Optimizing Registered nurse roles in the delivery of cancer survivorship care within primary care settings

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By

LINDSAY YUILLE, BSc.N, B.A. (Hons)

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AUTHOR: Lindsay Yuille, BSc.N, B.A. (Hons) (McMaster University)

SUPERVISOR: Dr. Denise Bryant-Lukosius

SUPERVISORY COMMITTEE: Dr. Ruta Valaitis

 Dr. Lisa Dolovich

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**LAY ABSTRACT**

 The current approach to cancer survivorship care (CSC) in Canada is unsustainable due to the rapidly increasing number of cancer survivors at a time when there is a shortage of human and financial resources. Patients diagnosed with cancer are living longer and there is growing recognition of the chronic nature of cancer survivorship. Provincial cancer agencies have introduced new models of post-treatment follow-up involving earlier transition of cancer survivors from specialist care back to their primary care providers.
 Currently, there is a gap in research evidence regarding the role nurses working in primary care settings play in the delivery of CSC. This thesis will describe the results of a qualitative descriptive study that identified and examined the strengths, gaps, barriers, and opportunities for optimizing nursing roles in the delivery of CSC within primary care settings from the perspective of registered nurses practicing in primary care.

**Abstract**

 Current models of cancer care delivery in Canada are unsustainable due to the rapidly increasing number of cancer survivors at a time when there is a shortage of human and financial resources. With improvements in early detection, diagnosis, and treatment; patients diagnosed with cancer are living longer. There is also growing recognition of the chronic nature of cancer. Provincial cancer agencies have introduced new models of post-treatment follow-up involving early transition of cancer survivors back to their primary care providers. There is limited research evidence about the role nurses working in primary care settings play in the delivery of post-treatment follow-up and cancer survivorship care (CSC). The purpose of this study was to identify and examine, from the perspective of registered nurses, the strengths, barriers, and opportunities for optimizing nursing roles in the delivery of CSC in primary care.

 A qualitative descriptive study was conducted. Participants were recruited through membership lists from the College of Nurses of Ontario and the Canadian Family Practice Nurses Association Ontario and snowball sampling. Purposeful and maximum variation sampling techniques were employed. Participants completed an oral demographic questionnaire and individual semi-structured in-depth telephone interviews. Data collection and data analysis were conducted concurrently.

 The final study sample included 18 primary care registered nurses from 9 of 14 Local Health Integration Networks across Ontario. Overall, participants’ involvement in CSC was quite limited. Registered nurse involvement in CSC was categorized into three relevant themes: care coordination and system navigation; emotional support, and facilitating access to community resources. Barriers and facilitators to optimizing nursing involvement in CSC related to individual participant, practice setting, and primary care team factors. Participants recommended multiple strategies for expanding the role of nurses in CSC.

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# Format and organization of this thesis

 This thesis was prepared in the standard thesis format as outlined in the McMaster University School of Graduate Studies Thesis Preparation Guide. This thesis is comprised of five chapters: introduction, literature review, methods, results, and discussion and conclusion.

# Chapter 1 Introduction

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life (National Cancer Institute (NCI), 2012). Cancer survivorship care (CSC) is broadly defined and should be the patient-centred offering of varied combinations of healthcare services that match the individual needs of cancer survivors. Examples of these services include annual physical assessments, blood tests, diagnostic imaging, nutrition counselling, mental health and counselling services, health teaching and exercise coaching (Chapman & Wiernikowski, 2011; NCI, 2012). The burden of cancer survivorship is significant. In 2009, there were 810,045 Canadians living with a cancer diagnosed in the previous ten years and in 2014 191,300 new cases of cancer are expected (Canadian Cancer Statistics, 2014). According to recent estimates, cancer survivors represent 2.5% of the population in Canada (Canadian Cancer Society’s Advisory Committee on Cancer Statistics, 2013). In Ontario alone, it is predicted that by 2020 the number of newly diagnosed cancer cases will reach 91,000 per year (Cancer Care Ontario, 2003). With significant advances in treatment, the number of cancer survivors in Canada is increasing at twice the rate of those with newly diagnosed cancers (Health Canada, 2004). Coinciding with improved survival rates and rapidly rising demands for care, is growing recognition of the chronic nature of cancer survivorship (Institute of Medicine (IOM), 2013). Healthcare and resource planning for this growing population of complex patients with long-term healthcare needs is crucial. In order to facilitate sustainable CSC and decrease wait times for newly diagnosed patients; new models of survivorship care delivery need to be explored and evaluated (Ristovski-Slijepcevic, 2008).

Provincial cancer agencies have identified the need to develop safe and effective models of care that promote 1) early transition of cancer survivors back to their primary care (PC) providers post-treatment and 2) greater involvement of primary care providers throughout the cancer care continuum (Alberta Health Services, 2005; BC Cancer Agency, 2013; Cancer Care Manitoba, 2004; Chomik et al., 2010; Ristovski-Slijepcevic, 2008; Saskatchewan Cancer Agency, 2014; Sussman et al., 2012). This shift away from long-term follow-up of survivors by cancer specialists has the potential to increase access for new patients entering the cancer care system and better address the long-term health needs of cancer survivors (Chomik, 2010). Increasing the involvement of PC providers throughout the cancer care continuum is timely. Over the past decade, Canadian provinces and territories have implemented PC reform initiatives to strengthen the infrastructure and establish funding models to promote performance improvement (Agarwal & Hutchison, 2012). Financial and strategic support for building a strong Canadian PC sector continues to mount with evidence that high-performing, comprehensive, and coordinated PC provides the foundation for effective and efficient healthcare systems, superior health outcomes at lower costs, and improved chronic disease management (Agarwal & Hutchison, 2012; Browne, Birch, & Thabane, 2012; McMurchy, 2009). Capitalizing on the strengths of the PC sector to facilitate patient transitions from cancer specialist treatment to post-treatment follow-up care in community PC settings may provide a promising option for improving CSC.

Primary care is defined as the “level of a health service system that provides entry into the system for all new needs and problems, provides person-focused (not disease-oriented) care over time, provides care for all but very uncommon or unusual conditions, and co-ordinates or integrates care provided elsewhere by others” (Starfield, 1998, p.8-9). Canadian government leaders, healthcare professionals, and citizens are united in their commitment to building a strong PC system that is patient centred, accessible, effective, efficient, safe, coordinated, and population-health oriented (Agarwal & Hutchison, 2012). Canada’s vision and commitment to building such a comprehensive PC sector is evidence informed. Research has shown that countries with strong PC sectors have demonstrably better health outcomes, lower mortality rates, better equity and lower overall costs for healthcare (Agarwal & Hutchison, 2012; Macinko, Starfield, & Shi, 2003; Starfield & Shi, 2002; & Starfield, 2012). These defining attributes make PC the ideal hub for CSC.

 Nurses working in PC settings are the first and most consistent points of contact for patients (CNA, 2005). In Ontario all three core categories of nurses, nurse practitioners, registered nurses (RNs), and registered practical nurses work in PC settings. Registered practical nurses obtain a two or three year diploma in practical nursing and have a focused body of foundational knowledge (HealthForceOntario, 2013). Registered nurses obtain a four year bachelor degree in nursing and are trained to manage the nursing needs of complex patients autonomously (HealthForceOntario, 2013). Finally, nurse practitioners are experienced RNs who have completed additional education and have a broader legislated scope of practice (HealthForceOntario, 2013). Nurses working in PC are pivotal in the delivery of chronic disease management care (Browne, Birch & Thabane, 2012) and thus are well positioned to facilitate, coordinate and provide CSC. Furthermore, research has documented the underutilization of RN roles and scope of practice in the delivery of PC services in Canada (Allard, Frego, Katz, & Halas, 2010; Registered Nurses Association of Ontario (RNAO), 2012; Schoen et al., 2005). As a result, there is tremendous potential to leverage untapped nursing expertise in PC to increase access to timely, high quality CSC. Increasing responsibility and involvement in CSC is one of many ways nursing roles can be maximized and expanded to ensure that health human resources are being utilized in an effective and efficient manner.

 The purpose of this qualitative descriptive study is to examine the perceptions of RNs working in PC settings regarding: 1) their current role and involvement in providing care for cancer survivors, 2) how this role in CSC compares to their role in providing chronic disease management for patients with other chronic conditions, 3) barriers and facilitators to their involvement in CSC, 4) how they could further contribute to CSC, and 5) possible solutions to expand their involvement in CSC.

Nursing roles from diverse PC settings will be examined to identify and understand how nurses are currently involved and the potential for augmenting their roles in providing CSC. This research is important because gaining an understanding of what nurses in PC are doing and opportunities to optimize their chronic disease management expertise for CSC, will establish the foundation for the future design and evaluation of new models of care delivery. Finally, this study will fill a gap in the current literature about how Canadian nurses working in PC settings provide care for cancer survivors. To the best of our knowledge, no Canadian studies have explored the role nurses play in the provision of CSC in PC settings.

**CHAPTER 2 LITERATURE REVIEW**

 This chapter begins by outlining the search strategy and identifying the key challenges and current issues involved in the provision of CSC. After exploring the blurred parameters of CSC, contextual background information at the national, provincial, and local level is provided. Next nursing’s role in CSC, the Chronic Care Model and the model’s fit with the study is examined. Finally, overall study goals and research questions are defined.

**Search Strategy**

With the guidance of a health sciences librarian the student researcher began by constructing a list of pertinent key words, terms, and phrases linked to CSC. Using the Boolean search method, the student researcher combined the list of key terms and initially searched CINAHL, Cochrane Library, MEDLINE, and PubMed databases. After identifying and retrieving relevant journal articles from these initial database searches, the student researcher scanned reference lists to identify frequently citied CSC books, articles and standard texts. Retrieving these additional sources allowed the student researcher to stretch and strengthen the literature review to include government documents, books, commissioned reports, and applicable grey literature. The student researcher also drew on clinicians and researchers in the field of CSC to identify both gold-standard and obscure CSC sources. Finally, in December 2014, with the assistance of a health sciences librarian, this literature review search was updated to ensure no recent important publications were excluded.

**Problem Identification**

 With recent improvements in early detection, diagnosis, and treatment; patients diagnosed with cancer are living longer (IOM, 2013; McCorkle et al., 2011). The number of cancer survivors and the demand for CSC in Canada is rapidly increasing (Canadian Cancer Statistics, 2013). Over the past five years there has been increasing recognition of cancer as a chronic versus an acute episodic condition (Feuerstein & Ganz, 2011; Harrison, Young, Price, Butow, & Solomon, 2009; McCorkle et al. 2011; Nolte & McKee, 2008). Chronic conditions are complex and encompass a broader range of health circumstances than the traditional definition of chronic disease (Nasmith et al., 2010). Chronic conditions are defined as conditions that require ongoing, adaptive care and management over an extended period of time by patients, health care providers, and family members (Nasmith et al., 2010). A defining characteristic of chronic conditions is that they “persist over time regardless of treatment” (Starfield, 2010, p.4). Given these parameters, cancer clearly fits the definition of a chronic condition. Specifically, the diagnosis of cancer is accompanied by disease specific co-morbidities, long-term and late effects, changes in physical and cognitive function, and changes in overall well-being and quality of life (Feuerstein & Ganz, 2011).

 Research evidence about the unmet needs of cancer survivors suggests that current models of care delivery are not effective (McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2010). A systematic review found that survivors have more unmet health needs during the post-treatment phase compared to survivors at any other phase of cancer care (Harrison et al., 2009). It has been suggested that cancer survivors would benefit from a chronic disease management approach to their long-term care (Feuerstein & Ganz, 2011). A chronic disease management approach to CSC would include management of co-morbid illnesses, assessment of emotional and physical distress, monitoring of diet, weight, and activity levels, ongoing health teaching, and periodic discussions of quality of life and return to work issues. Although cancer survivors may have needs unique to other chronic conditions, application of such a comprehensive approach to CSC may lead to improvement in the quality of care and health outcomes for this patient population. Primary care healthcare providers may have transferable chronic disease management experience and skills that are relevant to the delivery of CSC in the community (Feuerstein & Ganz, 2011). In the absence of comprehensive research on CSC, evidence from chronic disease management research may inform future care delivery approaches for cancer survivors (Feuerstein & Ganz, 2011). Proponents of CSC may be able to draw on relevant chronic disease management research to inform innovation in CSC and guide the development of effective CSC models of care.

**Defining Cancer Survivorship Care**

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life (National Cancer Institute (NCI), 2012). This broad inclusive definition is consistently used throughout survivorship literature. In contrast, there is no clear internationally recognized definition for CSC. Cancer survivorship care is broadly defined and encompasses varied healthcare and social services related to: health promotion, symptom management of common long-term and late effects, nutrition support, access to community resources, return to work barriers/vocational rehabilitation, family counseling, psychosocial services, spiritual care services, occupational therapy, physical therapy, mental health counseling/supports, lymphedema services, enterostomal services, and sexual health (Cooper et al., 2010; Harrison et al., 2009, Howell et al., 2011; McCabe et al., 2013). Without a concrete definition or clear focus, CSC has remained a grey phase of the cancer trajectory and until recently a neglected area in health policy, education, clinical practice, and research (Hewitt, Greenfield, & Stovall, 2005). Lack of consensus about what constitutes CSC likely contributes to the high variability in how CSC is funded, organized and delivered across Canada. However, a universal definition for CSC may not be possible because of the heterogenic needs of cancer survivors based on their type of cancer, treatment modality, co-morbidities, support systems, socio-economic status, geographic location, and ability to access resources (Hewitt et al., 2005).

 Authors Hewitt, Greenfield, and Stovall provided some clarity in arguing that there are four essential components of high quality CSC (Hewitt et al, 2005). These essential components include: 1) prevention of recurrent and new cancers, and other late effects; 2) monitoring and assessment for cancer spread, recurrence, second cancers, and medical and psychosocial late effects; 3) interventions to address the consequences of cancer and its treatment; and 4) coordination between specialists and PC providers to ensure comprehensive patient-centered care (Hewitt et al, 2005). These essential components are useful because they apply broadly across all cancer types and can serve as a starting point for policy makers and clinicians initiating new CSC programs.

**National, Provincial, and Local Context**

 **National CSC context.** In April of 2011, an expert panel published the *Pan-Canadian Practice Guideline on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors* (Howell et al., 2011). This guideline included 11 evidence-based recommendations related to the organization and care delivery structures of survivorship services and eight recommendations related to psychosocial and supportive care interventions (Howell et al., 2011). Four of the organization and care delivery recommendations call directly for increased involvement of the PC sector. Specifically, the expert panel recommended that PC providers: 1) review survivorship care plans; 2) play an active role in care coordination, monitoring for recurrence, and managing long-term and late effects; 3) integrate rehab, psychosocial, and employment counseling into their plan of care, and 4) educate themselves about how to screen and physically assess for common post-treatment survivorship issues as well as provide effective self-management support (Howell et al., 2011). The role of PC health care providers is also featured prominently in the eight psychosocial and supportive care intervention recommendations in this guideline. Primary care practitioners are encouraged to use theory-based approaches to: support healthy lifestyle behaviors, manage concerns regarding sexual health and manage psychosocial concerns/distress (Howell et al., 2011). As the most consistent point of care and as gatekeepers to specialty referrals, PC providers play an integral role in the ongoing management of key recommendations related to: monitoring for symptoms and long-term and late effects, and managing post-treatment fatigue, vasomotor symptoms, and disruptions in sleep-wake patterns (Howell et al., 2011).

 A strength of this guideline is the systematic and comprehensive approach to examination of the literature. However, as the authors note, the quality of research evidence informing this guideline is weak. Moreover, the guideline does not provide evidence or insight about the economic and health human resources necessary to implement the recommendations. The lack of decision-maker involvement in developing the guideline may also be a barrier to dissemination and implementation buy-in at multiple levels of the Canadian healthcare system including PC.

 **Provincial CSC context.** Recognizing a need for change and that the current model of CSC in Ontario is ultimately unsustainable (Sussman et al., 2012); Cancer Care Ontario commissioned a practice guideline on CSC models.This guideline sought to answer the following research questions: 1) What models for follow-up care of adult cancer survivors are described in the literature? and 2) Are certain models favored for survivors of specific cancer types? (Sussman et al., 2012). Guideline recommendations indicated that “discharge from specialist care to family physician care appears to be a reasonable alternative to the usual specialist-coordinated care in breast cancer and colorectal cancer” (Sussman et al., 2012, p.28). In comparing the two models of care, no differences were found in surveillance for recurrence and medical outcomes. Further strengthening the argument for the transition to family physician-led CSC; several studies suggested that patient satisfaction and cost of care within family physician-led CSC models of care were “equivalent to if not better than, specialist-coordinated models within institutions” (Sussman et al., 2012, p. 28).

