I had no appetite, and the chemotherapy did not help with the appetite. It completely distorted my sense of smell and my sense of taste. So, nothing came back to normal until, I would probably say 2 years after my chemotherapy finishes, that things started to taste and smell normal again. But the most damaging would have been the physical issue, the exhaustion, yeah”.

- Hair loss

“My hair started to fall a little, and I panicked, and they told me it was ok, just come to the hospital, we will take a look. And when I got to the hospital, they told me that it was more over because of the stress instead of the chemotherapy because I only had half of a dose.

- Menopause

“Because I had external radiation and internal radiation, at my age of 45 at the time, I went right into menopause, and so they told that it was coming. Your ovaries are going to be like, that’s it, I went straight into menopause. And that, that is a vital piece of information that women should be informed as well. I was. Sometimes, when you have a male doctor, they forget to mention things that our body go through, as supposed to as a men’s. It was the mood swings, it was the hot flashes, I mean I went to my front lawn and stood in the snow in my bare feet, in order to lower my body temperature because my hot flashes were so bad. Then there the emotional torn, like I’m 45 and I’m already in a menopause right now, somehow that could an upside. Uh, but another thing too is that a lot of women see that being a down side in their femininity. There, you know, in the western civilization and such, the change, because, that was a term my mother used actually. The change in your body that you experience when you naturally goes into menopause was thrust upon me because of my treatments and I don’t think, uh, women, some younger women, don’t realize what that does for your body, and your mind, because you have hormones, the uh emotional torn, the quite possibly the lack of femininity, its just, that could play a part in the identity piece as well, menopause for me was, I wouldn’t want to say swift, because it was just a feel years. First year was absolutely devastating, the hormonal influx because I had external and internal radiation, my ovaries were essentially fried form the radiation. So my hormones was essentially depleted because of the radiation, thus my bodies cannot regulate or do whatever they do during menopause, and it was, it was quite a ride, it was quite a rollercoaster ride. That could play a part in the identity piece, where apart from you were pre-cancer, and then you were cancer, and you were post cancer. Not only you have to figure out who you are now as a women, because I'm a women, so you have to figure out who you were now, but you still have to capture what you were a little bit before, you ended in menopause, that is going to change you now, that's also an identity piece, you know, doubting, you know, who am I, what part of me can I keep with me, how can I change new me, into something I'm going to love when I'm with everybody else".

- Patient education
    - What is next

"When my treatment was finished, I finished my external radiation first, and, then my chemo therapy, I still had 2 brachy therapy to reserve, to receive. Right from the beginning they (oncology nurses) told me what I was going to receive and how it will be implemented to my body. Without the oncology nurses being there for me, whether we were laughing or crying or anything during the treatment, without the oncology nurses, uh, I don't think my treatment would have been as emotionally successful for me as it was. Let me think. When it was all set and done, if there was absolutely anything I needed, I could just telephone them. And I phoned them regularly anyway, if things started".

-
    - Exercise and diet

"They (nurses) had advised me that because I had, my body has taken such, for the lack of a better term, abuse, for being through the cancer process and the treatment that to start exercising again, just to start walking, to make sure my diet was up to par, and vitamins, certain kind of supplements, and vitamins I can use to amend my body and heal it again. Umm, they had always said to me that, if I felt like going to a walk, go for a walk. If I have felt like going for a longer walk, go for a longer walk. Even if it was just for around the block more than once, just do that.

- Cancer care from oncologists and nurses

“The transition from being non cancer to being told I had cancer, was a physical and emotional onslaught. I had scheduled for hysterectomy, and because the cancer had spread rapidly, we have decided that the hysterectomy was not going to happen, I was going to come back straight to Oshawa and start radiation chemotherapy, and that’s where I have met my physician and my oncology nurses. And throughout the entire cancer journey, and it was probably all in total, it was close to 30 weeks of non-stop treatment, including a double blood transfusion, keratin-isolation on the cardiac floor upstairs, umm, nothing was left to question, I always felt comfortable enough to ask why this is happening and what is going on, and I don’t know if I was lucky enough to develop that kind of relationship with my nurses and my oncologist, but they were a, uh, if anybody, if religion comes into play, they were godsended because if without them, I don’t think I would have been as emotionally successful through my entire cancer treatment, in transitioning from the end of that back to real life, I’m only on, it’s been a few years where I’m still on the 6 to 8 month follow up to make sure it does not re-occur, and I see the same nurse and my same oncologist all the time and I’m actually looking forward to seeing them. Even though they could give me bad news if the cancer came back, I look forward to seeing them, the emotional attachment we built with each other was phenomenal, whether it was in hospital or me telephoning them asking them for advice, or if I just happen to be here and I saw them. The resources, they told with all the information and resources, that no matter what, I could always come back to them with questions or concerns or something changed. I didn’t utilize a lot of the community resources because I want to stay here at the hospital, I want to stay here. They were very helpful, very understanding, I think they probably went through it a million times before, but without them, the transition would have not run as smoothly as it did from being a cancer patient to a cancer free patient at the hospital”.

“They (nurses) always showed such concern with me. They always made me feel like at that time, even after now, when I still do see them, I’m still the main priority. Because my health is their priority. And I noticed she mentioned something like primary care. My family physician, I went to see him numerous times since my cancer treatment, and his, all he ever asked me is how you feeling. He never went into any detail regarding my cancer treatment. So, I don’t know if that, that is something that you hear a lot or you don’t hear a lot. I don’t think the primary care physicians are, apart from your general health, I don’t think they are, may be in depth, listening to somebody as detailed as they need to after cancer care, however, the staff here, the oncology nurses here, and my oncologist, they would always set aside time, even the slightest thing, the slightest inconsistency in your body when you trying to get over a cold, inconsistency when your body is going through change, of anything you have noticed a difference, and help you figure out where it started, what happened, what is going on, nothing to worry about, that kind of thing. But the physical side of things, that is the most damaging”.

