How Cancer Survivors' Challenges After Treatment Impact Transition to Primary Care-led Follow-up Care

by

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Dalhousie is located in Mi'kma'ki, the
ancestral and unceded territory of the Mi'kmaq
We are all Treaty people.

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Abstract

Background and Rationale: The transition of cancer survivors from oncology-led care to primary care-led follow-up care is a complex process that can significantly impact their well-being and outcomes. This study aimed to investigate how the transition status of a cancer survivor differs according to the challenges they face and their individual circumstances. The goal was to identify associations between survivor-reported challenges and the transition to primary care-led follow-up care. Additionally, the study explored what influence these challenges or circumstances have on oncologist's decisions to transition cancer survivors from follow-up care at cancer centres to primary care.

Methods: This research utilized a novel approach, linking administrative health data with responses from the comprehensive Canadian Transitions Survey (CTS) to gain comprehensive insights into the cancer survivor population and the factors associated with whether they have been transitioned from oncologist-led care to primary-led care. The CTS provided individual-level data on survivor-reported challenges and experiences with follow-up care. The administrative data provided information on individuals' disease-specific information and healthcare visits. Regression analyses were conducted to assess if challenges and circumstances were associated with transition status (yes/no). An oncologist survey and expert discussions were used to explore the factors influencing transition decisions.

Results: The study found no significant association between reported challenges or circumstances and transition status. Common challenges, such as fatigue and fear of recurrence, were prevalent across cancer types and transition statuses. Logistic regression analyses indicated that challenges were not associated with transition status. The oncologist survey and discussions highlighted the pivotal role of access to primary care providers in transition decisions, potentially overriding the impact of a survivor's individual challenges and circumstances.

Conclusion: The study highlights the complexities surrounding the transition of survivors and the decisions made by oncologists regarding their transition. The findings suggest that challenges reported by survivors may not be the primary drivers of transition to primary care. The lack of consensus among oncologists on relevant challenges and circumstances for transitioning survivors coupled with the high number of challenges being reported regardless of transition status highlights the need for a personalized approach to survivor care. The study's strengths lie in the unique data linkage, allowing for a comprehensive analysis, and the insights obtained from survivor-reported challenges. These findings have important implications for policymaking, survivorship care reorganization, and the development of more personalized care models for cancer survivors.

List of Abbreviations Used

CIHI	Canadian Institute of Health Information
CPAC	Canadian Partnership Against Cancer
CTS	Canadian Transitions Survey
DAD	Discharge Abstract Database
HCN	Health Card Number
HDNS	Health Data Nova Scotia
IOM	Institute of Medicine
NACRS	National Ambulatory Reporting System
NRC	National Research Council
NSCR	Nova Scotia Cancer Registry
OPIS	Oncology Patient Information System
PCP	Primary Care Provider
RCT	Randomized Control Trial

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1.0 Introduction

1.1 Overview of Cancer Survivorship

Cancer remains one of the leading causes of death worldwide and is responsible for an estimated 10 million deaths annually [1, 2]. Canada is no exception to cancer's reach, as it is the number one leading cause of death in this country [2]. In 2022, an estimated 233 900 Canadians were diagnosed with cancer, and an estimated 85 100 cancer-related deaths occurred [3].

Despite the high incidence of cancer both nationally and globally, the number of individuals surviving the disease is steadily increasing [4]. In Canada, the five-year net survival for all cancers was once 55% in the 1990s but has since risen to a predicted five-year net survival of 64% in more recent estimates [4, 5]. Increases in survival have not occurred by accident; Canada has established itself as one of the leading nations in regard to cancer treatment and survival, with some of the highest reported survival rates worldwide [4]. This was made possible through a series of efforts including, but not limited to, expertly organized cancer screening programs, incremental treatment discoveries, as well as the development of evidence-based diagnostic and treatment guidance (e.g., standardized care pathways, clinical practice guidelines), which aid in reducing variation in diagnoses and treatment efforts [6, 7, 8]. It has been estimated that more than 51 000 cancer-related deaths have been avoided entirely due to these efforts and have saved more than $5 billion in cancer treatment costs [9]. Naturally, these improvements in detection and treatment have led to increases in the cancer survivor population. While increasing survival represents success in cancer care, it also has introduced new challenges for healthcare systems [10, 11].

There is much debate over what the definition of a “survivor” is in the cancer community. However, from a research perspective, a generally accepted definition internationally although not necessarily universally, is the one introduced by the Institute of Medicine (IOM) and National Research Council (NRC) in their 2006 report “From Cancer Patient to Cancer Survivor: Lost in Transition” [12]. In this report, the period of cancer survivorship was defined as the “phase of care that follows primary treatment” [12]. Though reaching this phase in cancer care is something most patients and physicians strive for, many patients find their lives are considerably changed by cancer and this continues into survivorship. The majority of cancer survivors report challenges adjusting to their “new normal” during this phase, with some reporting that they find their first-year post-treatment more difficult than the treatment phase itself [10]. Becoming a cancer survivor comes with its own set of challenges, which are sometimes different from challenges experienced while undergoing treatment.

Although the rising number of cancer survivors represents success in cancer care and control, the increasing population also introduces issues into an already overwhelmed health care system. Both nationally and internationally, the number of cancer survivors is increasing at such a rate that there are simply not enough oncologists, or capacity within cancer centres, to keep up with the demand [13, 14]. This demand for medical and radiation oncologists is primarily driven by the increase in new cancer cases and active cancer treatments. Some have suggested increasing the number of oncologist residencies offered, more oncologists delaying retirement or efforts to improve efficiency in physicians’ practices as potential ways to address problems [15, 16]. However, these changes still would not be enough to keep up with the current demand from both cancer patients and survivors [15, 16]. The financial implications of the survivor population are already of great concern, especially considering that the cost of cancer care surged by billions between

2005 and 2012 [17, 18, 19, 20]. Recent studies in the United States estimated survivorship care costs alone are $25-$48 billion annually [20]. Part of this issue stems from the costs of cancer care generally being estimated by the annual number of new cases, despite some believing this is a poor predictor as current survivors greatly outnumber current cancer patients [20]. The combination of these issues is resulting in reduced quality of life for many survivors, presenting as a plethora of ongoing physical, emotional and psychosocial challenges that often go unaddressed in our existing system [10, 21]. Some researchers argue that survivors are still just as "lost in transition" as when the original IOM and NRC report was published in 2006 [15].

1.2 Survivor's Risks and Challenges After Treatment

"Risk", as it refers to cancer survivors, is typically considered synonymous with the "challenges" survivors face after treatment in the literature. Yet, they are not synonyms, and thus it is important to explicitly define them as the confusion in literature magnifies present issues with survivorship care. Most use both terms to describe any suboptimal functioning of a patient after curative cancer treatment [15, 22]. Risk is the chance individual survivors have of developing disease-related comorbidities and/or cancer recurrence, short to long-term effects from treatment(s), and new primary cancers. This, combined with consideration of patient's ability to self-manage care and the level of professional intervention required, contribute to individual "risk assessment" [11, 23]. Oncologists are believed to implicitly consider risk when making decisions around transition to primary care, continuing to care for patients they feel are higher risk while transitioning those who are lower risk to other forms of care [11, 23]. Whereas challenges after treatment are the ongoing physical (e.g., sexual dysfunction, chronic pain), emotional (e.g., depression, fear of recurrence) and/or practical (e.g., return to work, financial struggles) challenges a survivor may face that would benefit from social and/or healthcare interventions [10, [12, 13, 21, 22, 24, 25]. These challenges require ongoing care with the goal of recovery from or management of these issues. Some ongoing issues may also include the late effects of cancer, which are conditions caused by cancer treatment that do not occur for months or years later. These are often physical challenges (e.g., nerve pain, cardiac dysfunction) [10, 12, 21, 25]. It is important to note that typical health care access literature focuses solely on health care, but this work expands on this by also including social care and supports.

Though risk is believed to be the main consideration by oncologists, challenges may also influence transition decisions. Fear of recurrence is an example of an ongoing challenge often requiring more attention than others and is considered a “higher risk” challenge by physicians. This is one example of how survivors’ ongoing challenges may contribute to their assigned risk assessment [11]. The number of challenges may also have an impact, with studies showing that more challenges require closer attention from oncologists [25].

1.2.1 High Level of Challenges

Cancer survivors are heterogeneous; certain subsets will have a greater probability of experiencing ongoing emotional, physical, and practical challenges than others after curative cancer treatment [21, 24]. Those with a great number of unmet emotional challenges are more likely not to adhere to their follow-up care recommendations; they are among certain subsets of survivors with an increased chance for ongoing issues in the eyes of oncologists [11]. Fear of recurrence in the absence of other reported emotional challenges also reduces adherence [11]. These individuals tend to have higher levels of healthcare utilization compared to survivors with moderate to low levels of fear of recurrence [26, 27]. Additionally, they are at an increased risk for anxiety or depression, overall reduced quality of life and reporting more emotional, physical and/or practical challenges and symptoms than other survivors [24, 28, 29]. They are patients who consult both oncologists and primary care physicians (PCPs) in an uncoordinated manner. An increase in their fear of cancer recurrence, as measured by self-report scales within the Fear of Cancer Recurrence Inventory, such as the severity, triggers, psychological Distress, and function scales, significantly raises the likelihood of their visits to either an oncologist or a PCP [24, 30, 31, 32]. Those individuals with increasing complexity in their circumstances tend to have a higher number of challenges and require more health/social care interventions; though, this often coincides with increased care-seeking behaviours [24, 26, 31, 32]. Although many of these visits may not be medically necessary, they may provide psychological support and reassurance to the patient [11, 26, 31]. Regardless, these visits do strain healthcare providers' ability to adequately care for other patients and survivors [26, 31].

1.2.2 Unmet Challenges

Many cancer survivors experience considerable unmet challenges after completing treatment. This is partly due to the limited health care resources available to support survivors and the lack of ongoing assessments of their challenges [33]. Survivors frequently report that they feel like they are not receiving or being directed to appropriate emotional supports (e.g., therapist, psychologist), frustrations with how their follow-up care is being managed and struggles with how their everyday lives have changed and lack of clarity on how to address this [33, 34]. One of the main barriers to cancer survivors accessing appropriate social care interventions to address their challenges is the lack of information on how to do so from their follow-up care provider [35]. These are just a few examples of what contributes to unmet challenges in cancer survivors.

In a cross-sectional pan-Canadian survey led by the Canadian Partnership Against Cancer (CPAC), the majority of Canadian survivors reported at least one physical, emotional or practical challenge after treatment not met by their current model of care [21]. Specifically, 81% reported at least one unmet physical challenge, 84% at least one unmet emotional challenge and 74% at least one unmet practical challenge [21]. Some of the most common ongoing challenges reported by survivors included fatigue, anxiety, fear of recurrence, depression, changes in sexual intimacy, sleep disturbances, cognitive impairment (e.g., changes in memory and concentration), and chronic pain; fear of recurrence is typically found to be the most reported unmet challenge after treatment [36, 37, 38]. Most of these issues are a result of the long-term effects of cancer treatment, and many survivors do not feel prepared to adequately manage these challenges when they enter the survivorship period [10, 11, 24, 39]. Given that these ongoing challenges can last for years after treatment and that research has found associations between increases in unmet challenges with reduced quality of life across several cancer types, it is clear that current models of follow-up care are suboptimal for these individuals [10, 39].

Compared to the general population, cancer survivors have been found to have overall poorer health status, increased activity limitations and more incurred medical expenses [24]. Although these challenges may be attributed to the late effects of treatment, many could still be managed with comprehensive and coordinated follow-up care [15, 24]. For example, although it is generally recommended that written survivorship care plans be an essential component of quality follow-up care, most survivors typically lack such a document or any similar guidance [40]. This has been deemed a key and important component of survivorship by LiveStrong, an American non-profit conducting cancer research and lobbying with government agencies, and the Institution of Medicine; furthermore, they are included in the care guidelines by organizations such as Cancer Care Ontario and BC Cancer [11, 39, 40, 41, 42, 43, 44]. The lack of survivorship care plan implementation is likely due to time constraints, a greater focus on current cancer patients, the lack of a financial incentive to construct a plan and the fact that randomized control trials (RCTs) have produced mixed results [40]. It is possible the lack of a care plan could lead to poorer outcomes in survivors, although again, RCT evidence is inconclusive on this matter [40, 42]. The lack of consensus on the matter, however, reflects the absence of coordination in the current survivorship care system. Furthermore, survivors with more unmet challenges are less likely to adhere to the guidelines they are given in follow-up care, creating a feedback loop that maintains a reduced quality of life and health status in survivors [11]. Some survivors attempt to manage their own care, but often are unaware of what is appropriate or available to them. Furthermore, in some instances they may be told care to address their concerns is unavailable [21, 45].

1.2.3 Relationship Between Patient Circumstances and their Challenges

Numerous individual circumstances contribute to differences amongst survivors in regard to the type or magnitude of their challenges after treatment. These circumstances consist of the key sociodemographic characteristics that distinguish survivors from one another, independent of cancer or treatments. This includes age, sex, education, income etc., all of which influence a survivor's challenges. Age and sex have been shown to be related to emotional challenges after treatment, as females and/or younger survivors are more likely to have higher fear of recurrence which leads to a reduced overall quality of life [24, 26, 27]. Several studies have demonstrated that age and sex are both statistically significantly associated with and may be a predictor of a higher number of unmet challenges and/or occurrence of psychosocial challenges in cancer survivors, independent of fear of recurrence [14, 21]. For example, compared to males, females have a statistically significantly lower likelihood of reporting unmet practical challenges [21]. Future research will be necessary to uncover what other influences sex may have on how survivors differ from each other regarding their unmet challenges. Age has also been found to be associated with unmet challenges in survivors [14, 21]. Younger survivors have been shown to generally have more unmet challenges [21, 37]. Furthermore, those younger survivors who have suffered from more aggressive forms of cancer are at greater risk of having a reduced quality of life [24].

Other circumstances, in addition to age and sex, may also contribute to how survivors differ according to their challenges. In a study from the LiveStrong group, individuals considered part of ethnic or racial minority groups were less confident in the management of their survivorship care [40]. Furthermore, it was observed that survivors in this lower confidence group had a higher odds of reporting poor self-rated health and were unlikely to have received a written survivorship care plan [40]. These findings highlight how the health inequalities that exist in our cancer systems also exist for those who have completed their cancer treatment. Similarly, lack of a college education is associated with poorer psychosocial health in survivors, as is unemployment [21]. In Canada, it was found that French-speaking survivors are significantly more likely to report more unmet challenges in all categories [21]. Social life and relationship status can also contribute to a survivor's well-being after treatment [21, 24, 36]. Unmarried survivors, especially those patients who were younger, are more likely to report having more unmet challenges [36]. Marriage, or even the presence of a partner in one's life, has been shown to be associated with a reduction in survivors' unmet challenges [21]. Loneliness and lack of a support system negatively impact the emotional well-being of survivors [24].

The "clinical characteristics" of survivors, which include individual's stage at cancer diagnosis, cancer type, comorbidities prior to diagnosis and the cancer treatment(s) received, may also contribute to differences in individual challenges [11, 46]. Treatment type, stage at diagnosis and type of cancer have all been found to be significantly associated with having unmet challenges after treatment [14, 21, 24, 36, 46, 47]. The pan-Canadian survey administered by CPAC found several ways in which survivors differ in this regard [21]. Those patients who were treated with chemoradiation after surgical interventions had a significantly higher likelihood of reporting more unmet emotional and/or physical challenges compared to those just receiving surgery [21]. More intense treatment is typically representative of a more severe stage of cancer and as such, each subsequent increase in cancer stage usually coincides with increased health-seeking behaviours and scheduled visits [47]. Where types of cancers are concerned, several patterns have been observed. In Nova Scotia, gynecologic cancer survivors have an increased likelihood compared to breast cancer survivors of having had more visits to a PCP [47]. Also, in Nova Scotia, it was found that prostate cancer survivors have a higher number of PCP visits than those surviving breast, colorectal or gynecologic cancer [46]. Survivors still seen by their oncologists are typically amongst those who incur a greater number of PCP visits and have a greater number of challenges [46].