 It is also important to note that this guideline highlighted recent evidence supporting nurse-led models of CSC. Multiple studies suggest nurse-led models of follow-up care may be “reasonable to consider within the context of ongoing follow-up within an institution” (Sussman et al., 2012, p.28). In a study examining follow-up care for breast cancer survivors during the first year following completion of treatment, there were no meaningful differences in patient satisfaction scores between nurse-led telephone follow-up care and traditional hospital based follow-up care (Kimman et al., 2010). A separate randomized multi-center study of patients with prostate cancer evaluated the effectiveness of an on-demand follow-up model of care by a specialist nurse compared to traditional follow-up by a urologist (Helgesen et al., 2000). The results showed no differences in access to care, medical safety, or the total number of interventions due to prostate cancer symptoms between the intervention groups. However, mean outpatient costs per patient were lower in the nurse-led group (Helgesen et al., 2000). This study concluded that men diagnosed with prostate cancer can be safely followed-up within a specialist nurse-led model of care and that this alternative to traditional urologist follow-up care is cost-effective (Helgesen et al., 2000). Lastly, in a study evaluating follow-up care of patients who had undergone curative surgery for oesophageal or gastric cardia cancer; researchers compared quality of life, patient satisfaction, and costs of a specialist nurse-led homecare model to standard care by surgeons (Verschuur et al., 2009). Results showed that compared to usual care, specialist nurse-led follow-up was associated with better spousal satisfaction; equivalent medical outcomes, quality of life and satisfaction with care; and lower medical costs (Verschuur et al., 2009). Further strengthening the argument for the expansion of nurse-led models of CSC; the Cancer Care Ontario guideline highlighted that nurse-led follow-up care is associated with 1) higher levels of patient satisfaction with care in comparison to conventional institution-based specialist-led care and 2) reduced use of other services such as hospital-based specialty consultations and diagnostic tests (Sussman et al., 2012). Though further research evaluating nurse-led models of CSC is needed, especially within the context of the Canadian healthcare system and in PC, international evidence published to date suggests that nurse-led models of CSC may be effective for patients with breast, prostate and colorectal cancer (Sussman et al., 2012).

 The Cancer Care Ontario practice guideline was constructive because it highlighted the need to change the current model of CSC in Ontario, evaluated current evidence regarding options for such change, emphasized the need for further research regarding CSC models of care, and noted serious limitations and gaps in the literature. The guideline shortfalls included the: 1) limited number of studies examining models of care for adult cancer survivors, 2) emphasis on survivors of breast cancer with few studies involving other patient populations, 3) inconsistency of study findings due to lack of standardization with measures, patient populations, and model of care approaches, and 4) paucity of Canadian research on cancer survivors and models of care (Sussman et al., 2012). Because studies varied so widely the authors were unable to pool the data to conduct a meta-analysis.

**Local CSC context.** In April of 2011, a diverse group of CSC stakeholders gathered at the McMaster Health Forum in Hamilton Ontario to examine patient transitions from treatment in regional cancer centres to survivorship in the Hamilton Niagara Haldimand Brant (HNHB) region (Lavis & Montesanti, 2011). The stakeholders reached three conclusions. First, the cancer care subsystem lacks a sustained approach to supporting cancer patients in the transition of care from regional cancer centres back to their primary healthcare providers in the community. Second, survivors are not living well after treatment due to gaps in the current cancer care system. Third, a comprehensive, organized approach to supporting patients to live well post-treatment is absent in the HNHB region (Lavis & Montesanti, 2011). Participants in this interprofessional dialogue suggested that to move the CSC agenda forward locally, the regional cancer centre should play a leadership role in developing a strategy to support cancer survivors in living well post-treatment and in facilitating the optimal use of current resources (Lavis & Montesanti, 2011). Dialogue participants argued that Cancer Care Ontario’s Program in Evidence-Based Care should prioritize the development of disease specific cancer survivorship support plans (Lavis & Montesanti, 2011). Finally, the group emphasized the importance of future CSC initiatives taking a holistic approach to patient care that targets both physical and psychosocial cancer survivor needs (Lavis & Montesanti, 2011).

In response to these key identified gaps, a Cancer Survivorship Committee was struck involving stakeholders from the Local Health Integration Network (LHIN) 4 region, McMaster University, the Juravinski Cancer Centre (JCC), and the JCC breast disease site team. The objectives of this committee are to: 1) create a sustainable, evidence-based, high-quality model of survivorship care for breast cancer patients who have completed curative therapy and are receiving follow-up care that enhances patient transition back to PC; 2) improve the care of breast cancer survivors in LHIN 4; and 3) enhance relationships between the regional cancer program and PC providers (Sussman & Forbes, 2012). Evaluation of this new model of care is now underway. The model involves a transition outpatient clinic led by an advanced practice nurse (APN) (Sussman & Forbes, 2012). Key activities include: clarifying health provider roles and responsibilities, acting as a resource to PC providers, and facilitating access back into the JCC for patients who develop recurrence (Sussman & Forbes, 2012). If this new model of care is proven successful upon final evaluation, extending this APN-led approach to CSC to prostate and colorectal cancer survivor populations is a promising possibility. Expert opinion has concluded that these cancers follow similar trajectories in terms of initial diagnosis, treatment, and follow-up care (Sussman et al., 2012).

In summary, from these national, provincial, and local agendas, several common themes surrounding CSC in Canada have emerged. Researchers and clinicians have called attention to the need for improved CSC and better understanding about how to organize and deliver cost-effective CSC services. Substantial knowledge gaps related to evaluation of current CSC services and models of care serve as barriers to quality patient care. Recognizing that the current approach to CSC in Canada is unsustainable, Ontario and other provincial cancer agencies have called for the development and implementation of new models of care to address the surveillance and follow-up care needs of cancer survivors (Alberta Health Services, 2005; Canadian Association of Provincial Cancer Agencies, 2010; Cancer Care Manitoba, 2004; Chomik, 2010; Ristovski-Slijepcevic, 2008; Saskatchewan Cancer Agency, 2014; Sussman et al., 2012). However, before effective change can occur, the following core needs must be addressed: 1) survivorship education for cancer and primary healthcare providers to raise awareness of CSC issues, appropriate follow-up care, and self-management support for patients and their family members (Howell et al., 2011); 2) increased multidisciplinary leadership for CSC research on post-treatment follow-up care and recovery (Howell et al., 2011; Lavis & Montesanti, 2011); and 3) nationally coordinated evaluations of current and newly implemented CSC services and models of care (Howell et al., 2011; Sussman et al., 2012).

A coordinated effort targeting priority gaps in the current body of evidence would be advantageous in the pursuit of improving CSC within Canada. At present, more research is needed on effective and feasible models of CSC outside of the breast cancer patient population (Sussman et al., 2012). Research and evaluation of models of care developed specifically for marginalized populations, men, and disease sites outside of the breast, prostate, and colon cancer patient population would aid healthcare planners and policy maker in determining the optimal use of CSC resources and would build on existing CSC knowledge (CCO, 2003). Lastly, a neglected but promising area of research that should be targeted for future Canadian studies is nurse-led community-based models of CSC (Sussman et al., 2012). If proven effective, nurse-led models of CSC could tap into underutilized PC nursing resources and decrease the burden of CSC currently placed on cancer specialist and PC physicians. This strategy for improving CSC in Canada is evidence based as multiple international studies have shown that nurse-led models of CSC are cost-effective, safe, and lead to similar outcomes when compared to traditional physician-led follow-up care (Helgesen et al., 2000; Kimman et al., 2010; Verschuur et al., 2009).

**Nursing’s role in CSC.**

 Nurses in PC roles “coordinate health care, deliver direct services and support clients in their self-care decisions and actions in situations of health, illness, injury, and disability in all stages of life” (Canadian Nurses Association (CNA), 2007, p.6). Practicing in a broad range of healthcare settings, nurses in PC roles improve patient access to comprehensive: health assessments, management of chronic conditions, health education, screening, preventative care, and care coordination with other health and social-service providers (CNA, 2013). Research examining the role of Canadian nurses in PC is growing but remains limited to date (Martin-Misener et al., 2014; Todd, Howlett, MacKay, & Lawson, 2007). Further, the contribution of RNs working in PC settings to support the delivery of CSC has also been overlooked. A recent scoping review of RN roles in PC confirmed a lack of research in this area (Martin-Misener et al., 2014). A comprehensive search of the literature, found no Canadian studies examining the role nurses working in PC settings play in the delivery of CSC. This is a significant knowledge gap that further supports the necessity and importance of this study.

Robust rationale and research evidence supported our exploration of the role nurses play in the delivery of CSC within PC settings. Nurses working in PC settings are ideally situated to contribute to CSC improvements. Nurses serve not only as principal caregivers to patients but also as chief advocates. Nurses are consistently proven to be effective patient advocates because more than any other healthcare professional, nurses are trained to manage patient health needs and social care needs simultaneously (Browne et al., 2012). Through their frequent and close interaction with patients and patient family members, as well as their ongoing commitment to relational continuity of care, nurses working in PC settings are able to identify chronic condition care situations that require further attention and facilitate the involvement of multidisciplinary team members (Browne et al., 2012). A recent Canadian Health Services Research Foundation report analyzing nursing and healthcare system outcomes recommended that proactive targeted models of nurse-led comprehensive chronic care be trialed and evaluated (Browne et al., 2012). Nurse-led comprehensive chronic care models of care also align with established evidence-based criteria for high-quality primary care (McMurchy, 2009). When supported with adequate education, physician support, and community resources; nurse-led models of care provide continuity; are accessible, coordinated, and comprehensive; and place attention on health promotion, secondary disease prevention, and chronic disease management (McMurchy, 2009).

 Capitalizing on nurses’ education, experience, and chronic disease management expertise through the implementation of nurse-led models of care will require a significant shift in delivery system design within most Canadian PC settings. Nurses practicing within PC settings will be challenged to step away from traditional physician directed task-based nursing roles and move towards innovative leadership roles within their practice settings. Opportunely, evidence shows that the majority of Canadian nurses working in PC settings are eager to take on this challenge. A recent survey exploring the role of nurses employed in Canadian family practice residency training programs showed that 88% of respondents indicated a desire to pursue further education to enhance their nursing skills (Allard et al., 2010). Respondents who reported working to their full scope of practice had significantly higher levels of reported job satisfaction, and key factors contributing to nurse job satisfaction included independence in role, broad scope of clinical practice, and comprehensive patient care (Allard et al., 2010, p. 23). Likewise, the Registered Nurses Association of Ontario (RNAO) Family Practice Nurse Interest Group has urged the Ontario government to utilize nurses working in PC settings to their full capacity (Alsaffar, 2005). Unfortunately, this enthusiasm for increased nurse involvement in the delivery of quality PC remains untapped in Canada. Recent research has shown that the majority of nurses working in Canadian PC settings are not working to their optimal scope of practice and their skills, competencies, and knowledge remains underutilized (Martin-Misener et al., 2014; RNAO, 2012). At the same time, many cancer survivors remain lost to systematic follow-up; especially during the post-treatment phase of cancer care where greater interface between cancer and PC providers is required (Hewitt et al., 2005; RNAO, 2012).

If CSC models of care evolve to include nurses as collaborative leaders, nurses working in PC settings would have the opportunity to enhance the quality of CSC delivery in numerous ways. Researchers have shown that nursing roles have the potential to contribute to the improvement of CSC thorough: patient advocacy, health teaching, care coordination, system navigation, physical assessments, screening for post-treatment complications and psychosocial distress, ensuring continuity of care, promoting surveillance protocols, and reviewing cancer survivorship care plans (Morgan, 2009; Cooper, Loeb, & Smith, 2010). Moreover, a recent study examining whether chronic disease management differed among four models of primary health care delivery for patients diagnosed with diabetes, congestive heart failure, and coronary artery disease found that the presence of a nurse practitioner across different models of PC delivery was a consistent and sole predictor of high-quality chronic disease management (Russell et al., 2009). The benefits of similar nurse-led care may be transferable to cancer survivors who require ongoing follow-up and management of long-term and late effects.

In summary, there is a gap in research evidence regarding the role nurses working in PC settings play in the delivery of CSC. What nurses working in PC settings are contributing to CSC remains unclear. The body of CSC research to date focuses on APNs and specialized oncology nurses working in cancer settings (Cooper, Loeb, & Smith, 2010; McCabe et al., 2013; Sussman et al., 2011). The current and potential role of nurses working in PC settings related to CSC is neglected. This study addressed this knowledge gap by providing insight into how nurses working in PC settings currently contribute to the delivery of CSC and how nurses *could* contribute to strengthening the quality of CSC delivered in Canadian PC settings.

**The Chronic Care Model**

 **Background.**

 The chronic care model is designed to guide the development of high-quality effective chronic illness management in PC settings (Bodenheimer, Wagner, & Grumbach, 2002). The chronic care model identifies six essential elements for the optimal delivery of chronic care including: community resources and policies, health care organization, self-management support, delivery system design, decision support, and clinical information systems (Bodenheimer et al., 2002). The ultimate goal of the chronic care model is to achieve “an informed, activated patient interacting with a prepared, proactive practice team, resulting in high quality, satisfying encounters and improved outcomes” (Bodenheimer et al., 2002, p.1777).

 **Fit of framework with proposed study.**

 The chronic care model was used to inform the methods for this study. It was selected because research has demonstrated the effectiveness of model application for improving PC delivery and health outcomes for patients with varied chronic conditions (Tsai, Morton, Mangione, & Keeler, 2005). A meta-analysis of chronic disease management interventions based on the chronic care model found that interventions containing one or more of the six model elements were associated with better clinical outcomes and processes of care (Tsai et al., 2005). Internationally, the chronic care model is widely used and has been adopted by most Canadian provinces to improve chronic disease management in PC (Health Council of Canada, 2012; Lavis, 2011; Nasmith et al., 2010). While there has been limited research on the chronic care model for cancer populations, a recent study evaluating cancer survivorship networks in the United States demonstrated the applicability of the chronic care model to cancer (Campbell et al., 2011). Further, the Institute of Medicine (IOM) (2013) has recommended application of similar chronic disease management approaches for improving CSC (IOM, 2013).

Achieving better physical and psychosocial health outcomes for cancer survivors will require improved access to PC that is evidence-based, coordinated, and tailored to their unique individual needs (Howell et al., 2011). The chronic care model aligns directly with these identified survivor needs and fits closely with the study’s overarching objective to identify strengths, gaps, and opportunities for optimizing nursing roles in the delivery of CSC within PC settings. The chronic care model is an ideal fit for this study because it is a comprehensive evidence-based model that uses a holistic system-focused approach to improve patient outcomes and the delivery and quality of chronic condition care (Coleman et al., 2009).

 The chronic care model elements of **self-management support, delivery system design**, and **care** **coordination** were selected to inform this study because current evidence demonstrates that these areas of care are commonly identified with high unmet needs of cancer survivors (Battersby et al., 2010; Browne et al., 2012; Feuerstein & Ganz, 2011; Hewitt et al., 2005; McCorkle et al., 2011; Wagner, 2000; Wagner et al., 2001). Addressing these chronic care model elements is critical for improving CSC. Our study tools focused on clarifying, defining, and understanding the role nurses working in PC settings played in the delivery of CSC for these highlighted chronic care model elements. These chronic care model elements were purposefully selected because: 1) they are directly linked to daily nursing practice; 2) nurses are fundamentally invested in these aspects of chronic condition care; and 3) nurses have agency to influence/enact change over these aspects of chronic condition care. The chronic care model literature addressing the self-management support, delivery system design, and care coordination elements was used to inform study methods for data collection.

**Overall Study Goal**

The overall goal of this study was to identify, from the perspective of RNs, the strengths, gaps, barriers, and opportunities for optimizing nursing roles in the delivery of CSC in PC settings. This research study was important because it tackled an urgent healthcare issue and built on current research evidence about effective chronic disease management to address key knowledge gaps and opportunities to improve CSC. Gaining a greater understanding of current nursing roles and responsibilities will aid further research to design, develop, and evaluate future interventions for optimizing nursing involvement in the delivery of CSC within PC settings. Furthermore, these study results will inform the development of a nationwide questionnaire addressing PC nurses involvement in CSC.

**Research Questions**

This study addressed the following research questions to examine the perceptions of RNs who work in PC settings regarding:

1. What is the current role of nurses in providing care for cancer survivors?
2. How does the nursing role in CSC compare to providing chronic disease management for patients with other chronic conditions?
3. How could nurses further contribute to CSC?
4. What barriers and facilitators influence nurse involvement in CSC?
5. What are possible solutions to expanding nurse involvement in CSC?

# CHAPTER 3 METHODS

 This chapter begins by describing the study design, setting and participants, and sampling and recruitment strategies. The data collection methods, management, and analysis are then outlined in detail. Finally, the steps taken to increase the rigor of the study are shared and ethical issues are explored.

**Study Design**

 A qualitative descriptive study was conducted. Qualitative descriptive studies draw from the general principles of naturalistic inquiry (Sandelowski, 2000). Examining a phenomenon through naturalistic inquiry involves studying the phenomenon in its natural state (Willems, 1967). Adhering to naturalistic inquiry principles requires qualitative descriptive researchers to commit to studying the targeted phenomenon as if it “were not under study” (Sandelowski, 2000, p. 337). This commitment prohibits researchers from manipulating study variables, pre-selecting themes/study variables, and establishing a priori opinions /theoretical views regarding the phenomenon under study (Sandelowski, 2000). Qualitative descriptive studies are developed and supported by existing research, critical linkages to previously completed work by researchers in the field and the clinical experience of the research team (Neergaard, Olesen, Andersen, & Sondergaard, 2009).

 When the strengths and limitations of qualitative descriptive studies are appropriately identified and understood; this approach to research can yield useful results within the field of health service research. Qualitative description has many strengths. This approach to qualitative research avoids interpreting data through the researcher’s lens and remains feasible when time, resources, and funds are limited (Neergaard et al., 2009; Sullivan-Bolyai, Bova, & Harper, 2005). Furthermore, qualitative descriptive study results often provide: 1) clear information regarding ways to improve patient care, 2) insight regarding questionnaire and intervention development, and 3) findings that are easily understood by participants, non-research based healthcare providers and policy makers (Neergaard et al., 2009; Sullivan-Bolyai et al., 2005). A noted limitation of qualitative description studies is that as an end product only a descriptive summary can be generated (Neergaard et al., 2009). Because qualitative description involves a low-inference approach and data is not generated or interpreted based on predictive theory; the ability for researchers to make generalizations is quite limited (Neergaard, Olesen, Jensen, & Sondergaard, 2010). However, the rich descriptive summaries resulting from qualitative descriptive studies are useful in generating hypotheses and informing future theory-based research (Neergaard et al., 2009).

