


A Scoping Review Exploring Access to Survivorship Care for Childhood, Adolescent, and Young Adult Cancer Survivors: How Can We Optimize Care Pathways?

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Abstract: Childhood, adolescent, and young adult (CAYA) cancer survivors are at risk of developing late effects associated with their cancer and its treatment. Survivors' engagement with recommended follow-up care to minimize these risks is suboptimal, with many barriers commonly reported. This scoping review aims to summarize the barriers to accessing follow-up care, using the dimensions of Levesque's framework for accessing healthcare. We retrieved quantitative studies addressing barriers and facilitators to accessing survivorship care in CAYA survivors from PubMed, EMBASE and CINAHL. Data was categorized into the five healthcare access dimensions outlined in Levesque's framework: i) approachability, ii) acceptability, iii) availability and accommodation, iv) affordability, and v) appropriateness. We identified 27 quantitative studies in our review. Commonly reported barriers to accessing care included a lack of survivor and provider knowledge of cancer survivorship, poor health beliefs, low personal salience to engage in follow-up care, high out-of-pocket costs and survivors living long distances from clinical services. Many studies reported increased barriers to care during the transition from paediatric to adult-oriented healthcare services, including a lack of developmentally appropriate services, lack of appointment reminders, and a poorly defined transition process. Healthcare-related self-efficacy was identified as an important facilitator to accessing follow-up care. The transition from pediatric to adult-oriented healthcare services is a challenging time for childhood, adolescent, and young adult cancer survivors. Optimizing CAYAs' ability to access high-quality survivorship care thus requires careful consideration of the quality and acceptability of services, alongside financial and physical/practical barriers (eg distance from available services, appointment-booking mechanisms). Levesque's model highlighted several areas where evidence is well established (eg financial barriers) or lacking (eg factors associated with engagement in follow-up care) which are useful to understand barriers and facilitators that impact access to survivorship for CAYA cancer survivors, as well as guiding areas for further evaluation.

Keywords: pediatric, adolescent and young adult, cancer, survivorship care, barriers, access to care

Introduction

Long-term survival rates for most childhood, adolescent, and young adult (CAYA) cancers have increased significantly over the last few decades owing to rapid advancements in diagnostic and treatment methods.^{1,2} The five-year survival rate for most CAYAs diagnosed with cancer is now above 80–90% in western countries, with the survivorship period extending decades into adulthood.^{1,2} Despite increased survival, CAYA survivors face a significant risk of developing late effects from their cancer and/or its treatment, which may develop years or decades later. Up to 96% of survivors are

likely to develop an average of five severe, disabling or life-threatening chronic health conditions as a result of their cancer and its related interventions.³ Common late effects include, but are not limited to, endocrine, cardiovascular, neurocognitive, pulmonary, reproductive disorders and premature aging.^{4–6}

Late effects are typically associated with unique treatment regimens and cancer diagnoses.^{7,8} For example, head and neck radiotherapy increases a patient's risk of developing pituitary and thyroid associated hormone dysregulation, while chemotherapies such as alkylating agents can cause gonadal dysfunction, leading to subsequent late effects including osteoporosis and infertility, as well as secondary cancers. Use of corticosteroid treatments – widely used across a range of cancer diagnoses and treatment regimens, including bone-marrow transplants – can similarly increase the risk of diabetes and metabolic syndrome.⁹

In addition to physical late effects, survivors may experience significant psychological, social, and functional late effects, as well as stress from their ongoing medical conditions, which is associated with poorer health outcomes across multiple psychosocial domains.¹⁰ While most long-term CAYA survivors do not report significant mental health conditions, they remain at a higher risk of developing psychological symptoms in comparison to the general population, impacting their quality of life.^{11,12} This includes being at a 20% higher risk of suicidality compared to age-matched peers from the general population.^{13,14} A subset of CAYA survivors are susceptible to developing symptoms of depression and anxiety, with elevated levels of distress still reported decades into the follow-up period.^{12,15,16} The psychosocial impacts of cancer survivorship are especially salient for adolescent and young adult patients, as they navigate multiple challenges in achieving developmental milestones such as gaining independence and the formation of self-identity.¹⁷ Diagnosis and cancer treatment as an adolescent can cause significant disruptions in family and social relations, educational and vocational aspirations and achievements as well as physical and psychosocial health challenges.^{17–19} Interruptions to education, work, financial independence, and changing personal relations may in themselves become barriers to receiving follow-up care, particularly for CAYA survivors for whom finances and/or family/carer support are critical enablers to follow-up attendance.¹⁷ Overall, the challenges associated with cancer diagnosis during adolescence can have far-reaching effects on survivors, affecting physical, emotional, and social well-being in the long term.