Patient participant experienced emotional concerns and received cancer care during treatment transition

- Fear

“Well, with the emotional part of this, going through cancer, you, first offered diagnosis, everybody relate cancer with death. So that was the first thing I thought as well”.

- Worries

“It was 2015, so I had, how old were they now, they were like 14, 12? My son was quite young, so I worry that if I leave, he would not have his mother, that played on me emotionally. The rest of my family, they would be ok, they would be alright, but I was more concerned with my son’s well-being than anybody else. That played a toll on you”.

“I did mention a word with my family. I told my kids that I had cancer, and I’m not going to die. At the time I didn’t know I’m not going to die, but I told them I’m not going to die. Hmm, they were quite upset about it, because at the time they did not know, I guess they went looking for a cause for the cancer, so they couldn’t, their young brains couldn’t put it together. And I’m emotionally worried that they would detach from me, I didn’t look normal, you know, I lost considerable amount of weight, my face was gone, I had no appetite, you know, when I was at home, I’m usually sleeping after my treatment”.

- Emotional support

“When I found out that I wasn’t going to die because of cancer, shouldn’t have been that severe or wouldn’t have been that severe. The emotional task was, am I going to be ok, am I ever going to bounce back from this? I was given a second chance at life, uh, and the, my nurses, the specifically paired up with my oncologist, they have been working together for quite a long time. She used to phone me and ask if anything was going ok.

She would make sure everything was going ok. Again, if I had any issues, I could just call them and I could come in, if it was just for a 15m minute talk to tell them how I feel emotionally and tell them what is going on in my head and in my heart. They genuinely understood and cared, and tried absolutely anything to make me feel better, by just doing nice things to myself, self-care, whether it is a nice meal, or going out for a nice meal, or just talking to people, talking to people all the time, about what has happened to me, how I'm healing from it, how I progressed through from the transition from a patient to a non-patient with my family,

"The nurses were always there, always there, even it's just for a phone call, or many just to listen. You know, they were the backbone of my cancer treatment journey".

Patient participant experienced social concerns and received cancer care during treatment transition

- Self-identity
    - Identity crisis

"It's almost like it's a crisis, that the terminal you feel inside, because you have developed these relationships, suddenly you are like what am I going to do now, can I go visit these people? Because they have made such a significant role in my life, my identity has become, almost like a no on again. It's almost like, uh, what is the word again, I don't want to say self-fulfilling prophecy, because it's like, well I guess it could be. You get up for your cancer treatment every day, and I try every time to look my best, except for when I need to go for surgery. I would get dressed, I would put my mascara on, I would make myself feel good by making myself look good. So, the cancer treatment, I thought, would work better. These people look forward to seeing you, you look forward to seeing them. And when it’s all done, it’s almost like this crisis because, you are left in limbo, you don’t have to be here anymore. It’s very, that was very emotional, that was like an emotional rollercoaster that I have to leave these people and not seeing them every day again. The hugs, the how are you, the are you ready, the laughter, the you look grumpy today, I would say I don’t want to be here, then they say we know you don’t want to be here but we have to be here”.

“One of the things I think that, I think it could have become a focus, is, if that, if that’s quite possibly what you are looking for in your work, in your research, uh, could be that, the uh, the potential for the identity crisis, because, I was still a mother, I was still a wife, I was still a sister. Both of my parents are deceased, so uh, I was an aunt, because my niece was here with me during my time at the hospital”.

- Whole person changed

“And then, your identity almost becomes synonymous with being a cancer patient, and when it’s done, you are, now, now what I do. It was a lot of internal torn on you that you realize how much these people mean to you, and how much you are going to miss them and it’s almost like you need to reclaim your identity again to be the person you were prior to them. But like I said before, I don’t know if that person still exists because I have gone through all these cancer treatments, I’m physically different, I’m emotionally different. My world view had changed, and you are just, what do I do now. So, you almost have to reclaim yourself, maybe that term survivorship comes in”.

- Loss of previous self-identity

“There is that loss of self-identity, because you are like, I wasn’t who I was before, I wasn’t cancer patient anymore, who would I be now? You know, how can I, how can I recapture, some of what I have, think about, how can I recapture what I have, to still be the same person, but I'm not going to be the same person.

  - New-self identity

"uh, I don't know I would like to say survivor, I would more like to say a victor. I battled it, and I was victorious at the battle, it didn't come to claim my life, so I was the winner, I was victorious in the battle. It's ok if you are called a survivor, because a lot of people don't know what to say, they don't know, like well you had cancer, so you are a survivor? No, I'm just victorious at the battle I had with cancer because after a while, we have gone through all the discussion and how we are going to proceed with care, I had finally learnt that it wasn't going to kill me. I just had to do these treatments and make sure it was gone. So, uh, the survivor, yeah, there's a lot of people that had much worse journey than myself and I would call them survivor. I was just victorious with my battle with cancer".

- Label of cancer survivors

"Uh, honestly, I would prefer to say that I beat it. I fought it and I beat it. Because I guess, you could use survivor, but it is not usually one of the terms I familiar myself with. I just uh, I like to say that, yes, I fought and I beat it, I'm the victor in the battle, I won that one. One for me, zero for cancer. Yeah, there's a lot of people that had a lot more vigorous battle with cancer, but it uh, survivor is a different term, survivor makes me think that, uh, when I think of survivor, well I don't want to describe what I have gone through, because it is traumatic. Well it is a big change in my life, it changed my view on my life, my advantage point in my life. But, survivor, when I think of survivor, I think of somebody that have gone through something that is a lot more difficult than I have. I would like to say I was victorious in my battle with cancer. I mean it’s a hard thing. I never think of myself as a cancer survivor.”

