EXPERIENCES OF ADULT CANCER SURVIVORS RECEIVING CANCER SURVIVORSHIP CARE FROM PRIMARY CARE PROVIDERS: AN INTEGRATIVE REVIEW

by

Ineke Rhebergen

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ABSTRACT

Cancer is a disease of increasing global prevalence, resulting in a rising need for cancer survivorship care (CSC; World Health Organization [WHO], 2024). While definitions of CSC vary, primary care providers (PCPs) are increasingly required to care for cancer survivors (Nekhlyudov et al., 2017). The purpose of this integrative review is to appraise existing literature to gain an understanding of the experiences of cancer survivors who receive CSC from a PCP. This review was guided by the research question: for adult cancer survivors, what is the experience of cancer survivorship care provided by a PCP? A systematic literature search was conducted, followed by an appraisal of the selected eight studies. The findings reveal the complexity and potential scope of CSC, revealing inconsistency and wide variability in patient experiences of receiving CSC from a PCP. While some study participants reported positive experiences of accessing CSC and the overall quality of their CSC from a PCP, others expressed dissatisfaction in these areas. Some consistency in cancer survivor experience was found in the areas of PCP knowledge levels and organization of CSC, with the overall perception being one of inadequacy. Given the numerous benefits of improving the care of cancer survivors, and the need to increase the role of PCPs in CSC provision, researchers, policymakers, and educators need to take note of these patient experiences to make positive improvements to CSC.

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LIST OF ABBREVIATIONS

CIHI	Canadian Institute for Health Information
CSC	Cancer survivorship care
CRC	Colorectal cancer
IOM	Institute of Medicine
NCI	National Cancer Institute
PCP	Primary care provider
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

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Introduction

Cancer is a disease that exists worldwide, and the number of individuals living with or beyond cancer is continually increasing (WHO, 2024). As these numbers continue to grow, the onus is increasingly placed on PCPs to care for cancer survivors (Nekhlyudov et al., 2017). Cancer survivors not only deserve to have their needs and experiences acknowledged, but they also merit improvements in the current delivery of care. Understanding patient experiences is essential for offering patient-centred care, which has been linked to greater satisfaction among patients and providers, enhanced perceptions of care quality, and improved health outcomes for patients (McMillan et al., 2013; Santana et al., 2017). Moreover, patient-centred care can reduce the use of health services and healthcare costs (Santana et al., 2017). In light of the current global shortages of healthcare practitioners and the resulting strain on healthcare systems, health policymakers, medical educators, PCPs, and government bodies can benefit from listening to the experiences of cancer survivors and implementing changes in existing systems (Lawson, 2023; Santana et al., 2017).

This integrative review assessed existing literature to understand the experiences of cancer survivors receiving survivorship care from a PCP. This review was guided by the research question: “For adult cancer survivors, what is the experience of cancer survivorship care provided by a PCP?"

Chapter One: Background

Cancer is a widespread global health concern, affecting approximately one in five individuals over their lifetime (WHO, 2024). In 2022, an estimated 20 million new cancer cases were reported worldwide, with this number projected to rise by 77%, exceeding 35 million affected individuals, by 2050 (WHO, 2024). This increasing cancer burden reflects population growth, aging, and exposure to risk factors such as tobacco and alcohol use, obesity, and air pollution (WHO, 2024). Additionally, improvements in early detection of cancers and advancements in the treatment and care of cancer patients mean that individuals are living longer after a cancer diagnosis (Miller et al., 2016; WHO, 2024). As the prevalence of cancer continues to rise, the population of those living with or beyond cancer is expanding significantly, resulting in a growing demand for comprehensive CSC.

Definitions

The definitions of "cancer survivor" and "cancer survivorship" vary considerably across the literature. Some definitions characterize survivorship as beginning after the completion of initial treatment, regardless of whether the individual remains cancer-free, while others define it as commencing only when a person is deemed cancer-free (Jefford et al., 2013). A more recent and widely accepted definition, provided by the National Cancer Institute (NCI, 2024), regards an individual as a cancer survivor from the time of diagnosis for the rest of their life. Furthermore, cancer survivorship is described as “a state of being that encompasses the perspectives, needs, health, and the physical, psychological, social, and economic challenges faced by individuals and caregivers following a cancer diagnosis” (NCI, 2024, para. 2). For this integrative review, the definition of CSC will align with that used by the NCI and encompass care for individuals from the time of diagnosis throughout the remainder of their lives.

The definition of a PCP varies, with no universally agreed-upon standard. PCPs are commonly recognized as general practitioners, family physicians, nurse practitioners, and physician assistants (Canadian Institute for Health Information [CIHI], n.d.). However, the term may also encompass other healthcare professionals such as nurses, dietitians, physiotherapists, and social workers when they provide primary care services (CIHI, n.d.). Given that the definition of primary care is that which "supports first-contact, accessible, continuous, comprehensive, and coordinated person-focused care" (WHO, n.d., para. 1), it is understandable why the title of PCP lacks a universally accepted definition. Including all licensed providers but focusing on specific practitioners, the NCI (n.d.) defines a PCP as "a doctor or other licensed medical professional, such as a nurse practitioner or physician assistant, who manages a person's health care over time" (para. 1). For the purposes of this integrative review, the term PCP will specifically refer to general practitioners, family physicians, nurse practitioners, and physician assistants.

Importance of CSC

Cancer survivors face a heightened risk of developing various physical and psychosocial conditions, either as a result of their cancer and its treatment, or independently of it (Nyarko et al., 2015). Approximately 70% of cancer survivors experience comorbid conditions (Hudson et al., 2012), which may include pain, fatigue, cognitive impairment, sexual dysfunction, depression, anxiety, fear of recurrence, immune suppression, cardiovascular disease, secondary cancers, and a general decline in quality of life (Nyarko et al., 2015; Sulik, 2013). Given the complex and long-term nature of these challenges, CSC must be comprehensive and lifelong, incorporating screening, assessment, and management of a wide range of cancer-related sequelae (Nekhlyudov et al., 2019).

CSC: What Is It?

CSC can be defined in many ways, and each healthcare system varies in its view of the CSC components. The NCI (2024) is the United States of America's (USA) federal cancer research agency that is widely referenced internationally, and it describes CSC as comprehensive care for people with a history of cancer, beginning at the time of diagnosis and carrying on throughout the cancer survivor's life. CSC aims to assess and mitigate the impact of cancer and any of the treatments that often coincide with the disease (NCI, 2024). The necessary components of CSC can be outlined as follows (NCI, 2024):

- surveillance and amelioration of physical, emotional, and psychological effects, including evaluation of risk, prevention, and management of late effects
- surveillance for recurrence and new cancers
- assessment and promotion of health behaviours (e.g., smoking cessation, physical activity)
- coordination of care between care team members, health systems, survivors, and caregivers
- addressing comorbidities and preventing and managing chronic conditions exacerbated by cancer and its treatment
- engagement in care planning, including discussing goals of care and advanced care planning
- provision of supportive health services (e.g., nutrition, occupational and physical therapy, rehabilitation, sexual health, fertility services, dental and podiatry services)
- genetic risk assessment or referral to genetic testing as appropriate
- management of social risks, health-related social needs, education and employment

- addressing financial hardship and insurance coverage

It is important to note that treatment of the disease itself does not seem to be considered part of CSC, despite the usual intention that CSC begin at the time of diagnosis. This detail was not found to be explicitly stated, despite searching multiple cancer care and cancer research platforms. However, the language seems to depict cancer treatment as treatment of the disease process, which is separate from CSC; instead, CSC manages all other aspects of a cancer survivor's health during and after treatment, including the effects of the cancer treatments (NCI, 2024). Due to the varying definitions of cancer survivor and CSC combined with the continually evolving understanding of CSC, the literature remains somewhat unclear on when CSC begins.

CSC: Whose Role Should It Be?

The Institute of Medicine (IOM, 2005) published a seminal report in 2005 titled *From Cancer Patient to Cancer Survivor: Lost in Transition*. This report was written in response to the alarming statistics regarding the large and rapidly growing number of individuals living with cancer, as well as the recognition that this population was understudied and often lost to follow-up by researchers and health services after the completion of active cancer treatments (IOM, 2005). The aim of this report from the IOM was to raise awareness of the multifaceted consequences of cancer and its treatment, define quality healthcare for cancer survivors, identify strategies to achieve quality healthcare for this demographic and enhance the quality of life of cancer survivors through the development of policies (IOM, 2005). Following this report, there was a notable global increase in CSC research and efforts to enhance it. The research conducted in the aftermath of the 2005 IOM report supported its findings and underscored the importance and necessity of increasing PCP involvement in CSC, as well as transferring more responsibility for CSC to PCPs (Jefford et al., 2020; Nekhlyudov et al., 2017).

Historically, CSC has been provided by surgeons, oncologists, PCPs, or a combination of these providers (Nekhlyudov et al., 2017). However, studies have demonstrated that PCP-led CSC improves healthcare costs while delivering similar quality outcomes to a more traditional specialist CSC model (Grunfeld et al., 2006; Vos et al., 2021). Beyond the financial benefits of increasing PCP involvement in CSC, some additional reasons that highlight the need for increasing PCP involvement in CSC include (Nekhlyudov et al., 2017):

- increasing demands for acute care by oncology providers due to increasing rates of new cancer diagnoses
- greater numbers of long-term cancer survivors in need of follow-up care and/or management of late and long-term effects of cancer and cancer treatments
- multi-morbidities among newly diagnosed cancer patients and long-term survivors
- emphasis on the importance of health behaviours and lifestyle modifications to optimize health

PCPs, therefore, have the potential to alleviate some of the financial strain on the healthcare system and to relieve some of the burdens that oncology providers bear. This could allow oncologists to see individuals with new cancer diagnoses and those needing active treatment while ensuring that individuals transitioning out of active treatment are not neglected. Furthermore, PCPs have experience with managing chronic diseases and individuals with multimorbid diseases, setting them up as excellent candidates for caring for the growing population of cancer survivors (IOM, 2005; Nekhlyudov et al., 2017). Finally, as providers who often see patients on a repeat basis and have the opportunity to build positive rapport with patients, PCPs are also well-positioned to provide education and care regarding health behaviours and lifestyle modifications that can optimize health, further addressing the complex needs of individuals living with or after cancer.

Purpose of Integrative Review

Despite global efforts to implement comprehensive and quality CSC, substantial gaps persist, underscoring the necessity for more effective strategies (Nekhlyudov et al., 2019). Addressing these gaps requires a deeper understanding of cancer survivors' experiences. Only after gaining an understanding of these experiences can current shortcomings be identified and strategies for improvement sought. As PCPs increasingly assume responsibility for CSC, insight into the experiences of adult cancer survivors receiving this CSC is important to guide future CSC. Therefore, this integrative review aims to explore the existing literature on adult cancer survivors' experiences with receiving CSC from a PCP.