Engagement with Survivorship Care

The goal of survivorship care is to screen for treatment-related toxicities including recurrent and secondary cancers, and to reduce the burden of late effects experienced by CAYA cancer survivors. A comprehensive and multidisciplinary approach to follow-up care focuses on preventing or managing late effects through education, surveillance and by discouraging risky healthy behaviors which may further heighten survivors' risk of late effects.^{20,21} Despite the documented benefits of follow-up care,²⁰ these services tend to be underutilized by survivors, particularly by childhood and adolescent survivors who often become disengaged from follow-up care following the transition from pediatric to adult healthcare. A study from the United States (US) involving 11,000 childhood cancer survivors showed that less than half of high-risk survivors engaged in follow-up surveillance for subsequent or secondary cancers (12.6%) and cardiac disorders (41.4%).²² An Australian and New Zealand bi-national study found that up to 68.5% of long-term childhood cancer survivors reported not engaging in any cancer-related follow-up care and highlighted several system, provider and patient-related barriers to care.²³ Even in Westernized countries with comprehensive healthcare systems, follow-up care rates are suboptimal with survivors' engagement diminishing as they age.^{23,24} It is plausible that these patterns of sub-optimal engagement in long-term follow-up care may be driven, at least in part, by a lack of consistent frameworks for follow-up care.

Barriers to Accessing Care

Barriers at the patient, provider, and healthcare system levels may contribute to sub-optimal engagement in survivorship care. At the patient level, childhood and adolescent survivors may have poor knowledge of their past cancer diagnosis and the treatment they received as well as their need for long-term follow-up care.²⁵ At the provider level, primary care providers (PCPs) may lack awareness of the complexities of survivorship care, including survivorship guidelines, surveillance and treatment needs, and consequently, may not refer survivors to recommend screening and management protocols.^{26–28} The presence of system-level barriers in the delivery of survivorship care reflects the abrupt transition of pediatric cancer patients to adult healthcare services and the lack of comprehensive guidelines governing the provision of survivorship care.^{24,29} Addressing these obstacles is critical to improving the quality of survivorship care for patients, as they can significantly impact the continuity and effectiveness of care across the cancer survivorship trajectory.

Multidimensional Nature of Accessing Healthcare

Efforts to improve access to survivorship care need to address an overarching conceptualization of healthcare access, acknowledging the various patient, provider and healthcare system factors that can limit access. The term “access to care” has varying definitions but is broadly used to describe the ability or opportunity to obtain appropriate healthcare resources.^{30,31} Levesque et al’s 2013 model defines access as the opportunity to receive healthcare, along the entire process from the moment patients identify the need for care, seek out and reach care, to the moment they utilize care that is appropriate for their needs.³² This model conceptualizes healthcare access as consisting of five dimensions: i) approachability, ii) acceptability, iii) availability and accommodation, iv) affordability, and v) appropriateness. The framework’s dimensions are further organized into supply- and demand-side factors. Supply-side factors relate to the healthcare provider (eg, location of services, quality of services provided), while demand-side factors involve the patients, families and communities who require care (eg, health literacy, income, social support; see Figure 1). This framework offers a clear structure that conceptualizes the obstacles that impede access to healthcare, so that they can be optimized. It is one of the most comprehensive frameworks for healthcare access, as it considers factors across all stakeholder perspectives and across the full trajectory of obtaining care.

Despite research studies reporting barriers or facilitators to accessing care, access to long-term follow-up care within CAYA cancer survivors remains complex and poorly understood. To advance research and clinical survivorship care, barriers and facilitators need to be conceptualized in terms of the level to which they impact on CAYA survivors’ ability to access and engage with survivorship care. The next clear step to achieve this aim is to cohesively map existing data on barriers/facilitators to inform a clear overarching conceptual model to identify opportunities for meaningful changes that