- Return to new normal life
    - Need to live new normal life

“I don’t know if, I don’t know if I would physically every be able to go back to what I was before, uh, emotionally, it, it changes a person, it does, it changes a person psychologically, emotionally, it changes a person’s view of themselves, a view of everybody around them. I don’t think, I maybe I don’t think that person exists anymore due to the transformation I have gone through because of cancer. And seeing what I have seen with the treatment I have had, just at the time when the treatment are happing, the things you are thinking, because, you know, it’s quite, it’s completely life altering, you don’t know what is at the end, or what is happening at the end. I’m not sure if that person will ever exist again, but I’m trying to get this person back up to the physical capabilities that I was before. Emotionally, I’m ok, but every now and then you know, someone would bring up the topic and they will ask you, you had cancer? What happened? You then relive it. It brings all your memories back to the front of your head when you are trying to get the recesses away. And it’s a very strange journey you go through. It almost like you are one person before and you are a different person after”.

-
    - Education for adjustment to new normal life

“Well, I was instructed that it was probably going to take some time for my body to recover. And emotionally I would probably take some time to recover as well. Because when my treatment needed in September of 2015, it wasn’t until the following April? April 2016, that found out my cancer was gone, because we had treatments, we had visits, we had MRI, examination as such to make sure that it was gone. It took all of that for me to make sure that it was completely gone. And then there was the follow-ups, the one-month, the three-month and the six-month, and then the eight-month. And from there, they said that if there's anything I needed, I could just call, or I could just come in. If I know my oncologist or my nurse was here, I could just come in, like walk in just to talk to them or something like that. Umm, just to make me feel better, just to make me feel that I was not losing my mind, or there was not anything physically wrong at the time. But they told me that it was going to take some time. It was not going to be cold on cold normal again. My body was going to have to adjust, I was going to have to adjust to a schedule again, a normal schedule, because when you are going through chemo therapy, radiation therapy, brachy, I remember after my first chemotherapy, I went home and slept for 16 hours. Uh, so, there was a lot of that, there was a lot of the fatigue, and the, and they said that it was normal, because your body was trying to heal yourself. And it was very difficult at time, trying to deal with the fact of not having the energy to do anything, but wanting to do stuff, and I knew from the back of my mind, I could hear my oncologist say that it was going to take some time for my body to come back. Just get up and go for a little up, just do whatever you want to do, get some fresh air. She knows I have a swimming pool in my backyard, so she told me to go for a swim, in circles, do whatever you need to do, just to get your back into doing things that it hasn't been doing for 6 month, whatever it was. So, uh, any questions I had to ask, they were willing to give me the answers. Anything that I wanted to try that was different, you know, vitamins, supplements, any kind of dietary changes, when I called them, they were always willing to assist me. Yeah, without them, I'm telling you, oncology nurses, they make, they make the difference, they do, yeah. I mean, my oncologist was my life saver, because she did my treatment plan, you know, my chemotherapy doctor, you know, all that. But those nurses, you know, they, they are just special, they are just special, and they really make you feel that no matter whatever you are going through, you will be fine, they will help you, they will do whatever they will need to do. They will laugh with you; they will cry with you. They make, they can make or break a person, when it comes to a cancer journey. I mean my oncologist was a wonder woman, she was fantastic. But the nurses are just, they touch, just amazing".

- Return to work
    - Work part time instead of previous full-time job

"I went back to work, I went back part time, for a little bit, to ease myself in, then I went full time, I realized I just could not sustain the full time hours, I was physically exhausted, like to the point that I was nausea when I finished a seven or eight-hour shift, I just, I couldn't do it. So, I work only 4-5 hours a week now, I go to school, and I found that just enough because it breaks it up. I don't know if it was, maybe, possibly, it could have been the situation of doing my same job as I was doing before, after I realized that I needed to do something different, I wanted something different. Physically, I can't do up ladders, down ladders, carries boxes and do this and do that. May be, I could utilize my body in a different way, and I could just help with the customer service aspect of the work of the location where I go to work. They were so receptive. They were so happy to have me back, uh, people were, you know, customer that recognize me that noticed that I was gone, and of course I have to explain to them what happened, when I felt like it, you know. If I didn't, I would just, you know. Work was like, exhausting, exhausting like, you don’t realize it was how much of a toll, doing cancer treatment on your body takes on your body, until you actually have to try to get back to what you were before. So, I was physically exhausted. I would cry, because I would just, I just don’t feel normal like myself. My body ached, it hurt. I had no strength left in me anymore, and, it’s, it’s damaging. Because from the physical aspect, it plays on your emotional side, right? And I just didn’t want to feel weak anymore. So instead of damaging myself to work a full-time job, I went down to part time. I feel fine, doing that, and school, just breaking it up, having something different to look forward to, so. And I get to sit down, at school. And I get to sit down and work, if I get too tired at work. And I don’t think people realize what that does to your body until you actually gone through, you know, because I have people say to me, how could you feel tired all the time. Well, I have completely eradicated cancer from my body with external radiation, chemotherapy, and internal radiation. I have, you know, I have a lot to bounce back from. I’m trying, I’m working on it”.