Chapter Two: Methods

The process for this integrative review was guided by the step-by-step approach to conducting an integrative review (Toronto & Remington, 2020). Toronto & Remington (2020) describe six main steps of an integrative review:

1. Formulate the research question and purpose.
2. Complete a systematic literature search.
3. Critically appraise the research.
4. Complete a literature analysis and synthesis.
5. Discuss the new knowledge.
6. Disseminate the findings.

This Methods chapter outlines the research process undertaken in the first three steps of the integrative review process. This includes details of the research question formulation; the search strategy, including the search terms and database searches; the screening process, which discusses deduplication, title and abstract screening, and inclusion and exclusion criteria; the critical appraisal process, including the appraisal tools that were used; and the results of the searches. Steps four through six will be discussed in detail in the Findings and Discussion chapters.

Research Question Formulation

A literature search was conducted to identify relevant publications to answer the research question: For adult cancer survivors, what is the experience of CSC provided by PCPs? This research question was formulated using the Population (P), Intervention (I), and Outcome (O) framework to guide the systematic search required for this integrative review (Melnyk & Fineout-Overholt, 2023). Within this framework, the population consists of adult cancer survivors, the intervention refers to CSC provided by PCPs, and the outcome is the experiences of the adult cancer survivors receiving this CSC.

Search Strategy: Search Terms

It was necessary to pay careful attention to the selection of search terms to be used, as several keywords within this research question had multiple possible variations, for example, PCP includes other titles such as nurse practitioners, general practitioners, family physicians or family doctors. This can be seen in further detail in Table 1 below, or as noted in the definitions section of the Background chapter. Overlooking any of these variations could have resulted in the exclusion of potentially relevant studies. These search terms were identified in consultation with an academic research librarian at the University of Northern British Columbia in October 2024 to ensure a comprehensive and systematic search. Table 1 provides the specific search terms for each database.

Search Strategy: Databases

Following a consultation with an academic research librarian at the University of Northern British Columbia in October 2024, three electronic databases were selected and systematically searched: the Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete, the American Psychological Association (APA) PsycINFO, and the Medical Literature Analysis and Retrieval System Online (MEDLINE (EBSCO)). These databases were chosen for their comprehensive coverage of disciplines relevant to the research question. Specifically, CINAHL encompasses medicine, nursing, and allied health; APA PsycINFO includes psychology and behavioural sciences; and MEDLINE covers medicine, nursing, and the broader healthcare system (University of Northern British Columbia, 2024). Following the completion of the database searches, Google Scholar was searched to further ensure the comprehensiveness of the search by potentially identifying grey literature and articles not embedded in the databases that were searched for this integrative review.

The preliminary searches of CINAHL, Medline EBSCO, and PsycINFO yielded a total of 84 results. There were 51 articles identified from CINAHL, 26 from Medline EBSCO, and six from PsycINFO. Three additional articles were identified through a Google Scholar search. No pertinent grey literature was identified for inclusion. Hand searches were done by searching through web pages of well-known institutes that discuss cancer-related care, for example, the NCI, WHO, Canadian Cancer Society, and European Cancer Organisation. Ancestry searches were done by looking through reference lists of relevant articles (some of which were included in this review, others that were not included but were relevant to CSC). The hand searches and ancestry searches did not uncover any further relevant studies to be included in this integrative review. Table 1 provides the specific retrieval numbers for each database.

Table 1

Search Strategy and Preliminary Results

Database	CINAHL	APA PsycINFO	MEDLINE EBSCO
Search Date	Oct 26, 2024	Oct 26, 2024	Oct 26, 2024
Search terms	(Cancer N3 survivor*) AND (“patient experience*” or “patient perception*” or “patient opinion*” or “patient attitude*” or “patient view*” or “patient feeling*” or “survivor experience*” or “survivor perception*” or “survivor opinion*” or “survivor attitude*” or “survivor view*” or “survivor feeling*”) AND (“survivor* care” or “survivor* treatment” or “survivor* aftercare” or “survivor* after care” or follow-up or “follow up” or aftercare or “after care” or “post treatment”) AND ("primary care provider*" or pcp or gp or "general practi" or "family doctor*" or "nurse practi*" or np or "family nurse practi*" or "family physician" or "primary care" or "primary healthcare" or "primary health care")	(Cancer N3 survivor*) AND (“patient experience*” or “patient perception*” or “patient opinion*” or “patient attitude*” or “patient view*” or “patient feeling*” or “survivor experience*” or “survivor perception*” or “survivor opinion*” or “survivor attitude*” or “survivor view*” or “survivor feeling*”) AND (“survivor* care” or “survivor* treatment” or “survivor* aftercare” or “survivor* after care” or follow-up or “follow up” or aftercare or “after care” or “post treatment”) AND ("primary care provider*" or pcp or gp or "general practi" or "family doctor*" or "nurse practi*" or np or "family nurse practi*" or "family physician" or "primary care" or "primary healthcare" or "primary health care")	(Cancer N3 survivor*) AND (“patient experience*” or “patient perception*” or “patient opinion*” or “patient attitude*” or “patient view*” or “patient feeling*” or “survivor experience*” or “survivor perception*” or “survivor opinion*” or “survivor attitude*” or “survivor view*” or “survivor feeling*”) AND (“survivor* care” or “survivor* treatment” or “survivor* aftercare” or “survivor* after care” or follow-up or “follow up” or aftercare or “after care” or “post treatment”) AND ("primary care provider*" or pcp or gp or "general practi" or "family doctor*" or "nurse practi*" or np or "family nurse practi*" or "family physician" or "primary care" or "primary healthcare" or "primary health care")
Database filter	Age 18 and older	Age 18 and older	Age 18 and older
Number of results for screening	51	26	7

Screening: Deduplication, Title and Abstract Screening

Following the preliminary search, 87 articles were identified and moved forward to the screening process. Duplicate studies were identified and removed using Covidence software, followed by manual verification to ensure accuracy. After deduplication, 68 studies remained and underwent title and abstract screening to ensure relevancy to the research question, resulting in the exclusion of 49 studies. The full texts of the remaining 19 studies were assessed for eligibility based on inclusion and exclusion criteria.

Screening: Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were applied to ensure that this review aligned well with the research question and to reduce the risk of bias (Melillo, 2020). This review focused on the experiences of receiving CSC from a PCP. Therefore, it was essential to limit included studies to those conducted in primary care settings, where CSC had been provided by a PCP rather than a specialist (e.g., a surgeon or oncologist). To adequately address the research question, which focuses on adult CSC, studies were only considered for inclusion in this integrative review if the participants were aged 18 years or older and had received a diagnosis of cancer. Studies were also only included if they were peer-reviewed to ensure validity and quality (Kelly et al., 2014). Finally, articles needed to be published in English to save time and resources, as this integrative review was completed by only one person whose ability to read and understand languages is limited to English.

During the full-text screening process, it became clear that several studies identified from the database searches concentrated on participants' perceptions of or preferences about PCP-led CSC before receiving care from a PCP. These perceptions primarily came from patients who had received their care from a specialist and were predicting pros and cons regarding PCP-led CSC or from cancer survivors who were currently undergoing active cancer treatments and were asked about their preferences for care following the completion of their treatments. As this review aimed to investigate actual experiences with CSC rather than anticipated perspectives, those studies were excluded. Due to the limited number of relevant articles that focused on this topic, no geographical or date restrictions were applied during screening.

After the full-text screening was completed for the 19 studies and inclusion and exclusion criteria were applied, 11 studies were eliminated from inclusion in this integrative review for the following reasons:

- two studies were eliminated for being about the perceptions of PCP-led CSC prior to receiving PCP-led CSC
- five studies were eliminated for the CSC being provided outside of a primary care setting
- two studies were eliminated because they were not about cancer survivor experiences
- two studies were eliminated because the CSC was not provided by a PCP

The complete inclusion and exclusion criteria are detailed in Table 2.

Table 2

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Peer-reviewed articles	Perceptions about PCP-led CSC prior to receiving PCP-led CSC
English language	
CSC provided in a primary care setting	
CSC provided by a PCP	
Adult population (age 18 years and over)	
Diagnosis of cancer received	

Critical Appraisal

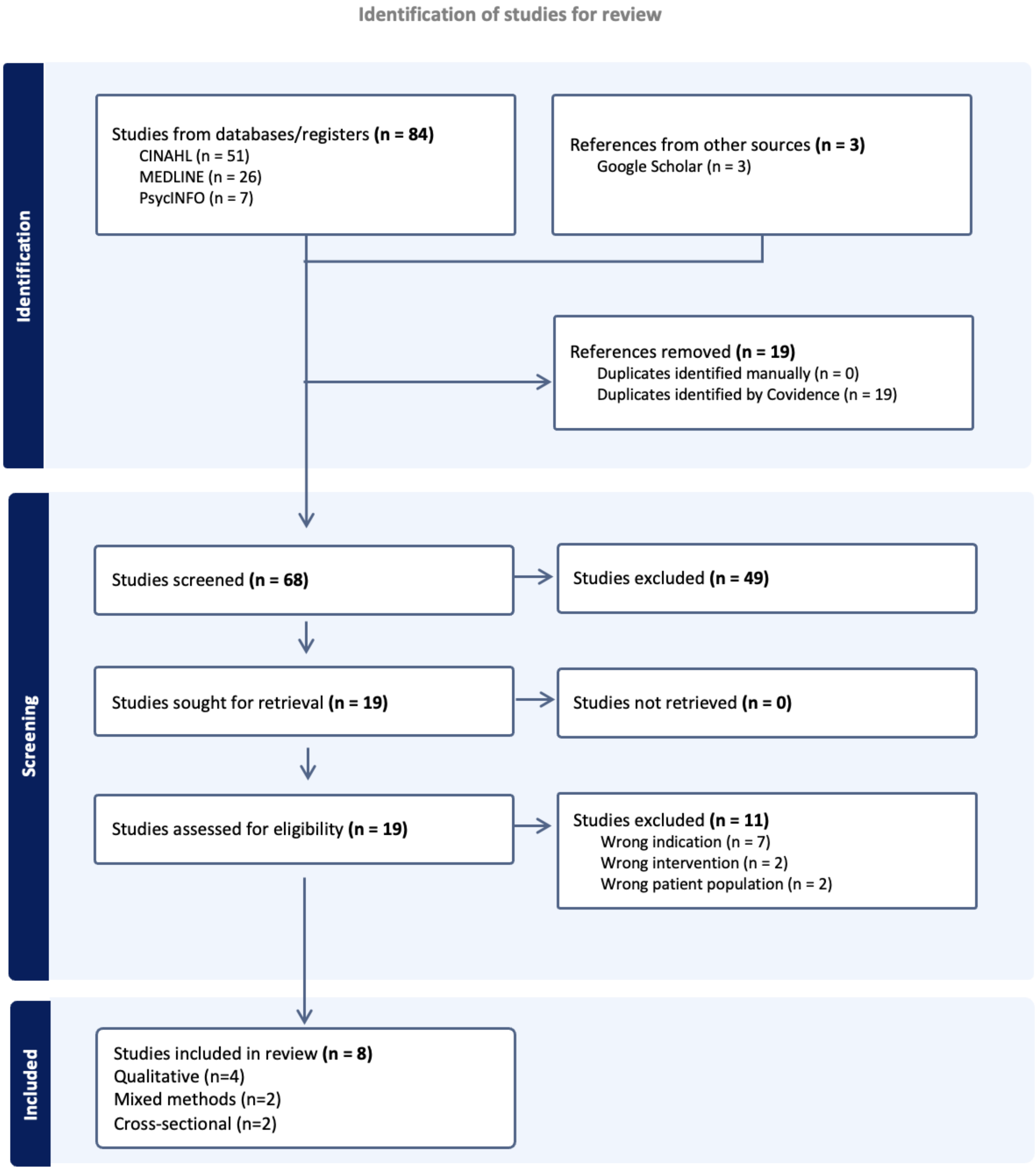
The author of this integrative review appraised the qualitative and cross-sectional studies using the corresponding Critical Appraisal Skills Programme tools (Critical Appraisal Skills Programme, 2024a; Critical Appraisal Skills Programme, 2024b) and the mixed-methods studies using the Mixed Methods Appraisal Tool (Hong et al., 2019). A detailed critical appraisal matrix is included in Appendix A.