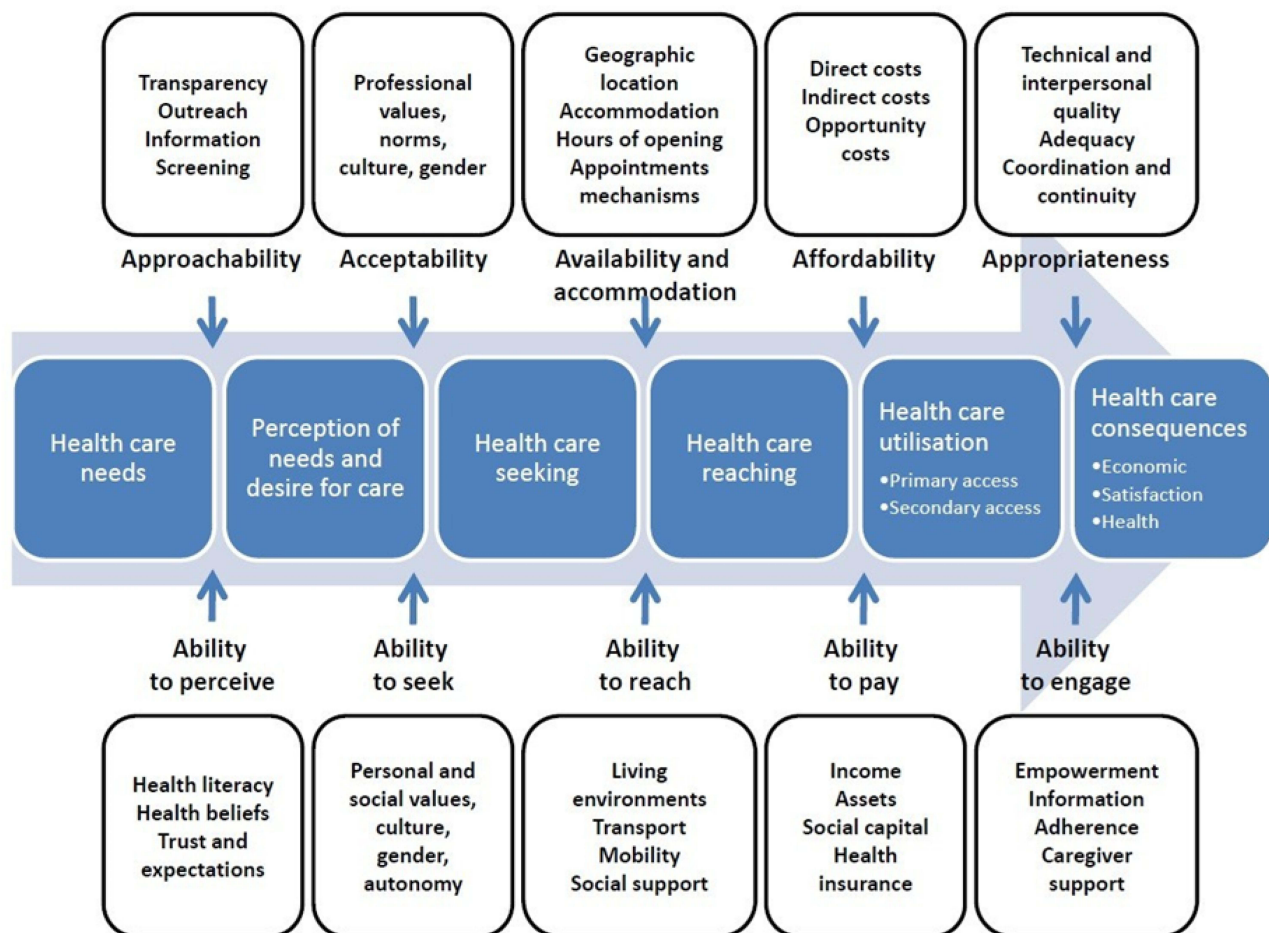


Figure 1 Levesque framework.

Notes: Reproduced from Levesque JF, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*. 2013;12(1):18. Creative Commons.³²

can be made to optimize successful healthcare access.^{24,33–35} Our review aimed to synthesize existing data and map this onto the conceptual dimensions of Levesque et al model of healthcare access.³²

Methods

Search Strategy

The literature search was performed in August 2022 for literature from the past 20 years (2002–2022) to maximize relevance to the current delivery of healthcare. We searched three databases (PubMed, Embase and CINAHL) and limited to papers published in the English language. Search terms were used to restrict the search to the CAYA cancer survivor population including (child OR paediatric OR adolescent OR young adult) AND (cancer OR oncology). These were combined with terms relating to survivorship care including (“long term follow-up care” OR “follow-up care” OR “survivorship care”). These were combined with the terms (access OR barriers OR facilitators). We prioritized manuscripts with original data and excluded non-original works such as conference abstracts or reviews.