  - Supports and education

“I was actually taken out of, I honestly think, my oncology team’s hands when I went back to work. My work was very understanding, I had to explain to them precisely that I can only do so much. And they were fine with that. They did not have any issues with me sitting down now and then, or taking an extra break or that kind of thing. And again, when I called to speak with the oncologist or the oncology nurses or any of the nurses in my team at the time, you know, they were so genuinely concerned. Like I said we have developed this emotional bound with each other. Throughout my journey, they were so genuinely concerned with what is going on with my body. So, if physically I couldn’t do something., If there was something wrong, they would want me to give then what I was doing prior, what I was doing after, and what I was doing in the middle and such. And they always suggest that if you want to take it easy, if you want to come in and see us, or if you want, if you want to talk to somebody, or if you want to go easy on yourself, don't go so hard on yourself physically, because you weren't who you were before. They were fantastic, you know, and I could physically tell you, without them, without a doubt, the treatment I received here, was absolutely, absolutely unsurmountable to any other treatment I have ever received at any other hospital or clinic at any other time of my life. And I firmly believe it was my oncologist, and probably her nurses, her right-hand nurses. When I had the brachy, when I was in recovery, I was seeing the nurses in my head, I can see the nurses. There was one, two, three specific nurses more over just the two with my oncologist's right hand nurse that made me feel that they, that there was such an emotional bound we have developed with each other, such an emotional attachment that they really did care, that I was feeling down, that I was feeling sick from the treatment, I was feeling pain form the brachy treatment. They did everything they humanly could to make me feel better, as a cancer patient, and also as a human being. And as the oncology nurses at down stairs, and the nurses you see here, they are phenomenal. They are an amazing set of, I have never had a mail doctor. They are an amazing set of female doctors, or nurses, sorry, that make you feel you matter, make you feel that even if it's for just that time, you are their main concern. And even after I come back from my follow up treatment, and when I see them, it's huge hugs, it's how are you doing, it's how are your life going, a lot of the nurses of the oncology happens to spend a lot of the time down stairs with the brachy, and the surgical suites and whatever needed. I truly feel that these nurses were an integral part of the healing process when it comes to the end of cancer treatment or the journey through the cancer treatment. Without them, you are just someone that comes out of the surgical room and lying in the recovery room wait till you can go home. And they make you feel like you matter. I truly, honestly can say form my heart, without lying, that I truly love these women for my life. And by the end of my treatment, I was so sad, so devastated that I don't get to see them anymore. They have become such a figure in my life, they made such a difference, and I was thoroughly, thoroughly going to miss them. I was saying good bye to them like family members. They made the journey, they made the cancer journey, everything, better, then I could have ever ever imagined that I was going to go through".

- Meaning of survivorship
    - Loss of previous full-time job and back to school

"I uh, went back to school full time, this year, after a few years of humming and hiding, going from full time of my job to part time because my physical level wasn't, they weren't coming back as quickly as I hope it would, but I have decided to come back to school. I guess my identity, there's me, and there will always be the stigma of, you know, having cancer and beating cancer".

-
    - Loss of friends

"I did lose a few people of my life I thought were closer to me, than they turned out being. They just fell off the radar, sort of speak, and I let them go, because if you don't want to be in touch of me, when I'm experiencing probably the hardest journey of my life, I probably don't need you anymore".

- Live a better life with the second chance

"Well, my life was completely turned around. I have decided to make better of my life. For normal life, it took me quite some time, I was tired all the time, still. I was grateful that I actually get to go out and socialize again at work and speak to people. They were so welcoming to have me back at work, it just, I guess it's something you have to give day by day because, it's, you never how you are going to feel. We could get out of here today, god forbidden, get into a tragic accident, that could, I could die by getting hit by a bus you know. My meaning of life has changed. I take this as my second chance, and you know, the universe doesn't hand them out too often. So, I think that, with my perception and my perspective of changing, and me wanting to change, how I do things in my life, how I want to be for the later part of my life, I think I'm on the right road of making a difference for myself, and for the path I have chosen. For my identity, I always think I would be me, and then I would always be, maybe, the term cancer survivor can come back to play. It would always be there, no matter what, who, where, or anything, cancer would always be there. It's a strange thing that is happening. It's probably something that is going to happen for the rest of my life. I don't really mind, you know, I beat it".

- Relationship with family enhanced

"You know they (family) are all willing to assist me and help me with what needed to be done. They were, because I could be very stubborn, I like the house a certain way. They did their very best to make sure that the house is up to my standards to make me happy".

"In fact, it made me to appreciate them more. Because it was tested. You know I have to go through this journey of cancer, and I have a very close relationship with my significant others, and my children and my sibling. I have one sibling that lives out of the country.

They were all proud and happy that I was victorious in the battle with the cancer. I mean the cancer does seem to run in my family genetically. So, yeah, I have taken a totally different perspective at life. You know, those things that used to bother me at life, they don't matter anymore. The little things at life that got you angry, that make you frustrated, you know, they don't bother me anymore, you know. Because you fought bigger battles, so the little silly ones, they don't worth it. It's not worth it, you spend more time with your family, you spend more time with your relatives, you keep them, you keep them close, I mean it could come back, I'm hoping to hope that it never come back, but it could come back. I keep my family close; I realize that I'm very lucky to have the opportunity to see my children grow up. I get to, you know, get to be an old lady someday, you know".