In summary, the CPAC survey, as well as other research, typically report that survivors whose challenges are being met have the following circumstances: they are older; richer; reside in an urban area; did not undergo chemoradiation; have English as their first language; and had coordinated care between their PCP and oncologist during follow-up care [21]. Upon publication of their findings, the main recommendation CPAC had was that results be used to help develop personalized models of follow-up care for Canadian survivors to better support their transition from active treatment to post-treatment (or follow-up) care [21].

1.3 Follow-up Care for Cancer Survivors

Regardless of the provider, follow-up care should consist of surveillance and prevention of new or recurrent cancers, interventions to prevent or manage secondary illnesses and treatment effects, a written care plan and effective communication between care providers [11, 14, 40, 42, 43]. Traditionally follow-up care is overseen by an oncologist; however, this will become increasingly challenging moving forward [39, 48]. Although guidelines exist for providing follow-up care (i.e., providing written care plans), their adherence is suboptimal. This may be partly due to existing guidelines being of low quality and based on a general consensus rather than research that has been done on the most effective models of care [39]. Although they have not traditionally been involved in follow-up care, both PCPs and nurses are capable of and have provided safe and quality follow-up care for cancer survivors [39, 48]. Ultimately, there is no one-size-fits-all model of care as cancer survivors are heterogeneous in their challenges, and more work must be done to better identify and understand these challenges and to develop comprehensive and coordinated models of care in order to best address them [14, 24].

1.3.1 Alternative Models of Follow-up Care

In Canada, follow-up care for cancer survivors has been traditionally managed by oncologists within a cancer centre environment and the same is true for Nova Scotians with a lesser amount managed by PCPs [46, 47]. Delivery of care between these two types of providers can vary, and their expectations for their role in follow-up care often differ, which may contribute to challenges being unmet in survivors [40]. For example, oncologists are more likely to treat physical symptoms and effects from treatment whereas PCPs are more likely to address psychosocial issues and encourage health promotion behaviours amongst their patients [49]. Some argue that PCPs may not be appropriate for managing survivorship care because they lack the education necessary to properly do so [10, 11, 50]. It is likely true that PCPs could benefit from increased education on caring for cancer survivors. Regardless, most unmet challenges reported by survivors can be adequately managed by PCPs [10, 11, 37, 50].

Much research has evaluated if PCP-led care is a safe alternative to oncologist/specialist-led care, especially in breast and colorectal cancer populations where multiple RCTs have compared an interventional group (PCP-led follow-up care) to the standard (oncologist-led care). When studying breast cancer survivors, a series of RCTs found that time to a diagnosis of recurrence, occurrence of serious clinical events and quality of life do not statistically significantly differ between the 2 groups [51, 52, 53]. Furthermore, similar RCTs have found that anxiety is not worsened in the primary care group and patient satisfaction may actually be greater in this group [54]. Specifically, survivors seeing a PCP were more likely to be satisfied with their service delivery, quality of consultation and continuity of care. When considering the financial aspect, the cost to patients was actually lower in the PCP-led group. This was commonly due to reduced travel costs and shorter wait times [53].

Other RCTs similar to those conducted within the breast cancer survivor population have been done within the colorectal cancer community. Much like in the discussed RCTs, a PCP-led group was compared to an oncologist/specialist-led group. One study found that at both the 12- and 24-month follow-up period, there were no statistically significant differences in health-related quality of life between the 2 groups [55]. This RCT also attempted to study differences in death and recurrence rates. There was not enough statistical power to detect a difference, although the researchers found no clear trends or differences between groups. An additional RCT similarly found that when a PCP was in charge of follow-up care, it did not negatively impact the quality of life in colorectal cancer survivors [56]. There was also no increase in the time to diagnosis of recurrence when in primary care and it was associated with lower costs to patients. Although there is more research and support in the breast and colorectal populations for transitioning to primary care, there is growing evidence for other cancer types. For example, one

RCT studying melanoma cancer survivors in North-East Scotland found that survivors seeing a PCP had greater adherence to care guidelines and reported greater satisfaction with care [56]. Although transition to primary care may not be possible for all survivors, results from these RCTs demonstrate that it is feasible for many different types of survivors across several cancer sites.

Evidence provided by these RCTs is supported by real-life examples of implementing alternative models of care into practice. In Canada, Cancer Care Ontario initiated a major project to determine if PCPs could safely and efficiently care for large numbers of survivors in the province [57, 58]. Funding was provided to identify breast cancer survivors best suited to be transitioned from oncologist-led to PCP-led follow-up across 14 Regional Cancer Centers in Ontario [57, 58]. These 14 care centers implemented their own models for follow-up care, which were carefully developed over an 18-month period [57, 58]. All care centers were able to successfully transition identified survivors and 85% of survivors reported feeling that they were prepared for their transition [57, 58]. Additionally, survivors who transitioned to follow-up care managed by PCPs had reduced hospitalizations, cancer-related visits and scans/imaging compared to those still seen by oncologists [57, 58]. It was estimated that the permanent implementation of these efforts would save $4257 in healthcare costs per survivor, equating to annual savings of $9.6 to $64.3 million [57, 58]. Transitioned survivors also had reduced care-related costs than those not transitioned [57, 58].

Ultimately, many survivors do benefit from a transitioned model of care in which a PCP manages their follow-up care and might even be the preferred method in many cases [14]. These survivors tend to have statistically significantly lower likelihoods of emotional, practical and physical challenges being unmet, which could possibly be attributed to PCPs generally following guidelines for survivorship care that do exist more closely than oncologists [21, 59]. This highlights that although both models of care are safe and effective for survivors, there may actually be slightly more benefits for survivors transitioned to PCP-led care [11, 13, 51, 55]. Although it is possible that in survivors with more complex challenges, patient outcomes may be better in those still seen by their oncologists as they may have more cancer-specific challenges [13]. A lack of clear guidance on who should lead a survivor's follow-up care are associated with worse psychosocial health and more unaddressed challenges. [36]. Though unfortunate, this can occur often due to poor communication between PCPs and oncologists [10, 11, 37, 50]. This highlights why we must work towards building a comprehensive follow-up care system that clearly identifies and addresses all survivors' challenges, and brings structures to those PCPs, oncologists or nurses providing that care.

1.3.2 How Models of Follow-up Care are Chosen

Upon curative treatment of a patient's cancer and entry into remission, it is the responsibility of the oncologist to determine how follow-up care will be provided to survivors [11 40, 42, 43]. That is, the oncologist makes a decision to continue seeing a patient for routine follow-up care, or to transition a patient back to a community-based provider (e.g., a PCP or surgeon) [11, 40, 42, 43]. Written survivorship care plans and other resources may support this transition back to the community [42, 43]. However, some studies have shown that 55% of patients do not receive such a care plan, which can increase uncertainty in terms of who is to provide a survivor's follow-up care [11, 40, 42, 43]. Regardless, oncologists tend to continue managing those patients deemed higher risk for cancer recurrence or developing primary cancers; they may also consider a patient's challenges in the same way they consider risk though this is not clearly defined in current guidelines [39]. This is likely true for Nova Scotia as well, where oncologists reported that they may implicitly “risk-stratify” their patients, often transitioning those they see as lower risk to be seen by PCPs [46]. However, due to the confusion surrounding the definition of “risk” and “challenges” in the literature, it is unclear if they consider both in some combination when making transition decisions. Regardless, the lack of a coordinated and comprehensive follow-up care system means that survivors may not be receiving the best possible care. This can lower their overall quality of life and increase costs to the healthcare system. Seeing as no one model of care will work for all survivors, work to better understand circumstances associated with the ability to transition to primary care-led care is necessary [37, 39, 49, 60, 61].

1.4 Demand for Personalized Models of Follow-up Care

Many researchers involved in follow-up care for cancer survivors have advocated for introducing more personalized models of care, which includes a transitioned care model for certain survivors [10, 21]. As discussed, individual survivors vary greatly in their experiences and supports required, which suggests that different models of care are necessary to reflect this diversity in patients [24, 39]. One possible method for more personalized care that has been discussed is considering the risk, challenges and individual circumstances of patients in combination; formerly referred to as “risk-stratification” of survivors [21, 62]. This involves assigning certain survivors to different care pathways based on the assessment of their overall condition and how this may impact individual health status and quality of life; however, there is a lack of consensus on exactly what combinations of risk, challenges and individual circumstances most threaten overall wellbeing [43]. Additionally, evidence on which combinations would most benefit from PCP-led care is lacking; it is hypothesized that since PCPs generally lack advanced cancer training, they are likely best suited to lead follow-up care for survivors who are deemed lower-risk and/or have fewer challenges [62]. Despite the unknowns, there is much evidence to support the personalization of follow-up care for survivors. This model is associated with an increase in the quality of care compared to others [62]. Furthermore, the transition of those deemed lower risk and/or having less challenges to PCP-led followed care has been found to be safe and cost-effective [58, 63]. Cancer Care Ontario's project likewise demonstrates that the wide-scale transition of these survivors to PCP-led care is feasible and manageable [57, 58, 63].

Several countries have already demonstrated the ability to formally introduce this model of care into their survivorship care programs namely, England, Northern Ireland and Australia [15]. England and Northern Ireland can be considered pioneers in personalized care of survivors, being amongst the first countries to officially introduce these models of care into their healthcare system [15]. Here, survivors are triaged to different pathways of care based on their risk of recurrence, risk of late effects, comorbidities, time since curative treatment and the availability of services; challenges though not explicitly included, are likely also considered when assigning patients to pathways [15, 22]. The currently used pathways include self-management for low-risk survivors, shared-care for moderate-risk survivors (i.e., self-management in combination with visits to an oncologist or PCP) and multidisciplinary care for high-risk survivors [15, 22]. Additionally, survivors can switch between these different pathways should their perceived risk level change [15, 64]. It is important to note that risk is still poorly defined in these models and likely includes this proposal's definition of "risk" and "challenges" in combination. These countries found there was no stringent requirement for clear-cut risk definitions so long as there were clearly defined care pathways survivors could be directed to [15]. Australia later adopted these practices into their own health care system, which has both publicly and privately financed health care [15, 65, 66]. The efforts of these countries have demonstrated how personalized care is both achievable and safe and may address many issues currently plaguing survivors in other countries [15, 64]. Additionally, all introductions of personalized care saw a reduction in costs to patients and the health care system, although its recommended that a formal cost-effectiveness analysis be conducted in the future [15].

Although there is evidence to support personalized survivorship care systems and this approach is used in other countries, Canada lags behind in this regard [48, 65, 67]. Many physicians hold a "business as usual" attitude, which makes it increasingly difficult to introduce any changes into the health care system [15]. More work has to be done to identify which survivors are best suited for transition to PCP-led care, as this is even lacking in countries already using personalized care models [15, 46]. Given the discussed unsustainability of the current survivorship care system in Canada, practice changes are inevitable [10, 15]. Northern Ireland has shown success in addressing this issue and noted a key part of their success in introducing a triage system was providing physicians with sufficient and mandatory training on how to change the way they presently provide care [15]. The body of literature on the subject generally agrees that current and future research should be used to develop personalized models of care and to identify which survivors are ready to transition to PCP-led care [14, 21]. Ultimately, there is support for the feasibility of a personalized survivorship care system, but more work must be done to develop tools that are valid and reliable in stratifying patients to the different care practices [43, 46]. Defining the subsets of survivors by their ongoing challenges, in combination with risk and individual circumstances is essential for informing formal guidelines of a personalized survivorship care system.

2.0 Objectives

The overall goal of this study was to contribute to the literature on cancer survivorship by investigating how the transition status of survivors differs according to their physical, emotional and/or practical challenges and individual circumstances after curative cancer treatment. It is critical to note that we are not looking at how challenges are being met, but rather if certain types of challenges are associated with the model of follow-up care a survivor receives.

The study's specific objectives were as follows:

(1) To identify those ongoing challenges and/or individual circumstances most likely to be considered by oncologists, when deciding whether or not to transition cancer patients from cancer centres to primary care-led follow-up care.

(2) To describe cancer survivors' transition to primary-led follow-up care by their self-identified challenges and individual circumstances after completing cancer treatment.

(3) To investigate if those ongoing challenges and individual circumstances identified in Objective 1 are associated with the transition to primary care after completing cancer treatment.

3.0 Methods

3.1 Study Design

This study employed a sequential multi-method design. This study design uses results from the initial stage of a research project to inform how the following stages will be conducted [68]. Compared to mixed methods which uses a combination of qualitative and quantitative methods, multi-method studies use some combination of qualitative and/or quantitative methods [68, 69]. This study used quantitative followed by quantitative methods to address each objective.

First, a modified Delphi survey was constructed and distributed to practicing medical and radiation oncologists in Nova Scotia treating breast and colorectal cancer patients to identify the challenges and individual circumstances they feel are most important to consider when transitioning a survivor to primary care. These cancer types are the most likely to be transitioned to primary care-led follow-up care [56, 57, 58]. However, as the survey had a low response rate (36%) and dissensus in its responses, conversations with clinical experts were held to better understand the variation in survey responses.

Next, a retrospective analysis of a linked survey-administrative health dataset detailing the follow-up experiences of individual Nova Scotian colorectal and breast cancer survivors was conducted. Survey responses came from the 2016 "Cancer Transitions Survey" (CTS) which captured detailed information on cancer survivors' self-reported challenges and experiences. All respondents were survey between 1-3 years after completing treatment. The follow-up period for this cohort began 2 years following a cancer diagnosis and ended up to 5 years after diagnosis. Data on all survivors were available up until December 31st, 2019. All individual responses were linked to several administrative health datasets in Nova Scotia.

Our intention was to consider the responses from the oncologist survey in combination with conversations held with clinicians (objective 1) to inform the specific survivor challenges and individual circumstances to be included as variables in our analyses of survivors transitioned to primary-led follow-up care (objectives 2 and 3). However, this was not possible, as discussed in the results section. This approach would have ensured the oncologists' perspective was included and incorporated across all stages of this study, which is lacking in current literature [47, 70].

3.2 Delphi Survey and Clinician Discussions

To address objective 1, we collected and analyzed responses from a modified Delphi survey completed by oncologists in Nova Scotia [71]. The Delphi method is a consensus-building technique used to obtain a consensus of opinion on a specific research question from a group of relevant experts [71, 72, 73]. In addition to expert input, key characteristics of a Delphi approach include anonymity, multiple survey iterations with controlled feedback and a statistical group response [73]. Consensus is garnered through multiple rounds of survey administration, which are followed by summarization and feedback to inform the next iteration [71, 72, 73]. Results were meant to obtain consensus on which challenges and individual circumstances they felt were most important to consider when making transition decisions. These results were meant to inform subsequent analyses in the next stages of this study. This did not occur, as discussed in the results section.

3.2.1 Survey Administration

The Delphi survey was electronically distributed to eligible oncologists (those active medical and radiation oncologists who treat breast and/or colorectal cancer patients in Nova Scotia) via their publicly available emails. The survey was based on the previously used and validated standard Delphi approach. Oncologists were asked to complete an initial round of the survey, which was expected to take less than 10 minutes to complete. The platform "Opinio" was used for formatting and distributing the survey. Eligible oncologists received an email invitation with the link to the survey from the supervisor. Before gaining access to the survey platform, respondents were required to read and sign an electronic consent form. Dr. Urquhart then sent two reminder emails to all respondents to maintain anonymity. The email acknowledged that some participants may have already completed the study and stated that if this is the case, they did not have to respond.

The initial survey consisted of 2 sections, the first listing all physical, emotional, or practical challenges survivors face after treatment, as described in the CTS (Figure 3.1) and the second listing all individual circumstances (Figure 3.2). Each section included an open-text response option, enabling respondents to incorporate any pertinent factors they considered important but were not part of the provided list. It is important to note that the term "discharge" is used in the survey distributed to oncologists rather than "transition", as they are more accustomed to this term. Oncologists were asked to rate each factor on a scale of 1-9 (1 = little to no importance; 9 = highly important). Eligible oncologists received an email invitation with the link to the survey from the supervisor. Before gaining access to the survey platform, respondents were required to read and sign an electronic consent form.