We downloaded papers to Endnote and removed duplicates. We then uploaded the remaining papers to Rayyan where the titles and abstracts of each of the paper were screened by two authors (JC, CS) to identify papers that focused on barriers/facilitators to care among survivors of child, adolescent, or young adult cancers. We then performed full text-reviews to screen for papers that provided a quantitative assessment of barriers or facilitators to long-term follow-up care. Figure 2 summarizes the screening process.

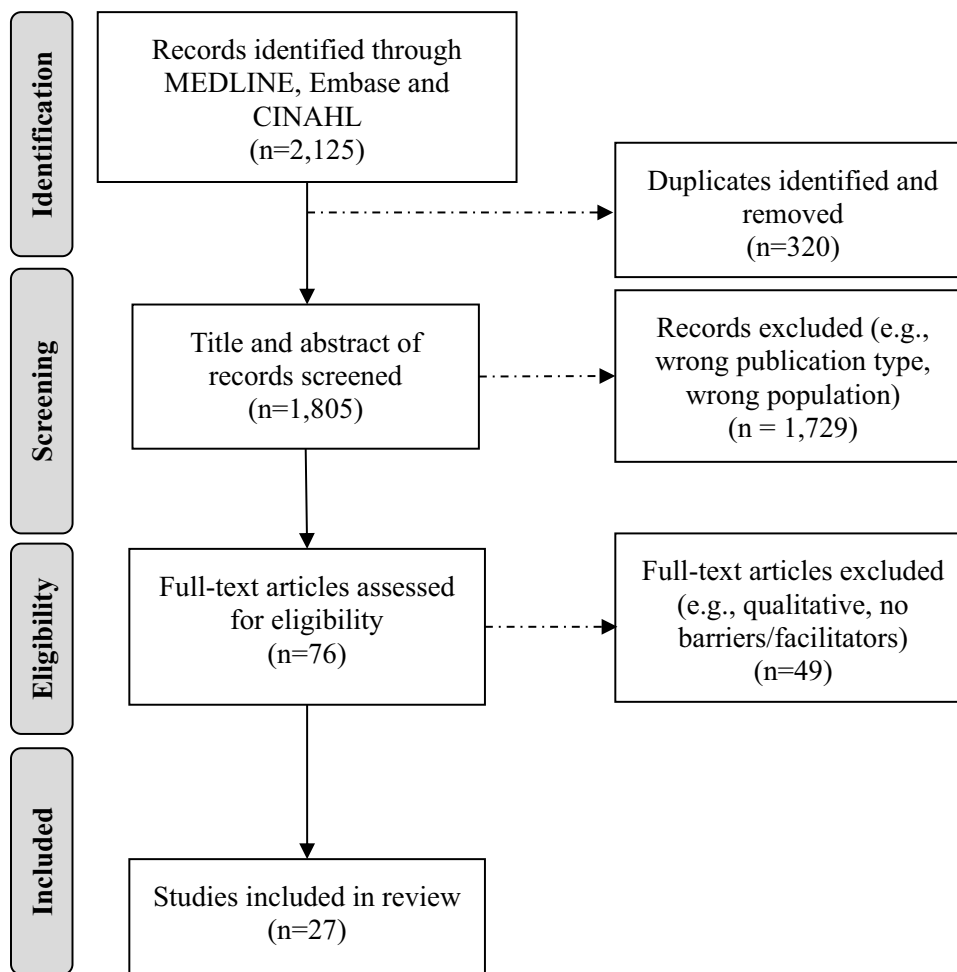


Figure 2 PRISMA flow diagram of studies identified for inclusion.

Inclusion and Exclusion Criteria

Research papers were deemed eligible for inclusion within the scoping review if the paper:

1. Assessed barriers or facilitators to long-term follow-up care in the CAYA survivor population (ie diagnosed before age 39 years). We considered all aspects of cancer-related follow-up care were included, eg, physical, functional and/or mental care needs.
2. Included original quantitative data identifying barriers or facilitators to long-term follow-up care.
3. Included self-reported data drawn from either patient and/or provider perspectives.