Search Results Summary

The full search and screening processes are depicted in Figure 1 using a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. The preliminary searches of CINAHL, Medline EBSCO, and PsycINFO yielded a total of 84 results, with three additional articles identified through a Google Scholar search. After deduplication, 68 studies remained and underwent title and abstract screening. This resulted in the further exclusion of 49 studies. The remaining 19 studies underwent full-text screening, after which a total of eight studies met all the criteria and were included in this integrative review.

Figure 1

The PRISMA Diagram Depicting Search Strategy and Results



Note. Diagram adapted from Covidence systematic review software.

Chapter Three: Findings

The searches of the database and grey literature conducted for this integrative review yielded a total of eight studies examining the experiences of adult cancer survivors receiving CSC from PCPs.

Study Features

Among the eight studies included in this integrative review, four are qualitative studies (Appleton et al., 2019; Garpenhag et al., 2024; Khan et al., 2011; Rutherford et al., 2023), two are mixed-methods studies (Kim et al., 2024; Vos et al., 2023), and two are cross-sectional studies (Mao et al., 2009; Nyarko et al., 2015). One study involved participants from 18 different countries, with 82% being from the USA, 2% from Canada, and 16% from 16 other countries not individually identified in the study (Nyarko et al., 2015). The remaining seven studies were conducted in individual countries, including two in the United Kingdom (UK) (Appleton et al., 2019; Khan et al., 2011), one in the Netherlands (Vos et al., 2023), one in Sweden (Garpenhag et al., 2024), two in Australia (Kim et al., 2024; Rutherford et al., 2023), and one in the USA (Mao et al., 2009).

Study Participant Details

The ages of participants included in each of the eight studies in this integrative review varied, ranging from 18 years to greater than 81 years. The age ranges included in each study are detailed below in Table 3.

Three of the studies included participants diagnosed with various types of cancer; one of these studies included participants who had a diagnosis of either breast, prostate, lung, colorectal, or malignant melanoma cancer (Garpenhag et al., 2024), another included participants diagnosed with either breast, colorectal, or prostate cancer (Khan et al., 2011), and a third included participants diagnosed with one of any of over 30 different types of cancer (Nyarko et al., 2015). Three studies exclusively included participants with colorectal cancer (Kim et al., 2024; Rutherford et al., 2023; Vos et al., 2023), one study focused solely on participants with a breast cancer diagnosis (Mao, 2009), and another study only included participants with a prostate cancer diagnosis (however, 3 participants did concurrently have another cancer diagnosis) (Appleton et al., 2019).

All eight studies included in this integrative review included varying levels of detail regarding patient sociodemographics. Table 4 below outlines each study's participant data on cancer types, treatment status (active treatment, completed treatment, or no treatment at any point), the presence of comorbid diseases, sex, and ethnicity as these were the most commonly recurring recorded data. Further details can be found in the Literature Review Matrix in Appendix A.

Table 3

Study Participant Ages

Study	Participant Ages in Years	# of Participants
Appleton et al. (2019)	61-64	2
	65-70	3
	71-75	3
	76-80	2
Garpenhag et al. (2024)	48-78	20
Khan et al. (2011)	18- 60	8
	61-70	10
	71-80	16
	81 and above	6
Kim et al. (2024)	30-39	9
	40-49	12
	50-59	17
	60-69	7
	≥ 70	6
Mao et al. (2009)	≤ 65	204
	> 65	96
Nyarko et a. (2015)	18-39	69
	40-64	203
	≥ 65	53
Rutherford et al. (2023)	20-29	2
	30-39	4
	40-49	2
	50-59	7
	60-69	3
	≥ 70	1
Vos et al. (2023)	67	Mean age, # not specified

Table 4

Study Participant Demographics

Study and **Total # of P**	Cancer Types	Treatment (tx) Status	Comorbid Diseases	Sex	Ethnicity
Appleton et al. (2019)- **10P**	Prostate (3 participants with other concurrent cancer diagnosis)	Active tx= 2P Past tx= 8P	Hypertension= 2P Stroke= 1P Arthritis= 1P High cholesterol= 1P Bowel problems= 2P	M (all)	White British= 8P White European= 1P Black Caribbean= 1P
Garpenhag et al. (2024)- **20P**	Breast Prostate Lung Colorectal Melanoma (malignant)	Included tx that was active, past, or never done (further details not provided)	Data not provided	11 M 9 F	Data not provided
Khan et al. (2011)- **40P**	Breast Colorectal Prostate	Minimum 5 years since diagnosis, tx status not specified	Data not provided	18 M 22 F	Data not provided
Kim et al. (2024)- **51P**	Colorectal	Past tx= (all) Active tx= not specified, but 6P had disease recurrence	15P with comorbid diseases (further details not provided)	11 M 40 F	Data not provided
Mao et al. (2009)- **300P**	Breast Stage I-III	Active tx= 0P Past tx= all P (note, all participants were taking aromatase inhibitor medication post-tx)	Data not provided	F (all)	Non-Hispanic White= 253P Non-Hispanic Black= 38P Hispanic= 3P Asian= 3P Mixed race= 3P
Nyarko et a. (2015)- **351P**	30 different types (main types= breast, lung, colon, ovarian, prostate)	Active or past tx (further details not provided)	Data not provided	58 M 293 F	White= 277P Non-White= 70P
Rutherford et al. (2023)- **19P**	Colorectal Stage I-III	Past tx	Data not provided	6 M 13 F	Data not provided
Vos et al. (2023)- **141P**	Colorectal Stage I-III	Completed tx a minimum of 3 months prior	0-1= 63P ≥ 2= 78P (further details not provided)	98 Males 43 Females	Data not provided

Note. Tx= Treatment, P= Participants, M= Male sex, F= Female sex

Identified Themes

The findings concerning cancer survivors' experiences receiving CSC from a PCP have been organized into the following themes: (1) access to CSC; (2) organization of CSC; (3) PCP knowledge of CSC; and (4) significance and quality of CSC.

Access to CSC

Patient experiences regarding access to PCP care varied across studies and even within the studies themselves. In Rutherford et al. (2023), those participants who generally felt that their care needs were being met also described positive experiences in accessing their PCP, stating that their PCP was even "accessible by email" or "squeezed me in for appointments" (p. 466). Within that same study, those who felt their care needs were unmet indicated that they had difficulty obtaining appointments with their PCP within a reasonable amount of time, and they often felt rushed during appointments with their PCP (Rutherford et al., 2023). The researchers did not expand upon these findings and did not identify any other potential contributors to patients reporting that their CSC needs were being either met or unmet by their PCP.

Participants in the Garpenhag et al. (2024) study reported both positive and negative experiences with accessing PCP-based CSC. Participants described that it took "self-reliance and activity to make [primary health care] work" (p. 3), and while many participants perceived the need for them to shoulder this responsibility for themselves as negative, the way in which this was characterized depended primarily on an individual's expectation of who would have or should have, held this responsibility (Garpenhag et al., 2024). Those participants who expected to have the responsibility of organizing and accessing their own CSC reported largely positive experiences with their ability to access PCP-led CSC. However, the majority of participants reported an experience of struggling to acquire adequate CSC from their PCP; participants expressed that they felt they had to be “stubborn” to obtain access to their PCP, or that their PCP was unavailable to provide the care that was needed (Garpenhag et al., 2024). The participants in the study by Garpenhag et al. (2024) expressed the importance of having sufficient language skills and the ability to express themselves to access the CSC they felt was needed. The researchers did not include any further elaborations on what participants deemed as adequate CSC, what made participants feel stubborn, or precisely what care they felt was needed but not provided. Such feelings of struggling to access care were often exacerbated by a participant’s state of overall health, with poor health status making it more challenging for participants to have the energy to be “stubborn,” as mentioned above (Garpenhag et al., 2024).

Participants in the Khan et al. (2011) study described positive experiences in accessing their PCP when they spoke about it in general terms; however, once they were asked about needing to access their PCP to receive CSC, they identified frustrations regarding accessing care with good continuity. Participants reported that receiving good quality PCP-led CSC was challenging when the PCP providing that CSC was inconsistent; the requirement to see different PCPs over time if a patient wanted to access CSC could be the result of a number of potential factors, such as high staff turnover, full provider schedules, or simply a clinic structure in which the PCPs were not assigned to particular patients (Khan et al., 2011). These types of situations resulted in participants feeling less important, as though their PCP was too busy to address their cancer-related issues. Participants also reported that the ability to have difficult, but needed, conversations about cancer was hindered when they did not have adequate opportunity to develop a strong, therapeutic relationship with a single provider (Khan et al., 2011). Participants in the Appleton et al. (2019) study had access to a consistent PCP for their CSC; as a result, they developed a therapeutic relationship with their PCP, and experienced continuity of care, which led them to report a positive experience with CSC provided in the primary care setting. However, the convenience sampling recruitment strategy used in this study may have been biased toward participants who were particularly positive toward their PCP (Appleton et al., 2019).