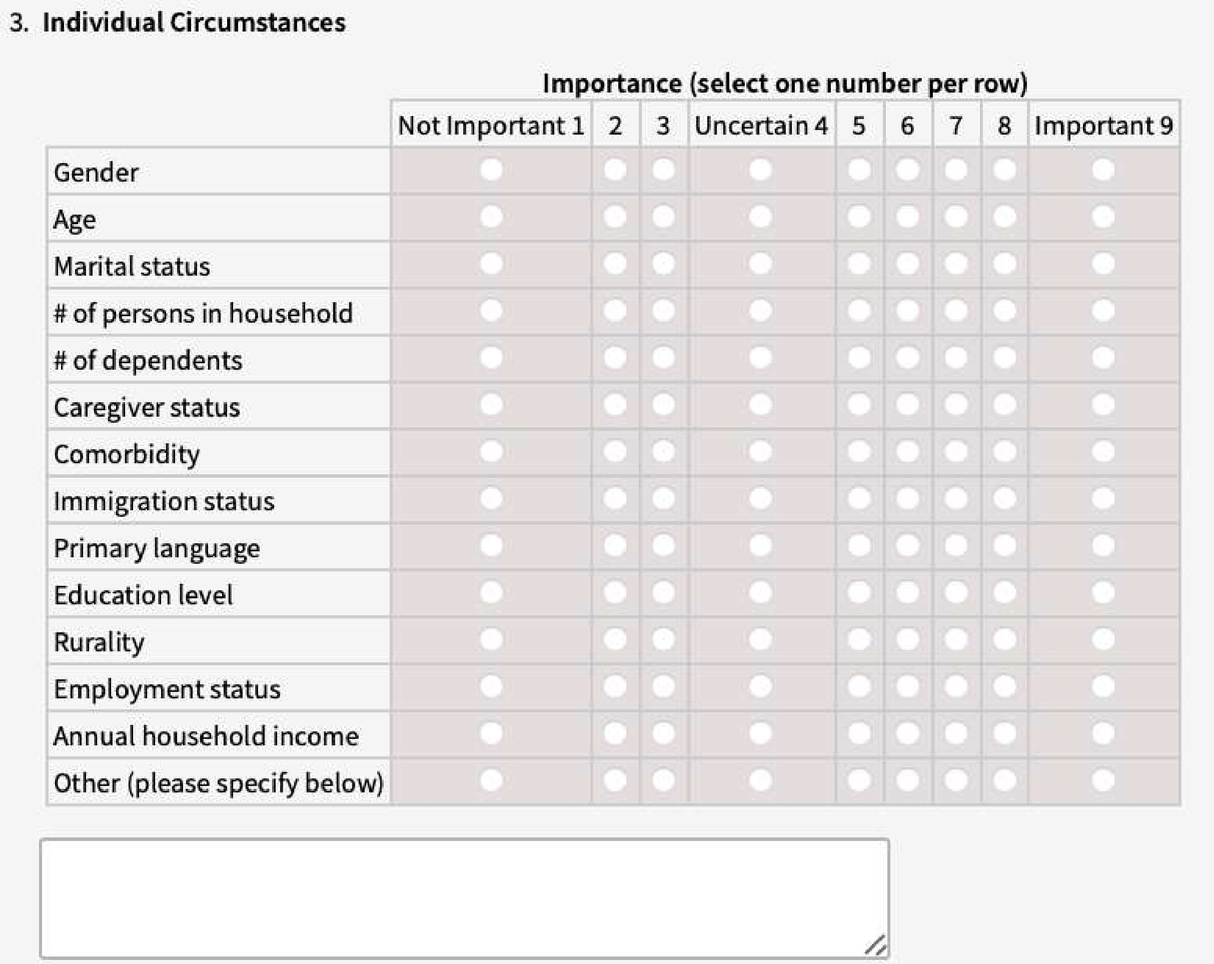
The initial survey was distributed in early January 2023 to all eligible medical and radiation oncologists in Nova Scotia (n=22). However, due to low uptake (n=8), and lack of consensus, a decision was made to end data collection of the survey and instead discuss the collected results with relevant clinicians. We held conversations with individual oncologists (n=3) that had been consistently responsive to our initial inquiries, which informed the final variable list for the subsequent analyses. We asked these individuals their perspective on why survey uptake was low and responses varied. This decision was made as survey responses were non-conclusive and could not be used for their intended purpose. As these discussions were informal, intended solely for variable selection assistance rather than drawing conclusions, no amendments to the research ethics board were pursued.

2. **Patient Challenges**

Importance (select one number per row)

	Not Important 1	2	3	Uncertain 4	5	6	7	8	Important 9
Lymphedema	○	○	○	○	○	○	○	○	○
Fatigue/Tiredness	○	○	○	○	○	○	○	○	○
Hormonal	○	○	○	○	○	○	○	○	○
Menopause	○	○	○	○	○	○	○	○	○
Fertility	○	○	○	○	○	○	○	○	○
Chronic/long-term pain	○	○	○	○	○	○	○	○	○
Bladder and/or urinary problems	○	○	○	○	○	○	○	○	○
Gastrointestinal problems	○	○	○	○	○	○	○	○	○
Nerve problems	○	○	○	○	○	○	○	○	○
Changes to concentration and/or memory	○	○	○	○	○	○	○	○	○
Sexual disfunction	○	○	○	○	○	○	○	○	○
Depression	○	○	○	○	○	○	○	○	○
Anxiety	○	○	○	○	○	○	○	○	○
Fear of recurrence	○	○	○	○	○	○	○	○	○
Changes in relationships with family/partners/friends/coworkers	○	○	○	○	○	○	○	○	○
Body image issues	○	○	○	○	○	○	○	○	○
Changes in sexual intimacy	○	○	○	○	○	○	○	○	○
Return to work or school	○	○	○	○	○	○	○	○	○
Getting to/from appointments	○	○	○	○	○	○	○	○	○
Taking care of a family member	○	○	○	○	○	○	○	○	○
Difficulty getting health or life insurance	○	○	○	○	○	○	○	○	○
Financial difficulties	○	○	○	○	○	○	○	○	○
Other (please specify below)	○	○	○	○	○	○	○	○	○

Figure 3.1: First question asked in the oncologist survey.



3. Individual Circumstances

Importance (select one number per row)

	Not Important 1	2	3	Uncertain 4	5	6	7	8	Important 9
Gender	○	○	○	○	○	○	○	○	○
Age	○	○	○	○	○	○	○	○	○
Marital status	○	○	○	○	○	○	○	○	○
# of persons in household	○	○	○	○	○	○	○	○	○
# of dependents	○	○	○	○	○	○	○	○	○
Caregiver status	○	○	○	○	○	○	○	○	○
Comorbidity	○	○	○	○	○	○	○	○	○
Immigration status	○	○	○	○	○	○	○	○	○
Primary language	○	○	○	○	○	○	○	○	○
Education level	○	○	○	○	○	○	○	○	○
Rurality	○	○	○	○	○	○	○	○	○
Employment status	○	○	○	○	○	○	○	○	○
Annual household income	○	○	○	○	○	○	○	○	○
Other (please specify below)	○	○	○	○	○	○	○	○	○

Figure 3.2: Second question asked in the oncologist survey.

3.2.2 Analysis

The planned analysis for the survey involved determining the level of agreement between responses following the RAND Appropriateness Criteria [74]. This is a well-established method for rating responses of a Delphi survey. It does so by breaking down rating options into brackets according to importance (1-3 = unimportant, 4-6 = uncertain importance, 7-9 = high importance). Individual responses are sorted into these brackets; when ~70% of responses fall within the median bracket, this is defined as agreement. The second survey would have followed the same format as the first, however, only items with disagreement or where agreement was uncertain would be included. If agreement had not been met after the second survey, another iteration would have been distributed.

As only one round of the survey was completed, use of the RAND Appropriateness Criteria was not necessary. Instead, responses from each question were used to generate bar graphs outlining the importance different oncologists give to each factor in terms of transition decisions. Discussions subsequently held with oncologists and relevant clinical experts were more largely relied upon to consider variable inclusion for the subsequent analyses.

3.3 Linked survey-administrative health data

To address objectives 2 and 3, survey responses from cancer survivors in Nova Scotia, linked at the patient level to several sources of administrative health data, were used. Both distribution of the CTS and linkage of Nova Scotian responses received prior REB approval. The cancer survivor survey and administrative health databases are described in detail below.

3.3.1 Data Sources and Study Population

A) Canadian Transition Survey:

Survey responses from the 2016 CTS were used for this project. This survey was administered across all Canadian provinces. It was an 83-item population-based survey asking cancer survivors about their experiences and challenges after completing treatment. For the purpose of this research, only responses from Nova Scotia were used. The questions were developed in consultation with a wide variety of stakeholders, including patients and survivors, and informed by the validated LiveStrong and Cancer Survivors Unmet Challenges Measure surveys [33, 46].

This survey was part of a larger nationwide study led by the Canadian Partnership Against Cancer (CPAC). The combination of each province-wide survey in CPAC’s nationwide research makes this the largest study of its kind; national results are currently available [45, 75]. The Nova Scotian survey was administered by the Nova Scotia Cancer Registry (NSCR) to all Nova Scotian adult cancer survivors meeting eligibility criteria (Appendix A; eligibility criteria for this study population). Participants were mailed a hardcopy survey package as an introduction to the study and completed it either online or via mail. Only cancer patients diagnosed between May 2nd, 2012, to May 2nd, 2014, were included in the CTS. Administrative data for individual respondents are available up until December 31st, 2019, to ensure 5 full years of follow-up data for each survivor. The response rate in Nova Scotia was 44.6% (n=1557), making it the second-highest country-wide for this type of research effort. Dr. Urquhart, a Principal Investigator on CPAC's national study and supervisor of this project, is the custodian of the Nova Scotia survey results. The dataset is currently stored on NSCR's servers.

No participant identifying information was collected in the CTS. Self-reported data on participants' sociodemographic information, marital status, education level, cancer type, physical challenges, emotional challenges, and access to healthcare services and resources were collected. All those who completed the survey gave their consent to the survey data being linked to administrative health datasets. A study "key" was held by the NSCR to enable data linkage.

B) Administrative Health Data:

Several administrative health datasets were used in this study, all of which are linked to the CTS responses. The administrative health datasets linked to the CTS and the key information they provide are shown below in Table 3.1.

Table 3.1. Summary of administrative health datasets and the key information they provide.

Date sets	Main Variables
Nova Scotia Cancer Registry (NSCR)	Cancer type, date of diagnosis, stage at diagnosis, cancer history
Oncology Patient Information System (OPIS)	Treatments received, disease recurrence
MSI Insured Patient Registry	Enrolment in the provincial, publicly funded, health insurance program
MSI Physician Billings	Provider specialty, dates of visits, diagnoses, procedure codes
Canadian Institute of Health Information (CIHI) Discharge Abstract Database (DAD)	Hospitalization dates, diagnoses, procedures to indicate cancer recurrence
National Ambulatory Care Reporting System (NACRS)	Day surgery, outpatient and community-based clinics, emergency department visits, procedures to indicate cancer recurrence

C) Study Population:

The original dataset comprised 1513 survey respondents who met the inclusion criteria for the CTS (Table 3.2). From this total, 702 respondents were excluded as they were survivors of hematologic, melanoma, prostate, or other cancers not considered part of this study's inclusion criteria. An additional 96 respondents were removed from the sample as they experienced a cancer recurrence within two years of completing treatment for their previous cancer. The exclusion of these individuals ensured that our cohort consisted solely of survivors who were being seen for follow-up care and not actively receiving treatment for cancer. Individuals who experienced recurrence two years after curative treatment were censored, meaning only healthcare visits prior to a recurrence were included in the analyses. None of the respondents were excluded due to missing data; instead, a "missing" category was introduced to response variables where appropriate. Ultimately, a total of 715 breast and colorectal cancer survivors made up the final study cohort.

The population for this study were all survey respondents who were breast (n=424) or colorectal (n=291) Nova Scotian cancer survivors, 1-3 years post-diagnosis. CTS data were collected on hematologic, breast, colorectal, melanoma, prostate and young adult cancer survivors. However, only breast and colorectal survivors were included in this study as the evidence demonstrates they are the most likely to transition to primary care-led follow-up care [47, 76]. We believe that this cohort is representative of breast and colorectal survivor populations in other communities, with the exception of those who are 80 years as older or 30 years or less, as these individuals were less likely to respond to the survey. Additionally, results from this study should only be generalized to breast and colorectal cancer survivors as primary care-led follow-up care is not a common occurrence amongst other cancer sites. Inclusion/exclusion criteria for breast and colorectal cancer participants in the CTS are provided in Table 3.2.

Table 3.2. Inclusion/Exclusion Criteria for Breast and Colorectal Cancer Survivors Participation in the 2016 CTS.

Disease Site	Inclusions	Exclusions
Breast	• Diagnosed between May 2nd, 2012 to May 2nd, 2014 • Female breast cancer cases only	• Stage IV at diagnosis • Lymphoma M95 to M98 (inclusive) • Sarcomas • Cases recorded as having died (at time of extraction)
Colorectal	• Diagnosed between May 2nd, 2012 to May 2nd, 2014	• Stage IV at diagnosis • Lymphoma M95 to M98 (inclusive) • Sarcoma • Cases recorded as having died (at time of extraction)

3.3.2 Variables

A) Outcome:

The primary outcome for objectives 2 and 3 was transition from specialist cancer centres to primary care-led follow-up care. This was calculated using administrative health data on individual survivors' visits to healthcare providers. The CTS survey asked all respondents who they believed was responsible for their follow-up care (family doctor/general practitioner/ nurse practitioner; oncologist, surgeon, or other cancer specialists; both; no one, and unsure). However, due to uncertainties in the validity of self-reported responses and the cross-sectional nature of the CTS, administrative data were used to determine a survivor's transition to primary care. Additionally, those survivors reporting that they see a combination of providers cannot be considered transitioned. This is because if an oncologist/specialist had transitioned a patient to primary-led care, they would not still be seeing that patient years after curative treatment. Thus, those seeing a combination of providers would be considered as having oncologist/specialist-led care, while seeking additional care from primary physicians. Because the survey was cross-sectional, some respondents may have also transitioned to primary care after they completed the survey. Therefore, using the administrative data allowed us to capture those respondents who may have transitioned after survey completion.

We calculated the number of follow-up visits to oncologists, general surgeons, and primary care providers for each survey respondent via the data linkage using a unique ID number. For this outcome, we considered general surgeons as 'oncologists' because, in certain instances, Nova Scotian cancer patients may not be seen at cancer centers but rather receive exclusive care from surgeons (e.g., persons with early-stage colon cancer). Access to this information allowed for computation of the transition to primary care even for those who transitioned after completing the survey. The follow-up period for measuring this outcome began 2 years after cancer diagnosis and ended 5 years after diagnosis. This follow-up period has been used in past studies of cancer follow-up care practices; this ensures the exclusion of visits related to treatments and acute post-treatment effects [77, 78, 79, 80].

Two of the administrative datasets included information on patients' visits to physicians, MSI physician billings and OPIS. The former recorded visits that occurred and were processed for billing and the latter visits that were scheduled to occur. Both were employed in coding the outcome variable, as this approach potentially accommodated visits not captured due to errors in either dataset. In both cases, visits to general surgeons, medical and radiation oncologists were combined. Visits to a PCP were considered on their own, and visits to all other specialties were categorized as "other". For the physician billings dataset, a variable for whether the visit was cancer-related had been included (0 = not cancer-related, 1 = cancer-related); any visits that weren't cancer related were excluded. This was not necessary for the OPIS data as it only captured cancer-related visits. We created a new variable, "transition status", using the total number of visits to a cancer specialist for each respondent. This was collapsed into 4 categories: 0 = respondent had no visits to a cancer specialist during the follow-up period; 1 = respondent had 1 visit to a cancer specialist during the follow-up period; 2 = respondent had 2 visits to a cancer specialist during the follow-up period; 3 = respondent had 3 or more visits to a cancer specialist during the follow-up period.