While there is agreement in the unique needs of the CAYA cohort,³⁶ the definition of childhood, adolescents, and young adults often varies. Children are generally considered those diagnosed under the age 14, 16 or 18 years, with the start of adolescence beginning around the age of 14/15, therefore there can be overlap between “children and adolescents” within countries depending on age restrictions on access to children’s services. Globally the definition of young adulthood varies for example the upper age limit in the United Kingdom is 24/25 years, compared to 29 years in Australia or 39 years in the United States. For the purposes of this review, we defined children as those who are diagnosed <16 years, adolescents those diagnosed between 14 and 21 years, and young adults as those diagnosed 21–39 years consistent with the broadest global definition.

Data Extraction

Quantitative data on barriers and facilitators were extracted from the eligible papers. Barriers and facilitators were categorized into Levesque’s five dimensions of healthcare access:³² approachability, acceptability, availability and accommodation, affordability, and appropriateness, as defined below:

- Approachability: refers to the capacity of individuals with health requirements to effectively recognize the availability of services, access them, and experience positive effects on their well-being.
- Acceptability: reflects cultural and social factors that influence an individual’s ability to accept aspects of care as well as how they judge the appropriateness of seeking care.
- Availability and accommodation: involve the physical existence of health resources with sufficient capacity to produce health services. Further, the ability of health services to be reached in a timely manner.
- Affordability: reflects the economic capacity for people to spend resources in terms of time and money to use appropriate resources.
- Appropriateness: denotes the fit between services and patients’ needs, its timeliness and the amount of care taken to assess health problems and determine the correct treatment, and the technical and interpersonal quality of the services provided.

We further categorized these according to the PRISMA flow diagram as shown in [Figure 2](#) and noted any factors that could not be incorporated into Levesque’s model of healthcare access. According to the model, barriers and facilitators were then organized into demand-side factors (relating to patient and parent/carer factors), and supply-side factors (relating to provider and health-system barriers).

To maximize coding validity, we employed a dual-coding method. The data was first coded by author JC and then blind-coded a second time by author AP. Any discrepancies were discussed by the wider authorship team until consensus was reached. Given the subjective nature of interpretation, and the way barriers expressed themselves in the studies, some barriers could have been categorized into several dimensions of the model. Where barriers appeared to relate to more than one dimension of the model, we categorized the barrier in the dimension it primarily related to.

Results

Study Characteristics

Twenty-seven studies were included in this review, representing 8255 CAYA survivors, 104 parents of CAYA survivors and 434 healthcare professionals, with data having been collected from across 574 institutions. Access to survivorship care was analyzed based on Levesque et al framework.³² The majority of papers reported on survivors from the US (18/29, 62%), followed by Australia (4/29, 14%), Switzerland (4/29, 14%), Germany (1/29, 3%) and Japan (1/29, 3%). Around two-thirds of participants represented in these studies were childhood or adolescent cancer survivors (diagnosed <18 years), and the remaining one-third were young adults (diagnosed 18–29 years). Other participant groups included parents, pediatric oncologists, medical institutions, primary care practitioners (PCPs), pediatric medical directors and clinical nurses. Most studies reported barriers from survivors' perspectives (48%), with other studies reporting barriers from institution (19%), oncologist/PCP (11%) and parent-reported perspectives (7%). Most studies assessed overall follow-up care (67%), and transition from adolescent to adult-based care (19%). The remaining care types (15%) primarily included PCP-led care and survivorship clinics. The study findings are summarized in [Table 1](#).

Dimension 1: Approachability and the Ability to Perceive

Approachability was reported in fifteen of the twenty-seven studies. Of these studies, thirteen evaluated the perspectives of AYA survivors with the remaining two including that of parents and PCPs.

Supply-Side Factors: Transparency, Outreach, Information and Screening

Patients reported several barriers associated with the approachability of survivorship and screening services, including a lack of transparency, outreach, and information provision. Patients reported being unaware that survivorship clinics and/or appropriate follow-up services existed. Most survivors reported feeling disconnected from their cancer treatment centers and lacked information about their need for medical follow-up, with many survivors unable to discern the purpose of accessing survivorship care.^{23,42,50,58}

Demand-Side Factors: Ability to Seek, Health Beliefs, Health Literacy, Trust and Expectations