Patient participant experienced self-care management transitioning from acute care hospital to home

- Self-care management

"Well, uh, one of the first things we did is we went on vacation. We, it was in, October, we went to Mexico for a week, just to completely get away from this life. Just to go away and relax, and of course I had to hide form the sun because I just had the radiation, I can't be in the sun. I did a lot of journaling for selfcare, to get out of my head, which I wanted to but I don't want to tell anyone else. Uh, usual things, I, I have sat in my backyard, I have got caught on some reading, and I just had to work through what it just happened in my life, in my head to make sure that I could be a good mom, I could be a good wife, you know, I didn't want to carry any additional baggage from the hospital to home. I tried to keep thee 2 separates, but when I have done all my treatment, and I come home, my family was wonderful when it comes to accepting me finishing my treatment. They always come to help me, and uh my self-care was working through what I worked through, almost in a way of being grateful. My parents, they were both deceased, they were not here to see me to go through the regiment of cancer treatment, uh, and, my kids were fantastic, we do a lot of talking again, uh, me explaining to them what happened. Well we did this throughout the whole thing, I thought I maybe should give a more detailed explanation. And, uh, what else did we do, we went on vacation, we took it easy before I went back to work, we went to see my brother, and being in the states for Christmas, to celebrate with him, because I haven't seen him, because he lives in the states, far out, so it was not just a drive. I uh kind of regrouped a lot with the family. Of course, I stayed close to my family, I made sure with her that I could fly. Uh, that's soon after all the treatment were set and done, I tried to get back to my diet that I had before, trying to regain the things that the chemotherapy had distorted. Because of the chemo therapy and the radiation, your body was completely 2 different things. Chemotherapy can cause you to have constipation, and radiation can cause you, because I had radiation in my abdomen, that can cause diarrhea, so, and I eat a lot of fruit and salads, so they told me that I have to stop eating that, and I told them I can't stop, that's my favorite food. However, chemotherapy distorted some of the taste of it, so I tried to get my diet back to normal. Just to take it easy, slow, not to push myself. It was after that I tried to get back to where I thought I could physically, I can't, I couldn't, uh, did a lot of soul searching, you know, and being forever grateful. Really after that, is when I started my journey of changing my life. Not just having a job that I want to, I wanted a career, I wanted to do something, I want to make my children more proud of me, not only that I have beat cancer, I wanted to do something that make them, you know, proud. I do a lot of self-care, even now, after all, I highly, highly value my alone time, my individuality that I left home by myself, to do my own thing, whether it was to read, to journal, to do crossword puzzles or word search or whatever it is, and my family respects and understands that. That, that, you need that. You need that.

- Education

“They had suggested pretty much that I do whatever I felt that I needed to do, uh, whether that was uh, a yoga class, you know, uh, anything but to take time for myself when I needed it, not to push myself, just let my, listen to my body, be in tune with my body, so, if I was over doing it my bodying is going to tell me anyway, so I have to listen. Again they suggested physical exercise, walking, maybe doing a little bit of higher walk, if I was going to the gym and use the treadmill, pick up the pace a little bit, because that way you are running the lung spot, my diet, vitamins, supplements, just to take care of myself, to do whatever I needed. It doesn’t matter whatever other people thought or suggested, it was to do what I needed. One of the ones was the trip to Mexico, I just left the kids at home. It was fabulous, because I didn’t do that or anything, we just laid on the beach, laid around the pool, had food, napped, it was a great escape, that’s what it was. And the Christmas visit with my brother, it was a great rebounding time. I did not realize how much I missed them, how much I was grateful of him, his wife, my nephew was in my life”.

Patient participant experienced communication transitioning from oncology team to primary care provider team

- Communication among cancer survivors, oncology team and primary care provider team

“Well uh, my family doctor has been my family doctor since 1991, uh, and for the length of the time I have known him, wonderful doctor, absolutely, and there really has been no hand over. I still come here (DRCC), uh, and I still, if I had to tell, if I have to tell you the truth, I feel more comfortable to come here and speak with the oncologist and the oncology nurses with any kind of physical issue that I’m feeling, or any kind of emotional issue that I’m feeling. It’s uh, I don’t think I want the hand over to ever occur. Even though my GP is a wonderful man, my oncologist and the nurses were there with me, so I don’t, I don’t think in my mind, I could be wrong, but it’s just my opinion, I don’t want my primary care giver, my family physician, my GP, I don’t want him to participate in that part of my life, I rather keep it with my oncologist and my oncology nurses. Uh, I think there’s just more, more attachment, as I mentioned before, the bounding through treatment, the genuine care and concern, they have as opposed to my primary care physician, and I like that relationship. And I think I would like them to stay separate. Yeah, I would rather my team to stay here at DRCC, keep everything happened here, rather than having to explain to my GP. I’m pretty sure that he knows what’s going on, he has read the notes and everything. But I rather keep that part of my life here, separate. I think it’s a good thing. Until that I’m completely discharged, then that’s totally different. But now I’m still visiting my oncologist for 6-8 month follow ups. I like it that way. I want to keep that part of my life with them”.

Patient participant experienced recovery of body function transitioning from acute cancer treatment to follow up care

- Recovery of body function

“My main concern was my energy levels. They (nurses) have advised that I do something, like I mentioned before, the yoga, doing some physical exercise, doing something you know that make me, because in order to create energy, you have to spend energy. I believe that, with my best interest in their hearts, they have told me that the physical exercise, you know doing something that would promote me to looking forward to doing something like that. They told me that anything that I felt I could do without straining myself, or uh, doing myself any damage physically or emotionally, I should try it. Don’t overdo or over try anything. Uh, but to do what I felt that I needed to do, like the walking, maybe joining my local gym, uh, what else, yoga classes, if I felt I was ready for it, I could do a dance class, you know, that kind of thing. Even maybe meeting up with groups, or, you know that kind of thing. It, it’s, for as much as they have advised me, they pretty much always left the ball at my core. Because I know what my body can do and cannot do. I have to listen to it, so, they advised that you know, anything I felt that I could do, I was ok to do it as long as I wasn’t straining myself, or it didn’t scare me”.