The two datasets were merged and any visits that occurred before commencement of the follow-up period (2 years after initial cancer diagnosis) were excluded. When the categorized visits from the two datasets disagreed, we made the following decisions: if one dataset suggested a participant had no visits to a specialist while the other indicated such visits, we considered the latter as definitive; if one dataset lacked visit information for a participant but it was present in the other, the latter was considered definitive; if one dataset had more recorded visits to a specialist for a participant than the other, the former was considered definitive. The outcome, dichotomized according to cancer type, was categorized as follows: for breast cancer survivors, a transition status coded as “0” or “1” (indicating no or 1 visit(s) to a specialist) resulted in classification as transitioned, in alignment with the standard practice for breast cancer survivors, who often undergo a scheduled mid-treatment assessment to discuss potential long-term endocrine therapy changes. Conversely, a code of “2” or “3” (indicating 2 or 3+ visits to a specialist) was categorized as not transitioned. For colorectal cancer survivors, a transition status coded as “0” (indicating no visits to a specialist) was categorized as transitioned, while codes “1,” “2,” or “3” (indicating 1, 2, or 3+ visit(s) to a specialist) were categorized as not transitioned.

Visit datum were censored to exclude visits relating to a cancer recurrence. If a recurrence occurred within 2 years of the initial cancer’s diagnosis date, these participants were excluded from the study. This is because multiple cancer diagnoses within these time periods likely increases the patient’s risk in the eyes of oncologists, who may then be less likely to transition these survivors after additional curative treatments. If a cancer recurrence occurred 2 years after the original diagnosis, healthcare visits that occurred on or after this recurrence were excluded from the study.

Recognizing the genuine concern of limited access to PCPs in Nova Scotia, we established a criterion: our results would only be influenced if the transitioned proportion in our study's cohort fell below 20-30%. This threshold aligns with patterns observed in prior research [51, 52, 53, 55, 56]. If the transition status falls within or exceeds the 20-30% range, the results are deemed reliable for interpretation.

B) Independent Variables:

The independent variables available for use in this study included information on patients' individual circumstances, cancer, treatment, and self-reported challenges; the full set can be found in Appendix B. The variables used in analysis in this study can be found in Table 3.3. With the exception of respondent’s cancer stage and geographic location (postal code), which came from administrative health data, all other information was taken from CTS responses.

Table 3.3. Independent variables included in analysis.

Variable Type	Response Options
Individual circumstances	
Sex	Male Female Other
Age at diagnosis	</=54 >55

Annual household income	< $50 000 >/= $50 000 to <$125 000 >/= $125 000
Geographic location	Rural Urban
Employment status	Full-time Part-time On leave Unemployed Student
Marital status	Partnered Not Partnered Separated/Divorced/Widowed
Education level	High School or Less Some Post-Secondary/CEGEP Post-Secondary +
Born in Canada	Yes No
Primary language	English French Both Other
Physical challenges	
Lymphedema	Yes No
Fatigue	Yes No
Hormonal, menopause, or fertility issues	Yes No
Chronic pain/long-term pain	Yes No
Bladder/urinary problems	Yes No
Gastrointestinal problems	Yes No
Nerve problems	Yes No
Memory problems	Yes No
Changes in sexual activity or function	Yes No
Emotional challenges	
Depression	Yes No
Anxiety/stress/fear of recurrence	Yes No
Relationship changes (family, partners)	Yes No
Relationship changes (friends, coworkers)	Yes No
Body image issues	Yes No
Changes in sexual intimacy	Yes No
Practical challenges	
Returning to work/school	Yes No
Getting to/from appointments	Yes No
Caring for family members	Yes No

Difficulty accessing insurance	Yes No
Difficulty paying bills	Yes No

3.3.3 Analysis

First, a descriptive analysis was conducted, summarizing the characteristics of this study's cohort and exploring how challenges and individual circumstances relate to transition status (objective 2). This involved summaries of frequency/prevalence of the different independent variables for breast and colorectal cancer survivors separately. When highlighting numerical differences in results between transitioned and non-transitioned survivors, chi-square tests were conducted to determine if the groups were statistically significantly different. Mean and standard deviation calculations were conducted when comparing the number of challenges of the survivor groups; 2-sample t-tests were used to determine if the means of the groups statistically significantly differed. A significance level of p=0.05 was used for both tests.

Investigation of statistical associations of ongoing challenges with transition status (objective 3) involved retrospective analysis of the population-based survey data linked to individual-level administrative health data. This included conducting a series of logistic regression models to identify which ongoing challenges were statistically significantly associated with survivors having been previously transitioned to primary care (dichotomized as yes/no).

Univariable logistic regression models were run for each independent variable (challenges and individual circumstances) to determine if a statistically significant relationship with transition status existed in the absence of all other variables, or, when controlling for clinical characteristics. Breast and colorectal cancers were evaluated both separately and together to determine if differences in transition status existed between cancer sites. All self-reported challenges and individual circumstances were included in univariable regression models. Should multiple variables have yielded a statistically significant result, the final set included in multivariable models were to be informed by results from the oncologist survey and expert discussions in combination with information from the literature. These models would have also controlled for clinical variables, including treatment(s) received and stage at diagnosis. This would ensure that challenges included in this study were reflective of the views of oncologists themselves when transitioning patients to primary care. For example, we knew from the literature that age, disease site, stage at diagnosis and household income all influence whether a survivor transitions to primary care [47]. Thus, the inclusion of these variables was already anticipated. Although sex and geography have not been found to affect transition, they were still considered in the univariable analysis [47]. However, multivariable models were not necessary, as explained in the results.

A power analysis was conducted to determine how many variables a multivariable model could have accommodated (Table 3.4). An effect size of 0.5 was used indicating 30% of the sample was transitioned; this is also the recommended default value in circumstances of uncertainty and can deduct a "medium" effect in analyses [81, 82]. Using the "powerlog" function in Stata which conducts power analysis for logistic regressions, Table 3.4 shows the number of predictors our models could have accommodated at 80%, 85% and 90% power and the required sample size [83]. Appropriate model fit was determined from the R-squared value and using the Hosmer Lemeshow test [84].

Table 3.4. Power analysis result for logistic regression models.

Power (%)	**Required sample size**				
	# of Predictors				
	6	***7***	***8***	***9***	***10***
80	225	281	375	563	1125

85	251	314	418	627	1254
90	285	356	475	713	1426

The results from the power analysis in Table 3.4 show that a model for breast cancer survivors (n=424) could have accommodated up to 8 predictors and a model for colorectal cancer survivors (n=291) could have accommodated up to 7, depending on the level of power we are willing to accept. A model for both cancer sites could have accommodated up to 9 predictors without power being an issue. Though again, where multivariable models were not conducted, power was not a concern for our analyses.

There were missing data in the survey responses and in the administrative health data. Where this occurred, additional categories called "missing" were added to account for these individuals.

A statistical significance level of p=0.05 was used for regression models. All statistical tests and summaries were conducted using Stata 16. Adjustments (i.e., manually adjusting the alpha level, or using a Bonferroni correction) for multiple comparisons were not made for these analyses. These adjustments are more beneficial for studies with larger sample sizes in which there is a greater chance of detecting a significant association where one does not actually exist [85]. Rather than allowing us to draw more confidence in our results as they are intended, the use of such a correction due to our sample size may result in a truly significant result appearing to be non-significant [85]. Furthermore, these corrections are more commonly used in ANOVA analyses, are known to reduce the risk of type 1 errors at the expense of increasing the risk for type 2 errors, and can lead to inaccuracies when interrupting results [86] Therefore, applying adjustments like the Bonferroni correction in studies with small sample sizes, which already have a higher risk of type 2 errors, as in our case, is debateable.[85, 86]

3.4 Data Access and Ethics

An application to the Nova Scotia Health research ethics board to conduct the oncologist survey (objective 1) portion of this study was submitted by Jessica Vickery [JV] and approved. The survey distributed to oncologists consisted of two brief questions. Prior to participating in the survey, all participants were required to provide explicit consent. To protect against any potential breach of privacy, no identifiable information was sought or accessed in the survey and all responses were anonymized. Responses were stored within Dalhousie's servers protected through their firewall.

To accomplish objectives 2 and 3 of this study, no primary data collection was required. Instead, only the database of CTS responses linked to administrative health data were used. This research is part of a larger research project headed by supervisor Dr. Urquhart, which was previously granted ethics approval. Data linkage involved the construction of a dataset consisting of both data sources and was developed and maintained within the Tri-Council's guidelines. This refers to guidelines concerning database linkage and privacy/confidentiality (Chapter 5) [87]. Cohort and study variables were extracted by authorized personnel from the NSCR and linkage was completed by Health Data Nova Scotia (HDNS) who used unique study IDs to avoid any direct identifiers being used in the final data set. This replaced the encrypted health card numbers (HCNs). The main ethical concern when working with secondary data is maintaining confidentially and protecting privacy; these steps address any potential security concerns. No researchers had access to any identifying information. The final dataset was held on a secure HDNS server. Any reported results use aggregate-level data with cell counts of five or greater. Additionally, no printed results include any patient or physician identifiers.

4.0 Results

4.1 Oncologist survey and clinician discussions (objective 1)

A total of 8 medical and/or radiation oncologists practicing in Nova Scotia completed both survey questions. The findings revealed no consensus among oncologists when it came to the influence of different survivor challenges on their transition decisions (Figure 4.1). Responses on the importance of each challenge ranged from “not important” to “uncertain” to “important.” This trend was also observed in question 2, which inquired about the significance of survivors’ individual circumstances on transition decisions (Figure 4.2). Both Figure 4.1 and Figure 4.2 show the individual responses from oncologists. For example, when rating the importance of financial difficulties (Figure 4.1), we see that 2 respondents rated it as “1”, 1 rated it as a “2”, 1 rated it as a “5”, 1 rated it as a “6” and 3 rated it as a “7”. In question 2, at least half of the surveyed oncologists rated individual circumstances as “not important,” except for gender. Specifically, six respondents rated gender as “1,” while the remaining respondents rated it as “2” and “3,” collectively indicating that gender is not a statistically significant factor in making transition decisions.

Beyond the included list of variables, oncologist responses to the open-text option discussed other important considerations for discharge decisions. These included system and resource constraints (i.e., more patients than physicians), necessary specialist follow-up care for more complex patients, availability of care guidelines for PCPs, and patient access to PCPs. Conversations with oncologists and clinical experts (n=3) revealed additional factors beyond those covered in the survey that influence transition decisions. One critical consideration highlighted by the experts is the availability of primary care providers for cancer survivors. Many Nova Scotians currently lack access to a primary care provider. Given the substantial strain on resources at the cancer center due to a high number of active cancer patients and survivors, oncologists are likely to opt for transitioning patients to a primary care provider when such an option exists. Consequently, individual circumstances or challenges may have less influence on the decision-making process, and if an alternative care provider is available, oncologists may proceed with the transition regardless of specific circumstances.

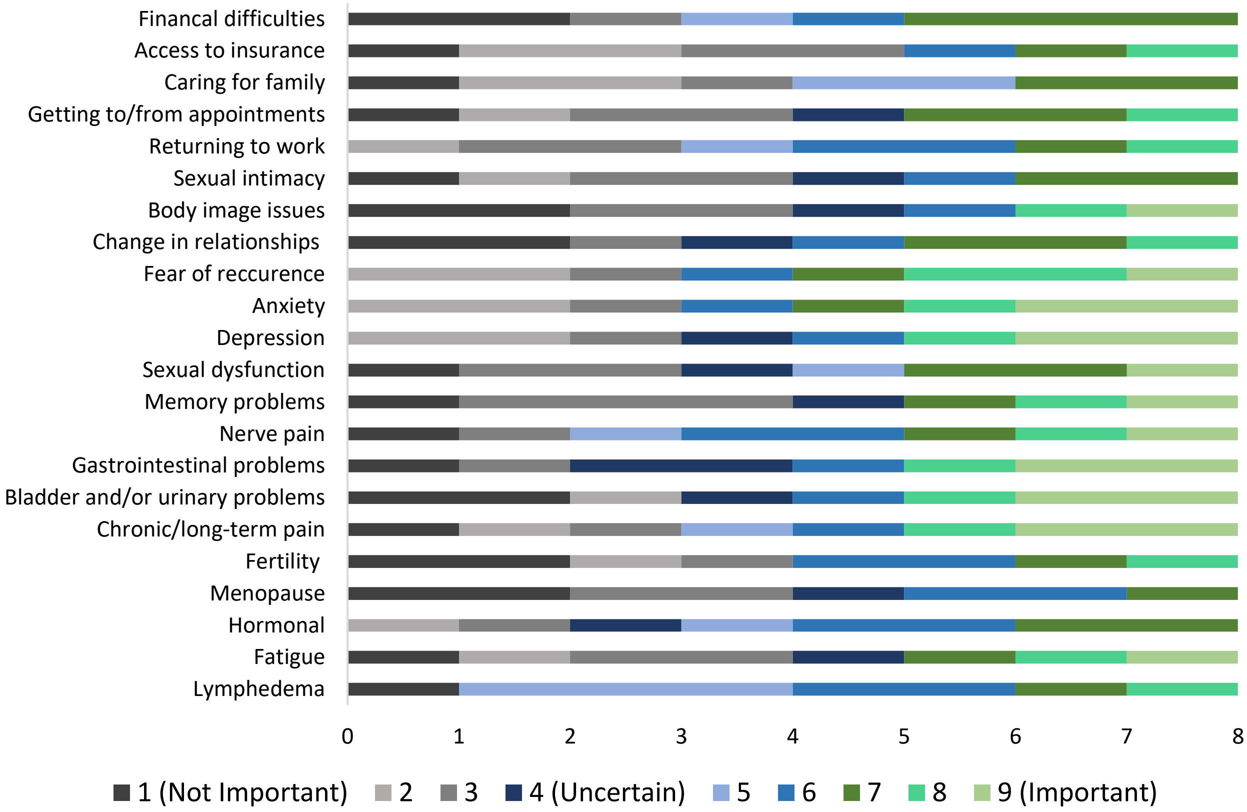


Figure 4.1: Oncologist responses to survey question 1.

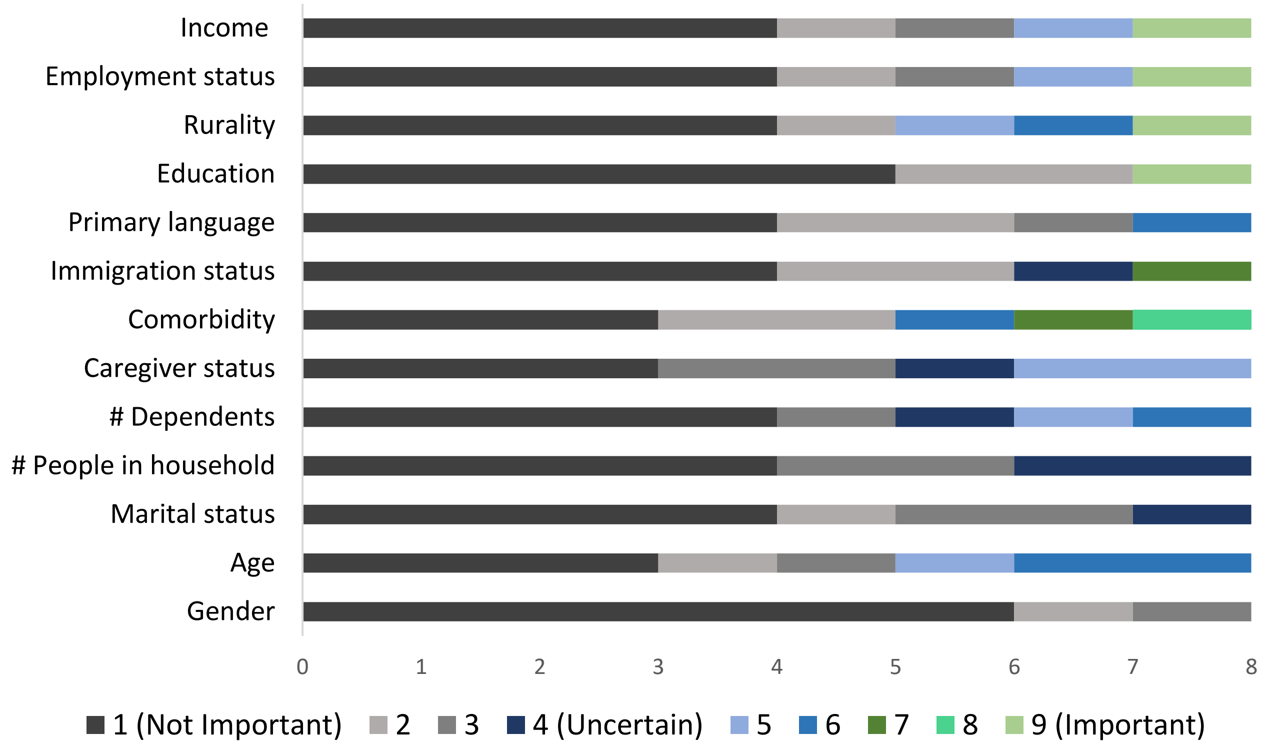


Figure 4.2: Oncologist responses to survey question 2.