The primary reasons survivors reported for not attending specialist follow-up care included a lack of information about follow-up care, the belief that follow-up care was unnecessary and a low perceived need to attend a survivorship clinic due to current good health.^{23,42,47,48,50,51,58} Some survivors lacked knowledge about their diagnosis, disease, the treatment they were given, and the late effects and risks associated with childhood cancer.⁶¹ The belief that follow-up care is unnecessary was associated with significantly decreased levels of attendance at follow-up care.^{23,47} Conversely, increased attendance was associated with survivors perceiving value in attending long-term follow-up care because it facilitated necessary yearly check-ups and cancer screening.⁶⁰ Knowledge about the need for follow-up care was also significantly associated with follow-up care attendance in the past two years.⁵⁰ Survivors in two studies reported, however, that they did not attend follow-up care on the advice of their healthcare providers who had reportedly indicated there was “no need”.^{42,48}

In terms of seeking survivorship care in the primary sector, patients in one study questioned whether PCPs had adequate knowledge about childhood cancer survivorship and lacked confidence in the PCPs' ability to provide satisfactory survivorship care.⁵⁷ Survivors reported perceiving that PCPs lacked appropriate knowledge regarding primary diagnosis, treatment and the potential risks of long-term complications, as well as recommended follow-up care. This was perceived as a barrier to seeking PCP-based follow-up care, in favor of oncologist-led care.²³ Two studies reported that competent providers and “being taken seriously” were most important to patients during appointments, with the latter creating trust in the PCP and strengthening rapport between doctor and patient.^{51,57}

Dimension 2: Acceptability and the Ability to Seek

Fifteen studies assessed aspects of healthcare acceptability, and the ability to seek care. Most barriers related to the acceptability of care were reported by healthcare providers, while barriers related to the ability to seek care were reported by survivors and parents of survivors.

Table 1 Key Findings Summarized According to Levesque's Five Dimensions of Accessing Healthcare³²

Author, (Year) Country	Participant Type, Number of Participants	Outcome Measure	Care Type	Dimension 1: Approachability/ Ability to Perceive	Dimension 2: Acceptability/Ability to Seek	Dimension 3: Availability and Accommodation/ Ability to Reach	Dimension 4: Affordability/ Ability to Pay	Dimension 5: Appropriateness/ Ability to Engage
Berg et al ²⁴ (2016) USA	106 survivors, diagnosed <18, 18–34 at survey	Survivor reported barriers, correlation of insurance with attendance	Survivorship clinics and annual health provider visit		<ul style="list-style-type: none"> Negative emotional reaction around doctors (7.6%) 	<ul style="list-style-type: none"> Attending college so time is an issue (34.3%) Relocated (12.4%) Parents not around to prompt (4.8%) 	<ul style="list-style-type: none"> Insufficient insurance coverage (10.5%) Lack of insurance positively associated with non-attendance (OR = 0.04, CI 0.01, 0.03, p = 0.02) 	
Bowers et al ³⁷ (2009) USA	145 COG institutions	Institution reported barriers	Overall follow-up				<ul style="list-style-type: none"> Lack of funding or dedicated time for survivors (22.9%) 	<ul style="list-style-type: none"> Inability to locate adult survivors (3.8%)
Christen et al ³⁸ (2016) Switzerland	160 AYA survivors, diagnosed 16–25	AYA survivor reported facilitators [measured by Likert scale of importance, 0–3, where 0 is not important and 3 is very important]	Overall follow-up	<ul style="list-style-type: none"> Be taken seriously (2–3) 			<ul style="list-style-type: none"> Paid by insurance (2–3) 	<ul style="list-style-type: none"> Competent staff (2–3) Same doctor (2–3) Same nurse (1–2) Regular appointments (2–3) Relationship quality (2–3)
Cousineau et al ³⁹ (2019) USA	235 survivors, diagnosed 5–15	Correlation between insurance coverage and attendance	Overall follow-up				<ul style="list-style-type: none"> Uninsured survivors were more likely to have received no cancer care compared with those with coverage (60% vs 29%, P < 0.0001). 	

(Continued)

Table 1 (Continued).