Overall, the experiences of accessing CSC from PCPs varied greatly, with both positive and negative experiences reported depending on both system and personal variables.

Organization of CSC

Poor organization and coordination of CSC provided by PCPs contributed to negative patient experiences across all eight studies included in this integrative review. Throughout the cancer survivorship journey, patients often experience multiple transitions, such as changes in care providers, healthcare facilities, or types of care, including primary care and specialist care. These transitions require good communication and the coordination of key elements, such as data transfer, timing, and resource identification and allocation.

After completing cancer treatment and transitioning to primary care, patients often reported feeling a sense of displacement (Appleton et al., 2019). In the study by Mao et al. (2009), only 28% of participants perceived effective communication between their PCP and oncology teams, and 56% rated the overall cohesiveness of their care as inadequate. No further details were provided regarding what the study participants considered adequate communication or care cohesiveness or why the scores were given by participants. The findings of Mao et al. (2009) relied solely on a cross-sectional design that employed Likert scales for measurement, thereby limiting participants’ ability to elaborate or clarify their responses. Although Nyarko et al. (2011) reported slightly higher rates of perceived communication, these rates remained low, with only 40% of participants indicating satisfactory communication. There was no detail provided on what participants in this study considered satisfactory communication.

Patients frequently reported insufficient provision of essential information during the transition to primary care after cancer treatment was completed. One participant in the study by Appleton et al. (2019) mentioned that there was a slowness in communication when transitioning from specialty care to primary care, while multiple participants in the study from Garpenhag et al. (2024) reported feeling compelled to take on the role of a healthcare liaison due to deficient communication between specialty and primary care, personally managing and transferring medical information between practitioners due to the use separate electronic medical records. This responsibility proved particularly challenging for those facing more significant health challenges or for individuals lacking a personal support system to assist them (Garpenhag et al., 2024; Rutherford et al., 2023). One participant in Rutherford et al. (2023) stated that "the problem with overseeing your own care is that when you are quite ill, the other people need to make the effort…you can't advocate and reach out yourself." Another participant noted that coordinating their own care when they felt unwell would have been very challenging without the support of their family (Rutherford et al., 2023). While most participants found the need to coordinate their own care burdensome, some stated that they valued taking on the role of healthcare liaison because it provided a sense of involvement and control over their healthcare decisions (Rutherford et al., 2023).

Study participants from Rutherford et al. (2023) further described feeling that there was a lack of a plan provided when transitioning into primary care after cancer treatment. Other key areas of concern regarding insufficient information provision during the transition into primary care included a lack of guidance on post-treatment expectations, self-management strategies for treatment-related sequelae, appropriate contacts for assistance, warning signs requiring medical attention, and the availability of supportive services (Rutherford et al., 2023).

After transitioning to primary care for CSC, Rutherford et al. (2023) and Vos et al. (2023) discovered that participants often felt that they lacked a designated point of contact, creating confusion about follow-up schedules and where they would receive their CSC. Vos et al. (2023) did not clarify what would be considered a designated point of contact. However, multiple participants in the study by Rutherford et al. (2023) felt that nurses could be an excellent single point of contact for patients, helping them navigate the transition from active treatment to primary care by answering questions, directing them to the appropriate resources, or even attending appointments with them if they needed extra support.

Patients also encountered difficulty remembering and tracking necessary follow-up tests and assessments (Vos et al., 2023). The participants in Vos et al. (2023) received a follow-up schedule, which they found valuable despite being confusing. The researchers did not elaborate on why the participants felt the schedule was confusing. Notably, the PCPs in the study by Vos et al. (2023) were providing follow-up cancer care for the first time. The researchers noted this and suggested that the PCP's communication skills and ability to coordinate care may improve over time with further experience providing CSC (Vos et al., 2023). The other seven studies included in this integrative review did not discuss using follow-up schedules, so it is unclear if they were used in these studies.

The overarching theme noted across the eight studies was the inadequacy of communication and care coordination during the transition to and throughout primary care. While some participants were less affected by these challenges, most viewed them as a significant and negative aspect of their care experience.

PCP Knowledge of CSC

Across all eight studies included in this integrative review, most cancer survivors perceived their PCPs as lacking adequate knowledge of cancer care. Specifically, each study indicated that participants believed PCPs did not possess a comprehensive understanding of the disease, its diagnosis, and the available treatment options (Appleton et al., 2019; Garpenhag et al., 2024; Khan et al., 2011; Kim et al., 2024; Mao et al., 2009; Nyarko et al., 2015; Rutherford et al., 2023; Vos et al., 2023). Participants also noted specific deficiencies, including the requirements for follow-up care (Nyarko et al., 2015), referral processes (Rutherford et al., 2023), lab test interpretations (Vos et al., 2023), and the short- and long-term effects of cancer treatments (Khan et al., 2011; Vos et al., 2023; Rutherford et al., 2023). While the findings from Kim et al. (2024) were specific to colorectal cancer and may not apply to all cancer types due to differing illness symptoms, treatments, and sequelae between cancer types, only 31% of participants in the study felt their PCP had a solid understanding of treatment-related sequelae. Due to this perceived lack of knowledge among PCPs, some participants felt compelled to seek information about their disease from alternative sources, such as the internet or social media, despite believing that this information should be provided by their PCP (Rutherford et al., 2023).

Notably, one study acknowledged that while participants felt PCPs lacked sufficient cancer knowledge, they also recognized it was unrealistic to expect PCPs, as generalists, to possess comprehensive expertise in cancer care (Rutherford et al., 2023). The study emphasized the need for systemic healthcare improvements to better support general practitioners in enhancing their knowledge of cancer care (Rutherford et al., 2023). Neither the study participants nor the researchers made recommendations for changes in the healthcare system; however, the researchers acknowledged specific system-level issues that could be addressed. These issues include inadequate financial support for allied health sessions for cancer survivors and patient out-of-pocket expenses for support not covered by the healthcare system, both of which can increase the workload for PCPs trying to fill this care gap in areas where others may have more expertise (Rutherford et al., 2023). Another identified issue was unfunded non-clinical work by practitioners, potentially limiting the incentive for further training or education in CSC (Rutherford et al., 2023).

PCP knowledge emerged as a consistent theme across all eight studies, yielding complementary findings. While Rutherford et al. (2023) emphasized that the healthcare system inadequately supported PCPs in acquiring sufficient cancer care knowledge, all studies agreed that participants viewed PCPs as lacking adequate knowledge in this domain.

Significance and Quality of CSC

Perceptions of Overall CSC

Participants had considerable variability in their overall experiences with PCPs providing CSC across the eight studies included in this integrative review. Most participants in Rutherford et al. (2023) viewed their PCP as essential to post-treatment care, noting that the PCP is in a position where they can influence all aspects of the care experience post-treatment. In contrast, Khan et al. (2011) found that most participants in their study did not see their PCP as playing a significant role in their long-term cancer care. Similarly, Nyarko et al. (2015) reported generally unfavourable perceptions of CSC provided by PCPs, whereas Vos et al. (2019) found that participants were satisfied with the care they received.

The primary factors influencing perceptions of overall PCP care included ethnicity, trust in the PCP, time spent with the PCP, and pre-existing relationships with the PCP (Appleton et al., 2019; Mao et al., 2009; Nyarko et al., 2015; Rutherford et al., 2023). Participants from non-white racial backgrounds reported more positive perceptions of PCP-led CSC; however, this finding was only measured in the two cross-sectional studies included in this integrative review and not across all the studies (Mao et al., 2009; Nyarko et al., 2015).

The studies by Appleton et al. (2015), Mao et al. (2009), and Nyarko et al. (2009) reported that spending more time with a PCP was associated with higher levels of trust, which in turn contributed to more favourable perceptions of overall care. Rutherford et al. (2023) found that participants who had a pre-existing relationship with their PCP had more positive perceptions of the care they received, partly due to increased comfort in discussing their health concerns. However, while most participants who had a pre-existing relationship with their PCP expressed increased comfort levels, some participants with a pre-existing relationship with their PCP expressed that this decreased their comfort levels when discussing sensitive issues like fertility, mental health, or intimacy (Rutherford et al., 2023).

The quantitative portions of the mixed methods and cross-sectional studies varied significantly, rating overall PCP-led CSC as 65 out of 100 (Mao et al., 2009), 59.8 out of 100 (Nyarko et al., 2015), and 9.6 out of 10 (Vos et al., 2023). In Kim et al. (2024), half of the participants were satisfied with the help they received from their PCP while the other half were dissatisfied.

Perceptions of Specific Areas of CSC

Beyond the perceptions of overall PCP-led CSC quality, some specific areas of PCP-led CSC were discussed in the eight studies in this integrative review. The study participant endorsement levels for specific aspects of care, as reported in the quantitative sections of the mixed-methods studies (Mao et al., 2009; Nyarko et al., 2015), are summarized in Table 5 below. These care areas include general care, health promotion, cancer symptom diagnosis and management, follow-up care, surveillance for late effects of therapy, holistic care delivery, and psychological care. Neither of these mixed-methods studies provided any further explanation of these categories.

Verifying the accuracy and generalizability of these reported findings is challenging due to variations in the specific elements assessed across studies, differences in data collection methods, and diverse sample populations, as noted in Tables 3 and 4 above and the literature review matrix in Appendix 1. These inconsistencies limit the ability to make direct comparisons across studies. For example, both Nyarko et al. (2015) and Mao et al. (2009) had predominantly white sample populations. The sample population in Mao et al. (2009) was further restricted to early-stage breast cancer survivors drawn from a single tertiary care centre, whereas Nyarko et al. (2015) included participants who were survivors of more than 30 different types of cancer. These variations complicate the comparison of the data and the application of the findings to other populations. The exclusive use of Likert scales, as seen in Mao et al. (2009), or internet-based surveys, as seen in Nyarko et al. (2015) for data collection introduces potential selection bias and diminishes the study’s clinical significance by limiting participants' ability to elaborate or clarify their responses.

The qualitative studies included in this review revealed additional perceptions about specific aspects of PCP-led CSC. These included the need for more comprehensive information during long-term CSC, particularly regarding available resources, disease specifics, available treatment options, and holistic care plans, including follow-up strategies (Khan et al., 2011; Kim et al., 2024). Furthermore, participants expressed a desire for more timely notifications of test results (Khan et al., 2011). Some of the participants in the studies from Garpenhag et al. (2024) and Rutherford et al. (2023) also felt that clinical guidelines were not being adequately followed, therefore forcing cancer survivors to create their own allied healthcare teams or “fix and mend things on [their] own,” although specific examples of this were not provided.