4.2 Characteristics and self-identified challenges of the survivorship cohort (objective 2)

The majority of the cohort was female (76.64%), though this is largely due to many of the respondents being breast cancer survivors (59.30%). Male survivors of breast cancer were excluded from participating in the original CTS. Most respondents were aged 55 years or older (86.15%) and were retired (60.42%). Education attainment varied, with 41.12% having completed at most a high school degree, while 20.42% completed a post-secondary degree. Regarding income, only 6.43% reported earning $125,000 or more annually, while 42.66% earned $50,000 or less. Transition status was similar across both cancer sites, with 37.03% of breast and 30.24% of colorectal cancer survivors determined to be transitioned. Additional demographic information can be found in Table 4.1.

Table 4.1. Characteristics of the breast and colorectal cancer survivor cohort.

Variable	Breast Survivors N (%) 424	Colorectal Survivors N (%) 291	Total N (%) 715
Transitioned			
Yes	157 (37.03)	88 (30.24)	245 (34.27)
No	267 (62.97)	203 (69.76)	470 (65.73)
Sex			
Female	422 (99.53)	126 (43.40)	548 (76.64)
Male	1 (0.24)	162 (55.67)	163 (22.80)
Other	-	1 (0.34)	1 (0.14)
Prefer not to answer	1 (0.24)	2 (0.69)	3 (0.42)
Age at diagnosis			
</= 54 years	84 (19.81)	12 (4.12)	96 (13.43)
>/= 55 years	338 (79.72)	278 (95.53)	616 (86.15)
Prefer not to answer	4 (0.94)	2 (0.69)	6 (0.84)
Annual household income			
< 50K	166 (39.15)	139 (47.77)	305 (42.66)
>/= 50K to <125K	116 (27.36)	70 (24.05)	186 (26.01)
>/=125K	29 (6.84)	17 (5.84)	46 (6.43)
Prefer not to answer	92 (21.7)	54 (18.56)	146 (20.42)
Missing	21 (4.95)	11 (3.78)	32 (4.48)
Geographic location			
Rural	244 (57.55)	184 (63.23)	428 (59.86)
Urban	164 (38.68)	100 (34.36)	264 (36.92)
Missing	16 (3.77)	7 (2.41)	23 (3.22)
Employment status			
Part-time	42 (9.91)	17 (5.84)	112 (15.66)
Full-time	77 (18.16)	35 (12.03)	59 (8.25)
On leave	17 (4.01)	9 (3.09)	26 (3.64)
Unemployed	36 (8.49)	10 (3.44)	46 (6.43)
Retired	222 (52.36)	210 (72.16)	432 (60.42)
Student	3 (0.71)	-	3 (0.42)
Prefer not to answer	9 (2.12)	3 (1.03)	12 (1.68)
Missing	18 (4.25)	7 (2.41)	25 (3.5)
Marital status			
Partnered	295 (69.58)	211 (72.51)	506 (70.77)
Not partnered	26 (6.13)	11 (3.78)	37 (5.17)
Separated/divorced/widowed	99 (23.35)	67 (23.02)	166 (23.22)
Prefer not to answer	4 (0.94)	2 (0.69)	6 (0.84)
Education level			
High school or less	154 (36.32)	140 (48.11)	294 (41.12)
Some post-secondary	158 (37.26)	87 (29.90)	245 (34.27)
Post-Secondary	93 (21.93)	52 (18.21)	146 (20.42)
Prefer not to answer	4 (0.94)	5 (1.72)	9 (1.26)
Missing	15 (3.54)	6 (2.06)	21 (2.94)
Born in Canada			
Yes	377 (88.92)	269 (92.44)	646 (90.35)
No	34 (8.02)	18 (6.19)	52 (7.27)
Prefer not to answer	1 (0.24)	1 (0.34)	2 (0.28)
Missing	12 (2.83)	3 (1.03)	15 (2.1)
Stage at diagnosis			
I	243 (57.31)	84 (28.87)	327 (45.73)
II	139 (32.78)	94 (32.30)	233 (32.59)

III	42 (9.91)	113 (38.83)	155 (21.68)
Treatment received			
Radiation	20 (4.72)	2 (0.69)	22 (3.08)
Chemotherapy	2 (0.47)	11 (3.78)	13 (1.82)
Surgery	59 (13.92)	138 (47.42)	197 (27.55)
Combination	326 (76.88)	113 (38.82)	439 (61.40)
Other	10 (2.36)	2 (0.69)	12 (1.68)
None	7 (1.65)	25 (8.59)	32 (4.48)

The prevalence of the different physical, emotional, and practical challenges among breast and colorectal cancer survivors is detailed in Table 4.2. For breast cancer survivors, the most frequently reported challenges were fatigue (73.82%), anxiety/stress/fear of recurrence (65.57%), and body image issues (52.83%). Among colorectal cancer survivors, the most prevalent challenges included fatigue (57.73%), gastrointestinal problems (57.73%), and anxiety/stress/fear of recurrence (49.48%). Although most survivors reported no struggles with practical challenges, the most common practical challenge across the entire cohort was related to returning to work or school (20.00%).

Table 4.2. Reported physical, emotional, and practical challenges within the breast and colorectal cancer survivor cohort.

Challenges		Breast N (%) 424	Colorectal N (%) 291	Total N (%)
Physical challenges				
Lymphedema				
	Yes	145 (34.20)	36 (12.37)	181 (25.31)
	No	253 (59.67)	223 (76.63)	476 (66.57)
	Missing	26 (6.13)	32 (11.00)	58 (8.11)
Fatigue				
	Yes	313 (73.82)	169 (57.73)	481 (67.27)
	No	88 (20.75)	98 (33.68)	186 (26.01)
	Missing	23 (5.42)	25 (8.59)	48 (6.71)
Hormonal, menopause, or fertility issues				
	Yes	140 (33.02)	28 (9.62)	168 (23.50)
	No	256 (60.38)	228 (78.35)	484 (67.69)
	Missing	28 (6.60)	35 (12.03)	63 (8.81)
Chronic/long-term pain				
	Yes	151 (35.61)	78 (26.80)	229 (32.03)
	No	248 (58.49)	183 (62.89)	431 (60.28)
	Missing	25 (5.90)	30 (10.31)	55 (7.69)
Bladder/urinary problems				
	Yes	69 (16.27)	70 (24.05)	139 (19.44)
	No	332 (78.30)	188 (64.6)	520 (72.73)
	Missing	23 (5.42)	33 (11.34)	56 (7.83)
Gastrointestinal problems				
	Yes	104 (24.53)	168 (57.73)	272 (38.04)
	No	295 (69.58)	98 (33.68)	393 (54.97)
	Missing	25 (5.90)	25 (8.59)	50 (6.99)
Nerve problems				
	Yes	177 (41.75)	81 (27.84)	258 (36.08)
	No	224 (52.83)	182 (62.54)	406 (56.78)
	Missing	23 (5.42)	9.62 (51.00)	51 (7.13)
Memory problems				
	Yes	187 (44.10)	86 (29.55)	273 (38.18)
	No	216 (50.94)	175 (60.14)	391 (54.69)
	Missing	21 (4.95)	30 (10.31)	51 (7.13(
Changes in sexual activity or function				
	Yes	136 (32.08)	84 (28.87)	220 (30.77)
	No	266 (62.74)	183 (62.89)	449 (62.8)
	Missing	22 (5,19)	24 (.825)	46 (6.43)
Emotional challenges				
Depression				
	Yes	184 (43.40)	96 (32.99)	280 (39.16)
	No	187 (44.10)	144 (49.48)	331 (46.29)
	Missing	53 (12.50)	51 (17.53)	104 (14.50)
Anxiety/stress/fear of recurrence				
	Yes	278 (65.57)	144 (49.48)	422 (59.02)
	No	97 (22.88)	99 (34.02)	196 (27.41)
	Missing	49 (11.56)	48 (16.49)	97 (13.57)

Relationship changes (family, partners)			
Yes	122 (28.77)	61 (20.96)	183 (25.59)
No	289 (68.16)	209 (71.82)	498 (69.65)
Missing	13 (3.07)	21 (7.22)	34 (4.76)
Relationship changes (friends, coworkers)			
Yes	82 (19.34)	39 (13.40)	121 (16.92)
No	325 (76.65)	233 (80.07)	558 (78.04)
Missing	17 (4.01)	19 (6.53)	36 (5.03)
Body image issues			
Yes	224 (52.83)	81 (27.84)	305 (42.66)
No	183 (43.16)	191 (65.64)	374 (52.31)
Missing	17 (4.01)	19 (6.53)	
Changes in sexual intimacy			
Yes	136 (32.08)	81 (27.84)	217 (30.35)
No	268 (63.21)	190 (65.29)	458 (64.06)
Missing	20 (4.72)	20 (6.87)	40 (5.59)
Practical challenges			
Returning to work/school			
Yes	101 (23.82)	42 (14.43)	143 (20.00)
No	297 (70.05)	216 (74.23)	513 (71.75)
Missing	26 (6.13)	33 (11.34)	59 (8.25)
Getting to/from appointments			
Yes	76 (17.92)	42 (14.43)	118 (16.50)
No	331 (78.07)	224 (76.98)	555 (77.62)
Missing	17 (4.01)	25 (8.59)	42 (5.87)
Caring for family members			
Yes	69 (16.27)	18 (6.19)	87 (12.17)
No	333 (78.54)	244 (83.85)	577 (80.7)
Missing	22 (5.19)	29 (9.97)	51 (7.13)
Difficulty accessing insurance			
Yes	49 (11.56)	26 (8.93)	75 (10.49)
No	349 (82.31)	234 (80.41)	583 (81.54)
Missing	26 (6.13)	31 (10.65)	57 (7.97)
Difficulty paying bills			
Yes	89 (20.99)	48 (16.49)	137 (19.16)
No	316 (74.53)	217 (74.57)	533 (74.55)
Missing	19 (4.48)	26 (8.93)	45 (6.29)

Next, survivor challenges were examined based on transition status for breast and colorectal cancer sites (Table 4.3). Across both cancer types, the most prevalent challenges reported by survivors remained consistent with the results reported in Table 4.2, regardless of transition status. These challenges included fatigue, anxiety/stress/fear of recurrence, and body image issues for breast cancer survivors, and fatigue, gastrointestinal problems, and anxiety/stress/fear of recurrence for colorectal cancer survivors. Chi-square tests were employed to assess potential differences in the number of respondents reporting challenges based on transition status. Overall, no statistically significant differences were found, except for fatigue in breast cancer survivors. A higher percentage of transitioned breast cancer survivors (77.90%) reported struggling with fatigue compared to non-transitioned survivors (66.88%). However, it is essential to interpret this finding cautiously, as the p-value from the chi-square test was 0.042, indicating a weakly statistically significant result.

Table 4.3. Prevalence of physical, emotional and practical challenges within the breast and colorectal cancer survivor cohort, by transition status.

Challenges	**Breast N (%) 424**			**Colorectal N (%) 291**		
	Not transitioned	Transitioned	Chi-square test (p-value)	Not transitioned	Transitioned	Chi-square test (p-value)
Physical challenges						
Lymphedema						
Yes	90 (33.71)	55 (35.03)	0.544	24 (11.82)	12 (13.64)	0.889
No	158 (59.18)	95 (60.51)		156 (76.85)	67 (76.14)	
Missing	19 (7.12)	7 (4.46)		23 (11.33)	9 (10.23)	
Fatigue						
Yes	208 (77.90)	105 (66.88)	**0.042**	117 (57.64)	51 (57.95)	0.967
No	46 (17.23)	42 (26.75)		68 (33.5)	30 (34.09)	
Missing	13 (4.87)	10 (6.37)		18 (8.87)	7 (7.95)	
Hormonal, menopause, or fertility issues						
Yes	91 (34.08)	49 (31.21)	0.823	21 (10.34)	7 (7.95)	0.638
No	159 (59.55)	97 (61.78)		156 (76.85)	72 (81.82)	
Missing	17 (6.37)	11 (7.01)		26 (12.81)	9 (10.23)	
Chronic/long-term pain						
Yes	102 (38.20)	49 (31.21)	0.348	56 (27.59)	22 (25.00)	0.893
No	150 (56.18)	98 (62.42)		126 (62.07)	57 (64.77)	
Missing	15 (5.62)	10 (6.37)		21 (10.34)	9 (10.23)	
Bladder/urinary problems						
Yes	42 (15.73)	27 (17.20)	0.722	45 (22.17)	25 (28.41)	0.440
No	212 (79.4)	120 (76.43)		133 (65.52)	55 (62.50)	
Missing	13 (4.87)	10 (6.37)		25 (12.32)	8 (9.09)	
Gastrointestinal problems						
Yes	67 (25.09)	37 (23.57)	0.927	118 (58.13)	50 (56.82)	0.920
No	184 (68.91)	111 (70.70)		67 (33.00)	31 (35.23)	
Missing	16 (5.99)	9 (5.73)		18 (8.87)	7 (7.95)	
Nerve problems						
Yes	115 (43.07)	62 (39.49)	0.716	57 (28.08)	24 (27.27)	0.787
No	137 (51.31)	87 (55.41)		125 (61.58)	57 (64.77)	
Missing	15 (5.62)	8 (5.10)		21 (10.34)	7 (7.95)	
Memory problems						
Yes	123 (46.07)	64 (40.76)	0.565	58 (28.57)	28 (31.82)	0.809
No	131 (49.06)	85 (54.14)		123 (60.59)	52 (59.09)	
Missing	13 (4.87)	8 (5.10)		22 (10.84)	8 (9.09)	
Changes in sexual activity or function						
Yes	84 (31.46)	52 (33.12)	0.842	62 (30.54)	22 (25.00)	0.623
No	168 (62.92)	98 (62.42)		125 (61.58)	58 (65.91)	
Missing	13 (4.87)	7 (4.46)		16 (7.88)	8 (9.09)	
Emotional challenges						
Depression						
Yes	116 (43.45)	68 (43.31)	0.910	70 (34.48)	26 (29.55)	0.650
No	119 (44.57)	68 (43.31)		97 (47.78)	47 (53.41)	
Missing	32 (11.99)	21 (13.38)		36 (17.73)	15 (17.05)	
Anxiety/stress/fear of recurrence						
Yes	172 (64.42)	106 (67.52)	0.770	99 (48.77)	45 (51.14)	0.873
No	64 (23.97)	33 (21.02)		71 (34.98)	28 (31.82)	
Missing	31 (11.61)	18 (11.46)		33 (16.26)	15 (17.05)	