Experience influencing delivery of cancer care and quality of life

- Positive experiences promoting delivery of cancer care and quality of life
    - Emotional support

“Well, I honestly, I don’t think my oncologist or the oncology nurses could have done any more for me emotionally. They were there for me, they held my hand when I was going into surgery, they held my hand when I came out or brachy therapy, uh, same with my MRIs, we walked the halls together. The emotional attachment you develop just improves your overall cancer journey. And I'm a firm believer that it can improve your overall rate of healing and survival, because you realize that you have these people, who almost in a sense that loves you and want you to get better, you know, in probably in some way, they don't want to see you again because they know you have healed, unless you are coming back for a visit. The treatment transition, you know I'm still going through my 8-month follow up appointments, I look forward to coming in to see these people because they made such an impact in my life. They made me feel that, that I mattered. They, I honestly, there's probably not much left that they could have done to improve the quality of life during my cancer treatment, and during the transition out, because, and they, one of the ladies in the chemotherapy suite actually told a joke that "I don't want to see you anymore" and it was a good thing because that means I didn't need any more chemotherapy. They are, it's just, these women, these oncology nurses make such a difference in your journey, in your treatment, and even the days where I had brachy treatment and I was in so much pain, I was crying, and the one nurse was crying with me, because it hurt her to see me hurting. After a while, it sinks in after it's all set and done, you realize that these people do really care about you, you know. For the emotional needs, they, like I said they held my hand while I was going under sedation they were there when you wake up, you know the "how are you feeling", "how do you feel" "what do you need", or even they were just sitting and talking to you during recovery to make sure that you were ok, they make the transition from, uh, they make the transition from being a cancer patient to somebody that has victoriously beat cancer or being a cancer survivor, because you matter to them. They want to make sure you survive. Anything, anything that I needed to improve the quality of my life, all I need to do was to ask them, and they, there was no holds bars when I came to them for an answer. They were honest, they were genuine, they, you know, without those oncology nurse, I think, my treatment would have been devastating".

- Barrier inhibiting delivery of cancer care and quality of life

"I didn't have any".

"Yeah, I can honestly, honestly tell that, I didn't have any. Other than the discomfort of the treatments that was saving my life, I had nothing, nothing at all bad to say about the treatment a received form anybody in this hospital ever. Even when I was upstairs, because I had a treatment for brachy, and I got up because my doctor, my oncologist and my nurse was taking me to the bathroom because I was sedated. And, or just coming out of the sedation, I coughed, it sounded wet, and both the oncologist and the nurse looked right at them and right at me, my oncologist said where did that come from, I said I don't know. She said that that was wet, and it turned out that I had an infection, and it was a cyst that nobody knew, was there, because they couldn't see it because it was burnt from the radiation, but it had led to an infection. And I ended up being admitted that day to the hospital, and they are sitting and waiting for a bed to come clean in the cardiac floor because of isolation. One nurse, the one oncology nurse that was with me that day, she stayed here until 8 o'clock that night with me, until I got my room. We said good bye, went upstairs, and I went up there, and I had, I had stopped, for a lack of a better term, I stopped making my own blood. Uh I had went grey, my skin was horribly ashen, I felt obnoxious, my blood pressure I think was 60 over 40, uh, they decided that I need 2 transfusions, both with intravenous antibiotics, and that day, probably, was probably that a realize that I was living on borrowed time without that transfusion, and everybody being as concerned as they were. And I was on that floor for 3 days for isolation. Even then, I honestly had nothing, nothing bad to say about the treatment I received here from any oncology nurse, my oncologist, anybody. And it, when you were faced with cancer, apart from where you were faced with cancer, you are making all these life changes, this is happening, that is happening, the people here make the difference, and I have nothing, nothing bad to say, at all, about anything, anything about the nurses, my oncologist, the people that were up at the cardiac floor, I don't even know what floor they were on. The people in the MRI suites, the CTs when I was getting treatment, elevators, even, it was phenomenal treatment that I receive. I will always hold a special place in my heart for the Durham Region Cancer Center because the team that was here at the time saved my life, and they made the difference, and I, there nothing bad I can say, nothing bad ever happened to me, there was no rushed appointment, no missed appointment, something went wrong, nothing like that. I guess you could probably say that I own my life to the people here because they saved it, they give it back to me. Without the nurses being there, holding my hand, the oncologist laughing with me, I really don't know where I would be, when I'm done this".

Suggestions and recommendations to improve delivery of cancer care and quality of life

- Not rush from cancer patients to cancer survivors

"Ummm, I think, I think maybe, if, like I said the identity crisis part, that might be something that, I think sometimes, people do feel rushed with their appointments afterwards, maybe they could allow the oncologist, the doctors when you come back for a visit a little bit more time. Just to talk and to catch up, you know, if you have any questions or concerns, or anything like that. I know sometimes they feel rushes. I know a lot of people"

- Encourage patients to ask questions

"I myself, I never feel rushed. I can always, I, I'm coming here for me, it's my priority, I want to speak to you regardless of the time that it takes, that's how long it's going to take. I'm the one that is never afraid to ask the questions. But I feel that sometimes, patient of different generation might be a little bit more reserved to ask questions and regards to their treatment plans, and or their quality of life during, and after that kind of thing. I just, it's, I guess it boils down onto something that is more of a personal level, that, people shouldn't be afraid to ask any questions. It you feel that you need more time talking to your doctor, don't be afraid to tell your doctor. I'm not finished, I just want to talk to you about a couple more things. But, if, I don't know, maybe if they can, the oncology nurses that are coming in from the school, that are graduating, that are coming in from the school, pay attention to the lady that have been in here for a while, if you are lucky enough to have you know".