The goal of qualitative descriptive studies is to produce a comprehensive, low-inference, summary of events written in the plain terms of those events (Sandelowski, 2000). Researchers applying qualitative descriptive methodology stay close to the data, the surface of the events described, and the words used by research participants (Sandelowski, 2000). Qualitative description is a suitable method when researchers are interested in conceptual clarification, gaining a first insight into the participants’ views of a narrow topic, intervention development or refinement, and needs assessment (Neergaard et al., 2009). As this study was the first to examine nurses’ perceptions of their role related to CSC within PC settings, and the information gathered will be used to inform the future development of interventions targeting nurses’ involvement in CSC, qualitative description methodology was an appropriate fit with the stated research aims.

 **Setting and participants.** Registered nurses working in PC settings including family health groups (FHGs), family health networks (FHNs), and family health organizations (FHOs); community health centres (CHCs); family health teams (FHTs); and solo family practices across Ontario were invited to participate in this study. Family health groups, FHNs, and FHOs were purposely grouped together as one of four PC organizational model categories because all three models have: 1) physician-led governance; 2) limited interprofessional team members; and 3) blended fee-for-service or capitation physician reimbursement funding (Hutchison & Glazier, 2013). These common characteristics make these practice settings similar and therefore we expected that nurses practicing in these PC models would share similar experiences. Community health centres were a separate PC organizational model category because CHCs are distinct in that they 1) focus on needs of specific populations; 2) offer salaried employment; 3) are oriented to outreach and health promotion; and 4) are governed by community boards (Hutchison & Glazier, 2013). Family health teams were a separate PC organizational model category because this organizational model uses an interprofessional team based approach to provide patient care and therefore has significantly different resources in comparison to the other three PC organizational models (Hutchison & Glazier, 2013). Finally, solo family physician practices, formally known as comprehensive care PC models, were a separate PC organizational model category because 1) this model of PC is designed for a single physician; 2) outside of nurses usually no other interprofessional team members are included in this model; and 3) after-hours care requirements are optional (Hutchison & Glazier, 2013). Including these PC practice settings with diverse organizational structures, resources and healthcare team composition was a strategy for identifying the different ways nurses are involved in CSC.

 To be eligible to participate in the study, participants needed to meet specific inclusion criteria. All study participants were: 1) registered nurses, 2) currently working in an Ontario PC settings, and 3) had three or more years’ of work experience in PC. Registered practical nurses (RPNs); primary care nurse practitioners (PCNP); and novice RNs with less than three years of PC nursing experience were not eligible to participate in the study. Registered Practical Nurses and PCNPs were excluded from the study due to feasibility issues associated with time and resources. Nurses working in PC settings for less than three years were purposely excluded because they may not have had enough experience to provide sufficient details or insight about their role in providing chronic disease management or CSC.

 **Sampling and recruitment.** Purposeful and maximum variation sampling techniques were employed to ensure strategic selection of both demographically diverse and information-rich research participants (Neergaard et al. 2010; Sandelowski, 2000). Recruitment of such diverse participants aided the student researcher to gain broad insights into how nurses are involved in caring for cancer survivors in varied PC contexts (Neergaard, 2009). To achieve a maximum variation sample the following strategies were used. The student researcher recruited: 1) a minimum of two participants from each of the four PC organizational model categories outlined above; 2) both degree prepared and diploma prepared participants; 3) experienced RNs (10+ years of work experience within PC) and less experienced RNs (3-5 years of work experience within PC); and 4) RNs from diverse LHINs and geographic locations across Ontario. Inclusion of diverse participants that fit the sampling criteria outlined above facilitated examination of various practice setting and nurse related factors that may have impacted participant experiences and perceptions of CSC. It was important to differentiate delivery models from payment models because research has shown that “different models of primary care serve different patient populations and are associated with different outcomes” (Glazier, Zagorski, & Rayner, 2012). Furthermore, differences in how healthcare providers are compensated can impact on nursing roles in PC settings. For example, PC settings that have salaried physicians and healthcare staff are more likely to have fewer barriers to interprofessional collaboration when compared to settings that use a fee-for-service payment model (McMurchy, 2007; McMurchy, 2009; O’Malley et al., 2005). Similarly, varying levels of education may impact nurse involvement in CSC. Recent reports suggest that there is high variability in nurse knowledge, skills and expertise in PC settings across the province (RNAO, 2012). Participants with different educational preparation, especially those with additional oncology nursing education, may have varying scopes of practice, levels of confidence, and skills. Including both degree prepared and diploma prepared RNs would permit examination of the impact of education and experience on role implementation and RN involvement in CSC.

 A sample size of twelve to eighteen telephone interviews was anticipated. The decision to stop recruitment was planned to be critically reviewed by the student researchers’ full committee and to be based on the extent to which the research questions had been adequately and feasibly addressed.

 Eligible participants were identified and recruited through the College of Nurses of Ontario (CNO) registration list, snowball sampling, and the Canadian Family Practice Nurses Association Ontario (CFPNA) e-mail mailing list. Annually, practicing nurses in Ontario submit a registration application form to renew their membership to the CNO. This registration is mandatory in order to practice as an RN in Ontario. Applicants to the CNO must indicate their employer, practice setting, position in nursing, their primary area of practice, and their willingness to participate in research (CNO, 2013). This data is used to generate yearly CNO membership statistics and aided the student researcher in selecting eligible participants for this study. A formal application to the CNO requesting the release of home mailing addresses of eligible study participants (see Appendix A) was successfully submitted by the student researcher. Eligible participants were then contacted by mail and invited to participate. At the end of each telephone interview participants recruited through the CNO mailing list were asked by the student researcher if they had PC RN contacts that may be interested in participating in the study. When contact information for potential participants was obtained using this snowball sampling method the student researcher proceeded to send out study invitations and related information via e-mail. Finally, Ontario members of the CFPNA received study invitations and information via e-mail from the CFPNA executive. Ontario CFPNA members interested in participating in the study were asked to contact the student researcher via e-mail or phone to confirm eligibility and organize subsequent study participation. Each participant who completed the telephone interview received a $20 Chapters gift card as a small token of appreciation.

 Currently there are 4,364 nurses working in PC settings in Ontario who may have been eligible for this study (CNO, 2013). Of these nurses, 591 agreed to be contacted about participating in nursing research when they renewed their annual membership with the CNO. Please see Appendix B to review the initial stepwise participant recruitment protocol developed for the original research proposal.

 Typically, response rates in nursing research are low (Ulrich & Grady, 2004). The research team accurately anticipated some difficulties with recruitment. Some specific recruitment challenges included: 1) getting nurses to commit to a lengthy (60 min) telephone interview during their personal unpaid time; 2) having each eligible participant complete the oral questionnaire and the interview in full; and 3) obtaining the ideal mix of participants necessary to meet the purposeful and maximum variation sampling techniques outlined above. To minimize these participant recruitment barriers the following recruitment strategies were used. The mailed invitation to participate was succinct, informative, easy to understand and stressed the important contribution this study would make to improve the future delivery of CSC and the optimization of RN roles in PC practice settings (Creswell, 2013). Two separate friendly reminders to eligible participates were also mailed two weeks after the initial invitation and four weeks after the initial invitation, to the first 100 randomly selected RNs who did not respond to the initial mailing or the initial reminder. Finally, all of the telephone interviews were scheduled at a time that was convenient for the participant (Burke & Miller, 2001). Throughout the study the student researcher remained fully committed to working with participants to ensure participation in this study was accessible and as simple as possible (Creswell, 2013).

**Data Collection Methods**

 **Demographic and practice settings oral questionnaire.** An oral questionnaire including nine basic demographic questions and eleven practice setting questions was completed by the interviewer for each study participant at the start of the telephone interview. The demographic questions focused on participants’ educational preparation, nursing experience, and experience working in PC settings. The practice setting questions focused on practice setting, community services, setting resources, staff mix, team dynamics, collaboration, delivery of care, nursing roles, and nursing activities. The student researcher used this information during data analysis to examine how certain demographic characteristics may have impacted nursing roles and nurses’ involvement in CSC and to explore how certain practice setting characteristics may have impacted nursing roles and nurses’ involvement in CSC (see Appendix C).

 **Interview guide.** Individual and/or focus group semi-structured interviews with open-ended questions are the most common data collection techniques used in qualitative description studies (Neergaard et al. 2009; Sandelowski, 2000). Because we were interested in accessing individual nurses’ perspectives on and experiences with CSC; individual semi-structured in-depth interviews were used to collect data for this study. The choice to use individual interviews enabled the student researcher to explore the complex phenomenon of CSC delivery within diverse PC settings from the perspective of nurses who had access to varied resources, supports, educational backgrounds, and payment models. It was opted to conduct telephone rather than face-to-face interviews because of the advantages for facilitating the participation of eligible nurses working in different LHINs and geographic locations across Ontario. The student researcher suspected that nurses’ experiences working in PC settings and access to resources would be affected by geographic location and population centre classification (Statistics Canada, 2012). This information was collected in the oral questionnaire, discussed during each telephone interview, and analyzed during the data analysis phase for emergent themes. Telephone interviews also offered greater ease and flexibility for scheduling and averted expensive travel costs that were beyond the resources of this study. Compared to face-to-face interviews, telephone interviews are a less intrusive process and may have encouraged participants to disclose more information due to greater anonymity (Novick, 2008). However, relevant disadvantages of telephone interviews should also be noted. The choice to use telephone interviews may have made it more difficult for the interviewer to develop rapport with participants and the interviewer did not have access to non-verbal cues during the interview (Fontana & Frey, 1994). To minimize these potential limitations, the student researcher used a number of strategies. In the initial mailed study package, each participant received a copy of the overarching interview questions (Burke & Miller, 2001). The copy of the overarching interview questions provided a visual cue that may have made it easier for participants to follow along over the phone. Providing this information in advance also gave participants time to think and reflect about their answers which may have contributed to more thick and rich data from participants (Burke & Miller, 2001). To compensate for the absence of nonverbal cues/responses, the student researcher paid close attention to and took note of intonation, hesitations, and sighs while participants spoke (Novick, 2008). Finally, the student researcher conducted all of the telephone interviews from a quiet room free from distractions and interruptions (Creswell, 2013).

 All of the interviews were conducted by the student researcher at a pre-scheduled time that was convenient for the participants. A flexible semi-structured interview guide consisting of focused and open-ended questions was used to guide each interview. At the start of the interview the student researcher: introduced herself; provided a general overview of the study; relayed the confidentiality of participant responses; explained how the information would be used; sought verbal consent and provided an estimate of the interview’s length (Burke & Miller, 2001). The student researcher consciously strove to conduct each interview in a courteous, conversational, and unbiased manner. At the end of each interview the student researcher: clarified any unclear responses; provided an opportunity for the participant to share any final thoughts/comments; answered participant questions; and finally thanked the participant for their time and contribution to the study.

 The duration of each interview varied according to participants' experiences. On average most of the interviews took approximately 60 minutes to complete. During each interview the student researcher took notes. With the permission of the participants, all of the interviews were audio recorded. Two recorders were used to capture each interview to ensure data collection coverage in the event that one recorder failed. After each interview the student researcher made detailed field notes. These field notes served to track what happened during each interview and enabled the student researcher to record any reflections about the data during the data collection phase (Creswell, 2013). During data analysis the student researcher used these detailed field notes to confirm context, question assumptions, and support emerging themes when applicable. The audio-taped interviews were immediately transcribed verbatim by a transcriptionist in preparation for analysis.

 The interview guide was developed on the basis of current evidence, clinical experience, consensus discussions among the research team, and extensive literature review (Neergaard et al., 2010). Since we were interested in learning more about nursing expertise and experiences related to chronic disease management and the potential transferability of these assets to CSC, evidence relating to the pertinent chronic care model elements of self-management support, delivery system design, and care coordination were used to inform the development of interview guide questions and probes. Please see Appendix D to review the interview guide in full. Prior to the commencement of data collection, five nurses with extensive nursing experience in Ontario primary care settings critiqued the demographic and practice setting oral questionnaire and the interview guide. In-depth constructive feedback was received and guided necessary changes to both study tools. Finally, the student researcher conducted pilot interviews with two RNs to practice interview skills and tease out any final changes to the study tools. Both pilot interviews were included in final study results.

 **Data management and analysis.** When completing a qualitative description study, content analysis is the most fitting data analysis strategy (Sandelowski, 2000). Qualitative content analysis is the best choice because it is the “least interpretative of the qualitative analysis approaches” (Sandelowski, 2000, p. 338). When applying qualitative content analysis there is no expectation to manipulate or re-present the data in other terms (Sandelowski, 2000). The goal of this data analysis approach is a “straight descriptive summary of the informational contents of data organized in a way that best fits the data” (Sandelowski, 2000, p.339).

 Following general qualitative research principles, data collection and data analysis for this study occurred concurrently which facilitated each process to influence and shape the other (Sandelowski, 2000). Qualitative content analysis is an iterative flexible process that is ultimately data driven (Sandelowski, 2000). The student researcher followed the analytic strategies outlined by Miles and Huberman (1994) that are typical of numerous qualitative traditions. All transcripts were read multiple times to gain an overall impression before the commencement of initial coding (Neergaard, 2010). All meaningful text units from interview transcripts were identified and coded using NVivo10 software. During data analysis the student researcher also coded emergent data related to all six essential elements of the chronic care model. Some of the chronic care model elements emerged as themes during data analysis; the chronic care model was then used as a lens to further explore/understand the data collected.

 After coding the first two transcripts and developing a rough coding template, the student researcher met with her committee to review, critique, and refine the coding process. During this meeting a coding template was drafted by consensus agreement. Once polished and formatted the final coding template was reviewed and approved by the committee. Employing this method of consensus agreement and triangulation early in the coding process enhanced reliability (Creswell, 2013). The student researcher continually memoed to record insights and reflections on data obtained (Miles & Huberman, 1994). Meaningful text units were examined and sorted to identify similar patterns, themes, and crucial features (Miles & Huberman, 1994). Commonalities and differences among the text units were highlighted and extracted, leading to a set of core codes (Miles & Huberman, 1994). Staying close to the data, the student researcher then identified emerging themes (Miles & Huberman, 1994). Finally, the student researcher, with the guidance of her committee members, examined newly developed knowledge in light of current evidence (Miles & Huberman, 1994).

**Rigor**

Because the student researcher had limited experience conducting interviews, prior to the start of the study; she conducted pilot interviews with two RNs. These pilot interviews allowed the student researcher to receive feedback, further develop interview skills, build confidence, and anticipate/prepare for any challenges. Throughout the data collection phase, the student researcher worked closely with her research supervisor to review interview transcripts, evaluate the quality of completed interviews, and further build on her training as a research interviewer. The student researcher’s supervisor provided ongoing guidance, constructive feedback, and recommendations to improve the interview process.

 Following the framework proposed by Whittemore, Chase, and Mandle (2001), the student researcher employed multiple strategies to enhance the rigor of this study. The credibility of this study depended on the researcher’s ability to capture nurses’ perspectives regarding what their role is in caring for cancer survivors within PC settings and represent that perspective accurately (Milne & Oberle, 2005). The student researcher worked to ensure that research results accurately reflected the experience of the participants in a believable way through member checking (Whittemore et al., 2001). After analyzing each telephone interview, the student researcher compiled a one to two page summary of each participant’s main thoughts and ideas. Every participant received an e-mail requesting that they review the summary, fill out a structured feedback form, and return the feedback form via e-mail. This process of member checking ensured that the student researcher’s analysis of participants’ responses was truly reflective of participants’ experiences. Fourteen participants completed the member checking process in full. All fourteen participants agreed with the student researchers’ interview summaries. A few participants provided comments to clarify or further detail minutia related to their specific practice setting or interprofessional team. After completing the member checking process the student researcher discussed participant feedback with her committee. Establishing authenticity required the researcher to value and pay close attention to participants’ voices (Milne & Oberle, 2005). The researcher used the following techniques to promote authenticity: purposeful sampling, interview probes to facilitate clarification, richness and depth of data, accurate transcription, and data driven coding (Neergaard, 2009). The researcher demonstrated criticality, the critical appraisal applied to every research decision, through respondent validation and continuous reflective memoing throughout the duration of the study. Lastly, integrity “the process to assure that interpretation is valid and grounded within the data” (Whittemore et al., 2001, p. 53) was established through member checking, ongoing honest reflection regarding researcher bias, and peer review (Neergaard et al., 2009).

**Ethical Issues**

This study received ethics approval from the Hamilton Integrated Research Ethics Board (HIREB) student research committee (Appendix E). The student researcher worked closely with the HIREB to protect the rights, safety, and well-being of all of the study participants (HIREB, 2013). Before beginning each interview the student researcher: 1) provided information explaining the details of the study and the time commitment necessary; 2) reviewed and described data collection and management plans (including the use of audiotapes to record telephone interviews), and 3) obtained informed verbal consent. Formal written consent was not required by the HIREB because all interested study participants contacted the student researcher via phone or e-mail regarding study participation. This participant initiated contact/follow-up was deemed sufficient consent.

Each participant was also reminded that they could refuse to answer any of the interview questions and that they could withdraw at any time during the study. Finally, participants were reassured that their participation in this study, or withdrawal should they choose to do so, would in no way influence their professional standing or employment.