Relationship changes (family, partners)						
Yes	72 (26.97)	50 (31.85)	0.210	48 (23.65)	13 (14.77)	0.213
No	189 (70.79)	100 (63.69)		140 (68.97)	69 (78.41)	
Missing	6 (2.25)	7 (4.46)		15 (7.39)	6 (6.82)	
Relationship changes (friends, coworkers)						
Yes	52 (19.48)	30 (19.11)	0.164	31 (15.27)	8 (9.09)	0.364
No	208 (77.9)	117 (74.52)		159 (78.33)	74 (84.09)	
Missing	7 (2.62)	10 (6.37)		13 (6.40)	6 (6.82)	
Body image issues						
Yes	146 (54.68)	78 (49.68)	0.296	62 (30.54)	19 (21.59)	0.292
No	112 (42.32)	70 (44.59)		128 (63.05)	63 (71.59)	
Missing	8 (3.00)	9 (5.73)		13 (6.40)	6 (6.82)	
Changes in sexual intimacy						
Yes	83 (31.09)	53 (33.76)	0.061	61 (30.05)	20 (22.73)	0.428
No	176 (65.92)	92 (58.6)		128 (63.05)	62 (70.45)	
Missing	8 (3.00)	12 (7.64)		14 (6.90)	6 (6.82)	
Practical challenges						
Returning to work/school						
Yes	63 (23.60)	38 (24.20)	0.792	30 (14.78)	12 (13.64)	0.712
No	186 (69.66)	111 (70.70)		152 (74.88)	64 (72.73)	
Missing	18 (6.74)	8 (5.10)		21 (10.34)	12 (13.64)	
Getting to/from appointments						
Yes	47 (17.60)	29 (18.47)	0.650	28 (13.79)	14 (15.91)	0.446
No	211 (79.03)	120 (76.43)		160 (78.82)	64 (72.73)	
Missing	9 (3.37)	8 (5.10)		15 (7.39)	10 (11.36)	
Caring for family members						
Yes	47 (17.60)	22 (14.01)	0.618	13 (6.40)	5 (5.68)	0.629
No	206 (77.15)	127 (80.89)		172 (84.73)	72 (81.82)	
Missing	14 (5.24)	8 (5.10)		18 (8.87)	11 (12.50)	
Difficulty accessing insurance						
Yes	29 (10.86)	20 (12.74)	0.825	20 (9.85)	6 (6.82)	0.428
No	221 (82.77)	128 (81.53)		164 (80.79)	70 (79.55)	
Missing	17 (6.37)	9 (5.73)		19 (9.36)	12 (13.64)	
Difficulty paying bills						
Yes	59 (22.10)	30 (19.11)	0.710	37 (18.23)	11 (12.50)	0.351
No	197 (73.78)	119 (75.8)		150 (73.89)	67 (76.14)	
Missing	11 (4.12)	8 (5.10)		16 (7.88)	10 (11.36)	

* Bolded value indicates a significant result

The mean number of survivor challenges was investigated to examine potential differences based on transition status for breast and colorectal cancer survivors (Table 4.4). Separate analyses were performed for physical, emotional, and practical challenges, as well as considering all challenges collectively. Two-sample t-tests were employed to assess the significance of differences. Across both cancer types, no statistically significant differences were observed when comparing transitioned survivors to those who were not transitioned. For physical challenges in breast cancer survivors, the mean number of challenges was 3.45 (±2.52) for non-transitioned and 3.19 (±2.47) for transitioned survivors, with a non-statistically significant p-value of 0.2864. Similarly, emotional and practical challenges showed no statistically significant differences based on transition status for both breast and colorectal cancer survivors. When considering all challenges together, the mean number was 6.77 (±4.98) for non-transitioned and 6.52 (±4.93) for transitioned breast cancer survivors, and 5.21 (±4.66) for non-transitioned and 4.77 (±4.28) for transitioned colorectal cancer survivors, with both cancer types yielding non-statistically significant t-test results ($p > 0.05$).

Table 4.4. Mean number of survivor's challenges by transition status.

Mean # of challenges	**Breast**			**Colorectal**		
	Not transitioned (SD)	Transitioned (SD)	t-test (p-value)	Not transitioned (SD)	Transitioned (SD)	t-test (p-value)
Physical challenges	3.45 (±2.52)	3.19 (±2.47)	0.286	2.75 (±0.17)	2.74 (±0.26)	0.974
Emotional challenges	2.40 (±1.98)	2.45 (±2.00)	0.797	1.83 (±1.96)	1.49 (±1.70)	0.159
Practical challenges	0.92 (±1.33)	0.89 (±1.21)	0.803	0.63 (±1.03)	0.55 (±0.86)	0.498
All challenges	6.77 (±4.98)	6.52 (±4.93)	0.616	5.21 (±4.66)	4.77 (±4.28)	0.455

4.3 Association of survivor challenges and circumstances with transition (objective 3)

Table 4.5 presents the results of the univariable logistic regression analyses, examining the challenges associated with breast cancer survivors' transition from specialist-led to primary care-led follow-up care. Among breast cancer survivors, fatigue and changes in sexual intimacy showed a statistically significant association with transition status (p=0.015). However, as previously discussed, the practical significance of these relationships may be limited and may be an effect of the sample size rather than a true effect so this result should be interpreted with caution. For other challenges, such as hormonal, menopause, or fertility issues, chronic/long-term pain, and memory problems, there were no statistically significant associations with the transition status. Similarly, for colorectal cancer survivors, Table 4.5 shows that preference for not reporting income ($p=0.044$) had a statistically significant association with the transition status. All other challenges demonstrated no statistically significant associations, as all the p-values were above the threshold of significance ($p > 0.05$). For both breast and colorectal cancer survivors, no other specific challenges exhibited statistically significant associations with the transition status. Due to these results, no subsequent multivariable analyses were conducted. These models would have controlled for clinical variables, including treatment(s) received and stage at diagnosis.

Table 4.5. Univariable logistic regression of challenges and circumstances associated with ability to transition to primary care for breast cancer survivors.

Variable	Breast			Colorectal			All		
	Odds Ratio	95% CI	p-value	Odds Ratio	95% CI	p-value	Odds Ratio	95% CI	p-value
Lymphedema (ref=no)									
Yes	1.016	0.667-1.549	0.940	1.164	0.550-2.464	0.691	1.139	0.798-1.627	0.474
Missing	0.613	0.248-1.512	0.288	0.911	0.400-2.073	0.824	0.738	0.403-1.354	0.327
Fatigue (ref=no)									
Yes	0.553	0.342-0.893	**0.015**	0.990	0.575-1.697	0.965	0.760	0.403-1.354	0.126
Missing	0.843	0.334-2.124	0.716	0.882	0.333-2.332	0.799	0.868	0.448-1.682	0.675
Hormonal, menopause, or fertility issues (ref=no)									
Yes	0.883	0.575-1.356	0.569	0.722	0.294-1.776	0.478	0.932	0.643-1.351	0.710
Missing	1.060	0.477-2.360	0.885	0.750	0.334-1.682	0.485	0.870	0.494-1.521	0.619
Chronic/long-term pain (ref=no)									
Yes	0.735	0.481-1.125	0.156	0.868	0.484-1.557	0.636	0.800	0.568-1.127	0.202
Missing	1.020	0.441-2.363	0.962	0.947	0.409-2.200	0.900	0.940	0.521-1.695	0.836
Bladder/urinary problems (ref=no)									
Yes	1.136	0.667-1.935	0.640	1.343	0.751-2.402	0.319	1.178	0.799-1.738	0.408
Missing	1.359	0.578-3.193	0.482	0.774	0.329-1.821	0.557	0.934	0.518-1.684	0.820
Gastrointestinal problems (ref=no)									
Yes	0.915	0.575-1.458	0.710	0.916	0.534-1.570	0.749	0.831	0.599-1.153	0.269
Missing	0.932	0.399-2.181	0.872	0.841	0.318-2.220	0.726	0.832	0.444-1.560	0.566
Nerve problems (ref=no)									
Yes	0.849	0.564-1.278	0.433	0.923	0.522-1.633	0.784	0.910	0.655-1.264	0.573
Missing	0.840	0.342-2.064	0.500	0.731	0.294-1.818	0.500	0.758	0.402-1.432	0.393
Memory problems (ref=no)									
Yes	0.802	0.534-1.205	0.288	1.142	0.655-1.990	0.640	0.942	0.680-1.305	0.721
Missing	0.948	0.377-2.385	0.910	0.860	0.360-2.057	0.735	0.848	0.453-1.587	0.605
Changes in sexual activity or function (ref=no)									
Yes	1.061	0.693-1.625	0.785	0.765	0.429-1.363	0.363	0.951	0.677-1.338	0.777
Missing	0.800	0.315-2.030	0.639	1.078	0.43602.661	0.871	0.911	0.476-1.735	0.772
Depression (ref=no)									
Yes	1.026	0.673-1.565	0.906	0.767	0.434-1.354	0.360	0.949	0.679-1.328	0.761
Missing	1.148	0.614-2.148	0.665	0.860	0.429-1.724	0.671	0.994	0.626-1.580	0.981
Anxiety (ref=no)									
Yes	1.195	0.736-1.941	0.471	1.153	0.657-2.021	0.620	1.233	0.859-1.771	0.257
Missing	1.126	0.550-2.306	0.745	1.526	0.544-2.442	0.711	1.141	0.680-1.192	0.617

	Odds Ratio	95% CI	p-value	Odds Ratio	95% CI	p-value	Odds Ratio	95% CI	p-value
Relationship changes (family, partners) (ref=no)									
Yes	1.313	0.850-2.027	0.220	0.550	0.279-1.082	0.083	1.022	0.715-1.460	0.905
Missing	2.205	0.722-6.738	0.165	0.812	0.302-2.184	0.679	1.025	0.589-2.466	0.610
Relationship changes (friends, coworkers) (ref=no)									
Yes	1.026	0.620-1.696	0.921	0.555	0.243-1.265	0.161	0.880	0.577-1.341	0.552
Missing	2.540	0.942-6.849	0.066	0.992	0.363-2.712	0.987	1.537	0.779-3.035	0.215
Body image issues (ref=no)									
Yes	0.862	0.575-1.294	0.474	0.623	0.343-1.130	0.119	0.845	0.613-1.165	0.304
Missing	0.241	0.670-4.926	0.241	0.938	0.340-2.583	0.901	1.294	0.646-2.595	0.467
Changes in sexual intimacy (ref=no)									
Yes	1.221	0.800-1.872	0.358	0.677	0.376-1.220	0.194	1.001	0.711-1.409	0.997
Missing	2.870	1.133-7.269	**0.025**	0.885	0.324-2.413	0.811	1.615	0.841-3.101	0.150
Returning to work/school (ref=no)									
Yes	1.011	0.634-1.611	0.964	0.950	0.458-1.972	0.891	1.038	0.704-1.532	0.849
Missing	0.745	0.314-1.770	0.504	1.357	0.630-2.922	0.435	0.991	0.561-1.750	0.974
Getting to/from appointments (ref=no)									
Yes	1.085	0.649-1.814	0.756	1.250	0.618-2.528	0.534	1.156	0.764-1.750	0.493
Missing	1.563	0.588-4.158	0.371	1.667	0.712-3.903	3.904	1.512	0.800-2.857	0.203
Caring for family members (ref=no)									
Yes	0.759	0.437-1.319	0.329	0.919	0.316-2.672	0.876	0.855	0.526-1.389	0.526
Missing	0.927	0.378-2.272	0.868	1.460	0.657-3.246	0.353	1.128	0.623-2.041	0.691
Difficulty accessing insurance (ref=no)									
Yes	1.191	0.647-2.191	0.575	0.703	0.271-1.825	0.469	1.032	0.622-1.710	0.904
Missing	0.914	0.400-2.115	0.833	0.322	0.682-3.212	0.322	1.134	0.645-2.000	0.662
Difficulty paying bills (ref=no)									
Yes	0.842	0.513-1.381	0.495	0.666	0.320-1.384	0.276	0.797	0.531-1.197	0.274
Missing	1.204	0.471-3.078	0.698	1.400	0.604-3.244	0.434	1.244	0.667-2.318	0.492
Age (ref=</=54)									
>55	1.281	0.787-0.111	0.319	0.200	0.025-1.570	0.126	1.177	0.754-1.838	0.474
Prefer not to answer	1.793	0.111-28.928	0.681	-	-	-	0.981	0.088-10.880	0.987
Geographic Location (ref=rural)									
Urban	1.409	0.937-2.118	0.099	0.672	0.389-1.161	0.154	1.091	0.790-1.505	0.598
Missing	0.882	0.300-2.622	0.821	0.807	0.152-4.277	0.801	0.863	0.347-2.145	0.751

	Odds Ratio	95% CI	p-value	Odds Ratio	95% CI	p-value	Odds Ratio	95% CI	p-value
Marital Status (ref=partnered)									
Not partnered	0.853	0368-1.978	0.710	0.547	0.115-2.603	0.448	0.807	0.390-1.673	0.565
Separated/divorced/widowed	0.843	0.523-1.357	0.481	1.464	0.821-2.608	0.196	1.052	0.729-1,519	0.786
Prefer not to answer	0.537	0.055-5.224	0.592	-	-	-	0.382	0.044-3.292	0.381
Education Level (ref=post-secondary)									
Some post-secondary	0.944	0.586-1.492	0.777	1.071	0.602-1.904	0.816	1.003	0.700-1.439	0.987
Post-secondary	1.593	0.942-2.693	0.082	0.976	0.490-1.940	0.944	1.377	0.914-2.076	0.126
Prefer not to answer	5.556	0.564-54.710	0.142	-	-	-	1.015	0.249-4.147	0.983
Missing	0.673	0.205-2.216	0.515	0.451	0.051-3.979	0.474	0.635	0.226-1.783	0.388
Employment Status (ref=full-time)									
Part-time	1.101	0.517-2.348	0.802	0.857	0.192-3.830	0.840	1.070	0.557-2.059	0.839
On leave	0.286	0.076-1.076	0.064	1.143	0.193-6.753	0.883	0.429	0.150-1.224	0.113
Unemployed	0.667	0.292-1.524	0.337	1.714	0.351-8.373	0.505	0.871	0.421-1.803	0.710
Retired	0.737	0.434-1.249	0.257	1.957	0.815-4.704	0.133	0.938	0.607-4.316	0.773
Student	2.667	0.232-30.672	0.431	-	-	-	0.360	0.317-40.948	0.302
Prefer not to answer	0.667	0.155-2.864	0.586	8.000	0.631-101.369	0.108	1.286	0.383-4.316	0.684
Missing	0.667	0.227-1.961	0.461	1.600	0.255-10.045	0.616	0.847	0.336-2.136	0.725
Annual Household Income (ref=>/=$125000)									
>/= $50 000 to < $125 000	0.996	0.613-1.617	0.986	0.990	0.524-1.869	0.975	1.033	0.705-1.513	0.869
>/= $125 000	1.231	0.556-2.726	0.608	1.350	0.468-3.898	0.579	1.321	0.702-2.487	0.388
Prefer not to answer	0.565	0.325-0.984	**0.044**	1.238	0.630-2.429	0.536	0.784	0.511-1.201	0.263
Missing	0.758	0.290-1.977	0.570	1.414	0.392-5.098	0.596	0.983	0.457-2.117	0.966
Born in Canada (ref=yes)									
No	0.792	0.375-1.672	0.540	0.893	0.308-2.586	0.834	0.843	0.458-1.553	0.584
Missing	0.604	0.491-0.744	0.761	1.160	0.104-12.980	0.904	0.948	0.320-2.809	0.924

* Bolded value indicates a significant result

5.0 Discussion and conclusions

5.1 Discussion

This study used administrative health data linked with CTS survey responses to explore whether and, if so, how cancer survivors differed based on transition status, considering their reported challenges and individual circumstances. The main findings from this study were that there were no notable differences in survivors by transition status. The most frequently reported challenges remained consistent across cancer types and transition statuses, but there were no statistically significant differences in their prevalence by transition status. Similarly, univariable logistic regression analyses found that almost no challenges were statistically significantly associated with transition status. These findings may point to similar patterns in cancer survivors' experiences, regardless of their transition status. Results from the oncologist survey, coupled with conversations with experts, provided insight into why it may appear that survivors' challenges and characteristics do not differ by transition status. These findings underscore the need for personalized care for cancer survivors in Nova Scotia. However, given the null or nonsignificant results in this study, drawing conclusive reasons for this current lack of personalization from care providers is not possible. Future research is needed to delve deeper into the current decision-making processes for transitions and better understand the factors involved.