Table 5

Participant Endorsement Levels for Specific Aspects of PCP-led CSC

Element of care endorsed	Participant endorsement
General care	61.1% (Nyarko et al., 2015)
Health promotion care	73% (Mao et al., 2009)
Cancer symptom diagnosis and management	41% (Mao et al., 2009)
Follow-up care	50% (Mao et al., 2009)
Surveillance for late effects of therapy	59% (Mao et al., 2009)
Holistic care delivery	66.8% (Nyarko et al., 2015) 78% (Mao et al., 2009)
Psychological care	64.2% (Nyarko et al., 2015) 73% (Mao et al., 2009)

Psychological Care. A specific recurring theme across the studies was the psychological care component of CSC. In addition to the quantitative findings in the table above, the qualitative data revealed mixed experiences. In Rutherford et al. (2023), perceptions of psychological care largely depended on the patient-PCP relationship; those with favourable views of their PCP appreciated the emotional support provided, whereas others felt uncomfortable scheduling an appointment to discuss their emotional needs, though the specifics regarding their discomfort were not detailed. Similarly, Vos et al. (2023) found that while participants did not initially perceive an important role for their PCP in psychological care, they also expressed an expectation that their PCP would "look further than only their wound and physical recovery" (p. 118), revealing a degree of contradiction in their perspectives. Participants in the Khan et al. (2011) study also expressed a desire for increased psychological support from their PCP during CSC. These participants specifically expressed a desire for ongoing psychological counselling, with one example provided by a breast cancer survivor who felt that her practitioner should have done more to assess and address her ongoing depression (Khan et al., 2011).

The study done by Appleton et al. (2019) compared the experiences of PCP-led and specialist-led CSC. They found that while study participants struggled to discuss sensitive issues in both settings, PCPs were viewed as more approachable, less intimidating, and more effective in reducing anxiety, which promoted discussions of psychological concerns (Appleton et al. 2019). One participant attributed this to the primary care environment having a more personal touch, meaning that it was smaller, and, therefore, felt less busy and less rushed (Appleton et al., 2019).

When it came to discussing sensitive psychological issues such as sexual and emotional well-being, feelings of isolation, cognitive challenges, and financial stressors, Kim et al. (2024) reported that 80% of their study participants reported difficulties in this area. Some participants in the study by Rutherford et al. (2023) also expressed discomfort with discussing sensitive issues, while others felt comfortable raising these concerns. Those who expressed a sense of discomfort attributed it to things like feeling there was insufficient time to discuss both cancer and general well-being, feeling awkward discussing negative emotions in general, or preferring to talk to somebody like a counsellor or healthcare provider that they did not previously know (Rutherford et al., 2023). As noted earlier, while some participants expressed decreased levels of comfort discussing sensitive issues with a PCP that they had a pre-existing healthcare relationship with, a pre-existing patient-PCP relationship typically increased comfort levels with discussing sensitive issues (Rutherford et al., 2023).

Overall, experiences related to the quality and significance of CSC provided by PCPs varied considerably, both in terms of overall care and specific aspects of care.

Chapter Four: Discussion

This integrative review examined adult patient experiences of receiving CSC from a PCP. Across the eight studies included in this review, participants' experiences varied significantly. While many participants reported positive experiences with receiving CSC from a PCP, particularly regarding their access to care and the overall quality of care provided, others expressed dissatisfaction in these areas. Notably, all eight studies underscored consistent concerns about the organization of care being provided and PCP knowledge levels regarding specific aspects of CSC.

Understanding the experiences of cancer survivors who have received CSC from PCPs is essential for ensuring patient-centred care in this context. Patient-centred care is linked to enhanced patient satisfaction with treatments, improved quality of life, and the fulfillment of needs; perceived quality of care; and better health outcomes, such as higher rates of treatment adherence and reports of diminished subjective symptoms like pain and anxiety (McMillan et al., 2013; Rathert et al., 2012; Santana et al., 2017). The research does not clarify whether patient-centred care significantly impacts long-term objective health measures such as body mass index or blood pressure (Rathert et al., 2012; Santana et al., 2017). As the population of cancer survivors continues to grow and PCPs take on an increasingly vital role in delivering CSC, it is crucial to consider effective strategies for optimizing CSC in this context (Jefford et al., 2020; Rubin et al., 2015). This discussion will address each of the themes from the Findings chapter.

Access to CSC

Patient experiences of accessing CSC from a PCP were notably inconsistent, both across and within studies, which highlights the need to understand the underlying factors that may contribute to this variability.

Needs and Perceptions

The diverse experiences of study participants who received PCP-led CSC highlight the subjective nature of what will be regarded as suitable CSC access compared to poor CSC access. There is no universally accepted standard for what constitutes "good" or sufficient or timely access to care, and perceptions of the services received will vary among individuals. As previously noted, cancer survivors have complex and multifaceted needs that may be influenced by factors such as pre-existing health conditions, cancer type and stage, required or chosen treatments, absence of treatment, treatment-related sequelae, and the extent of personal support systems (Garpenhag et al., 2024; Rutherford et al., 2020). These factors may interact in unique ways to contribute to an individual's perception of care accessibility. For instance, an individual who has undergone less invasive cancer treatment modalities before starting CSC may experience fewer treatment-related complications and require less frequent medical interventions from their PCP as part of CSC; consequently, that person may perceive their access to CSC provided by their PCP more positively due to a limited need for such interactions. However, an individual who has multiple pre-existing comorbidities, has undergone multiple invasive treatments as part of their cancer care, and is experiencing significant treatment sequelae may still report a positive experience with access to care if they have a strong personal support system and/or have an established therapeutic relationship with their PCP.

Barriers

Beyond the variations in individual perspectives that contribute to inconsistencies in reported experiences of accessing PCP-led CSC, the perception of accessibility is also often influenced by the presence or absence of structural and systemic barriers. While specific barriers may differ across countries and even within different regions of the same country, research shows that certain challenges are consistently faced on a global scale (Corscadden et al., 2018). Unfortunately, no research was found regarding global barriers to accessing the CSC aspect of primary care, so the barriers discussed in this section concern accessing generalized primary care. Although barriers to accessing the CSC aspect of primary care provision likely differ from those related to general primary care access, the generalized primary care data offers insight into where the problems may lie until further research is conducted in this area.

Lower income status, mental health conditions, chronic illnesses, and being born outside the country where an individual is seeking care consistently present significant obstacles to accessing primary care internationally (Alemu et al., 2024; Corscadden et al., 2018). One of the reasons that low-income status may be a barrier to accessing primary care is a possible provider lack of understanding of living in poverty, leading to the development of care plans that do not account for an individual's social circumstances (Corscadden et al., 2018). Being born outside the country where primary care is sought may cause barriers due to language and cultural differences between patients and PCPs (Corscadden et al., 2018). Those living with mental health conditions may experience barriers to accessing primary care secondary to the stigmatization of mental illness and/or the lack of preparedness of PCPs to deal with mental health issues (Corscadden et al., 2018).

In addition to universal access barriers, each country faces their own unique barriers to accessing primary care. In a 2024 report comparing the performance of health systems in 10 countries (Australia, Canada, France, Germany, Netherlands, New Zealand, Sweden, Switzerland, UK, and USA), access to care was one the elements that was assessed (Blumenthal et al., 2024). This report by Blumenthal et al. (2024) is not specifically about access to primary care but rather general access to healthcare. However, it is still applicable as primary care is a large component of healthcare and speaks to the healthcare systems of the included countries. In this comparison report written by Blumenthal et al. (2024), the Netherlands has the best access to care and ranks highest (first), followed by the UK (second), Germany (third), Sweden (fourth), New Zealand (fifth), France (sixth), Canada (seventh), Switzerland (eight), Australia (ninth), and the USA (10th).

A key factor influencing access to primary care is the distinction between publicly funded and privately financed healthcare systems (Blumenthal et al. 2024; Heba et al., 2023). This distinction may help explain these rankings, as the Netherlands, the UK, Germany, and Sweden all operate publicly funded healthcare systems, whereas Australia has a publicly funded system but with an option of paying for health insurance that allows for faster access to care for some (and as a result slower access for those who cannot afford the health insurance) (Blumenthal et al., 2024). The USA relies primarily on private healthcare financing, which makes access unaffordable for many individuals (Blumenthal et al., 2024). To further improve access to primary care, countries like the Netherlands and Germany have also made it mandatory for primary care physicians to provide a certain number of work hours each year for primary healthcare services available after regular business hours and on the weekends (Blumenthal et al., 2024).

Unfortunately, despite healthcare systems that may theoretically allow for improved access to care through avenues like ensuring that care is affordable via publicly funded systems, many countries still experience limited access due to shortages of healthcare practitioners, resulting in unfilled positions and long wait lists for patients, and this is especially evident in primary healthcare (Boniol et al., 2022; Russo et al., 2023). This shortage of primary healthcare providers is a global issue that threatens equity in healthcare and is present in both private and publicly funded systems (Blumenthal et al., 2024; Boniol et al., 2022).

Study Specifics

A few key points stand out when examining how the factors discussed above correlate with the eight studies included in this integrative review. Firstly, the study by Nyarko et al. (2015) involved participants from multiple countries, thereby potentially enhancing its general applicability to various regions by including internationally gathered data from diverse political and healthcare systems and the barriers that exist in these differing landscapes (Nyarko et al., 2015). Additionally, the study by Nyarko et al. (2015) encompassed various types of cancer diagnoses, further enhancing its general applicability to populations with different cancer types. However, it is important to note that Nyarko et al. (2015) may have faced selection bias due to its internet-based survey, which could exclude populations with limited internet access, such as older adults or those from lower socioeconomic backgrounds, potentially decreasing its level of general applicability.

The other seven studies were confined to participants from individual countries or specific regions within those countries, rendering them less globally generalizable due to the differences in participant demographics and healthcare system structures. Six of these studies were conducted in countries with publicly funded healthcare systems: two studies were from the UK (Appleton et al., 2019; Khan et al., 2011), two from Australia (Kim et al., 2024; Rutherford et al., 2023), one from Sweden (Garpenhag et al., 2024), and one from the Netherlands (Vos et al., 2023). The study by Mao et al. (2009) was conducted within the private pay system in the USA. The stages and types of cancer diagnoses represented across these studies (as noted in Appendix 1) also varied, which could have impacted participant experiences.

The factors discussed regarding access to care can influence needs, perceptions, and barriers to accessing PCP-led CSC, potentially explaining some of the variations in the reported experiences of accessing this care.

Organization of CSC

The experiences regarding the organization and coordination of PCP-led CSC were reported by study participants as predominantly negative across all eight studies included in this integrative review. The primary underlying issue seems to be inadequate communication, both among healthcare providers and between cancer survivors and their PCP.