 As the interviews were completed, the audio recordings were transcribed verbatim and imported into N-Vivo10 software by the student researcher. Care was taken to store study data in a secure manner. Audio recordings and paper-based notes were stored in a locked cabinet in a locked office at the Juravinski Cancer Centre. Electronic data was secured with password protected access. The demographic and practice setting oral questionnaire and the interview transcript documents were anonymized using a numeric code. Instead of recording participant names, a single numeric code was created for each participant and used to label the two study data collection documents (Burke & Miller, 2001). The master list linking participants’ names to numeric codes was secured in a locked cabinet at the Juravinski Cancer Centre. The student researcher assured all study participants that care would be taken to ensure that no easily identifiable information would be published in subsequent reports. The audio recordings and paper based notes will be destroyed after the 10 year time mark, suggested by the HIREB, has lapsed. Data collection for this study occurred over a three month period; please see Appendix F for a timeline and activity chart for this study. Planning for a flexible data collection period was necessary because the number of eligible RNs willing and able to participate in this study was low and the student researcher had difficulties with recruitment.

 The student researcher recognized and respected the contribution of the study participants by adhering to interview time limits, scheduling interviews at times convenient for the participants, and by distributing an executive summary of the final report to those interested in the research findings. Lastly, the research team anticipated that issues may have arisen due to the student researchers’ professional background as a RN. To prevent and manage blurring of roles, the student researcher disclosed that she was an RN at the beginning of every interview but she also explained that her role while interacting with the research participant was strictly as a student researcher.

**CHAPTER 4 RESULTS**

 The purpose of this chapter is to summarize the results of this study. The chapter begins by describing the characteristics of study participants including demographic and practice setting data collected from the oral questionnaire. Results from the interviews are then outlined in relation to each of the following five study questions examining PC RN perceptions of: their current role in providing CSC, how their CSC and chronic disease management roles compare, opportunities for expanding their role in CSC, factors influencing their involvement in CSC, and solutions for optimizing their role in CSC. For each question, specific themes arising from the data analysis are identified, described and substantiated by direct quotes from the transcripts. The chapter concludes with a brief summary of overall study results.

**Characteristics of Study Participants**

 The final study sample included 18 RNs working in PC practice settings across Ontario. One hundred and seventy-five RNs identified as potential participants from the CNO mailing list received an invitation to participate and two separately mailed friendly study reminders. Eleven study participants were recruited from these mailings. Due to low response rates and significant recruitment difficulties, the student researcher expanded recruitment techniques to snowball sampling and recruitment through the CFPNA Ontario e-mail list. Six participants were recruited through snowball sampling and one participant was recruited through the CFPNA e-mail list.

 After completing fifteen telephone interviews the student researcher met with her thesis supervisor to discuss the consistent and reoccurring themes emerging from transcript content analysis. At that time it was decided that the student researcher would complete two to three more interviews to ensure no new themes emerged. After eighteen interviews were completed the full committee met and decided by consensus to stop recruitment because the research questions had been adequately and feasibly addressed and no new information or themes were emerging.

 Figure 1 provides a summary of the demographic characteristic of the final study sample. The final study sample included 18 RNs from nine of 14 LHINs, working in varied PC practice settings across Ontario. The remaining five LHINs (1, 2, 5, 6, and 13) were not captured due to lack of response from multiple recruitment mailings. No important identifiable common characteristics between the five uncaptured LHINs were noted by the student researcher. The mean age of study participants was 47. Ten participants were degree prepared and eight participants were diploma prepared. Five participants had less than five years of primary care work experience, six participants had five to ten years of primary care experience, and seven participants had greater than ten years of primary care experience.

*Figure 1*.Demographic Characteristics

Table 1 provides a summary of primary care organizational models included in the final sample. Four participants worked in family health groups, networks, or organizations. Three participants worked in community health centres. Nine participants worked in family health teams and two participants worked in solo-family physician practices. The diversity of organizational structures, resources and healthcare team composition across these four varied primary care practice settings aided in identifying the different ways PC RNs were involved in CSC.

Table 1

*Primary Care Organizational Model and Number of Participants*

|  |  |
| --- | --- |
| **Primary Care Organizational Model** | **Number of Participants** |
| Family Health Group (FHG), Family Health Network (FHN), & Family Health Organization (FHO) | Overall Total= 4FHG= 2FHN= 0FHO= 2 |
| Community Health Centre (CHC) | 3 |
| Family Health Team (FHT) | 9 |
| Solo-Family Physician Practice | 2 |

**Research Questions and Related Themes**

 During individual telephone interviews PC RN participants candidly shared their individual experiences and opinions. With minimal probes from the researcher, participant responses explored key issues at the individual, practice setting, and systems level. Participants’ perceptions of CSC in general and the role PC RNs play within this specific area of patient care were insightful.

 In this section, themes related to each study question are presented. A summary of the research questions and related themes is found in Table 2.

Table 2

*Research Questions and Themes*

|  |  |
| --- | --- |
| **Research Question** | **Themes** |
| 1. What is the current role of nurses, working in primary care settings, in providing care for cancer survivors? | * Care coordination and system navigation
* Emotional support
* Facilitating access to community resources
 |
| 2. How does the primary care nursing role in CSC compare to providing chronic disease management for patients with other chronic conditions? | Significant differences identified in the following areas of care delivery:* Patient assessment
* Long-term monitoring and management
* Promoting healthy lifestyle choices and behaviours
 |
| 3. How could primary care RNs further contribute to CSC? | * Care coordination
* System navigation
* Emotional support
 |
| 4. What influencing factors impact primary care registered nurses’ involvement in CSC? | *Provider Influencing Factors** CSC knowledge, experience, education, and confidence
* Knowledge and understanding of CSC community resources
* Understanding of healthcare system, system navigation, and patient’s cancer journeys.

*Practice Setting Influencing Factors** Time
* Interprofessional team function
* Electronic medical records
* Level of CSC structure
* Role autonomy

*Systems Influencing Factors** Communication and exchange of patient information across healthcare settings
* Clinical information systems
* ‘Gold standard’ CSC tools, assessments, and best practice guidelines (BPGs)
* CSC funding models within PC practice settings
 |
| 5. What are possible solutions to expanding nurse involvement in CSC? | * Protected time to provide CSC
* CSC education for PC RNs
* CSC tools and resources
 |

**What is the current role of nurses, working in primary care settings in providing care for cancer survivors?**

When participants were asked to describe their role and how they are involved in providing care to patients diagnosed with cancer in their clinic setting there was a wide range of responses. The main activities and responsibilities outlined by the majority of participants could be categorized into three relevant themes: care coordination and system navigation; emotional support; and facilitating access to community resources. Primary care RN contributions to cancer survivor care that were discussed with less frequency included specific nursing tasks, promoting health, and supporting the development of basic patient self-management skills.

 **Care coordination and system navigation.**

 A major theme that emerged when participants spoke about nursing care and specific tasks was care coordination and system navigation. Care coordination is defined as “the deliberate organization of patient care activities between two or more participants involved in a patient’s care to facilitate the appropriate delivery of health care services” (McDonald et al., 2007, p.41). Broadly conceived, system navigation involves an individual, in this case a PC RN, who assists patients and their support-person through an illness experience (BC Cancer Agency, 2005). Key activities encompassed in system navigation include preparation for procedures/tests, linking patients with applicable professional and community networks, and assisting with transitions between healthcare providers (BC Cancer Agency, 2005). Care coordination focuses on seamless transitions of patient health information and patient care between multiple points of care while system navigation focuses on sharing information and professional experiential knowledge that helps patients access the services they need and smoothly negotiate the greater healthcare system as a whole. As illustrated in the quotes below many participants emphasized the essential role they play in care coordination and system navigation for their cancer survivor patient population.

 ***System navigation.***

 “…we are sort of that background ‘go to’ person to help support them in the whole process.” *Community Health Centre, RN*.

 “…I mean helping, helping patients navigate through the healthcare system to when they are dealing with cancer. You know all the steps the processes that they need to go through. It can be overwhelming for them and not just for the patient but for the family. So if you can help the whole family navigate through what’s next, what to expect, it just makes things a little easier for the patient and the family.” *Family Health Team, RN.*

 ***Care coordination.***

 “…so we ask, okay when is your next appointment? Do you have to have imaging before your appointment? Do you have those lab requisitions? Those types of things to help, to make sure that their care is as seamless as possible.” *Family Health Team, RN.*

 Participants consistently provided detailed examples of their day-to-day role in coordinating diagnostic imaging tests; varied follow-up care; and facilitating transitions between healthcare providers and settings. Primary care RNs’ understanding of the healthcare system and the care coordination expertise required to support cancer survivors' access to multiple services were revealed to be an invisible part of day-to-day PC RN roles. Multiple participants commented that these activities were generally not captured in formal nursing documentation or workload measures.

 **Emotional support.**

 Another major theme that emerged when participants spoke about their nursing role with cancer survivors was emotional support. Most of the participants reflected on their role in providing ongoing emotional support to their patients as well as the patient’s family members. As demonstrated in the direct quotes below, participants were confident in their ability to provide emotional support and meet patient’s changing emotional needs throughout their cancer journey.

 “…I think a lot of times they feel more comfortable talking to us about these things then they do at the clinics, you know, the specialists…because they’ve had a long, long standing relationship with us.” *Family Health Team, RN.*

“I would say a huge part of it is emotional support and letting them ask their questions and hopefully finding the answers for them.” *Solo Family Physician Practice, RN.*

 Many participants highlighted their well-developed skills in therapeutic communication, basic counselling, and listening. The direct quotes outlined above demonstrate the unique, long-term, and trusting relationship PC RN participants have with their patients.

 **Facilitating access to community resources.**

Facilitating access to community resourceswas the final major theme that emerged related to the RN role in providing CSC. Many participants lived in the communities they served or had been working in the same community for several years. Their familiarity with available resources and their long-term connections to established community agencies helped them link cancer survivors with the services and supports they required. As indicated in the quotes below, the majority of participants recognized the value of community resources and readily utilized such supports to aid their patients diagnosed with cancer.

 “There is actually a pretty strong support system in this community for folks going through cancer so sometimes; we also refer to those resources.” *Family Health Team, RN.*

 “…making sure that they are aware of the resources that are available and that they are willing to use them.” *Family Health Team, RN.*

 In their responses, participants shared that they used a combination of formal referral processes, brochures/advertisements, and professional relationships to assist cancer survivors in accessing community resources. Variability in the degree PC RNs were involved in facilitating access to community resources was apparent. Some participants simply informed survivors of the community resources available while others connected patients directly with community resources and followed-up during subsequent PC appointments regarding service utilization and satisfaction.

 Outside of the three major themes identified above, a few participants discussed their contribution to cancer survivor care through specific nursing activities to promote patient health and the development of basic self-management skills. Other specific nursing tasks outlined by a few participants included: triage, symptom management, documenting patients’ past medical history, management of episodic illness, and concurrent management of patients’ other chronic diseases. Some participants shared that they promote health within their survivor patient population by coordinating and/or carrying out basic cancer screening and through basic patient education. Examples included facilitating the completion of PAP and fecal occult blood tests, and scheduling mammograms and colonoscopies. When discussing their role in survivor patient education, a few participants shared that they provide basic information regarding: cancer prevention, healthy lifestyle choices, risk reduction, and the rationale behind cancer screening. Lastly, a couple of participants discussed their role in supporting survivor self-management. Participant’s involvement in self-management support included interventions such as goal setting, supporting patients to manage at home, and choosing healthy lifestyle choices and behaviors.

**How does the nursing role in CSC compare to providing Chronic Disease Management for patients with other chronic conditions?**

 In contrast to responses regarding their role in CSC; when asked to describe their role and how they were involved in providing care to patients diagnosed with other chronic conditions participants’ responded quickly with more clear, confident, and detailed descriptions. In the student researcher’s constant reflective memoing notes, it was repeatedly noted that participants required less probes when asked to discuss their role in chronic disease management than when asked to discuss their role in CSC. The student researcher frequently observed that participants spoke effortlessly about their contribution to chronic disease management and were consistently able to provide detailed examples of their involvement. In contrast, when asked to discuss their role in CSC many participants hesitated to respond, struggled to articulate their involvement in CSC, and required more probes from the interviewer. Ultimately, the following major themes emerged from participants’ descriptions of their role in chronic disease management: patient assessment, long-term monitoring and management, and promoting healthy lifestyle choices and behaviors. A few participants also discussed their contributions to chronic disease management through care coordination, patient education, self-management support, and facilitating access to community resources. However, such activities were discussed with less attention and frequency.

 **Patient assessment.**

 The majority of participants highlighted their role in completing standardized and sometimes disease/condition specific patient assessments. Many participants spoke about predetermined/set electronic assessment documentation (e.g., ‘stamps’) and standardized flow sheets. As illustrated in the quote below, participants emphasized how these assessment tools aided in streamlining patient care, improving clinic and documentation efficiency, and clarifying their nursing role for certain chronic conditions.

 “We see our diabetics every three months. There is a specific stamp that we use in the electronic medical record and we go through different assessments every single time they are there [in the clinic]. So the nurse’s role would be to do their weight, their waist measurement, their blood pressure, verify all of their meds, check their feet and ask them about their lifestyle. So that one is a lot more structured – that’s with the diabetics.” *Family Health Organization, RN.*

 “…we do have pre-assessment appointments so they are for patients who have a diagnosis of diabetes or hypertension… anyone coming for their regular follow-up for those issues with their provider will also see the nurse twenty minutes prior. So in those appointments we’re doing serial blood pressure monitoring; checking their blood sugars; measuring their waist circumference; also talking about stress how to manage their stress; looking at diet – things like that.” *Community Health Centre, RN.*

 As the quotes above indicate, participants had a clear understanding of what patient assessments to carry out for common chronic conditions such as diabetes and hypertension. The majority of participants spoke easily and in detail about their role in ongoing patient assessment for patients diagnosed with common chronic conditions.

 **Long-term monitoring and management.**

 Another major theme that emerged from analyzing participant responses regarding their role in chronic disease management was the long-term approach to monitoring and managing chronic conditions. Most of the participants indicated that there was a high level of structure and organization to support chronic disease management within PC. As evidenced in the quotes below, established timelines for appointments, standardized assessment and documentation tools, consistent lab work, and the opportunity to continually monitor and compare patients’ conditions over time notably strengthened participants’ confidence in their ability to provide quality chronic disease management.

 “So the biggest impact I would have with chronic disease management is the diabetics. So if someone has been a long time since lab work or follow-up work with physicians, again I run a search, looking for anybody that’s been six months and out and either call them by phone or send out a message to one of the staff to give them a call and say ‘You are due for your lab work. Do you need requisitions?’ As I can, I do more. We have a custom form for the diabetic screening, questioning, reviewing our labs, reviewing our drugs, putting in weights – you know graphing for them [the physician] and showing the trends for everyone.” *Family Health Organization, RN*

 “Yes, we always make sure that our diabetics or hypertensive patients are followed regularly.” *Family Health Group, RN.*

 The quotes above illustrate that the structured and organized approaches to chronic disease management within PC may help to clarify patient care expectations and in turn the role PC RNs play in the long-term management of common chronic conditions. Clear processes for chronic disease management and access to appropriate logistical supports may also have contributed to participants’ distinct comfort and confidence in discussing this specific area of patient care.

 **Promoting healthy lifestyle choices and behaviors.**

 The final major theme that emerged from participants’ responses regarding their role in chronic disease management was promoting healthy lifestyle choices and behaviors. Many participants shared that a considerable part of their chronic disease management nursing role was promoting healthy lifestyle choices and behaviors through the following core activities: goal setting, providing ongoing patient support, smoking cessation services, general health promotion, and prevention management. As evident in the quotes below, participants’ were involved in the promotion of healthy lifestyle choices and behaviors at different levels of intensity and in widely varied circumstances. Some participants shared examples of their basic involvement in promoting healthy lifestyle choices and behaviors stating:

 “…we do a lot of prevention management. So if they are pre-diabetic for example they often will come and see us and we’ll chat about lifestyle, mainly exercise, nutrition, just positive lifestyle things they could do to prevent the onset of diabetes.” *Family Health Team, RN.*

 “Because your blood pressure patients normally are sedentary so you are focusing on chronic disease prevention through goal setting right? So what’s your goal? Are you going to reduce your sodium intake? How are you going to do that? Is that a realistic goal for you? Same thing with weight management I find that a lot of people struggle. So okay, you want to lose weight – how are you going to do this? What’s realistic for you? So you are constantly goal setting with people...” *Family Health Team, RN.*

Other participants shared examples of more complex interventions that they delivered in promoting healthy lifestyle choices and behaviors stating:

 “We do a ‘creating change group’. It’s more for people that we might identify as over eaters or emotional eaters or those who just identify as having bad relationships with food. So I co-facilitate. We do it about four or five times a year. It is a five week group and I do it with our diabetes education program. So there’s a diabetes dietician and nurse and we rotate and do it in pairs.” *Family Health Team, RN.*

 Regardless of participants’ basic or complex involvement in this important aspect of chronic disease management, promotion of healthy lifestyle choices and behaviors did seem embedded in day-to-day nurse-patient interactions.

**Key Differences in PC RN role in Chronic Disease Management vs. CSC**

After describing their role in chronic disease management and CSC separately, participants were asked how their role in caring for patients diagnosed with cancer differed from their role in caring for patient with other chronic conditions. Participants repeatedly highlighted the lack of CSC tools, resources, and structure; that CSC was not systematically addressed within PC; and finally that most PC RNs lack confidence, knowledge, education, and expertise in CSC. These key differences in CSC were depicted as ongoing challenges within PC and ultimately barriers to PC RN involvement in the delivery of CSC. Contrastingly, a minority of participants contended that there are no differences between PC RN roles in chronic disease management and CSC.