Descriptive analyses of the study cohort revealed that transitioned and non-transitioned survivors closely resembled each other. Fatigue and fear of recurrence were two of the most prevalent challenges reported, irrespective of cancer type or transition status, consistent with previous findings [36, 37, 38]. There were no meaningful differences in the prevalence of challenges by transition status, and the mean number of challenges did not statistically significantly differ between the groups. Results from our logistic regressions found that the challenges we investigated lacked meaningful associations with transition status. However, it is possible that unmeasured factors, namely access to a PCP as well was patient preferences and health literacy, are also associated with transition status. Results from the oncologist survey support this idea, as no challenges or patient circumstances seem to drive transition in practice. A recurring theme that emerged from conversations with clinical experts was that health system factors seem to drive transition decisions, namely patient access to PCPs and constraints within the cancer care system. Some expressed that if a survivor has access to a PCP, they will almost always be transitioned due to the overwhelming number of patients seen at the cancer centre.

Nonetheless, it is important to consider that our main finding (i.e., no differences between those transitioned and those not) does not mean our cohort had favourable outcomes. The number of challenges reported by survivors suggests the opposite. Previous studies have demonstrated that as the magnitude of challenges increases, so does the level of care interventions required, while quality of life is inversely affected [24, 26, 31, 32]. In our study, survivors reported a high number of unmet challenges regardless of the type of follow-up care they received or cancer diagnosis. This is further aggravated by challenges not being mitigated by care providers [33]. In fact, the lack of difference by transition status may be troubling, as it may suggest that in Nova Scotia, neither model of care is adequately addressing the challenges patients report struggling with. Previous research has found that different types of challenges (physical, emotional and practical) can be better managed by different models of care [49].

However, our results suggest that self-reported challenges are not associated with one's model of care and are not the driving factor behind transition in the province, which to the best of our knowledge has not been found by previous research. For survivors in Nova Scotia, this raises concerns about a potential gap between the challenges they face and the care they receive. If individual circumstances are not the primary factor guiding the choice of care, it could have a negative impact on their well-being and overall quality of life. Personalizing care for individual cancer survivors has demonstrated benefits, not only in improving their outcomes but also in alleviating existing strains on cancer specialists' resources—such as transitioning survivors from cancer centres to accommodate new active cancer patients. While acknowledging the valid concern about access to PCPs, a strategic shift toward transitioning survivors well-suited for PCP-led care and who have access to these providers could positively impact their experiences and outcomes.

Healthcare constraints are a real problem in Nova Scotia and could very well be at the forefront of oncologists' minds [88]. The number of individuals without a family doctor in the province has steadily risen over the years, increasing from 60 154 (6.10%) in 2021, to 133 595 (13.50%) in February of 2023 [89, 90]. At the same time, if these health system constraints are driving care, this means that care is not being personalized to individual survivors. We know that survivors are a heterogenous group, although these findings may initially suggest otherwise. As such, it is reasonable to believe different individuals may benefit from different models of care. As these challenges increase, the need for healthcare interventions also rises. Therefore, someone's circumstances may affect the amount of care they need.

Although this study did not find associations between one's challenges or circumstances and transition status, we know from the literature that survivors can differentially benefit from models of care. For example, studies have shown that oncologists tend to focus on treating the physical challenges of a survivor, while PCPs are more attentive to the psychosocial/emotional challenges [49]. Oncologists and patients have both voiced their concerns about PCPs' ability to adequately manage follow-up care, particularly as it relates to managing physical challenges and monitoring for new or recurring cancers [91, 92, 93, 94]. However, RCTs over decades have shown that patient outcomes under PCP-led follow-up care are comparable to or even better than those under oncologist-led care [51, 52, 53, 55, 56.] In light of these findings and the existing evidence, it becomes clear that tailoring survivorship care according to an individual's challenges and unique circumstances is highly important. This personalized approach acknowledges the diversity of survivors, allowing healthcare models to be finely tuned for comprehensive and effective follow-up care. This may not only foster improved outcomes and overall well-being but also reflects a patient-centered focused approach in cancer survivorship care.

In the context of Nova Scotia's healthcare system, it is possible that oncologists' transition decisions are driven by health system factors. The high patient volume within the cancer care system affects various aspects of care delivery. It is also possible that no factors are consistently driving transition decisions and transition decisions are random and haphazard in practice. However, the results from this study do not allow us to draw any conclusions on this matter. Regardless, the current approach to follow-up care may have negative repercussions for both cancer survivors and oncologists. That is, survivors continue to grapple with unaddressed challenges due to the lack of personalized follow-up care, regardless of the care provider. Oncologists may also be unknowingly placing further strain on their own resources. A previous study from Nova Scotia found that follow-up visits to the cancer centres are increasing with time, not decreasing; between 2014 and 2021, follow-up visits to the cancer center increased by 52% [95, 96]. Typically, the risk level of a cancer survivor decreases with time should they not develop a secondary cancer or recurrence. These individuals can be adequately cared for by PCPs, with evidence for this supported by several RCTs [51, 52, 53, 55, 56]. Failing to transition these individuals, who stand to benefit, potentially limits the time oncologists can spend caring for all patients. Moving forward, a coordinated follow-up care system that supports the tailoring of transition decisions to individual patients' challenges could mitigate, rather than exacerbate, resource constraints [97, 98, 99.]

5.2 Study Strengths

This study's strengths include: the novelty of objective 1; the rare ability to link administrative health data to survey responses; the wealth of individual-level data available from a population-based survey that had a high response rate; and access to survivor's self-reported challenges allowing for investigation of how challenges are associated with the transition to primary care-led follow-up care for the first time.

Despite the low uptake of the oncologist survey, the results are still important and novel. Survey responses in combination with expert discussions demonstrated the lack of consensus on which challenges or patient circumstances are most important when making transition decisions. Additionally, they highlighted the influence of patient access to PCPs on these decisions. These results are important as they document the perspectives of Nova Scotian oncologists on transition to care, which was previously unavailable. They also help to understand the results the of logistic regression models conducted in this study.

The data linkage reflects a key strength of this study. Specifically, this study is one of the first that we know of, worldwide, to link a large, comprehensive population-based survey on cancer survivors' experiences and challenges to administrative health data. This allowed for investigation of how individuals' challenges impact their healthcare utilization and transition to primary care – information that is inaccessible through the individual data sets alone. Using administrative data alone, we require proxies to estimate survivor challenges representing a limitation for this data source. However, linked data eliminates the requirement for proxies. Additionally, the availability of administrative data greatly reduces the chance for recall bias, which was discussed as one of our study's limitations.

Outside of the ability to link these two sources of data, access to responses from the CTS is a strength of this study. The survey is a rich source of information, comprising 83 items that cover various subjects. Importantly, it provides insights into survivors' circumstances and their challenges during care. Much research has been done around the emotional, physical, and practical challenges of survivors as they move from active treatment to routine follow-up care. However, very rarely are direct responses from survivors detailing their perspective on care and challenges available. Without these individual-level responses, it would not have been possible to investigate whether and how one's challenges after treatment are associated with transition back to primary care. Furthermore, the CTS was administered to the entire Nova Scotian population of cancer survivors. This ensures that results from this study are representative of the population in Nova Scotia in which we plan to introduce policy changes. Previous research lacked the comprehensive data, to which we had access, necessary to explore how a survivor's challenges relate to transition status after treatment. Therefore, this study posed a novel and crucial question, only answerable with data from these different sources.

5.3 Study Limitations

This study's key limitations include the validity of self-reported survey responses, the presence of missing data, some aspects of the CTS and administrative data, and the oncologist survey.

Self-reported data are important in capturing the authentic experience of each individual survivor. However, some factors may impact the validity of self-reported responses which are often acknowledged in research. First, cognitive issues while completing the survey pose a potential issue [100]. The CTS is considerable in length with 83 response items. It is likely that some respondents had difficulty and may have incorrectly or not answered certain items. This could be due to genuine confusion in what was being asked or issues with recollection. Despite the efforts taken to ensure the survey was written in terms comprehensible by all respondents, it is impossible to guarantee all are 100% familiar with the content of the survey. Additionally, while more time passes after entering the survivorship period, respondents may be unable to recall certain information about their experiences. Normally this can be a considerable issue since administrative data are not typically available in combination with survey responses. The availability of administrative data in this study remedies this issue to a degree by ensuring access to some information (i.e., cancer stage, geographic location etc.). However, it cannot account for all potential issues in responses. At the same time, the argument can be made that there is no one better to identify their challenges than a survivor themselves.

The second issue with self-reported data is the potential for response bias and non-response bias. Some respondents may have felt that certain items, for example, income, have a socially desirable response. This may have influenced some respondents to answer certain items inaccurately to provide what they felt was a more socially desirable response [101]. Actions to reduce the likelihood of bias were taken while constructing the survey, by ensuring respondents' responses would be anonymized and that honesty is crucial to the study. Nonetheless, there are missing data in the survey responses for this study, meaning non-response bias may have occurred [102]. Individuals not responding tend to have poorer health status and less health-seeking behaviours, though this cannot be said with certainty for our study’s cohort.

To account for non-response bias, we included a “missing” category with response options throughout analyses. While the strategy of using a 'missing' category for handling missing data is a commonly employed practice, it is not without its limitations. If the missing data can be attributed to unobserved variables not considered in this study, it introduces the risk of bias. This approach also assumes homogeneity in the nature of missing data, which may not hold true in all instances. Moreover, interpreting the results associated with certain missing categories can be challenging, especially in the absence of prior literature addressing such specifics.

Alternative methods, such as multiple imputation, could have been considered to handle missing data[103]. However, a previous study using this dataset indicated that the missing data were not completely at random, an assumption of multiple imputation although one that is not always met [103, 104]. Given this, in combination with the complexity of this method, we opted against its use. A limitation of not using multiple imputation is that it might result in an underestimation of the true variability in the data [103]. To address this concern, we could have conducted a sensitivity analysis to explore how different imputation methods might impact our findings, providing valuable insights into the robustness of our results [105].

We considered complete case analysis, where only cases with complete data would be included [103]. However, we chose not to utilize this method to avoid potential bias, especially if the missing data are related to certain participant characteristics or the outcome variable [103]. Additionally, this method was avoided as it would have further reduced our already small sample size, potentially compromising the robustness and generalizability of our study outcomes [103]. While complete case analysis has the advantage of simplicity and maintaining the integrity of observed data, its use may introduce bias if missingness is related to specific participant characteristics or outcomes [103]. The decision to avoid complete case analysis was driven by the need to balance the benefits and drawbacks, ensuring the reliability and validity of our study findings.

The response rate for the Nova Scotian CTS, although the second highest in Canada, is low when compared to other population-based surveys. A study reviewing global response rates for these survey types found that the average response rate for mailed surveys is 65%, while web-based surveys have an average response rate of 46%[106]. The CTS achieved a response rate of 44.6%, with 78.7% of responses collected via mail and 21.3% completed online. This means that more than half of eligible respondents did not participate, and the response rate was lower than the global average. This must be considered and acknowledged when interpreting the results of this study as it could introduce a non-responder selection bias which may impact the validity of results [106]. This bias often results in fewer responses from individuals with lower socioeconomic backgrounds [102]. When combined with our assumptions about the missingness of our data, it suggests that our study may not fully capture the experiences of these individuals. Additionally, results cannot be confidently generalized to breast and/or colorectal cancer survivors older than 80 or less than 30, as they were less likely to respond to the CTS (prior analysis completed by CTS study team in Nova Scotia).

Although the CTS and subsequent data linkage are rich in information, it does lack some information that would have been relevant to this research. Specifically, we lack data concerning survivor preferences on who should be responsible for their follow-up care. Seeing as there are many instances in which patient preference is heavily considered regardless of other factors, we must acknowledge the absence of this information as a limitation to our study. Similarly, access to a PCP was not included in the distribution of our study's survey to oncologists, as this was not asked in the CTS. Only those variables included in the CTS or via data linkage were included in the survey so that they may be included in later analyses. This is a limitation as well as discussed, access to a PCP is an increasing problem in Nova Scotia. Additionally, racial and ethnic data were not collected in Nova Scotia at the time of CTS distribution [107]. Although this represents a limitation for all studies conducted using Nova Scotian data, findings from this study may not be applicable to all racialized groups.

The administrative data in the linked dataset has certain limitations. It captures information recorded within healthcare settings, focusing on physician visits and omitting interactions with non-physician providers or services outside traditional healthcare settings (e.g., group counseling). One constraint is our reliance on recorded visits. Any healthcare visits not recorded due to human or mechanical error could potentially impact the accuracy of our primary outcome, introducing an element of uncertainty.

There are limitations related to the oncologist survey introduced in this study. First, this was not intended to be a validated study for future usage but rather a simple information gathering tool. As such, there may be uncertainty in the survey's reliability and its ability for findings to be generalized beyond the scope of this study; though again, it was not our intention for the findings to be used beyond the purpose of this study. The low response rate was an additional limitation, which minimized the survey's usefulness. The well documented burnout amongst oncologists may have contributed to their ability or desire to respond to our survey. The lack of any incentive to participate likely further exacerbated this. Additionally, the Opinio platform included the ability to create unique identifiers for respondents, allowing for individual follow-up while maintaining anonymity. However, it's important to note that this feature was not utilized in our study as we became aware of its existence only after the survey was published. The use of this feature may have positively impacted the response rate.

5.4 Future Directions and Knowledge Translation

As this study was primarily exploratory, it opens the door to several future research opportunities. Our findings highlight the existing uncertainties and variations in the decision-making process for transition decisions after cancer treatment. Future studies similar to ours could enhance their findings by including additional variables, especially those related to access to a PCP and perceptions of the healthcare system. Adding these variables would offer a more thorough understanding of survivors' experiences while also addressing broader systemic issues. Moreover, with a larger sample size, similar studies could explore advanced statistical techniques like multiple imputation, which were not employed in our study. These techniques have the potential to provide a more comprehensive and nuanced understanding of the relationships under investigation. To gain a more complete understanding, qualitative research using semi-structured interviews with Nova Scotian oncologists, general surgeons, PCPs, and cancer survivors would be beneficial. Such a study could more definitively identify how transition decisions are made, from the perspective of all relevant parties. This approach would offer a more holistic perspective on the factors influencing survivor follow-up care, contributing to the development of structured and comprehensive care guidelines.

As we move forward, it may be valuable to consider incorporating personalized follow-up care for cancer survivors. The study findings emphasize the importance of tailoring survivorship care plans to individual challenges and circumstances, ensuring that the care provided aligns with the unique situation of each survivor. Personalized follow-up enhances the overall quality of care and contributes to improved survivor outcomes and experiences [62,64].

Additionally, future focus on supported self-management could empower survivors to actively manage their ongoing concerns, regardless of the model of care they receive. By integrating self-management strategies, survivors can gain valuable tools to address the challenges they face, fostering a sense of autonomy and resilience. This approach complements the personalized follow-up model, providing survivors with resources and support to navigate the complexities of post-treatment life.

Incorporating both personalized follow-up and supported self-management into survivorship care guidelines would contribute to a comprehensive and patient-centered approach to follow-up care in Nova Scotia. Potentially, this could not only address the immediate concerns identified in this study but also lays the foundation for a more holistic and adaptive survivorship care framework moving forward.

Several steps are being taken to ensure that results are made available to all relevant parties and stakeholders. This includes cancer survivors, researchers, healthcare providers and decision-makers from different cancer programs and organizations.