Participants described feelings of displacement (Appleton et al., 2019), a lack of cohesive care (Mao et al., 2009), confusion regarding follow-up needs (Rutherford et al., 2023; Vos et al., 2023), and the need to act as their own healthcare liaison (Rutherford et al., 2023; Vos et al., 2023). Notably, some participants in the study by Rutherford et al. (2023) expressed appreciation for this self-advocacy role, as it provided them with a sense of control over their health; however, no specific data was available on these individuals in terms of their health status, support systems, health literacy levels, or other things that may influence their appreciation for taking on this role.

Further research is required among those reporting more negative experiences with the self-advocacy or liaison role to investigate the factors influencing these differing perspectives, such as the invasiveness of their treatments, the strength of their personal support systems, health literacy levels, or racial or socioeconomic status variations. Similarly, future research could also focus on these same aspects among those reporting positive experiences with taking on the healthcare liaison role to better understand the factors affecting this experience.

Communication between healthcare providers and between PCPs and cancer survivors was a consistent concern for participants in all eight of the studies included in this integrative review. A potential strategy for improving this communication and enhancing care coordination is implementing a structured follow-up schedule or care plan that outlines the cancer survivor's diagnosis, treatment plan, follow-up requirements, and ongoing care management. Theoretically, this approach could improve communication among healthcare providers and between healthcare providers and cancer survivors by passing along individualized information for these key elements, keeping patients informed about their current and future care needs, and reducing the risk of patients becoming lost during transitions in care. This strategy shows the potential for improving cancer survivors' experiences, as demonstrated in the study by Vos et al. (2023); participants were provided with a follow-up schedule, which was generally appreciated despite some reported confusion. As mentioned in the Findings chapter, the PCPs in this study by Vos et al. (2023) were brand new to providing follow-up cancer care, suggesting that the noted confusion may improve with time and experience, furthering the appreciation and benefit of the provided follow-up schedules.

It is worth noting that the seminal 2005 report by the IOM, as discussed in the Background chapter, recommended CSC care plans to facilitate transitions from active treatment to post-treatment care. However, subsequent studies have found that CSC care plans did not significantly improve health outcomes or patient-reported experiences as anticipated (Boekhout et al., 2015; Grunfeld et al., 2011). Further research would be beneficial to understand why the care plans did not improve outcomes or experiences or if changes to the care plans could produce different results.

PCP Knowledge of CSC

Participants in all eight studies included in this integrative review felt that their PCPs exhibited inadequate knowledge of the cancer disease process, encompassing diagnosis, treatment, potential complications, and follow-up requirements (Appleton et al., 2019; Garpenhag et al., 2024; Khan et al., 2011; Kim et al., 2024; Mao et al., 2009; Nyarko et al., 2015; Rutherford et al., 2023; Vos et al., 2023). This perceived knowledge gap regarding CSC among PCPs was consistent across the studies, indicating that this concern exists across various countries, cancer types, healthcare systems, medical education programs, and patient demographics.

Despite the perceived lack of CSC knowledge among PCPs, the study by Vos et al. (2023) found that participants were still satisfied with the care they received. However, it is important to note that, as the researchers indicated, there was potential for selection bias in the Vos et al. (2023) study, which may have favoured the inclusion and, consequently, possible overrepresentation of patients who were already positive about their PCP. This suggests that the findings of the Vos et al. (2023) study may not be broadly applicable to all cancer survivors receiving CSC from a PCP.

The perceived lack of PCP cancer knowledge may reflect the inherent generalist nature of the PCP position, as acknowledged by some participants in the study by Rutherford et al. (2023), who expressed that it is unreasonable to expect PCPs to possess in-depth expertise in cancer care because of this. Nevertheless, every study included in this integrative review reported this lack of specialized knowledge as a significant barrier to a positive CSC experience. Therefore, to address this barrier to a positive PCP-led CSC experience, further research is needed on how to enhance CSC knowledge among PCPs.

One proposed solution to decrease the CSC knowledge gap among PCPs is the integration of oncogeneralists (PCPs who receive additional training in oncology), who could provide direct clinical care and serve as educational resources for their peers (Nekhlyudov et al., 2017). However, given the increasing population of cancer survivors and the global shortage of PCPs, this is unlikely to be a definitive or timely solution. Therefore, it is crucial that all PCPs acquire fundamental competencies in CSC, as oncogeneralists alone cannot fill this gap (Nekhlyudov et al., 2017).

The questions remain, then, regarding what fundamental competencies in CSC are and how this education can be provided to PCPs to ensure these competencies are achieved on a large scale. As a result, further research should examine the essential knowledge and skills required for PCPs to care for this patient population effectively. Furthermore, several questions merit additional examination in future research: Should healthcare systems offer greater institutional support for PCPs to access specialized oncology education? Should medical school curricula include more extensive CSC training? Could CSC care plans serve as a means to bridge existing knowledge gaps by providing the necessary information for PCPs? Addressing these questions could help inform strategies for enhancing PCPs' understanding of CSC and improve survivorship experiences.

Overall Quality of CSC

Similar to experiences with access to care, study participants' perceptions of overall care quality varied considerably across the eight studies included in this integrative review. As highlighted in the Background chapter, cancer survivors have complex and multifaceted needs that differ significantly among individuals, likely influencing their evaluations of the quality of care received (Rutherford et al., 2020). This variability in experiences may also be linked to differences in healthcare systems across the countries represented in the studies included in this integrative review, as well as changes in healthcare policies, clinical practices, and provider availability over the 16-year period of the included studies. Moreover, differences in sample populations across the studies may have impacted the reported care quality. These differences might encompass factors such as ethnicity, race, financial stability, the presence of personal support systems, or residence in urban versus rural areas.

Some of the eight studies included in this integrative review also identified notable features that may have influenced the perceptions presented in the research. For instance, Vos et al. (2023) noted that their study could be biased towards participants with a positive view of their PCP. The study by Garpenhag et al. (2024) recruited participants through advocacy groups, often attracting individuals who are more engaged in their health and generally healthier. Additionally, Nyarko et al. (2015) and Kim et al. (2024) utilized electronic surveys and recruitment methods, potentially excluding the viewpoints of those with limited internet or computer access, such as elderly individuals or those from lower socioeconomic backgrounds (Nyarko et al., 2015; Kim et al., 2024).

Two studies included in this integrative review found that non-white participants rated the overall quality of their PCP-led CSC more favourably than white participants (Mao et al., 2009; Nyarko et al., 2015). Mao et al. (2009) also noted that individuals with lower levels of education and increased medical comorbidities had more positive perceptions of their PCP-led CSC. They suggested that this difference may be attributed to non-white cancer survivors relying more on PCPs rather than specialists due to potentially improved access, communication, and culturally responsive care that is facilitated by the continuity of care often associated with care provided by a PCP (Mao et al., 2009). This finding highlights the potential significance of the generalist role of PCPs in CSC, as their long-term relationships with patients may enable a more holistic approach to care that addresses diverse patient needs (Reeve et al., 2011). However, it is important to acknowledge that the sample populations in both Mao et al. (2009) and Nyarko et al. (2015) were predominantly white, meaning the small number of non-white participants may not accurately reflect the experiences of non-white cancer survivors on a larger scale. There was wide variability in the sociodemographics among the participants in the eight studies included in this integrative review. This wide variability, combined with only some of the included studies factoring in things like ethnicity, the presence of other household members for support or medical comorbidities while other studies did not, makes it challenging to identify potentially significant patterns in the data.

Overall perceptions of PCP-led CSC were also influenced by trust in the PCP, time spent with the PCP, and pre-existing relationships with the PCP (Appleton et al., 2019; Mao et al., 2009; Khan et al., 2011; Nyarko et al., 2015; Rutherford et al., 2023). It seems that spending more time with a PCP, which typically occurs through a pre-existing relationship, positively affects trust levels in the PCP. This, in turn, enhances cancer survivors' overall perception of the quality of care from the PCP (Appleton et al., 2019; Mao et al., 2009; Nyarko et al., 2009). This further highlights the benefit of having a PCP who can provide long-lasting continuity of care. Unfortunately, due to the global shortage of PCPs that has worsened with the recent pandemic, individuals find it challenging to establish and maintain this continuity of care with a PCP (Lawson, 2023; Russo et al., 2023). Addressing this shortage of PCPs is beyond the scope of this integrative review, but it is essential for researchers and policymakers to acknowledge the impact it has on CSC experiences, as PCPs continue to deliver increasing amounts of CSC.

Future Considerations

The critical role of PCPs in CSC is well-established in the literature and discussed throughout this integrative review (Jefford et al., 2020; Vos et al., 2021). However, evidence from this integrative review suggests that adult cancer survivors receiving CSC from PCPs often report dissatisfaction with their care. The significant variety in findings discussed throughout this integrative review emphasizes the complex nature of CSC and the challenges in delivering universally effective CSC. In addition to the recommendations for future research outlined in this Discussion chapter, this integrative review underscores that a single model of care is unlikely to be suitable for all healthcare systems, types of cancer diagnoses, or patient demographics (Nekhlyudov et al., 2017). While some insights from this integrative review and the included research can be applied broadly, future research should focus on developing and evaluating models of care that can be tailored to different contexts to address the diverse needs of the cancer survivor population.

Limitations

This integrative review has several limitations. First, despite the thorough use of search terms, some relevant studies may have been overlooked during the database and grey literature searches. Additionally, excluding non-English language articles may have restricted the data and insights in this integrative review by omitting information that could enhance the understanding of the global experiences of cancer survivors and help identify recurring themes on a global level. Furthermore, since this review was conducted by a single researcher, there is an increased risk of personal bias influencing the analysis and interpretation of findings. This concern is particularly relevant given the researcher's personal connection to the topic, as an immediate family member is a cancer survivor.

Due to the subjective nature of the topic for this integrative review, along with the geographically and socio-demographically diverse sample populations contributing to the eight studies included, many variables were present. These numerous variables led to findings that did not provide any clear direction for improving PCP-led CSC. However, as this integrative review aimed to understand the experiences of adult cancer survivors rather than to find definitive answers, this may not represent a true limitation but rather an opportunity to gain a deeper understanding of this topic's complexity.

Chapter Five: Conclusion

This integrative review examined the experiences of adult cancer survivors receiving CSC from a PCP. Through data collection and analysis, this review highlighted the complex nature of CSC, as evidenced by the inconsistent and variable findings across and within the included eight studies. While some participants reported positive experiences with accessing CSC and the overall quality of their care from a PCP, others expressed dissatisfaction in these areas. Concerns regarding PCP knowledge and the organization of CSC were noted in all the studies in this integrative review, reflecting participants' dissatisfaction and underscoring the need for substantial changes in these areas.