- Everyone matters

"Pay attention to the women who have been doing what they have been doing here, for quite some time, because they are the ones that develop the relationship. Don't every brush anybody off, don't ever make anybody feel that they don't matter, because they do. And if you ate here receiving cancer treatment, your life if probably hell, for you emotionally, psychologically, maybe even physically depending on what type of treatment you are receiving. But if you can learn from the women who are already been oncology nurses for some time, and men, which ever one you are lucky to get, because it's not all women, I had all women. Because they can teach you, just that little bit extra that would make a patient to feel a little more important, a little bit more comfortable, uh, a little bit less anxious, or a little bit more comfortable to ask questions or to say little things, you know to ask for help. Always remember to be nice to people, because cancer journey is hell. So, if somebody is a bit aggressive or abrasive, just take it and strive, because it's going to happen, people are going to be grump. They were trying to save their own life".

- DRCC

"I, uh, uh, never ever go anywhere again, and I remember when it was being built all those years ago, Durham Region Cancer Center, and I thought this is going to change, this is going to change Oshawa. And then you realize that, people in the waiting room, they are coming from 3, 4 hours away in order to see a specific doctor. This place makes am impact, this place saves life. The oncology nurses and the oncologist here, they make a different in people's life, they save them. Sometimes they save their sanity as well, by being the kind of person that they are listening, and holding on, and realizing that people that are going through cancer journey needs support, so, it's uh, I have nothing bad to say, it's a wonderful place and it saved my life".

K8.	Patient Participant (P5) Narrative

Patient Participant (P5) Narrative

Patient participant experienced physical concerns and received cancer care during treatment transition

- Pain and nausea

“I had everything. I was nauseated, I had bone pain, I had, uh, mouth sores, I had every physical symptom that I could possibly had. I have neuropathy, where my hand and feet hurt and went numb. So I suffered a lot of symptoms that they listed off, I had them all”.

“Well physically, whether the radiation or the cancer treatment, I had a lot of the side problems. I had neuropathy in my hand and in my feet”.

- Tiredness

“I have less energy. And so, I’m more tired sometimes, and uh, there are things that I cannot do that I did before”.

- Lymphedema

“You know, the only thing is, when I started to look like I had lymphedema, the nurses, there was one nurse that was able to say, lymphedema, you look like you are going to have lymphedema, you should have that checked”.

- Scar tissues

“I still have a lot of scar tissue that causes my mobility to be different. The scar tissue has done a lot; I don’t have much mobility. Uh, the nurses haven’t provided me with anything, but I do a lot of other treatment. I do a lot of massage, for the scar tissue, and I have to go to the chiropractor, I have to take medication so my feet don’t burn. I just return to work part time because I cannot do full time”.

- Chemo brain

“I still have memory issue that I have to work on. Brain fog, you know, there are things that just happens and you just have to work with them. I forget where I’m going, I forget where I have put things, I was tired all the time. Uh, I forget names that I used to remember names a lot. Those kinds of things a lot”.

- Active self-care management

“I, uh, actually don’t think I received a whole lot of information. I was able to do some research on my own, and I came prepared with what I thought would be good for me, and discuss it with them. I asked them about the information that I have found, they didn’t actually give me any information”.

- Patient education

“The other staff were saying to me the stuff that I have already know in terms of, you know, I was pro-active, so I have already gotten information as to what would make me feel better during treatment, or what are the things that could happen. They did give a booklet, so I was able to read through the booklet”.

- Therapy

“I was provided what I was prescribed, I also went to have acupuncture, and I had, uh naturopathic oncology, so I did a lot of the natural stuff to help with my symptoms, which did help a lot”.

- Support

“The oncology nurses. She either say ok, come in, or wait I’m going to check with the doctor and call you back, umm, they would send prescriptions to the pharmacist for me”.

Patient participant experienced emotional concerns and received cancer care during treatment transition

- Frustration

“Because I always wanted to do things that I used to do, you know, and so sometimes you get really frustrated and upset that you cannot do those anymore. So now you realized that you just have to do things differently or those things will eventually come back. I just work with what I have, right?”

- Stay positive and active

“I’m a very positive person. So My faith really helped me to stay positive. I spend time a lot with prayer, and I spend time a lot with positive people and trying to continue with the activities that I normally do, I try to do them, so I spend time try to do walks, I spend time on those. When I couldn’t, I spend a lot of time in bed, playing music, and resting and reading, and so those things really helped me.

“Yeah, nothing, they thought I was coping well, so they didn’t provide anything”.

Patient participant experienced social concerns and received cancer care during treatment transition

- Label of cancer survivors

“I don’t think there is an appropriate term that can describe me”.

“I would say, yes, because I am still surviving. But I mean, I had a friend who had passed away because of cancer. But I still refer her as a cancer survivor till her death, we all lived cancer, but we lived life. Thus the cancer survivor is very minimal, because sometimes, it feels more like an overcomer, sometimes it feels more like a warrior, sometimes you feel like, you know, cancer survivor, it's fine, because it is, we are surviving, we are not just surviving, we are thriving, so we are not insulted by it.

- Return to new normal life

"How would I define survival? Uh, it's a new normal, that's for sure".

"uh, I mean, cancer does a lot of things, not just physically affect you, but emotionally and mentally. And you never look at things the same way. You decide what are the important priorities, you make some changes that you need to make, and your body doesn't even respond the same way when you come out of it. And even when they say you done well. That's why they usually say, it's a new normal. And so, I'm more tired sometimes, and uh, there are things that I cannot do that I did before. Will I do them again? Maybe, but right now, it's a working progress. So, it is a new normal because it taken out somethings and you add somethings. And most things that you add are some stress, so you don't over add things that you used to stress over before. A new normal, it's not the same".