 **Lack of CSC tools, resources, and structure.**

 As shown in the quotes below, many participants lacked awareness about available CSC best practice guidelines and assessment tools. Participants indicated that standardized CSC assessment and documentation tools were simply unavailable in many of their PC practice settings. Furthermore, a few participants shared that PC practices using standardized electronic documentation and flow sheets to monitor patients’ common chronic conditions over time had not established similar mechanisms to support monitoring of cancer survivors.

 “There's no specific pathway for recovery or a guideline you know to say this is where they [cancer survivors] should be a certain point, it's all just individual. You know every chronic disease has their individuality of course but I think because there's a guideline for some other chronic conditions, standards so to speak, that makes it easier for primary care.” *Community Health Centre, RN.*

 “So the resources and the structure and the tools that are currently available for things such as diabetes or hypertension in primary care those things are just completely absent for cancer survivorship right now.” *Family Health Team, RN.*

Without knowledge of or access to basic CSC delivery supports participants often struggled to address CSC in their day-to-day nursing practice.

 **CSC not systematically addressed within PC.**

 Many participants stressed that CSC is not systematically addressed within PC. An overall lack of structure to support the delivery of CSC within PC practice settings was made apparent through the following participant responses.

 “I think there is a huge disparity…I think where there's a difference with cancer care and with other chronic conditions is there's more structure with hypertension or diabetes or even chronic pain – hypertension and diabetes particularly.” *Community Health Centre, RN.*

 “We don’t actually have any rostered cancer visits.” *Family Health Team, RN.*

 “We don’t have a defined [CSC] program at all.” *Family Health Team, RN.*

Participants’ consistent and honest responses indicate that currently the delivery of CSC within PC practice settings is an undefined area of patient care. Many participants openly acknowledged this gap in patient care and identified their need for further guidance and supports.

 **Lack of PC RN confidence, knowledge, education, and expertise in CSC.**

 Participants shared that they were uncomfortable or less confident in their ability to provide appropriate CSC compared to chronic disease management. Multiple participants elaborated that this lack of confidence and comfort stemmed directly from their lack of experience and knowledge of cancer care.

 “I think we do lack some knowledge in primary care about the cancers and that comfort level to be able to really give the support that we do for other chronic illnesses. I think a lot of times what we do is sort of resort to saying ‘oh well you should follow-up with your oncologist’…I know for the whole team that sometimes you’re really not sure –okay what is the plan? What should I be telling this person? So I think maybe there is a lack of comfort and confidence and knowledge in caring for patients with cancer as opposed to other chronic conditions. Where we seem to have more – where I feel like I have more knowledge and expertise to be able to deal with that as opposed to cancer.” *Community Health Centre, RN.*

 As the quote above illustrates, there is a high degree of uncertainty and unease surrounding CSC for many PC RNs. The current lack of CSC education, tools, structure, and accessible resources within PC may contribute to these feelings and ultimately lead to a lack of PC RN role clarity in the delivery of CSC.

 **No differences in PC RN role in Chronic Disease Management vs. CSC.**

 In contrast to the key differences described by the majority of participants regarding PC RN roles in chronic disease management and CSC, a small minority of participants shared that they found no differences in their nursing role for chronic disease management and CSC.

 “I try to be flexible and try to work with where the person is at. What are their questions? What is their intent? What’s the reason for their visit? What do they want to accomplish? And then I try to go from there. So if I saw a diabetic versus somebody who was having breast cancer I don’t know if I would per say be different. I think I would just kind of feel out the situation and try to pull out what the issues are with them at that time.” *Family Health Team, RN.*

 Such participant responses illustrate taking a patient-centred generalist approach to nurse-patient interactions. Participants emphasized that this approach to care involved identifying and addressing the patients’ priority concerns not following a predetermined or prescribed PC appointment script based on the patients’ health history.

**How could PC RNs further contribute to the delivery of CSC?**

 Moving forward, participants were asked to identify ways PC RN roles could be enhanced to improve the delivery of CSC within PC practice settings. Reflecting on their individual skill sets and potential opportunities to positively impact the delivery of CSC within their own practice settings, participants discussed the expanded contributions they could make for their survivor patient population. Three prominent themes emerged from participant responses: care coordination, system navigation, and emotional support.

 **Care coordination.**

 Multiple participants pointed out that PC RNs are already ideally situated and capable of further contributing to survivor care coordination. As the quotes below demonstrate, many participants spoke confidently about their skills in coordinating patient care.

 “I think that in an ideal situation we in primary care we could kind of be that hub of information that centre point… we would be the ‘go to’ person… we would know what is going on with everything and really be able to support that patient.” *Community Health Centre, RN.*

 “I think that the nurses could be used for more care coordination and case management and for support for patients who are cancer survivors or who are going through cancer treatment. We just don’t utilize our nurses the way we probably could.” *Community Health Centre, RN.*

 Participants spoke frequently about their in-depth patient knowledge and their long-term relationships with patients. If provided the opportunity to expand their role in care coordination for cancer survivors PC RNs could draw naturally on these unique relational factors to improve the quality of survivor care coordination.

 **System navigation.**

 Several participants openly recognized that patients’ cancer journeys involve accessing multiple care providers as well as multiple points of care. The quotes below indicate that there is a need to explore the effectiveness of PC system navigation roles for survivors faced with complex care transitions. Participants suggested that such expanded system navigation services could potentially be provided by PC RNs.

 “I would love to see a transition where when people were done their active chemo treatment they had a place to come after for follow-up care. See if they had any lingering side effects, you know? Find out what their needs are… almost like a navigator transition clinic instead of just going to active treatment and just being done.” *Family Health Team, RN.*

 “I think that we would have a system navigator. We would then be able to individualize care plans and guide people in a more appropriate way. And we would have one of our team members assigned specifically to care for survivors of cancer. And we would have that person develop their competencies and knowledge base to be better able and equipped to manage some of the things that the patients [survivors] are facing.” *Family Health Team, RN.*

 Some participants’ responses suggest that effective system navigation required specialized knowledge. Acquiring and applying this specialized knowledge to assist cancer survivors to navigate the healthcare system through-out their cancer journey was one way participants repeatedly proposed PC RNs could expand their contribution to the delivery of CSC.

 **Emotional support.**

 Lastly, many participants explored different ways they could contribute to supporting and addressing survivors’ emotional needs. Participants discussed the potential to expand the delivery of survivor emotional support through nurse-initiated telephone contact, one-on-one nurse-patient appointments, and nurse-facilitated survivor support groups.

 “I think offering them emotional support is one of the key factors…the emotional support for the life changing issues that they are facing is key I think because attitude has a lot to do with how someone survives. And a positive attitude can go a long way, and just knowing somebody cares can make a huge difference to a person.” *Family Health Team, RN.*

 “After I think when you are done chemo maybe some people just need to talk, it’s been a scary thing.” *Family Health Team, RN.*

 As demonstrated in the quotes above, participants persistently emphasized the need for and importance of ongoing survivor emotional support. Many participants conveyed that expanding their contribution in this particular area of patient care was a logical fit with their PC nursing role. Moreover, participants consistently spoke confidently about their skill and expertise in listening, basic counselling, and therapeutic communication.

**What are the influencing factors that impact PC RN involvement in CSC?**

 When asked what factors aided and inhibited their involvement in CSC, participants eagerly provided detailed responses. Participant responses revealed that PC RN involvement in CSC is influenced by a plethora of factors at the provider, practice setting, and systems level. Based on individual participant context, practice setting context, and primary care team composition key influencing factors were often discussed as a barrier or a facilitator. The common barriers to PC RN involvement in CSC were often the mirror version or absence of common facilitators. The quotes below are organized into provider, practice setting, and systems level key influencing factors to promote clarity and organization of this large dataset.

 **Provider level influencing factors.**

 The provider level influencing factors identified by most participants during their interviews were: CSC knowledge, experience, education, and confidence; knowledge and understanding of CSC community resources, and understanding of healthcare system, system navigation, and patient’s cancer journeys.

 In the quotes outlined below, novice nurse participants and participants without oncology specific experience or education reported that lack of knowledge contributed to their lack of confidence in delivering safe effective CSC. In contrast, seasoned or expert nurses and participants with oncology experience indicated they drew on such expertise when delivering CSC within their PC practice setting.

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| **CSC Knowledge, Experience, Education, and Confidence** |
| **Barrier** | **Facilitator**  |
| “I feel like there’s a gap for sure in the knowledge, skills and expertise when it comes to cancer care because I guess it’s something that we’ve not had a really big focus on in the last couple of years in my practice. So I don’t feel as though I’m up to par if you want to call it with my skills in that area.” *Family Health Team, RN.* “I would say my comfort level and my knowledge is not nearly as high as it is with a lot of the other chronic conditions that we work with every single day and that we are given training in.” *Family Health Team, RN.* |  “…my background [13 years’ experience as an oncology nurse] definitely helps you know? My connections definitely help too, people just know that’s what I do, so even though they don’t have a role here for it, they don’t have an actual position I do still get people coming through, but it’s only through word of mouth that people know what I do.” *Family Health Team, RN.*“…some of it is just experience over the years and you know, using what I have learned over the years to help.” *Solo Family Physician Office, RN.*  |

Overall the majority of participants indicated that they were interested in and willing to expand their involvement in CSC. However, their lack of oncology specific education and experience inhibited their current level of involvement, confidence, and comfort within this area of patient care.

 All participants recognized the value of community services and resources for their cancer survivor patient population. However, while some participants felt well connected to their local cancer community resources others felt greater awareness of available services would aid them in their delivery of CSC.

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| **Knowledge and Understanding of CSC Community Resources** |
| **Barrier** | **Facilitator** |
| “…I don’t know if the nurses are necessarily aware of all the resources that are out there…” *Family Health Team, RN.*“…I don’t know what is available in the community you know? If there is lots of support that way?” *Family Health Team, RN.* “…I know some resources but there are probably more resources, they are coming out with new things all the time.” *Family Health Team, RN.*  | “…so the community resources – being able to refer out to a service that knows one hundred times more than we do about what’s available and they are able to offer weight gaining and wig fitting and all those things that we don’t. We don’t have that option with our family health team. So to be able to refer it to them is phenomenal because they can offer fabulous services and they’re good at it.” *Family Health Team, RN.* “…just knowing the resources in the community – that really helps us as well.” *Community Health Centre, RN.*  |

The participant quotes outlined above demonstrate the importance of ensuring PC RNs are aware of local cancer related community services and resources and how to access such supports.

 As evident in the quotes below, participants’ level of understanding regarding their patient’s complex cancer journeys heavily influenced their ability or inability to provide CSC.

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| **Understanding of HC System, System Navigation, and Patient’s Cancer Journey** |
| **Barrier** | **Facilitator** |
| “…I don’t know a lot about the typical oncology plan of care for so many different types of cancers. Most of the time I rely on the person, well what did they tell you next?” *Family Health Team, RN.* “…there are so many new versions of treatments and things that because that really is a specialty area I don’t know that the primary care team is a source of information for patients.” *Family Health Team, RN.*  | “…I mean helping patients navigate through the healthcare system too when they are dealing with cancer. You know all the steps the processes that they need to go through. It can be overwhelming for them and not just for the patient but for the family. So if you can help the whole family navigate through what’s next, what to expect, it just makes things a little easier for the patient and the family.” *Family Health Team, RN.* “…often the questions from them are who to contact. Is it the specialist? Is it cancer care? Is it the physician here? Is it the team? The family health team? So sometimes it is just those kinds of who is the coordinator of my care? There are a lot of different providers involved.” *Family Health Team, RN.*  |

Some participants indicated that basic care coordination, system navigation, and case management for patients diagnosed with cancer were expectations of their PC RN role. Nursing activities outlined in such participant responses included: answering patient and care provider questions, following-up on patient referrals, keeping the patient informed about next steps, and assisting patients to identify the appropriate healthcare provider to contact for varied health needs/concerns. In contrast, some participants spoke honestly about their lack of cancer care understanding and their extremely narrow involvement in this area of patient care. Such participant responses often spoke about facilitating patients’ cancer journeys as a specialty skill outside of their generalist PC scope.

 **Practice setting level influencing factors.**

 Participants identified numerous practice setting specific influencing factors. Time, interprofessional team function, electronic medical records, level of CSC structure, and role autonomy were identified by most participants as the main influencing factors at the practice setting level. Participants shared that time is a limiting influencing factor in the delivery of CSC within their day-to-day nursing practice. Workload, clinic flow, short appointment times, and multiple competing priorities were repeatedly identified by participants as constant pressures on nurse time within their practice setting. A couple of participants explained that, despite their busy clinic schedules, they managed to find time to listen and talk with their patients one-on-one.

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| **Time** |
| **Barrier** | **Facilitator** |
|  “…if they are coming in for something different you often only have time to deal with that you don’t have time to also check-in with them and see how things are going in terms of their history of cancer.” *Community Health Centre, RN.* “So there are a lot of challenges and different priorities for time so it’s difficult when you have that many folks in and out and so many competing priorities.” *Family Health Team, RN.*  | “…we give our patients the time that they need, we don’t rush them through and say oh, I’m too busy for that. Even if I am busy I will just say, ‘let’s talk’...There’s nothing more important than having a patient nurse relationship and that they can have trust in you and that you can take the time to listen to them.” *Family Health Group, RN.*  |

 The quotes above illustrate that finding adequate time to address CSC issues is a constant struggle for PC RNs.

 Many participants commented on how physician understanding and support of nursing roles in PC and interprofessional team function positively or negatively influenced their involvement in CSC.

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| **Physician Understanding and Support of RN Roles & Interprofessional Team Function** |
| **Barrier** | **Facilitator** |
| “I find physicians are very hesitant to use nurses to their full scope of practice. And so there’s a definite gap for physicians to trust in what we can do and what we can do for them. So there’s a lack of understanding on the physicians part…” *Family Health Organization, RN.*  “…I feel that sometimes some of the doctors here may not understand that a lot of the nurses have experience and they can gain information from them…” *Community Health Centre, RN.*  | “Key factors? I think just having a supportive team, you know? I think you need a very supportive physician group that is nursing friendly and supportive. Also management that’s supportive as well. Because then it allows you to be able to see where the issues are, where maybe new programs could be started.” *Family Health Team, RN.* “…we support each other. But we also support our patients in a collaborative way… I think that’s been a key factor in developing relationships with our cancer survivors as well as the people that are going through treatment. Because if they have questions they know they can always come to one of us and if one of us doesn’t have the answer we can go to someone else on the team.” *Community Health Centre, RN.*  |

 Several participants shared that poor physician understanding of PC RN roles and lack of communication between interdisciplinary team members inhibited their involvement in CSC. In contrast, many participants described how collaborative team-based approaches to patient care and support from management aided them in the delivery of CSC. Participants working in such supportive environments consistently acknowledged that they were not currently equipped to support survivors on their own. However, as demonstrated in the quotes above, drawing on their interdisciplinary team members’ areas of expertise participants felt they could find answers to survivors’ questions and help patients navigate through the different stages of their cancer journeys.

 Clinical information systems, specifically patients’ electronic medical records (EMR), were shown to play a large and directive role in the delivery of PC RN cancer prevention and cancer survivorship patient care. Participants’ responses indicated that there is wide variability in how PC practices across Ontario utilize EMRs.

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| **Electronic Medical Record** |
| **Barrier** | **Facilitator** |
| “…it’s [cancer] not marked in a consistent way in all patients charts in the EMR. That’s a huge barrier to providing follow-up care.” *Family Health Team, RN.* “…lots of times you wouldn’t even really know that they’ve been through that [cancer] unless it comes up in conversation.” *Family Health Team, RN.* “In terms of flagging a new [cancer] diagnosis where it would sort of pop-up – we don’t have that.” *Community Health Centre, RN.*  | “We have electronic medical record. The system is quite sophisticated… nurses can actually create a search of all the records and pull up the data you want…I can pull out all of our women over 50 who are due, who haven’t had an FOBT or colonoscopy or hasn’t had a mammography in the last 2 years or they’ve never had it…” *Family Health Team, RN.* “…last year I did a critique for Cancer Care Ontario on setting up reminders and searches to find high risk patients. So we can run a search to find anybody that is in need of, whoever needs follow-up and has been too long since their last mammogram.” *Family Health Organization, RN.*  |

How EMRs are utilized across Ontario PC practice settings is inconsistent. Some PC practices have set patients’ EMRs up to aid PC RNs in tracking and coordinating patients’ cancer screening while other PC practices are yet to utilize EMR technology in this capacity. The quotes above illustrate that currently EMRs are focused on cancer screening rather than systematic identification of cancer survivors to facilitate ongoing monitoring and surveillance post diagnosis and treatment. Multiple participants shared that often they are not aware of patients’ diagnosis or history of cancer when they are seeing patients for routine appointments or follow-up tied to another chronic condition. This important finding illuminates one of the reasons the opportunity for PC RNs to provide proactive CSC is frequently lost.

 No participants discussed a structured approach to CSC within their PC practice setting. Participants consistently disclosed that the lack of structure in CSC delivery within their PC practice setting inhibited their involvement in CSC.

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| **Level of CSC Structure Within PC Practice Setting** |
| **Barrier** |
| “…in our situation we have no models, no protocols, no physician directed interventions that we have been taught and explained and told that we are allowed to implement. So I would say we have a lack of – just a lack of structure really there is nothing specific that I can think of.” *Family Health Organization, RN.* “…we don’t have any of those set models or education models or anything. We are very limited in our ability to use any skills specifically related to cancer… We have no real directives from the physicians specifically related to dealing with cancer patients. So I would say it needs more attention and organization and we don’t have a lot of guidance or models to work from.” *Family Health Group, RN.*  |

 Many participants explained that without a clear model of CSC, standardized CSC assessments, and mechanisms to document CSC delivered expectations around PC RNs role in CSC remains unclear.