As cancer rates continue to rise globally, so does the demand for CSC (WHO, 2024). In a world facing shortages of healthcare providers (Boniol et al., 2022; Russo et al., 2023), it is crucial for healthcare providers, policymakers, researchers, educators, and government bodies to understand the experiences of cancer survivors. These experiences can inform future strategies to enhance the increasingly essential PCP-led CSC (Jefford et al., 2020; Nekhlyudov et al., 2017).

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Appendix A

Integrative Literature Review Matrix

Author	Appleton et al.	Garpenhag et al.	Khan et al.	Kim et al.	Mao et al.	Nyarko et al.	Rutherford et al.	Vos et al.
Title	"Good care" throughout the prostate cancer pathway: Perspectives of patients and health professionals	"Being ill was the easy part": exploring cancer survivors' reactions to perceived challenges in engaging with primary healthcare	A qualitative study of unmet needs and interactions with primary care among cancer survivors	Experiences and perspectives of colorectal cancer survivors and general practitioners on the delivery of survivorship care in general practice: a mixed methods study	Delivery of survivorship care by primary care physicians: The perspective of breast cancer patients	Cancer survivors' perspectives on delivery of survivorship care by primary care physicians: an internet-based survey	Experiences of colorectal cancer survivors in returning to primary coordinated healthcare following treatment	Patient experiences of GP-led colon cancer survivorship care: a Dutch mixed-methods evaluation
Journal	European Journal of Oncology Nursing	International Journal of Qualitative Studies on Health and Well-Being	British Journal of Cancer	Australian Journal of Primary Health	Journal of Clinical Oncology	BioMed Central Family Practice	Australian Journal of Primary Health	British Journal of General Practice
Year	2019	2024	2011	2024	2009	2015	2023	2023
Country	UK	Sweden	UK	Australia	USA	USA	Australia	Netherlands
Objective	Investigate patient and primary care based health professionals' perspectives of what constitutes 'good care' for men with prostate cancer, including limiting or facilitating factors	Explore reactions to and opinions about perceived challenges associated with PHC access and quality among cancer survivors in Sweden, including how they have acted to adapt to challenges	Explore the experiences of individuals who have survived at least 5 years following a cancer diagnosis, and to describe perceived unmet needs and interactions with primary care	Explore the experiences and perspectives of CRC survivors and GPs on current approaches to monitoring and managing sequelae of CRC treatment	Describe the perceived survivorship care delivered by PCPs, identify the factors that are associated with higher rankings in survivor-perceived survivorship care, and identify survivor recommendations for breast cancer follow-up care	Evaluate cancer survivors' perspectives on PCP-delivered survivorship care	explore CRC survivors experience of post-treatment care in the community and their perspectives on the role of their GP in coordinating supportive care	Explore patients' experiences of GP-led versus surgeon-led survivorship care

Author	Appleton et al.	Garpenhag et al.	Khan et al.	Kim et al.	Mao et al.	Nyarko et al.	Rutherford et al.	Vos et al.
Study Design	Qualitative investigation	Qualitative descriptive	Qualitative	Mixed-methods	Cross-sectional survey	Cross-sectional survey	Qualitative with interpretive description	Mixed-methods (randomized controlled trial with qualitative portion)
Data Collection	Semi-structured interviews	Digital focus group interviews	Interviews (open-ended and semi-structured)	Cross-sectional surveys and one-on-one qualitative interviews	Self-administered survey at routine follow-up appointment	Internet-based cross-sectional survey	Semi-structured interviews	Questionnaires sent to participants for quantitative portion (3, 6, 12 months post cancer treatment) Interviews (open-ended and semi-structured) for qualitative portion (done 3-6 years post cancer treatment)
Recruitment Method	Participants were recruited from five GP practices whose practice nurses were attending a training course in cancer follow up Eligible patients were identified by the practice nurse using a convenience sampling approach	Advertisements spread digitally by six patient advocacy groups representing people with the relevant diagnosis	Iterative and purposive sampling Selected from respondents to a linked survey covered by Oxford Cancer Intelligence Unit and Northern and Yorkshire Cancer Registry Participants selected for maximum variation based on tumour site, age, gender, geographical location, time since	Electronic advertisement with information sheet and link to complete an anonymous survey or express interest for interview (distributed through major professional primary care and consumer societies and organizations across Australia) Also advertised through email invitations to researchers' collegial	Research assistants screened medical records and approached potential study participants for enrollment at their regular follow-up appointments	Questionnaire placed on OncoLink website (no external advertising/recruitment)	Advertised through investigators' collegial networks, consumer organizations and social media Done through either an invitation email or an open advertisement on a notice board, membership newsletter or social media page with appropriate approvals	Quantitative portion: Recruited by treating physicians or oncology nurses after surgery or after chemotherapy Qualitative portion: Call was placed in the study newsletter and participants responded. Then, purposive sampling used to obtain representative patient sample.

Author	Appleton et al.	Garpenhag et al.	Khan et al.	Kim et al.	Mao et al.	Nyarko et al.	Rutherford et al.	Vos et al.
			diagnosis, responses to questionnaire subscales on depression/anxiety/cancer-related needs	networks and social media sites Snowball recruitment used after participants completed a survey			Also used snowball recruitment strategy upon interview completion	
Sample	10 participants	20 participants	40 participants	51 participants	300 participants	352 participants	19 participants	Quantitative: 303 were randomized Qualitative: 26
Cancer Type(s)	Prostate	Breast, prostate, lung, colorectal, or malignant melanoma	Breast, colorectal, prostate	Colorectal	Breast	30 different types	Colorectal	Colorectal
Inclusion Criteria	Men who had ever received a diagnosis of prostate cancer Men who were registered to one of the participating GP practices	Age 18 years or older Self-reported initiated treatment for breast, prostate, lung, colorectal, or malignant melanoma cancers	At least 5 years post diagnosis of cancer	18 years old or older Had completed primary treatment in Australia following a CRC diagnosis Could share thoughts and experiences in English Able to give written informed consent	Postmenopausal History of histologically confirmed, stage I to III, hormone receptor–positive breast cancer Currently taking a third-generation aromatase inhibitor (anastrozole, letrozole, or exemestane) Seen between April and October 2007 Completion of chemotherapy or	None stated	Aged ≥18 years Had completed treatment following a CRC stage 1–3 diagnosis Spoke English	Quantitative: Stage I-III colon cancer survivors Qualitative: All patients had to be finished 3 year follow-up period

Author	Appleton et al.	Garpenhag et al.	Khan et al.	Kim et al.	Mao et al.	Nyarko et al.	Rutherford et al.	Vos et al.
					radiotherapy at least 1 month before enrollment Approval of the patient's primary oncologist patient's ability to understand and provide informed consent in English			
Exclusion Criteria	None stated	Terminal phase cancer Non-Swedish speaker	None stated	None stated	Discontinuation of aromatase inhibitor therapy Metastatic disease Not keeping scheduled appointments	None stated	None stated	Hereditary colorectal cancer, rectal cancer, inflammatory bowel disease related cancer, history of second primary cancer within 15 years Previous participation in other research with conflicting endpoints Not able to speak Dutch or English Needing specialised care after surgical treatment
Findings- Positive Experiences	Appreciated the efforts made by PCP's to seek information on their behalf	None noted	Primary care services were generally perceived as easy to access	None noted	Survivors highly endorsed the care provided by their PCP on items related to psychological well-being, health	66.8% endorsed PCP delivery of holistic care	Most felt that GPs were vital in post-treatment supportive care and viewed as a key person that could influence all aspects	9.6/10 satisfaction with GP-led, 9.4/10 with surgeon-led survivorship care (SD 1.1 and confidence interval -0.08-0.5)

Author	Appleton et al.	Garpenhag et al.	Khan et al.	Kim et al.	Mao et al.	Nyarko et al.	Rutherford et al.	Vos et al.
	Talking to GP's often reduced anxiety Time spent with GP's increased trust overall GP visits often facilitated discussion of sensitive issues, which was welcomed More personal than specialist appointments Friendlier, less intimidating, less hurried (than specialist care) Continuity with same practitioner was positive		Some GPs had encouraged their patients to contact them with any ongoing problems Feelings that 'they're [the GP] there and attend to matters in a timely way		promotion, and holism (73%, 73%, and 78%, respectively) Primary Care Assessment Survey trust score of the sample was 73 out of maximum score of 100, with a standard deviation of 15	64.2% endorsed PCP delivery of psychosocial support 61.1% endorsed PCP delivery of General Care 8/10 PCP trust score	of a patient's care experience post-treatment 'Valued the support' (when needs were met) Participants who were positive about their GP experiences described their GP as 'sympathetic' and 'provided emotional support': 'My GP was accessible by email', '…squeezed me in for appointments', '…prioritised me when I was sick' and '…phoned to check up on me'. GP was someone who they trusted and had established good rapport For those with a longstanding relationship with their GP, they were a 'good	Appreciated a follow-up schedule that was provided to patients in GP and surgeon led trial arms Access to the eHealth platform was rarely used, most felt it would not have any added value since they had little complaints to begin with