Study results will be disseminated through publication to relevant academic peer-reviewed journal(s) (e.g., Journal of Cancer Survivorship, Current Oncology). They will also be presented at an academic conference(s) (e.g., Symposium on Cancer Survivorship for Clinicians). Preliminary findings have already been presented at The Canadian Centre for Applied Research and Cancer Control (ARCC) 2022 conference, the Cancer and Primary Care Research International Network (Ca-PRI) 2023 conference and the 2023 World Congress of Psycho-Oncology. To reach survivors, findings will be summarized in lay terms and sent to relevant organizations and networks.

To ensure relevant healthcare providers and decision-makers in Nova Scotia are reached, the supervisor will arrange presentations via traditional procedures such as Grand Oncology Rounds and the Provincial Cancer Network Meeting. Additionally, she is a co-leader of efforts to reorganize survivorship care in Nova Scotia, and results from this study will directly inform that work. Relevant stakeholders, like committee member Dr. Porter, will be consulted throughout the study's progression to keep them up-to-date and allow them to inform study design or decisions. Presentations will also be arranged with Nova Scotia Health's Cancer Care Program, which will commence discussions on policy implementation. As results are highly anticipated outside of Nova Scotia, meetings will be arranged with the Canadian Partnership Against Cancer to share results and discuss how the development of more personalized models of follow-up care could be introduced in other provinces.

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Appendices

Appendix A: Survey Inclusion and Exclusion Criteria

Inclusion and exclusion criteria for adults > 29 years of age:

Disease Site	Timeframe*	Inclusions	Exclusions
Breast	May 2, 2012 to May 2, 2014	• ICD-O-3[b] topography code C50.0 to C50.9 (inclusive) • Behaviour code = 3[c] • Female breast cancer cases only	• Stage IV at diagnosis • Lymphoma M95 to M98 (inclusive) • Sarcoma • Cases recorded as having died (at time of extraction)
Colorectal	May 2, 2012 to May 2, 2014	• ICD-O-3 topography codes: C18.0, C18.2 to C18.9, C19.9, C20.9 and C26.0 • Behaviour code = 3	• Stage IV at diagnosis • Lymphoma codes M-95 to M-98 (*inclusive*) • Sarcomas • Cases recorded as having died (at time of extraction)
Prostate	May 2, 2012 to May 2, 2014	• ICD-O-3 topography code C61.9 • Behaviour code = 3	• Stage IV at diagnosis • Cases recorded as having died (at time of extraction) • ICD-O-3 histology codes: 9050-9055, 9140 and 9590-9992
Melanoma	Nov 2, 2012 to Nov 2, 2014	• ICD-O-3 topography code C44 • ICD-O-3 histology codes 8720 to 8790 (inclusive) • Behaviour code = 3	• Stage IV at diagnosis • Cases recorded as having died (at time of extraction)
Hodgkin Lymphoma	Aug 2, 2012 to Aug 2, 2014	• ICD-O-3 histology codes: 9650–9655, 9659, 9661–9665, 9667	• Hodgkin Lymphoma and Diffuse Large B-Cell Lymphoma: Stage IV (Cotswold Staging System), Stage IV (Ann Arbor Staging System) or collaborative stage IV at diagnosis • Cases recorded as having died (at time of extraction)
Diffuse B-cell lymphoma	Aug 2, 2012 to Aug 2, 2014	• ICD-O-3 histology codes: 9680	
Acute myelogenous leukemia	Aug 2, 2012 to Aug 2, 2014	• ICD-O-3 histology codes: 9840, 9861, 9865-9867, 9869, 9871-9874, 9895-9897, 9898, 9910-9911, 9920	
Acute lymphocytic leukemia	May 2, 2010 to May 2, 2012	• ICD-O-3 histology codes: 9826, 9835-9836 • For the following histology codes: 9811-9818 and 9837, apply these topography codes C420, C421 and C424	

* The timeframe pertains to the time period in which persons were diagnosed

Inclusion and exclusion criteria for adults > 29 years of age (adolescent and young adult [AYA] cohort):

Individuals diagnosed from May 2, 2012 to May 2, 2014 who received a primary diagnosis of any invasive cancer (behaviour code = 3) between the ages of 18 to 29 years (inclusive). The following exclusion criteria will apply to the cohort:

- Stage IV at diagnosis (except for testicular cancer)
- Non-melanoma skin cancer
- Kaposi's sarcoma
- Cases recorded as having died (at time of extraction)

Appendix B: Survey Variables Included in Data Linkage

Questions from the Cancer Transitions Survey to be included in the data linkage.		
Variable/covariates	**Description**	**Source**
Patient demographics		
Sex	Gender (male, female, other, prefer not to answer)	Survey (#2)
Age	Age at time of survey completion (categorical)	Survey (#3)
Marital status	Marital status at time of survey completion (single, married, partnered, separated, divorced, widowed, prefer not to answer)	Survey (#4)
Number of persons in household	Number of individuals residing in patient's household (I live alone, 2, 3, 4, 5 or more)	Survey (#5)
Number of dependents	Number of children under the age of 18 (0, 1, 2, 3 or more)	Survey (#6)
Caregiver status	Patient provides support or care to an adult friend or family member (yes, no)	Survey (#7)
Comorbidity	Chronic conditions present prior to diagnosis (select all that apply from list and specify 'other')	Survey (#10)
Immigration status	Whether individual was born in Canada (yes, no, prefer not to answer)	Survey (#73)
	If no to above, number of years residing in Canada (<5, 5-10, >10, prefer not to answer)	Survey (#74)
Primary language	Language spoken most frequently at home (participant to choose from list provided, or specify 'other')	Survey (#75)
Education level	Highest level of education achieved (grade school or less, some or all high school, some or all college/technical school/CEGEP, some university, highest degree achieved, prefer not to answer)	Survey (#76)
Rurality	Description of current place of residence (acreage/ranch/farm; town, population < 2000; town, population 2000-10,000; small city, population 10,000-50,000); large city, population >50,000)	(Survey #78)
	Current place of residence same as during treatment (yes, no)	(Survey #77)
Employment status	Select option that best describes current employment situation (part time, full time, on vacation/ paid leave, sick leave/disability, home-maker/stay-at-home parent, full-time student, retired, unemployed, prefer not to answer)	(Survey #79)
Annual household income	Total annual household income before taxes (< 25 K, 25-50K, 50-75K, 75-125K, >125K, prefer not to answer)	(Survey #80)
Disease-related		
Prior cancer diagnoses	Patient to indicate whether they had been diagnosed with multiple cancers (yes, no, unsure), and instructed to complete survey based on most recent.	Survey (#12)
Cancer type	Cancer for which patient most recently completed treatment (select from list or specify 'other')	Survey (#13)
Diagnosis date	Year of diagnosis (prior to 2010, 2010, 2011, 2012, 2013, 2014, 2015)	Survey (#14)
Disease stage	Cancer was diagnosed as metastatic (yes, no but it spread afterwards, no and it did not spread, unsure)	Survey (#15)
Treatment-related		
Treatment received	Type of treatment received (select from list or specify 'other'), or indicated if no treatment received	Survey (#16)
Treatment completion	When patient last received treatment at a cancer centre or hospital (within last 6 months, 6 months to 1 year, 1-2 years, 2-3 years, 3-5 years, more than 5 years, have not received treatment)	Survey (#17)
Receipt of maintenance medicines	Patient has received maintenance medicine in the past, or is currently receiving maintenance medicine (yes, no, unsure; specific if 'yes').	Survey (#18)

Participation in clinical trial	Whether treatment included participation in a clinical trial (yes, no, unsure)	Survey (#19)
Challenges		
General challenges	Main challenge experienced after cancer treatment (free text)	Survey (#33)
Physical challenges	The extent to which each of the physical issues listed (e.g., swelling, fatigue, pain, gastrointestinal issues, etc.) were a concern for the patient post-treatment.	Survey (#34)
	Other physical issues they experienced that were not captured in question #34 (free text).	Survey (#37)
Emotional challenges	The extent to which each of the emotional issues listed (e.g., depression, anxiety, body image, sexual intimacy, etc.) were a concern for the patient post-treatment.	Survey (#44)
	Other emotional issues they experienced that were not captured in question #44 (free text).	Survey (#47)
Practical challenges	The extent to which each of the practical issues listed (e.g., return to work, transportation to appointments, childcare, our-of-pocket costs, etc.) were a concern for the patient post-treatment.	Survey (#54)
	Other practical issues they experienced that were not captured in question #54 (free text).	Survey (#57)
Services and supports		
Supports address physical challenges	Select all individuals or services accessed to obtain support for physical challenges (e.g., navigator, mental health specialist, massage therapist, social worker, spiritual leader, etc.)	Survey (#42)
Supports to address emotional challenges	Select all individuals or services accessed to obtain support for physical challenges (e.g., navigator, mental health specialist, massage therapist, social worker, spiritual leader, etc.)	Survey (#52)
Supports to address practical challenges	Select all individuals or services accessed to obtain support for practical challenges (e.g., navigator, mental health specialist, massage therapist, social worker, spiritual leader, etc.)	Survey (#62)
Access to support or counselling	Select types of support or counselling services accessed from the list provided (e.g., therapy, peer support, social media, wellness programs, retreats)	Survey (# 64)
Support from family and friends	Whether patient received support for physical, emotional, or practical challenges from their family or friends (yes, immediate family; yes, extended family; yes, friends; other; no)	Survey (# 65)
Survivorship care plan	Whether patient received a survivorship care plan (yes or no)	Survey (# 68)
Copy of medical records/files	Whether patient received a copy of the medical records/relevant files after completing treatment (yes or no)	Survey (# 69)
Other		
Physician in charge of follow-up	The physician in charge of overseeing follow-up care (primary care, oncology, both, none, unsure)	Survey (# 20)
Frequency of physician visits by specialty	Frequency of visits to primary care, oncology team, or acute care for years 1, 2, and 3 post-treatments	Survey (# 23)

Appendix C: Administrative Health Data Variables Included in Data Linkage

Data Source	Variables	Why this is required
Nova Scotia Cancer Registry	Date of birth (month and year)	Age will be used as a covariate in the analysis. Age at time of survey completion was captured, however, there were a number of missing values. By obtaining date of birth from the NSCR we will be able to examine the effect of age for all participants.
	Postal code at diagnosis	This will be used to derive former District Health Authorities to examine regional variation. Knowing the regions in which issues or gaps in care are occurring is critical to both understanding why these issues/gaps are occurring, and to developing targeted, context-specific strategies to improve care.
	Date of diagnosis (for all recorded cancers)	The diagnosis date for the cancer that survey responses were based on (i.e., index diagnosis) will be used to identify prior and subsequent cancers.
	Stage at diagnosis (or extent, if staging not available)	We are requesting stage for the index cancer. Detailed staging data was not collected as part of the survey (participants were only asked if their cancer was metastatic), however, this is an important piece of information for understanding post-treatment challenges and patterns of healthcare utilization.
	Date of death	Required for censoring.
Oncology Patient Information System	Visit date (for all visits within the specified timeframe)	This is required to identify cancer centre visits that occurred during the follow-up period.
	Provider type	We will use this to this to identify visits to oncology. Although most visits are captured in billings data, some may be missed because many oncologists are reimbursed under an alternate funding plan (AFP) and may not submit claims for all visits.
	Treatment data (i.e., radiotherapy or chemotherapy) *	Required for censoring. We will censor if treatment dates indicate the receipt of radiotherapy or chemotherapy during the follow-up period.
	Date of recurrence (where available)	Required for censoring. This variable may not be complete, but we are requesting it whenever it is available.
Medical Services Insurance (MSI) Physician Billings	Visit date	This is required to identify all visits that occurred within the follow-up timeframe.
	Diagnosis codes	These will be used to categorize physician visits as cancer-specific or non-cancer-specific.
	Provider specialty (main and billing)	This will be used to identify visits to oncology providers and primary care providers.
	Procedure codes	These will be used for censoring and will include procedure codes indicating recurrence (e.g., resections) as well as receipt of treatment (i.e., IV chemotherapy). Codes are listed in Appendix D.

MSI Insured Patient Registry	Program start and end dates	This will be used for censoring (i.e., to determine eligibility dates for MSI coverage)
Canadian Institute for Health Information Discharge Abstracts Database (DAD)	Procedure dates	This is required to determine whether procedures occur within the study timeframe.
	Procedure codes	These will be used for censoring and will include procedure codes indicating recurrence (e.g., resections) as well as receipt of treatment (i.e., IV chemotherapy). Codes are listed in Appendix F.

Appendix D: Challenges correlation matrix

	Lymphedema	**Fatigue**	**HMF**	**Chronic pain**	**Bladder issues**	**Gastrointestinal**	**Nerve issues**	**Memory problems**	**Sexual issues**	**Depression**	**FOR**
Lymphedema											
Fatigue	0.4709										
HMF	0.475	0.5104*									
Chronic pain	0.4623	0.5342*	0.5102*								
Bladder issues	0.332	0.4035	0.3792	0.4574							
Gastrointestinal	0.3271	0.4601	0.31	0.3962	0.4858						
Nerve issues	0.4653	0.5029*	0.4514	0.5487*	0.4001	0.3972					
Memory problems	0.4361	0.5427*	0.5348*	0.5155*	0.5345*	0.4568	0.5385*				
Sexual issues	0.3582	0.4611	0.4984	0.4373	0.3968	0.3866	0.439	0.5442*			
Depression	0.289	0.3994	0.3769	0.3944	0.2689	0.2805	0.3332	0.4218	0.323		
FOR	0.257	0.3501	0.2979	0.3202	0.2641	0.2515	0.2759	0.3837	0.2981	0.7058**	
CR Family	0.3397	0.3536	0.4002	0.4186	0.327	0.2385	0.3293	0.4304	0.5136*	0.4423	0.4197
CR Friend	0.3319	0.3815	0.4412	0.4157	0.2917	0.2625	0.3628	0.4319	0.4045	0.4474	0.3741
Body Image	0.3488	0.4116	0.4552	0.4176	0.2883	0.278	0.3688	0.4103	0.4298	0.4821	0.4214
Intimacy	0.2624	0.4143	0.4199	0.3698	0.3142	0.3016	0.3548	0.4462	0.7232**	0.3838	0.3325
Return to work	0.3106	0.3849	0.4307	0.3692	0.2716	0.3171	0.2911	0.4152	0.3548	0.3843	0.355
Getting to apts.	0.3129	0.2929	0.3251	0.321	0.2752	0.2622	0.2982	0.3119	0.2469	0.2694	0.3051
Care taking	0.324	0.3525	0.366	0.3596	0.2884	0.2522	0.3289	0.3693	0.328	0.3024	0.3097
Insurance	0.2771	0.3262	0.3109	0.2895	0.2812	0.2708	0.3082	0.3571	0.3418	0.2625	0.2752
Paying bills	0.3073	0.358	0.321	0.4123	0.3171	0.3201	0.3855	0.4293	0.3414	0.3587	0.3469

Lymphedema	CR Family	CR Friend	Body Image	Intimacy	Return to work	Getting to apts.	Care taking	Insurance
Fatigue								
HMF								
Chronic pain								
Bladder issues								
Gastrointestinal								
Nerve issues								
Memory problems								
Sexual issues								
Depression								
FOR								
CR Family								
CR Friend								
Body Image	0.6855*							
Intimacy	0.5443*	0.5223*						
Return to work	0.6384*	0.531*	0.5104*					
Getting to apts.	0.4206	0.3929	0.3885	0.4111				
Care taking	0.3282	0.3813	0.3532	0.2733	0.3867			
Insurance	0.355	0.3727	0.412	0.3644	0.4808	0.5296*		
Paying bills	0.3533	0.3371	0.3785	0.3735	0.5277*	0.418	0.576*	
Lymphedema	0.3701	0.3799	0.4277	0.3897	0.4214	0.5736*	0.5411*	0.4992

* Indicates moderate correlation

**Indicates strong correlation