 Participants spoke openly about their varying levels of role autonomy. Some participants shared that their involvement in CSC was inhibited by non-nursing task work. Others frankly shared that physicians were influential in determining the scope of practice and if and how nurses were involved in CSC.

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| **Role Autonomy** |
| **Barrier** | **Facilitator** |
| “…nurses tend to be lowest on the totem pole in the family health team …a lot of the things fall in the nurses lap such as answering phones, stacking shelves, doing that kind of stuff. And it doesn’t leave time for you to do things that really make an impact that matters.” *Family Health Team, RN.* “…I would describe it as the doctors sort of have a short rein on what we can do…in looking at all of this it is funny to see how with every other chronic illness we are allotted a lot more autonomy and you know we direct the initial patient assessment with diabetes and everything like that but with cancer there is really nothing specific whatsoever.” *Family Health Organization, RN.* “The biggest barrier and the biggest facilitator is the physician that you work with, because he makes or breaks it because it’s his practice.” *Family Health Team, RN.*  | “…our pay check comes from the XXX Family Health Team not the physicians whose practice we are in so little bit of an interesting dynamic.” *Family Health Team, RN.* “The other thing that drew me to primary care is I really got to work to my full scope of practice and you get to push the envelope a little bit with having it like that.” *Family Health Team, RN.*  |

 In contrast a limited number of participants spoke about working in PC practice settings that allowed them to work to their full scope and funding models that enabled greater PC RN role autonomy.

 **Systems level influencing factors.**

 Overall, participants found it more difficult to critically reflect about systems level factors that influenced their involvement in day-to-day CSC. Despite this common initial struggle, some key systems level influencing factors did emerge from participant responses related to: communication and exchange of patient information across healthcare settings; clinical information systems; ‘gold standard’ CSC tools, assessments, and best practice guidelines (BPGs); and CSC funding models within PC practice settings.

 When discussing communication between healthcare providers and the exchange of patient information between cancer centres and PC practices, many participants expressed their desire for more frequent communication and greater transparency.

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| **Communication and Exchange of Patient Information Across Healthcare Settings** |
| **Barrier** | **Facilitator** |
|  “I find family physicians get very little information back as to where they [the patients] are at in their treatment. The specialists are not really sharing as much as they could.” *Family Health Organization, RN.* “I’d say the doctors are relying on what the patients are coming in for follow-up and telling them. There’s not necessarily any information from the Regional Cancer Clinic.” *Solo Family Physician Office, RN.*  | “It’s really that communication between the interdisciplinary team which really helps.” *Community Health Centre, RN.* “…our oncologists here in XXX are amazing and often we get their consult notes back from any type of visit within twenty-four hours. So we know what happened in your last oncologist visit – this is who you were referred off to for this that and the other. So it really helps us in terms of caring for that patient and looking at that case management.” *Family Health Team, RN.*  |

 Participants shared that PC physicians and PC RNs often rely on the patient for up-to-date information regarding their cancer treatment. Participants repeatedly remarked that increased accessibility to patients’ latest labs, diagnostic imaging, and oncology related consult notes would help them to provide CSC. In contrast, a few participants shared that interorganizational rapport, communication between the patients’ interdisciplinary team, and timely exchange of oncology consult notes facilitated their involvement in CSC. Overall, the majority of participants conveyed interest in greater collaboration and connections between patients’ various healthcare providers and points of care.

 As demonstrated in quotes below, many participants were unaware of available CSC tools, assessments, and best practice guidelines.

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| **‘Gold Standard’, Accessible, and Evidence-based CSC Tools, Assessments, and Best Practice Guidelines** |
| **Barrier** |
| “…I never looked at like Cancer Care Ontario or that kind of thing. There is nowhere specific that I would go for cancer handouts at all.” *Family Health Team, RN.*  “I don’t even know if there are and I’ve never looked at, are there any recommendations or guidelines? So I guess looking to see if there is any sort of evidence out there or resources or things to use.” *Family Health Team, RN.* “I’ve never looked into that to see if there is anything [CSC best practice guidelines]. It would be helpful if there was just so then you are delivering care that you know does have some evidence behind it.” *Family Health Team, RN.*  |

Multiple participants also disclosed that they did not know where to find CSC guidelines or evidence based CSC aids/tools suitable for PC.

 Lastly, a few participants spoke about how funding limited their involvement in CSC. These participants alluded that without specific allocation of funds for CSC within PC this aspect of patient care will remain neglected.

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| **CSC Funding Models within PC Practice Settings** |
| **Barrier** |
| “…so there’s not the financial drive there to provide any extra services I guess or to have the staff to do it [CSC].” *Family Health Organization, RN.* “…right now whatever hours I’m doled out here it’s for hypertension, INR and we’ve got like some of the girls do the COPD, some of them do diabetes. So we all kind of have these roles that are funded. But it hasn’t really been mandated for cancer survivorship…” *Family Health Team, RN.* “…cancer navigator we don’t have that role yet but that comes down to the funding.” *Family Health Team, RN.*  |

A couple of participants with oncology experience and/or oncology specific additional education shared that they were interested, capable, and could be more involved in CSC however, without funding this simply was not part of their day-to-day PC RN role.

 Participant responses detailing the influencing factors that impacted their level of involvement in CSC were multilayered and complex. The diverse influencing factors participants chose to highlight in discussion were often similar but occasionally divergent. Universally participants’ experiences with CSC were consistently and heavily impacted by individual context, practice setting context, physician priorities, and primary care team composition and leadership.

**What are possible solutions to expanding nurse involvement in CSC?**

 To explore possible solutions to expanding PC RN involvement in CSC, participants were asked to identify two or three specific strategies that would increase their ability to provide quality care for cancer survivors. Most participants identified a mix of RN, practice setting, and systems focused strategies. As demonstrated in the quotes outlined below, the majority of strategies forwarded by participants centre around clear gaps in current CSC within PC.

 When discussing RN focused strategies participants fixated on the need for CSC education. The majority of participants were keenly interested in expanding their involvement in this area of patient care. However, in their responses participants made it clear that in order to effectively increase their involvement in CSC they would require further CSC education.

 “If we could have somebody with advanced practice education specifically in that [CSC] – they could even do in-services with us until we were ready to implement any new assessments. Because it would just be so brand new… it would help us to get an idea of what patients go through because we don’t know what is involved emotionally, mentally, physically when they are going through treatment or have been for treatment. We don’t know what is out there in the community that they can use to support themselves and their families. So I think having someone who has that knowledge and has that extended education would be a great idea.” *Family Health Organization, RN.*

 “…a little more education that would be a good place to start. In terms of: What are the issues? What should we be talking about? What is the evidence? What makes the difference? What doesn’t?” *Family Health Team, RN.*

Many participants were particularly interested in learning more about: 1) typical patient cancer journeys, 2) CSC nursing assessments, 3) the role of the cancer centre pre, during, and post active treatment and 4) community resources available to survivors and their family members. Some participants elaborated on potential forums for the delivery of CSC specific education targeting PC RNs, suggestions included: formal courses, in services, access to CSC best practice guidelines and ongoing partnerships with oncology advanced practice nurses.

 When sharing practice setting focused improvement strategies participants routinely recommended the development of a standardized systematic approach to CSC and the allocation of protected time to address CSC patient issues. As exemplified in the quote below, participants stressed the importance of standardized tools and a consistent, long-term monitoring approach.

 “I think a flow sheet stamp would be effective because that is what we do with every other chronic disease. Keep it consistent I think that would be great.” *Family Health Organization, RN.*

Participant responses indicate that clear structures and processes, similar to those already in place for other common chronic conditions, would aid participants in expanding their involvement in CSC. Additionally, many participants spoke about the need for protected time to deliver CSC when discussing practice setting focused strategies.

 “It [CSC] probably right now doesn’t get the time that it deserves. So if we are looking at ideal scenarios what I would need would be more time which is always what we are asking for aren’t we?” *Family Health Team, RN.*

In line with the quote above, multiple participants commented on the current limitations of short patient appointment times and rigid clinic schedules. A few participants elaborated that clinic pressures often pushed PC RNs to overlook or neglect CSC.

 At the systems level, participants suggested strategies that were focused heavily on increased access to enhanced clinical information systems. As demonstrated in the quotes below, participants stressed that access to up-to-date patient information, improved transfer of information between varied points of care, and mechanisms to ease communication between healthcare providers would increase their ability to provide quality care for cancer survivors.

 “…just full access to the patient’s chart… I mean it would be phenomenal to see what’s going on with people and what they need. What services are they accessing? And how we can better help them in the community or community services? I think it would just be phenomenal if that happened.” *Family Health Team, RN.*

 “…having the information in a timely manner…information from their oncologist…if it’s actually in the chart then you can actually access it when you want to access it…I would be able to look at that with them and go through and review and explain things that they didn’t understand you know?” *Family Health Team, RN.*

 Uniformly participants spoke about clinical information systems as an integral part of their day-to-day nursing care. Participants explained that they rely on such systems to access patient information, document care provided, answer patients’ questions, and communicate with other healthcare providers. Participants shared that often they only had partial access to patients’ charts. This gap in accessible patient health information was highlighted as a hindrance to PC RNs ability to provide timely CSC. Participant responses indicate that significant progress with EMRs has been made but optimal utilization of clinical information systems across points of care and between care providers remains problematic.

 When asked to prioritize their proposed strategies, participants identified the following strategies as the most important in expanding PC RN involvement in CSC: protected time to provide CSC; CSC education for PC nurses; and CSC tools and resources. The quotes below support the prioritization of these top three strategies.

 “Time…when I’m going to four different rooms I just don’t have time to be in there.” *Solo Family Physician Practice, RN.*

 “…just to be up-to-date on what are the resources out there? What is the process the patient goes through when they are first diagnosed with cancer? And what does their journey look like? That I think would be really helpful for us to really understand what our patients are going through.” *Community Health Centre, RN.*

 “…clear direction on what we should be doing – kind of guidelines I guess. [CSC] Best-practice guidelines that would be nice if the RNAO can do a piece on that.” *Family Health Team, RN.*

**Summary**

 Interestingly, study results showed that our preconceptions regarding PC RN understanding of, involvement in and agency over the chronic care model elements of self-management support and delivery system design were incorrect. The majority of participants revealed only a basic understanding of self-management support and limited skill/involvement in this area of patient care. Similarly, the majority of participants shared that within their practice settings they had minimal influence over delivery system design. Contrastingly, participant responses indicated that most participants were confident in their care coordination skills and were heavily involved in this aspect of patient care. Lastly, participant responses distinctly highlighted the large impact the chronic care model element of clinical information systems had on their nursing role and day-to-day direct patient care. Analysis of study findings tied to the chronic care model will be discussed in greater depth in the discussion chapter.

 These results demonstrate that there is wide variability in PC RN roles across Ontario. PC RNs’ education, individual expertise, level of autonomy, team members, and practice environments were shown to impact day-to-day PC nursing practice and participants’ involvement in CSC. Overall, participants expressed interest and enthusiasm in expanding their involvement in CSC. Specific educational, practical, and practice setting needs that must be addressed to enable safe expansion of RN involvement in CSC were identified.

**CHAPTER 5**

**DISCUSSION AND CONCLUSIONS**

 In this chapter select study findings are further examined in relation to current literature. The chapter begins by examining the variability in RN roles across Ontario PC practice settings. Next the relevance of chronic disease management and the chronic care model to PC RN roles and CSC and key findings related to optimization of RN roles in CSC are explored. The strengths and limitations of this study are then discussed and important implications for practice and research are considered.

**Variability in RN Roles in PC**

 Study results demonstrate a high degree of variability in role activities and scope of practice among RNs in primary care. Some participants described complex role activities related to comprehensive patient assessments, chronic disease management and care coordination. Others described very limited scopes of practice, confined to triaging, providing injections and putting patients in examination rooms. Factors that influenced role variability included physician practice preferences and nurses’ knowledge, experience, and confidence. Some participants described how their scope of practice was constantly evolving and expanding over time based on the needs of their patient population, the vision of their practice leaders, and their own personal professional goals. In contrast, other participants described static, structured, and physician-centric roles.

 These findings demonstrating significant PC RN role variability are consistent with recent research examining Canadian PC RN roles. Maintaining flexibility in PC RN roles is essential because nurses need to be able to adjust the care they provide to the patient population they serve and unique patient needs. However, perpetuating wide PC RN role variability that accepts/encompasses static, structured, and physician-centric roles impedes role optimization. Recognizing that PC RN role variability can be a hindrance to the delivery of quality PC services and a disservice to patients, recent research and reports have focused on clarifying and unifying the role of PC RNs. After primary care networks were introduced in Alberta in 2003, the College and Association for Registered Nurses of Alberta (CARNA) recognized a need to clarify the specific contribution RNs and NPs make to the improvement of health care organization and the delivery of primary care services within interprofessional team settings (CARNA, 2011). While supporting the need to maintain role flexibility, in 2011 the CARNA published a document describing seven common contributions PC RNs make to the delivery of quality patient care. These seven contributions to patient care include: care of individual patients; coordination of care and case management; health promotion, disease prevention, and support for self-management; program development; management for chronic illness; liaison with hospital services; and administrative management in PC (CARNA, 2011). In describing the universal commonalities of PC RN roles CARNA articulated the specific impact all PC RNs have on the health and health care needs of patients (CARNA, 2011). Similarly, in 2012 the RNAO published a PC nurse task force report that explored the unique role of RNs and RPNs in PC. Noting the negative consequences of wide PC RN role variability across the province; this report aimed to strengthen PC RN role clarity and examine solutions for optimizing nursing roles within patient-centred interprofessional teams. Comprehensive recommendations to maximize and expand the scope of practice of PC nurses were reported (RNAO, 2012). Most recently, the CNA published a report in 2014 titled *Optimizing the Role of Nurses in Primary Care in Canada* (Martin-Misener et al., 2014). This report examined PC RN roles from a national perspective and provided further evidence of the negative impact of PC RN role variability across Canada. The report argues that the lack of consistent understanding of the legislative scope of practice of nurses and supports for Canadian PC RNs to work to their optimal scope of practice requires further attention (CNA, 2014). The accretion of these reports demonstrates that discussion around what PC RN roles could and should be is mounting within fields of nursing policy, research and practice. Establishing common PC RN competencies and a universal understanding of the role and value-add of PC RNs is important. Building this core foundation of understanding will lead to decreased role variability and in turn will ensure PC RN health human resources are being maximized across Canada.

 Addressing the optimization of PC RN roles in chronic disease management specifically, these reports forwarded the following recommendations: 1) evaluate varied staff mixes of generalist and specialized RN roles to determine the best combination of provider expertise for PC practice settings; 2) evaluate the impact of enhanced nursing roles on access and delivery of chronic disease management care; 3) establish case management PC RN roles for patients with complex chronic disease; and 4) amend legislation to authorize RNs to prescribe medication to prevent and/or treat chronic disease (CARNA 2011, CNA 2014, & RNAO 2012). No recommendations related to PC RN involvement in CSC were included in these reports. As the demand for chronic disease management and CSC increases health policy leaders will need to engage with frontline PC RNs to critically evaluate how PC nursing health human resources are currently being used and strategically plan how to capitalize on PC RNs diverse expertise in order to improve patient care and outcomes in the future.

 The results of this study further support the need for greater PC RN role clarity in chronic disease management and CSC as well as the need to ensure consistent and optimal scope of practice. Continued underutilization of PC RN roles is a disservice to both patients and the Canadian healthcare system as a whole. Further research evaluating the outcomes of new and varied PC RN roles and scopes of practice is needed.

**Chronic disease management and the chronic care model – Relevance to RN Roles and CSC in PC**

 The majority of study participants did not consider or treat cancer as a chronic condition. For many nurses participating in this study, it was the first time they had critically explored and discussed cancer as a chronic condition. This finding may be explained by the fact that the concept of cancer as a chronic versus an acute episodic condition has gradually emerged in published cancer literature over the last five to 10 years (Feuerstein & Ganz, 2011; Harrison, Young, Price, Butow, & Solomon, 2009; Hewitt et al., 2005; McCorkle et al. 2011; Nolte & McKee, 2008). Similar recognition of cancer as a chronic condition may take longer to infiltrate PC practice settings and to reach PC providers faced with many other clinical care priorities.

 The chronic care model was used to inform the oral questionnaire, interview guide, and methods of this study. The chronic care model was chosen as an ideal fit for this study because it is a comprehensive evidence-based model that uses a holistic system focused approach to improve patient outcomes and the delivery/quality of chronic condition care (Coleman et al., 2009). Furthermore, the chronic care model aims to promote linkages between chronic disease specialist and PC providers (Wagner, 2000). The six essential elements for the optimal delivery of chronic care outlined in the chronic care model include community resources and policies, health care organization, self-management support, delivery system design, decision support, and clinical information systems (Bodenheimer et al., 2002). At the outset of this study the chronic care model elements of self-management support, delivery system design, and care coordination were selected as areas of focus because current evidence demonstrates that these areas of care are commonly identified with high unmet needs of cancer survivors (Battersby et al., 2010; Browne et al., 2012; Feuerstein & Ganz, 2011; Hewitt et al., 2005; McCorkle et al., 2011; Wagner, 2000; Wagner et al., 2001). Additionally, the student researcher speculated that these chronic care model elements were an obvious fit for PC RN roles because: 1) they are directly linked to daily nursing practice; 2) nurses are fundamentally invested in these aspects of chronic condition care; and 3) nurses have agency to influence/enact change over these aspects of chronic condition care.