Author	Appleton et al.	Garpenhag et al.	Khan et al.	Kim et al.	Mao et al.	Nyarko et al.	Rutherford et al.	Vos et al.
							consistent part of my whole journey’	
Findings-Negative Experiences	Unclear information (about leaving specialty care) Feeling displaced (after leaving specialty care) Hard to communicate sensitive issues Switching to an unfamiliar GP could be unsettling	Even basic activities can be burdensome Being ill negatively affects the ability to act independently Struggle to acquire adequate help from PHC services Feeling forced to be persuasive or stubborn Feeling the need to make up for perceived non-action from PHC providers in terms of understanding and managing their condition Feeling as though they had to be a healthcare liaison Poor communication Feeling like there is no availability to see PHC providers (leads	Majority of cancer survivors did not see a substantial role for their GP in their long-term cancer care Most spoke of cancer being ‘in the past’, and assessed themselves as healthy individuals not requiring active monitoring. Desire for ongoing psychological support/depression treatment Lack of availability of complementary and alternative therapies within primary and secondary care during and after the treatment Expressed a need for more information during their long-term care, particularly	*n* = 41, 80% found it difficult to discuss certain concerns with their GP, such as sexual and intimacy concerns (*n* = 17, 33%), psychological or emotional concerns (*n* = 11, 22%), feelings of isolation (*n* = 10, 20%), cognitive issues (*n* = 9, 18%), and financial concerns (*n* = 6, 12%) Common reasons for not discussing post-treatment concerns were their perception that not much could be done to help (*n* = 17, 33%), and the cancer specialist had informed them that the problem would gradually improve (*n* = 15, 29%) Less common reasons were their perception that their concerns were minor (*n* = 12,	Only 28% of the survivors felt that their PCPs and oncologists communicate well Most items related to specific cancer survivorship care (symptom diagnosis and management, follow-up, and surveillance for late effects of cancer therapies) had lower endorsements (41%, 50%, and 59%, respectively) 56% gave a “poor” or “average” rating on cohesive care (ie, PCPs and oncologists working together to care for them)	Cancer care follow-up (42% perceived them as knowledgeable) Late or long-term effects of cancer therapy (44% perceived them as knowledgeable) Diagnosis and treatment of symptoms related to cancer or cancer therapy 41.8% perceived them as knowledgeable) 40% thought communication was good with cancer specialist Overall cancer survivors have unfavorable perceptions of cancer-specific survivorship care delivered by PCPs	Felt information should come from [their] health care team’ but were needing to find it elsewhere Better preparation at discharge, such as dedicated time to discuss and provide information on what to expect post-treatment, suggested self-management strategies, who to contact and for what issues, what issues they should be concerned about, and available allied health services, was needed Felt ‘unsatisfied’ and ‘disappointed’ when needs were not met Disappointed by their GP’s ‘lack of insight into local services’ and inability to adequately support	Despite being satisfied with care, both groups doubted if GP’s had sufficient knowledge to care for patients during the whole disease process Some patients noted their GP’s had difficulties interpreting test results Confusion about follow-up schedule No clear point of contact for patients in GP led care

Author	Appleton et al.	Garpenhag et al.	Khan et al.	Kim et al.	Mao et al.	Nyarko et al.	Rutherford et al.	Vos et al.
		to trying to change providers, arrange care outside of PHC, or seek advice from online support groups instead of PHC) Feeling excluded or forgotten after discharge from cancer care specialists Distrust in PHC professionals' competence in cancer-related matters Worry about how they will manage their needs in case of recurrence of cancer Feelings that clinical guidelines are not followed, or that the patient is responsible for ensuring they are Easier to be ill, harder to recover (because they knew where to go with cancer specialty care compared to PHC)	relating to late effects of cancer treatment Viewed GP's as non-experts in cancer Viewed GP's as too busy to be 'bothered' with cancer-related issues Felt that a lack of continuity in primary care hindered discussions relating to cancer and it's long-term effects (challenging to see the same PCP at repeat visits due to high turnover, full schedules, difficulty finding their own PCP) Want more notification of follow-up testing and results	24%), feeling awkward or embarrassed (*n* = 12, 24%), or lacking confidence to raise certain concerns (*n* = 12, 24%), feeling that their concerns were too sensitive or personal (*n* = 11, 22%), or thinking that the GP would not be able to help (*n* = 10, 20%). A small proportion of participants (*n* = 6, 12%) reported that they did not raise a concern or issue they were experiencing with their GP, because they felt that their GP seemed disinterested or hurried. Half of participants (*n* = 26, 51%) felt more comfortable discussing sensitive concerns if the GP brought it up Half of the survivor participants (*n* = 25, 49%) believed that their GPs had 'some'			them with referrals and access to services Unless the providers had experience in post-CRC treatment effects, or cancer more broadly, 'they were not particularly helpful'. Generally ' ...did not ask about cancer treatment or the impact it had Time was a barrier for discussion about general wellbeing after cancer' Felt ' …[their] GP did not understand cancer-related issues Difficult to talk about emotional concerns Some people had nobody to help them coordinate care, which was very challenging when they were too ill to do it	

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		Felt essential to have good language/expression skills to protect their interests Felt essential to have stamina and inner strength to make things happen and prevent feeling overwhelmed by adversity (severe illness and treatment side effects decreased this stamina)		understanding of the sequelae of CRC treatment, with slightly fewer (*n* = 16, 31%) feeling that their GPs had a ‘good’ understanding Felt that their GPs had a good (*n* = 18, 35%) or some (*n* = 19, 37%) knowledge of available services, resources and other local health care professionals to refer to			Difficulties getting prompt appointments and GP mobility contributed to dissatisfaction with the care received Rural GPs were perceived as having inadequate knowledge of cancer treatment effects, survivorship care and who to refer their patients to Patients without a GP felt they had to advocate for themselves and educate their GPs about side effects post-surgery	
Findings-Neutral Experiences				Almost half (*n* = 25, 49%) felt that GPs should be their main health care provider to coordinate follow-up care post-cancer treatment Almost half (*n* = 26, 51%) of participants were ‘satisfied’ with	Rated primary care survivorship care 65/100 with standard deviation of 17 Survivors who visited their PCPs more often had a higher rating on the PCDSCS (*P* < .001 for trend)	59.8/100 rating of PCP delivery of CSC Non-white patients and pts who visit their PCP frequently rate PCP CSC significantly higher (maybe they consider different things important, more	Acknowledged that ‘GPs are generalists’ and, therefore, it was ‘unreasonable to expect them to know about all cancer issues’ Felt that ‘the current health system needs improving, so that	Patients did not see an important role for the GP or surgeon regarding psychological care Expectation was that GP care would be more convenient, practical.

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				the help or support they received from their GPs. However, a further 37% (*n* = 19) were only somewhat satisfied or not at all satisfied with their care (11%)	Non white race independently predicted higher rating of survivorship care (β = 7.56; 95% CI, 1.81 to 13.31; *P* = .01 Trust in PCP was significantly associated with higher perceived survivorship care (β = 0.727; 95% CI, 0.62 to 0.83; *P* = .001)	frequent visits mean more time to build trust) Higher levels of trust with PCP generally meant higher scores for all areas (p<0.001) More frequent PCP visits, higher trust in PCP, and perceiving PCP as one of the people primarily responsible for care were associated with higher PCDSCS scores (p<0.001) Non-white patients had mean PCDSCS score significantly higher (p= 0.0035)	GPs were better supported Access and referral to health care providers after completing cancer treatment was varied 'Having an existing relationship with [their] GP made it easier for [them] to bring up difficult issues' Some liked being very involved in coordinating their care, others did not	Expected GP to look further than only the wound and physical recovery No important differences seen in quality aspects of care between groups (GP/Surgeon led) in quantitative portion
Critical Appraisal- Positives	Thematic analysis done Results clearly laid out and discussed Involvement of patient representatives in the data analysis. Enabled refining the themes identified by the study team and	Clear aim Appropriate methodology Clear data collection and analysis Findings were clear Recent study	Large sample size Diverse range of experiences regarding cancer type, time since cancer treatment, gender, needs, mental health Multiple types of cancer included, making it more generally applicable	Clear aim Survey developed, guided by the domains of enquiry and then pilot tested before administering Recent study	Clear aim Appropriate methodology with cross-sectional study Clear target population Sampling frame is representative of target population regarding clinical characteristics	Clear aim Used previously validated scale for measurement Fairly even mix between rural, urban, suburban→ increased generalizability 30 different cancer types responded→	Interviews done until data saturation met Iterative interviews to explore new issues raised to identify gaps in research Interview guide created by diverse group	Internal consistency good to excellent Interviews/surveys pilot tested Data collection/analysis done and checked by multiple researchers Member checks done

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	ensuring relevancy from patient perspective. Pre-determined recruitment target for patients (10) was attained Recent study	Thematic analysis done More than 1 researcher involved in data collection/analysis Thorough discussion	In-depth interviews completed (open-ended and semi-structured)		Clear inclusion criteria used for participant selection Only 5% declined enrolment Scale they developed was piloted and modified prior to administration Trust subscale used was previously verified Variables not significant at P= 0.10 level in bivariate analysis were not included Discussion of findings and contribution to existing knowledge and how it can be used moving forwards was thorough	increased generalizability Rigorous data analysis Objective measurements can decrease bias	Codes verified by 2nd researcher Thematic analysis used Multiple methods/places of recruitment to increase generalizability and clinical significance Newer study	Needed 64 participants in each group for clinical relevance, which they achieved Data saturation achieved with qualitative portion Thematic analysis done for qualitative portion Newer study
Critical Appraisal-Negatives	Small sample size High chance of bias due to convenience sampling	No discussion on researcher's potential bias's or relationship with participants	Poor representation from ethnic minorities Sample was taken from 2 specific areas	51 surveys from CRC survivors (small sample size for widespread distribution of survey)	Sample was limited to early-stage BCSs from a tertiary care centre, which potentially limits the	Internet based survey creates selection bias (those over 60, minorities, lower education are likely to be under sampled	Participants had to be English speaking, so may not represent general population and therefore less	Possible selection bias in quantitative portion for patients who are already

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	Poor generally applicability Data saturation not discussed No mention of the researchers' views and potential bias's	Data saturation not discussed Poor general applicability (Sweden's healthcare system is dissimilar to many other) Participants had to speak Swedish, excluding possible participants Poor general applicability (recruitment through patient advocacy groups which often include people who are more resourceful/healthy/engaged) No discussion of member checking Video conferencing used for interviews (not all people are comfortable with this)	of UK→ decreased generalizability as experiences may differ in other areas Data saturation not discussed Older study Limited discussion regarding ethics or the researcher's views, potential biases, or relationship with the research/participants No discussion regarding how many selected respondents accepted/declined participation	Response rate unknown Poor general applicability (CRC survivor survey responders were younger than the average CRC survivor) Poor general applicability (79% female) Electronic distribution/recruitment likely excludes many CRC survivor perspectives (elderly, low socioeconomic status, etc) No available copy of survey to view, unclear on exact questions and response options Measurements unclear	degree to which the data can be generalized Sample was predominantly white, limiting generalization of data Poorly implemented cross-sectional study (Likert scales used for measure, which does not leave room for participants to expand on or clarify their responses→ leads to poor clinical significance) Participants already part of a different study, potential for bias Participants all recruited from one cancer centre, limiting data generalizability Did not include variables such as duration of relationship with	due to less access to/use of internet) 80% Caucasian→ decreased generalizability/clinical No open-ended questions (leaves no room for other answers/opinions/explanations) No discussion of power calculation and unknown response rate 81.5% were living in the USA, 18.5% in 16 other countries (potential bias and decreased generalizability since majority were in one country) Older study	applicable to general population.	positive about their GP Challenging to measure aspects of quality of care with population size smaller than the usual for CQI Some missing data due to technology so one interview left out GP's providing care were all doing this for the first time, so confidence in GP led care could increase over time RCT not blinded 5% did not adhere and dropped out after 1 year Large number of eligible patients declined participation

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					PCPs, trust in oncology providers, and health status Older study			

Note. For studies that also included the experiences of healthcare providers, only the data from the patient experiences was included in this Appendix.