"I was a very active person, very go, go, go, go, go. But now I'm often resting. I do say no to things, I do take some time, I was very big about how clean my house was. But now, if it cannot be done, I don't care".

- Meaning of survivorship
    - Fighting against cancer

"The fact that I was able to make it through, is, uh, you know, I fought because I have a husband I love. I fought because I have children I love. I fought because I have a family. So, for me, uh, my meaning was to live for them. Right? To be able to experience life with them".

- Life goal

"You know, even though I'm different, I'm not as fast or busy, I want to enjoy every moment"

- Cancer care

"No. I don't think that, I don't think the oncology nurses, they treated me well there. There were really good to me when the cancer treatment is going through, or when the radiation is happening. But there has not been any contact after that where they have been giving me things say, here, how we can help you with what. I haven't got any information from the oncology nurses".

- Own coping strategy.

"My own? I talked to a lot of people, or where I go back and give back. I volunteered at the cancer center in Oshawa, the hearth place, again, not because of a nurse told me to go there, it's because my sister did or because I found it, myself. Uh, and you know, the hearth place provides exercises, and classes, lessons on memories, those things, I took upon myself but the nurses, they didn't really show me those things".

Patient participant experienced self-care management transitioning from acute care hospital to home

- Self-care management

"Well, for me, I don't feel like my experience was any different, because I was self-care managing anyways. I was proactive, I knew, I didn't want to be nausea, so what can I do that is not drug related that I can use to help with this. And it is the same care now, right? I was doing naturopathic oncology, and acupuncture, and massage, and, you know, chiropractic, and I am doing those things still, to help my body heal and adjust, so, it's the same things, the only change is that I'm not on chemo or radiation, but I was doing those things that helped me feel better when I was on chemo or radiation, I'm continuing to do those things to make me feel better now".

    - Support?

"No, no. But from the hearth place health care, so I do lymphatic swim, I do lymphatic exercise because I saw the lymphatic specialist at the hearth place. It wasn't because of the hospital and the nurses, it was because of the hearth place, that I have gotten more care for my issues".

Patient participant experienced communication transitioning from oncology team to primary care provider team

- Communication among cancer survivors, oncology team and primary care provider team
    - Contact both the teams

"Well, I'm only a year and a half out. So, I still see the radiologist and the oncologist and the specialist. I see the surgeon once a year, I see the oncologist twice a year. I see the radiation oncologist one a year. They have not handed me to my family doctor, and I don't think they do that until after 5 years. But my doctor is still involved, my family doctor. And between the 4 of them, I get very good care. So if I feel that if anything is wrong, I could call any one of them, and the appointment is made. And so, between the 4 of them, and I see any one of them, and I express my needs, and they do whatever they can to help and take care of me".

    - The two teams communicated by paper works

“I don’t know if there’s any, I don’t think there is communication, I think they send information, because I think it’s all on file. Or through the internet. But they don’t talk. They just sent paper”.

Patient participant experienced recovery of body function transitioning from acute cancer treatment to follow up care

- Recovery of body function

"I found it to be, like you are now out of acute care, then a lot of digging in term of, the questions and answers are all question marks. You know what’s going on, or just try this, or it will come back to you soon. It’s almost like, the care is not as specified, or it’s not as concentrated. They are busy, they have patients going through chemo, so my needs are not as important”.

Experience influencing delivery of cancer care and quality of life

- Positive experiences promoting delivery of cancer care and quality of life
    - Stay positive and active self-care management

“I think, for me again, it is the proactive nature that I have, I surrounded myself with my family, my staff, knowing that the hearth place is the second family for me, the hearth place cancer care center. I’m very involved in all that. When the hearth place has sessions on, you know, things that interest me, I go and I sit and I listen to those. Uh, I find that, again, it’s the same, going to church was important to me, going out with my friends and my family, getting involved in the sports my boys are doing, being able to watch them, doing those things help me transition well into normal life, and eating well. So for me, it’s knowing the things that make me feel good, knowing the things that help to fight cancer, I keep eating those things and doing those things. So that, mentally and physically, I know I'm feeling better because I'm making some good choices about what I eat, what I rest, where I go, who I spend time with, those were all positive factors in helping me cope".

- Barrier inhibiting delivery of cancer care and quality of life
  - Finance

"I think the barrier is financial in the sense that, I think in treatment, they think that it's good to take this long. But when it takes longer, and even after you used up, I don't know, I was a teacher, so I have insurance. But I only have so much insurance, and so then, the barriers are, I need consistent massage, or I need consistent physiotherapy. They think that it should be gone within this period of time, but everybody's body is different, so it's not gone, and I still need to do all those things, and it cost money, it cost money to do all those things. So those are really difficult because they cost money to repair the body that was damaged, you know, I'm doing more than I needed to do before and all and nobody is paying for it but me, right? But my family, right?".

Suggestions and recommendations to improve delivery of cancer care and quality of life

- To be treated in holistic way

"I really do think that cancer care involves the integration of all aspects of care. So, not just medicinal, but adding the natural, you know, being there to allow integrative care it's not just fight the cancer, but it's also strengthening the body. So you need to strengthen the immune system, you need to strengthen the mental capacity, and you need to be able to say, you know what, everybody's body is different, the journey is not just this long, it could take 2 years, it could take 3 years, it could take, and given the integration, and the health care that is needed for that period of time”

- Effectively communicate information

“I think it’s just being able to always talk to somebody. Because when you sick, you don’t necessarily read the information that is there, and so, knowing that what’s in there, should be talked about again, that would be great. Doctors talked about it, oncology nurses talked about it, it should be in the hospitals, you know, sometimes, you just don’t feel to read and it’s a lot of information, right? So, I think it’s just repetitive that should happen all the time”.