 Study results suggest that except for a few participants, most nurses had a basic understanding of self-management support and limited skill/involvement in this area of patient care. While participants were familiar with the concept; many were only sporadically engaged in basic self-management support activities including: discussing self-care at home, encouraging patients to attend appropriate follow-up care, simple goal setting, and basic patient education regarding medications and diagnoses. These findings suggest many RNs rarely went beyond basic self-management nursing interventions aimed at individual patients and that there is room for improvement in PC RNs contribution to self-management support.

 Similarly, the majority of participants conveyed that they had minimal input or influence over delivery system design. Multiple participants shared that their PC practice setting was ‘physician driven’ or ‘physician-centric’ and provided detailed examples of how this prominent focus on physicians ultimately led to delivery system design tailored toward roles, preferences, and goals of physicians. Nurses’ lack of involvement, influence, and control over delivery system design within their PC practice settings points to a need for strategies to increase interdisciplinary collaboration and develop eqalitarian PC practice environments.

 Contrastingly, the student researcher’s initial assumptions about the important role PC RNs play in the chronic care model element of care coordination were accurate. Most participants were confident in their care coordination skills and were heavily involved in this aspect of patient care. Interestingly, many participants spoke about their contribution to care coordination as an embedded habitual part of their nursing role or ‘second nature’ in their day-to-day delivery of patient care. When asked how this work was accounted for or documented participants routinely shared that it simply was not. This finding supports recent concerns regarding the sustainability and viability of PC RN roles in the literature. In a recent report published by the CNA, researchers highlighted that when PC RN roles are poorly defined and not captured in formal documentation the value-add evidence of nursing roles is lost and crucial nursing work and subsequent patient outcomes remain invisible (Martin-Misener et al., 2014). These cumulative findings suggest that there is a need to develop innovative mechanisms to capture the unique work of PC RNs. Such mechanisms would enable PC RNs to provide clear indisputable evidence of the value of their professional role within PC and to advocate for further supports and necessary change.

 Unexpectedly, participant responses distinctly highlighted the large impact the chronic care model element of clinical information systems had on their nursing role and their day-to-day delivery of direct patient care. Many participants spoke explicitly about how electronic medical records (EMRs) and computer supported electronic documentation shaped their PC RN role. Multiple participants shared that EMRs and electronic documentation increased clinic efficiency, streamlined patient assessments, and made patients’ full health records more accessible at the point of care. However, negative consequences of EMRs and electronic documentation were also revealed. Participants noted that the use of standardized patient assessments based on set computer documentation templates called ‘stamps’ were commonly used during nurse-patient interactions. Some participants felt that the use of such predetermined tools detracted from their ability to apply critical thinking skills and to draw on their clinical expertise. Thus while standardized processes may improve PC practice efficiency they may also represent a barrier to the optimal use of nursing expertise.

 Further demonstrating participants’ reliance on heavily structured approaches to chronic disease management; participants were quick to recommend similar strategies for providing CSC in their PC settings. This trend in PC practice settings to resort to highly structured or ‘checklist’ nursing requires further and careful examination. Such task focused, protocol driven models of nursing care have been criticized in the literature and place the future contribution of the nursing profession in a vulnerable position (Spitzer, 1998).

 Exploring this trend and its implications in greater depth, researchers Brooks and Scott (2006) have defined two contrasting types of healthcare workers ‘information workers’ and ‘knowledge workers’ and have begun to evaluate how nurses typically engage in each category. Information workers are defined as “passive consumers of work-related knowledge” (Brooks & Scott, 2006, p. 83). Knowledge workers are defined as those “who are able to critically reflect upon the explicit knowledge of the organization by adding personal, theoretical and tacit knowledge acquired from their own experience” (Brooks & Scott, 2006, p.84). In their study evaluating nurses’ use of computer-mediated communication technologies; Brooks and Scott found that nurse participants predominantly engaged in information work and that knowledge work was restricted to exchanges between senior level nursing staff (Brooks & Scott, 2006). Study participants’ desire for highly structured CSC processes and the documented tendency for nurses to engage primarily in information work citied in the literature; draws attention to the need for nurses to step back and reflect critically on the cost/consequences of such regimented task-oriented approaches to nursing care. As the approach to CSC within PC practice settings begins to take shape, PC RNs and the survivors they care for may be better served by models of CSC that gravitate away from checklist nursing. Empowering and supporting PC RNs to act as critical reflective thinkers during their interactions with cancer survivors has the potential to improve the delivery of CSC and ultimately lead to better patient outcomes. Employing PC RNs’ chronic disease management, scientific, and experiential nursing knowledge to aid in the development of an innovative approach to CSC within PC are sensible strategies moving forward.

 Overall, the chronic care model provided an intriguing lens to examine study data. The student researcher’s initial assumptions regarding the chronic care model elements of self-management support and delivery system design were rightfully challenged and unanticipated findings regarding the central role of clinical information systems provided important insights. There is a lot of work to be done surrounding the delivery of CSC within PC practice setting across Canada before the chronic care model goal of “an informed, activated patient interacting with a prepared, proactive practice team, resulting in high quality, satisfying encounters and improved outcomes” (Bodenheimer et al., 2002, p.1777) can be actualized. However, prospects are hopeful as the majority of study participants expressed that they are eager and willing to expand their PC RN roles to encompass this often neglected but crucial part of holistic care for cancer survivors.

**Is there a role? – Optimizing RN Roles in CSC**

 Cancer survivors are being transitioned from regional cancer centers back to the care of their PC providers earlier than ever before. Results from this study indicate that nurses receiving and caring for survivors in community PC settings are unclear about their role in CSC and to date are minimally involved in this aspect of patient care. These findings expose the need for further discussion and exploration of Canadian PC RN roles in CSC. Two essential questions need to be considered: 1) Is there a role for PC RNs in CSC? And if so, 2) What will fostering the role of PC RNs in CSC entail? (e.g., education, necessary supports, implementation, and evaluation).

 Many nursing researchers, policy makers and oncology nurse leaders have published detailed arguments outlining why nurses are in an ideal position to lead chronic disease management. Kennedy (2014) argued that family practice RNs are well positioned to get to know patients throughout the lifespan, understand social determinants of health that affect patients and families, and manage continuity of care and relationship building over time. In a study conducted by Attwell et al. (2012) it was shown that nurses’ knowledge of PC patient subpopulations aided in preventing and closing gaps in patient care. Further supporting this perspective, a recent Canadian Health Services Research Foundation report published in 2012, forwarded that “more than any other healthcare professional nurses have been trained to manage patient health and social care in general and to identify specific situations that require more expert input from members of the care team” (Browne et al., p. 24). Lastly, speaking more specifically about nurses’ roles in advocating for patients’ throughout their cancer journeys; Thorne and Truant (2010) contended that “nursing is well positioned within an informed care coordination capacity, and is appropriately situated to interpret the myriad of patient concerns within the interprofessional team context, nurses are ideal team members to ensure that no patient gets lost in the shuffle” (p. 120). The core concepts behind these broader arguments are transferable to the unique position of PC RNs. Multiple study participants spoke about their in-depth knowledge of patients’ social, economic, and familial histories, their contribution to continuity of care within PC practice settings, and the long term trusting nurse-patient relationships that they had formed with patients over many years. Such unique/rare nurse-patient relational qualities clearly place PC RNs in a favorable position to lead the delivery of CSC. Nevertheless, it is imperative to examine the corresponding consequences of adding CSC to PC RNs already strained list of responsibilities.

 The majority of study participants responded positively and enthusiastically to the idea of expanding their involvement in CSC. In contrast, a couple of study participants indicated that expanding their involvement in CSC was not feasible or necessary due to their overburdened workload, a lack of time/supports within their PC practice environment, or their regional cancer center adequately meeting survivor care needs. These contrasting viewpoints parallel the debate in published and grey literature regarding whether or not PC RNs should focus on strengthening their expertise in generalist care or develop further specialized PC RN roles focused on high need areas of patient care such as chronic disease management, CSC, diabetes management, and mental health care.

 Specialized PC RN roles in diabetes care, chronic disease management, cardiac care, and the management of vulnerable patient populations have already been established across Ontario. Instead of simply following this trend and designating certain PC RNs as leads/experts in CSC, it is important that primary care leaders and administrators engage with frontline PC nurses and re-examine the implications of further shifting and dividing PC RN generalist roles to specialist roles. Supporting the need for further exploration and critical examination of specialized PC RN roles, in 2014 the Canadian Centre for Advanced Practice Nursing Research (CCAPNR) interviewed thirteen PC key informants from seven provinces and one territory and found that PC nurses “placed a high value on their generalist expertise and the fact that they provided ‘cradle to grave’ care rather than specialized care or care focused only on specific patient populations” (Martin-Misener, et al., 2014, p. 4). Proposing an alternative approach, oncology nurse researchers Truant and Thorne (2014) forwarded the idea that it may be time for specialized oncology nurses to move beyond traditional oncology healthcare settings and enter into PC and home care settings (Truant & Thorne, 2014). This innovative approach to the delivery of CSC in ambulatory outpatient settings would allow PC RNs to remain focused on the generalist expertise they value while simultaneously providing access to CSC and oncology nursing expertise on an as needed basis. Another possible strategy for addressing CSC within PC would be to maximize the use of RN roles and expertise by integrating interdisciplinary models of chronic disease management to better address a broad range of chronic conditions.

 Furthermore, multiple researchers have recommended that new/more nurse-led models of chronic disease management and CSC be piloted and evaluated. Evidence to date demonstrates that nurse-led models of care are cost-effective; comprehensive; provide equal or better care when compared to physician-led models of care; and address social supports for vulnerable patient populations (CNA, 2013; Browne et al. 2012). Addressing nurse-led models of CSC specifically, researchers have shown that nurse-coordinated CSC follow-up is as efficient as specialist-coordinated follow-up care when comparing clinical outcomes and that nurse-led care may be beneficial for survivor quality of life outcomes (Sussman, 2012). Additionally, a recent systematic review noted that two included studies that focused on nurse-led interventions demonstrated closest adherence to the Institute of Medicine recommendations and goals for survivorship care (Hebdon, Abrahamson, McComb, & Sands, 2014).

 To date no one care provider has been identified as the ideal provider in CSC based on survivor outcomes (Hebdon et al, 2014). Though nurse-led models of CSC are in their infancy, the initial outcomes outlined above are encouraging and warrant further research/investigation. Canadian PC nurse-led models of CSC are yet to be developed. However, as more and more survivors begin to be repatriated from regional oncology centers back to their PC healthcare providers health service researchers will have an excellent opportunity to pilot such innovative models of CSC. The optimal role for PC RNs in CSC remains to be seen.

 **What are the challenges/issues in expanding PC RN involvement in CSC?**

 The findings of this study have called attention to a number of challenges tied to expanding PC RN involvement in CSC. Collectively, study participants indicated that in order to deliver safe and effective CSC they needed: 1) further education; 2) protected time to deliver CSC; 3) greater knowledge of/access to relevant community resources; and 4) improved access to patients’ oncology healthcare providers and treatment records. As post-treatment survivors across the province are already being transferred from regional oncology center care back to their PC providers earlier than ever before these pressing challenges need to be promptly addressed at the systems level.

 How to best address these identified challenges remains unclear. Reviewing CSC literature for possible solutions, authors Hewitt, Greenfield, and Stovall (2005) propose that there are four essential components of high quality CSC including: 1) prevention of recurrent and new cancers, and other late effects; 2) monitoring and assessment for cancer spread, recurrence, second cancers, and medical and psychosocial late effects; 3) interventions to address the consequences of cancer and its treatment; and 4) coordination between specialists and primary care providers to ensure comprehensive patient-centered care (Hewitt et al, 2005). These essential CSC components apply broadly across all cancer types and could be used as the foundation to build CSC education programs for PC RNs as well as a more comprehensive common approach to CSC across Canadian PC practice settings.

 Multiple study participants went on to explain in further depth/detail that currently many PC RNs are not aware of local cancer related community services/resources and do not have routine access to CSC assessments. By illuminating these precise gaps in support for the delivery of CSC within PC practice settings participants confirmed that evidence-based CSC aids have yet to penetrate PC practices across Ontario. Without knowledge of and access to CSC tools PC RNs will likely remain stunted in their involvement in CSC. Moving forward, oncology and PC leaders need to strategize ways to first infiltrate and then embed CSC tools within day-to-day PC patient care. Moreover, ensuring PC RNs are aware of local cancer related community services and resources and how to access such supports is a relatively simple and affordable intervention/step towards improving the delivery of CSC within PC practice settings. However, the more lasting and impactful goal of initiating, building, and strengthening relationships between PC practices, regional cancer center survivor services, and survivor related community resources/services will require deliberate effort and strategic planning from multiple stakeholders.

 In order to become effective care providers and advocates for cancer survivors, PC RNs want and need to know about patients’ typical cancer journeys, available community resources, and evidence based approaches to CSC. Greater collaboration and improved communication between patients’ oncology and PC healthcare providers has the potential to fill these knowledge gaps and needs to be earnestly pursued.

**Study Strengths & Limitations**

 **Strengths.**

 To the best of our knowledge, this was the first study to examine Canadian PC RN involvement in CSC to date. Gaining a better understanding of what PC RNs are doing in their day-to-day practice; where PC RN strengths and expertise in chronic disease management lies; how PC RNs are currently providing care to cancer survivors; and what they could be doing to optimize the delivery of CSC in PC practice settings is a critical first step towards improving the delivery of CSC within PC. Establishing a clear understanding of current practice and nurses’ perceptions of CSC filled the previous knowledge gap and will aid future research teams in designing, implementing, and evaluating new models of nurse-led CSC within PC settings.

This study incorporated a number of fundamental strengths that should be recognized. Firstly, despite initial difficulties with recruitment the final study sample met all of the maximum variation inclusion criteria (e.g. varied PC organizational models; degree and diploma prepared participants; experienced and less experienced RNs and RNs from diverse LHINs and geographic locations across Ontario) outlined in the original study proposal and captured a diverse mix of PC RNs. Secondly, telephone interviews were used to collect data. This choice facilitated increased access to geographically disparate subjects, allowed the student researcher to memo and take notes unobtrusively, and permitted participants more anonymity and privacy which in turn may have contributed to the open and honest responses collected (Novick, 2008). Thirdly, after detailed memoing and transcript review by the student researcher an individualized and detailed member-checking process was completed in full by fourteen of the eighteen study participants. All fourteen respondents agreed with the student researchers’ interview summaries and no changes were required. Lastly, throughout the study the student researcher was able to continually draw from her committee members’ expertise in oncology, primary care, and qualitative research. Access to this wealth of experience aided the student researcher to build her skills as a qualitative interviewer and achieve greater depth of analysis through ongoing supportive and constructive feedback.

 **Limitations.**

Ideally all interprofessional PC team members contributing to CSC would have been interviewed and included as participants in this study and the role of the team as a whole would have been examined. However, due to time, resource, and access constraints this study focused solely on PC RN nursing roles. To minimize an inaccurate portrayal that nurses work in isolation, care was taken to ensure that interview questions and data analysis clearly examined nurses’ roles within the context of the interprofessional PC team. Lastly, the student researcher intends to use the insight she has gained from completing this study regarding PC team dynamics within the delivery of CSC to shape and explore pertinent future research studies involving PC teams as a whole.

 Another limitation of this study that must be considered is the transferability of results to average PC RNs due to the use of a voluntary response sample. Because participants volunteered and contributed to this study on their own personal time, the study sample may not be representative of average nurses working in PC settings. This study most likely attracted keen nurses that were personally interested in PC reform, RN role expansion, and nursing research. However, these keen participants were engaged and consistently provided information rich data and insight.Finally, because the student researcher was new to the role of qualitative interviewer and data was collected over the phone; some depth in participant responses may have been lost due to the absence of visual or non-verbal cues, novice skills in interview probing, and time constraints. However, to minimize these potential weaknesses the student researcher completed extensive interview training before commencing telephone interviews and received detailed feedback from her supervisor on initial interview transcripts.

**Implications for Practice & Research**

 In regards to implications for clinical practice; policy makers, PC leaders, administrators, and clinicians, key stakeholders and PC researchers can use these findings to drive practice change and work towards better preparing PC RNs to care for cancer survivors discharged from regional cancer centres and living in the community. Study participants identified the need for further CSC education, protected time to deliver nurse-led CSC, and practical practice setting supports to enable them to expand their involvement in the delivery of CSC. By engaging directly with PC nursing leaders and frontline staff Canadian PC policy makers can strategize ways to overcome these current barriers and begin to explore potential opportunities to optimize PC RN expertise in chronic disease management in the delivery of quality CSC. Furthermore, these study findings affirm the notion that PC RNs need to vigorously advocate more vigorously for clinical information, data, and documentation systems that fully capture their unique contribution to patient care and patient outcomes. Until new methods of tracking and evaluating the outcomes of nursing work are established, the vital work of PC RNs will remain invisible. Allowing such a marked oversight to continue is unacceptable.

 Focusing on next steps and future research; these study findings point to multiple gaps in the current provision of CSC within PC practice settings. Further research is required to design, implement, and evaluate new sustainable models of nurse-led CSC within PC. Evaluating the outcomes of targeted CSC and chronic disease management self-management support nurse-led initiatives would also be advantageous as the prevalence and burden of chronic disease in Canada is predicted to increase exponentially (Kennedy, 2014; The Institute for Competitiveness & Prosperity, 2014). Active ongoing discussion and debate regarding the following is essential: Which survivor patient populations are most likely to benefit from PC nurse-led CSC? What supports are necessary to ensure sustainable nurse-led CSC in PC settings?: How PC nurse-led CSC will/should be delivered?: And, how PC nurse-led CSC will be evaluated? Answering these priority questions will inform ongoing efforts to develop a Canadian cancer care system that is built around the goals, values, and needs of patients and their families.