Author, (Year) Country	Participant Type, Number of Participants	Outcome Measure	Care Type	Dimension 1: Approachability/ Ability to Perceive	Dimension 2: Acceptability/Ability to Seek	Dimension 3: Availability and Accommodation/ Ability to Reach	Dimension 4: Affordability/ Ability to Pay	Dimension 5: Appropriateness/ Ability to Engage
DiNofia et al ⁴⁰ (2017) USA	41 parents of survivors diagnosed <21 years	Parent reported facilitators [Percentages represent the proportion of parents who perceive facilitators as (very important, important or very important)]	Transition to adult based care	<ul style="list-style-type: none"> Perceiving provider to be knowledgeable in childhood cancer (85%, 97%) 	<ul style="list-style-type: none"> Networking opportunities (28%, 77%) Survivor "readiness" (35%, 70%) Parent "readiness" (29%, 63%) 	<ul style="list-style-type: none"> Flexible scheduling (58%, 95%) 	<ul style="list-style-type: none"> Insurance acceptability (85%, 100%) Opportunity to get insurance counselling (73%, 97%) 	<ul style="list-style-type: none"> Offer comprehensive care (80%, 100%) Address both health and lifestyle issues (73%, 98%) Access to other sub-specialists (75%, 100%) A known pediatric provider as part of the team (75%, 95%) Access to necessary follow-up tests (73%, 100%) Access to mental health providers (62%, 90%) Access to vocational training (35%, 70%) A single identified contact person for transition (62%, 95%) Gradual transition (35%, 78%) Promote independence/personal responsibility (78%, 100%) Includes parents (83%, 100%)
Effinger et al ⁴¹ (2022) USA	153 COG institutions	Institution reported barriers	Overall follow-up		<ul style="list-style-type: none"> Lack of perceived need or support for late effects services by other oncologists (13.1%) 		<ul style="list-style-type: none"> Not enough funding for support of program (40.9%) 	<ul style="list-style-type: none"> Lack of dedicated time for late effects program development (57.7%)

Ernst et al ⁴² (2022) Germany	633 childhood cancer survivors, diagnosed <15 years	Survivor reported barriers	Overall follow-up	<ul style="list-style-type: none"> • Lack of information about medical follow-up and/or its purpose (66.2%) 	<ul style="list-style-type: none"> • Emotional/motivational reasons (6.3%) 	<ul style="list-style-type: none"> • Structural barriers (7.8%) 		<ul style="list-style-type: none"> • Medical follow-up was terminated by health-care provider (19.7%)
Eshelman-Kent et al ⁴³ (2011) USA	179 COG institutions	Institution reported barriers	Transition to adult based care		<ul style="list-style-type: none"> • Lack of perceived need or support for late effects services by other oncologists (7%) • Lack of oncology provider desire to “let go” of survivors (4.2%) • Perceived lack of interest from adult-oriented providers in caring for survivors (1.6%) 		<ul style="list-style-type: none"> • Not enough funding for support of program (20%) 	<ul style="list-style-type: none"> • Lack of dedicated time for late effects program development (29%) • Perceived lack of knowledge about late effects on the part of the clinician being referred to (28.5%)
Ford et al ⁴⁴ (2020) USA	975 survivors, diagnosed <21	Correlation of survivor reported factors with attendance	Overall follow-up	<ul style="list-style-type: none"> • Belief that cancer-related problem is likely (RR = 1.5, 95% CI 1.4–1.6) • Confidence in doctors (RR = 1.2, 95% CI 1.1–1.3) • Difficulty finding a doctor (RR = 0.9, 95% CI 0.8–1) 	<ul style="list-style-type: none"> • Interest in routine medical visit (RR = 1.3, 95% CI 1.2–1.4) • Perceived importance of cancer-related visit (RR = 1.4, 95% CI 1.3–1.6) • Health concerns and worries (RR = 1.6, 95% CI 1.4–1.8) • Painful memory of cancer treatment (RR = 1.2, CI = 1.1–1.3) 	<ul style="list-style-type: none"> • Transportation problems (RR = 1.4, 1.0–1.8) 	<ul style="list-style-type: none"> • Health insurance problems (RR = 1.4, 95% CI 0.9–1.1) 	

(Continued)

Table I (Continued).