 Additionally, there is a need for further research focused on the influence of PC organizational models, physician leadership, and organizational structures on the involvement of RNs in the delivery of CSC. This study had participant representation from a range of PC practice settings. However, the data collected is insufficient to draw conclusions about RN roles in different types of PC practice settings.

 Lastly, these study findings bolster the reoccurring persistent call for greater role clarity and role understanding for all levels of nurses working in the PC sector. As evidenced in the literature and participant’s interview transcripts, the lack of a consistent and clear understanding of the legislative scope of practice of PC nurses by physicians, patients, and nurses themselves continues to inhibit nurses from practicing to their optimal scope of practice (Martin-Misener et al., 2014; RNAO 2012). While it is essential that PC nursing roles remain flexible and adaptable to the patient populations they serve; exploration, discussion, and development of a nationally accepted PC nursing role description and a PC nursing core competency framework may be a pragmatic next step in advancing the Canadian PC nursing agenda (Martin-Misener et al., 2014).

**CONCLUSION**

 The cancer care system is challenged to provide efficient and effective healthcare services to a rapidly increasing number of patients at a time when there is a shortage of human and financial resources. Given the current emphasis and value placed on developing sustainable models of cancer care; these study findings are important because they can inform the development of innovative models of CSC within PC. Study findings also support further exploration of nurse-led models of CSC within PC. The rich data obtained from study participants can be used by Canadian health service researchers in the development, piloting, and evaluation of such new and innovative models of CSC.

 In summary, these study results: 1) provide insight in to how other common chronic conditions are managed within PC practice settings; 2) highlight current PC RN knowledge gaps regarding CSC; 3) identify priority needs and opportunities for improvement in the delivery of CSC within PC practice settings; and 4) expose the need to strengthen communication and connections between oncology interprofessional teams, PC interprofessional teams, and community services/resources. Findings from this study indicate that although survivors are already being transferred from regional cancer centers back to the care of their PC providers earlier post-treatment than ever before; many PC RNs and PC practices are not currently prepared or adequately equipped to deliver quality CSC. A tremendous amount of work remains to be done before survivors will be able to receive safe, comprehensive, and evidence-based CSC in PC community settings across Canada.

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**Appendix A**

**College of Nurses of Ontario Request for Home Mailing Addresses Form**

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**Appendix B**

**Step-wise Participant Recruitment Protocol**

1. Receive list of eligible participant **names** and **addresses** from College of Nurses of Ontario. (Expecting approx. 2000 – There are currently 4,364 nurses working in primary care settings in Ontario. It is anticipated that about 50% of these nurses will have agreed to be contacted regarding nursing research when they completed their annual registration with the CNO.)
* Eligible participants will be identified and recruited through the College of Nurses of Ontario (CNO) registration list. Every year practicing RNs in Ontario submit a registration application form to renew their membership to the CNO. This registration is mandatory in order to practice as an RN in Ontario. Applicants to the CNO must indicate their employer, practice setting, position in nursing, their primary area of practice, and their willingness to participate in research (CNO, 2013). This data is used to generate yearly CNO membership statistics and will aid the student researcher in selecting eligible participants for this study. Upon successful receipt of ethics approval from the Hamilton Integrated Research Ethics Board student research committee, the student researcher will submit a formal application to the CNO requesting the release of home mailing addresses of eligible study participants (see formal standardized form – Appendix A). Eligible participants will be contacted by mail and invited to participate.
1. Generate random sample of 100 RNs to initially contact.
* In order to manage the volume of eligible participants, a random sample of 100 RNs will be generated using a random numbers table. Using a random numbers table to generate the first sample of RNs to be contacted will ensure that each eligible RN has the same probability of being selected for the initial sample.
1. Send random sample of 100 RNs 🡪 I) invitation to participate, II) study information and consent form, III) unique assigned study number IV) general overview of interview guide questions and V) L. Yuille’s contact information (telephone number at the JCC and McMaster e-mail address).
* In the invitation to participate, eligible RNs will be asked to contact L. Yuille via phone or e-mail if they are interested in participating. Interested participants will be instructed to provide their I) unique assigned study number, II) their e-mail address, and III) their telephone number when they contact L.Yuille via telephone message or e-mail.
* Two options for initial contact [telephone message or e-mail] are purposely provided to minimize barriers to participation and make participation more convenient/accessible to eligible RNs.
1. Mail first participation reminder two weeks after initial contact package mailing date to all of the RNs that did not reply to the initial invite sent to the first random sample of 100.
2. Mail second participation reminder four weeks after initial contact package mailing date to all of the RNs that did not reply to the initial invite or the first mailed reminder sent to the first random sample of 100.
* Two mailed reminders to participate will be sent to each RN because evidence shows that follow-up contact with potential study participants significantly increases response rates (Edwards et al., 2002).
1. After receiving interested participants’ e-mail addresses and telephone numbers, L.Yuille will phone each participant. During this initial telephone conversation L.Yuille will:

- Answer any study related questions.

- Complete the oral demographic and practice settings questionnaire.

- Set up a date and time to complete the telephone interview with participants who meet sampling criteria needs.

1. L. Yuille will then complete telephone interviews with interested participants who meet the sampling criteria needs.
2. **If necessary**, based on the participant recruitment success rate of the initial recruitment mailing (random sample of 100 RNs contacted), L. Yuille will determine how many eligible RNs to contact with second round of mailings (expecting approx. 75-100).
3. A second random sample of eligible RNs will be generated using a random numbers table. The second random sample of RNs will receive identical recruitment mailings to the first random sample of RNs (**Mailing #1** Initial contact package including: I) invitation to participate, II) study information and consent form, III) unique assigned study number, IV) general overview of interview guide questions, V) L.Yuille’s contact information and VI) instructions to contact L.Yuille via telephone message or e-mail and provide their unique assigned study number, telephone number, and e-mail address, if interested in participating. **Mailing #2** First mailed reminder to participate two weeks after initial contact package mailing date. **Mailing #3** Second mailed reminder to participate four weeks after initial contact package mailing date).
4. Based on sampling criteria needs, L. Yuille will contact interested participants from the second random sample of RNs that meet sampling criteria gaps/needs. L. Yuille will then follow the exact process outlined above.

**Appendix C**

**Optimizing Registered Nurse Roles in the Delivery of Cancer Survivorship Care (CSC) within Primary Care Settings – Key Informant Oral Questionnaire**

**Introduction**

The purpose of this oral questionnaire is to gather basic participant demographic and practice setting information. This information will allow us to learn about whom you are, your professional experience, and your current work setting. Gathering this information is important as it will aid readers of the final study findings to interpret the findings and determine if the results are applicable to their individual nursing practice or practice setting.

**Instructions:**

Please answer all of the following questions as completely and accurately as possible. All of your responses will be confidential. Study results will be presented in aggregate form so that no individuals can be identified in the reporting of this information.

Before I begin, I want to remind you that you are free to not answer any of my questions. Do you have any questions?

**A. Demographic Data**

1) How many years in total have you practiced as a registered nurse?

* \_\_\_\_ years

2) How many years in total have you worked as a registered nurse in primary care/family practice?

* \_\_\_\_ years

3) What is your current role title? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

4) How many years have you worked in your current role?

* \_\_\_\_ years

5) Do you work full-time or part-time?

* \_\_Full-time
* \_\_Part-time

6) What is your highest level of **completed** education? (Check applicable category).

* \_\_Nursing Diploma
* \_\_ Bachelor of Science (Nursing)
* \_\_Baccalaureate (other than nursing)
* \_\_Masters of Nursing
* \_\_Masters of \_\_\_\_\_\_\_\_\_\_\_(specify)
* \_\_ Doctor of Philosophy
* Other:\_\_\_\_\_\_\_\_\_\_\_\_\_\_(specify)

7) What is your age?

• \_\_\_\_ years

8) Do you have current Canadian Nurses Association certification?

* \_\_Yes.
* \_\_No.

If so, in what specialty? (Examples: community health, gerontology, hospice palliative care, oncology, rehabilitation…)

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

9) Do you have any other additional nursing designations or certifications? (Please describe.)

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**B. Practice Setting**

1) In what type of primary care/family practice setting do you currently work?

* \_\_Community Health Centre
* \_\_Family Health Group
* \_\_Family Health Network
* \_\_Family Health Organization
* \_\_Family Health Team
* \_\_Solo Family Physician Practice
* \_\_Other Please Specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

2) Which Local Health Integration Network (LIHN) do you practice in?

* \_\_ LIHN 1 Erie St. Clair
* \_\_ LIHN 2 South West
* \_\_ LIHN 3 Waterloo Wellington
* \_\_ LIHN 4 Hamilton Niagara Haldimand Brant
* \_\_ LIHN 5 Central West
* \_\_ LIHN 6 Mississauga Halton
* \_\_ LIHN 7 Toronto Central
* \_\_ LIHN 8 Central
* \_\_ LIHN 9 Central East
* \_\_ LIHN 10 South east
* \_\_ LIHN 11 Champlain
* \_\_ LIHN 12 North Simcoe Muskoka
* \_\_ LIHN 13 North East
* \_\_ LIHN 14 North West

3) How would you describe the community that you work in?

* \_\_ Urban (e.g. city centre)
* \_\_ Rural (e.g. small town or village surrounded mostly by farm/agricultural land)
* \_\_Remote (e.g. outpost, northern fly-in community, secluded reserve)

4) What is the postal code of you practice setting? (This information will be used to determine if you provide care for a small, medium, or large population centre). \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

5) How many patients does your practice setting serve? (i.e., number of registered or rostered patients)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

6) In an average week, approximately how many patients would you see with a previous or current diagnosis of cancer? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

7) Please identify the types of health professionals who are members of the team in which you work on a day-to-day basis (Check all that apply).

* \_\_Family Physician
* \_\_Nurse Practitioner
* \_\_Registered Nurse
* \_\_Registered Practical Nurse
* \_\_Social Worker
* \_\_Physiotherapist
* \_\_Occupational Therapist
* \_\_Registered Dietician
* \_\_Support Staff/Receptionist
* \_\_Pharmacist
* \_\_System Navigator
* \_\_Health Educator
* \_\_Other **(please specify):** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

8) What types of chronic disease prevention and management services does your practice setting offer? (Check all that apply).

* \_\_group health education
* \_\_specialized chronic disease clinics
* \_\_care coordination
* \_\_self-management support
* \_\_referrals to community resources/supports
* Other (Please describe.)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

9) What types of services and supports does your practice setting provide for cancer survivors? (Check all that apply).

* \_\_survivorship care plan review
* \_\_post-treatment symptom management
* \_\_care coordination
* \_\_psychosocial support
* \_\_referrals to community resources/supports
* Other (Please describe.)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

10) Who is your immediate clinical supervisor? (Examples: physician, practice setting manager/administrator, nurse manager…)

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11) How is your position funded?

* \_\_ physician billings
* \_\_ salary through practice setting funding from the Ministry of Health
* \_\_ special initiative funding
* other (describe)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Thank-you!**

**Appendix D**

**Optimizing Registered Nurse Roles in the Delivery of Cancer Survivorship Care (CSC) within Primary Care Settings – Interview Guide**

Good Morning/Afternoon/Evening, \_\_\_\_\_\_\_\_\_\_\_\_\_-- thank-you for agreeing to participate in this study. I really appreciate you volunteering your time to contribute to this study. My name is Lindsay Yuille; I am a registered nurse and the graduate student leading this research study at McMaster University. Although I am a registered nurse, in my conversation with you today my role will be strictly as a student researcher.

The overall goal of this study is to identify, from the perspective of registered nurses, the strengths, barriers, and opportunities for optimizing nursing roles in the delivery of cancer survivorship care (CSC) within primary care settings. This research study tackles an urgent healthcare issue and will build on current research evidence to address opportunities to improve cancer survivorship care.

I want to remind you that everything you say will be confidential. I will take care to ensure that you remain anonymous in any presentation or publication that may arise from this study. No personal information will be shared and the demographic information I collect will only be reported in aggregate form so that no individuals can be identified in the reporting of this information. Quotes from your interview may be used but your identity will remain confidential.

I also want to remind you that you are free to not answer any of my questions and you are free to end this interview at any time with no negative consequences to you.

Lastly, our conversation will be audio-taped, and I will be making a few notes through-out the interview. Do you have any questions?

Before moving forward with the interview, I want to clarify the definition of cancer survivor. For the purposes of this study, an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life (National Cancer Institute, 2012). Do you have any questions regarding this definition?

**Ice Breaker Questions**

**Tell me a little bit about how long you have worked as a nurse in primary care and why you have chosen to work in this particular area of nursing.**

**Can you share/describe any oncology work experience that you might have?**

RESEARCH QUESTION #1: What is the current role and involvement of nurses in providing care for cancer survivors?

**Tell me about how you are involved in the care of patients diagnosed with cancer in your clinic?**

 **PROMPTS:**

* e.g. direct/indirect patient care, development/provision/evaluation of programs and services, care coordination, self-management support,...

RESEARCH QUESTION #2: How does the nursing role in CSC compare to the nursing role in providing chronic disease management for patients with other chronic conditions?

**Tell me about how you are involved in the care of patients diagnosed with chronic conditions (such as: diabetes, congestive heart failure, arthritis, etc) in your clinic?**

**PROMPTS:**

* e.g. direct/indirect patient care, development/provision/evaluation of programs and services, care coordination, self-management support,...

**Given what you just told me, how does your role in caring for patients diagnosed with cancer differ from your role in caring for patients with other chronic conditions?**

 **PROMPTS:**

* How is your role in providing care and developing services different between these two patient populations? And how is it the same?

UNTIL NOW WE HAVE DISCUSSED QUESTIONS RELATED TO BOTH CHRONIC CONDITIONS AND CANCER SURVIVORSHIP. THE REMAINING QUESTIONS WILL FOCUS ON CANCER SURVIVORSHIP CARE.

RESEARCH QUESTION #3: How could nurses further contribute to CSC?

**Can you comment on your ability to fully utilize your nursing knowledge, skills, and expertise when contributing to the care and services provided to patients diagnosed with cancer in your clinic?**

**PROMPTS:**

* e.g. On a day-to-day basis do you feel your skills; experience; nursing knowledge; critical thinking ability etc. are effectively utilized in your practice setting?

**In what ways could your current role in caring for and developing services/supports for cancer survivors be expanded or enhanced?**

 **PROMPTS:**

* e.g. If given appropriate educational and logistical support could your current role in providing care and developing services for cancer survivors be enhanced through: nurse-led clinics, conducting holistic assessments, care coordination, increased involvement at certain phases of cancer care, counselling, psychosocial support, health promotion, family support, connecting patients with community services etc.?

RESEARCH QUESTION #4: What barriers and facilitators influence nurses’ involvement in CSC?

**What are the key factors or things that help your role in caring for patients who have been diagnosed with cancer?**

 **PROMPTS:**

* e.g. cancer specific education, role autonomy, practice setting, physician/administrator support, funding policies, clinic room space, changes in role description/expectations…

**What are the key issues or things that inhibit or limit your role in caring for patients who have been diagnosed with cancer?**

 **PROMPTS:**

* e.g. lack of cancer specific knowledge, skills and confidence, lack of interest, limited role autonomy, practice setting, lack of physician/administrator support, funding policies, lack of clinic room space, current workload, role description/expectations…

RESEARCH QUESTION #5: What are possible solutions to expanding nurses’ involvement in CSC?

**What do you feel would increase your ability to provide quality care for cancer survivors?**

 **PROMPTS:**

* Can you identify 2-3 suggestions that you feel are MOST important?E.g. standardized evidence based cancer survivor nursing assessment tool, access to APN with specialized CSC training/knowledge, specific CSC education, mentorship with oncology RN, access to best practice guidelines for cancer survivors,…

**What do you think about the need for nurses working in primary care settings to have an expanded role in cancer survivorship care?**

 **PROMPTS:**

* e.g. Agree, Disagree, Outside of primary care nursing scope of practice, Great idea but nurses need more CSC education, Believe CSC is the responsibility of the regional cancer centre/treatment facility...?

**Ending Questions**

**Is there anything that you would like to share, related to the topics we have discussed, that we have not had the chance to discuss yet?**

 **PROMPTS:**

* Is there anything about your experience of caring for cancer survivors that you think I should understand better? Anything specific you would like to highlight?

**Do you have any questions for me?**

**Thank-You for speaking with me today!**

**Appendix E**

**Ethics Approval**

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**Appendix F**

**Timeline & Activity Chart**

Jan 2014 – Feb 2015

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Activity | **Jan** | **Feb** | **Mar** | **Apr** | **May** | **Jun** | **Jul** | **Aug** | **Sep** | **Oct** | **Nov** | **Dec** | **Jan** | **Feb** |
| Project Planning |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Ethics Review |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Pilot Testing of Interview Guide |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Sampling and Recruitment |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Data Collection:Individual Interviews |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Transcription and Data Cleaning |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Data Analysis |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Reflective Journaling |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Committee Debriefing |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Qualitative Write up |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Knowledge Translation |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Thesis Defense |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Submit For Publication |  |  |  |  |  |  |  |  |  |  |  |  |  |  |

*\*This is a rough draft the timeline and activity chart will remain flexible to necessary revision*