Author, (Year) Country	Participant Type, Number of Participants	Outcome Measure	Care Type	Dimension 1: Approachability/ Ability to Perceive	Dimension 2: Acceptability/Ability to Seek	Dimension 3: Availability and Accommodation/ Ability to Reach	Dimension 4: Affordability/ Ability to Pay	Dimension 5: Appropriateness/ Ability to Engage
Kenney et al ⁴⁵ (2016) USA	347 pediatric oncologists	Oncologist reported barriers	Overall follow-up	<ul style="list-style-type: none"> Provider attachment to family/patient (85.2%) 		<ul style="list-style-type: none"> Lack of adult providers with cancer survivor expertise (86%) 		
Klosky et al ⁴⁶ (2008) USA	941 survivors diagnosed <16 years	Survivor reported non-attendance reasons, correlation between insurance coverage and attendance	Clinic attendance			<ul style="list-style-type: none"> Work/school conflicts (19.3%) Personal/family health problem (12.2%) Poor clinic contact/rescheduling (6.4%) Transportation problems (1.4%) 	<ul style="list-style-type: none"> Survivors who were not insured were more likely to be non-attenders than those privately insured ($p < 0.001$, odds ratio 2.36) 	
Lupatsch et al ⁴⁷ (2015) Switzerland	410 survivors, diagnosed <16, 16–21 at survey	Correlation of health beliefs and attendance	Overall follow-up	<ul style="list-style-type: none"> Belief that survivorship care is unnecessary associated with less likely attendance (OR = 0.70, 95% CI: 0.50–1.00) Belief that follow-up care is suitable is associated with greater attendance (OR = 1.56, 95% CI: 1.07–2.27) 				
Maeda et al ⁴⁸ (2010) Japan	114 survivors, diagnosed <16	Survivor reported reasons for non-attendance	Any medical follow-up	<ul style="list-style-type: none"> Belief that “I am in good health” (26/56) The physician in charge said I did not need to visit anymore (33/56) 		<ul style="list-style-type: none"> Moved away (1/56) 	<ul style="list-style-type: none"> Cessation of public financial support (2/56) 	<ul style="list-style-type: none"> Changes in the physician in charge (2/56)

Mertens et al ⁴⁹ (2004) USA	17 healthcare policy experts	Healthcare policy expert reported barriers [Measures of importance, 1–7, where 7 is critically important]	Transition to adult based care			<ul style="list-style-type: none"> • Lack of healthcare personnel interested in providing follow-up care • Lack of healthcare personnel trained in providing follow-up care (5.29) • Few organized programs providing follow-up for survivors (5.85) 	<ul style="list-style-type: none"> • Lack of insurance due to pre-existing condition (5.77) • Insurance does not adequately cover preventative healthcare (5.69) • Expense of screening tests (5.15) 	<ul style="list-style-type: none"> • PCPs are unfamiliar with late effects of childhood cancer and their management • Disjuncture between pediatric and adult care (6.29) • Plan for follow-up not provided by oncologist (5.71) • Lack of communication between PCPs and cancer specialists (5.64) • Medical records may be difficult to track down (5.50) • Lack of uniform guidelines for follow-up (5.46)
Milam et al ⁵⁰ (2021) USA	1106 survivors, diagnosed <19	Correlation of facilitators with attendance	Overall follow-up	<ul style="list-style-type: none"> • Knowledge of the need for follow-up care (OR = 3.57, 95% CI 2.90–4.39) 	<ul style="list-style-type: none"> • Healthcare self-efficacy (OR = 1.23, 95% CI 1.09–1.39) 		<ul style="list-style-type: none"> • Health insurance (OR = 2.06, 95% CI 1.28–3.32) 	
Michel et al ⁵¹ (2011) Switzerland	1075 survivors, diagnosed <16	Correlation between health beliefs and attendance	Overall follow-up	<ul style="list-style-type: none"> • Belief that regular follow-up is unnecessary is associated with non-attendance (OR = 0.47, 95% CI 0.36–0.61, p < 0.001) 				
Michel et al ⁵² (2016) Switzerland	314 survivors, diagnosed <16	Survivor reported facilitators [Likert scale]	Overall follow-up	<ul style="list-style-type: none"> • Be taken seriously (2.70) 			<ul style="list-style-type: none"> • Insurance reimbursement (2.5) 	<ul style="list-style-type: none"> • Competent staff (2.74) • Relationship quality (2.5) • Doctor continuity (2–2.5) • Nurse Continuity (1–2)

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Table 1 (Continued).

Author, (Year) Country	Participant Type, Number of Participants	Outcome Measure	Care Type	Dimension 1: Approachability/ Ability to Perceive	Dimension 2: Acceptability/Ability to Seek	Dimension 3: Availability and Accommodation/ Ability to Reach	Dimension 4: Affordability/ Ability to Pay	Dimension 5: Appropriateness/ Ability to Engage
Miller et al ⁵³ (2016) USA	193 survivors, diagnosed 5–18	Correlation of healthcare self-efficacy with attendance	Overall follow-up		<ul style="list-style-type: none"> Healthcare self-efficacy 			
Mobley et al ⁵⁴ (2021) USA	1106 survivors, diagnosed <20	Correlation between insurance change and attendance	Overall follow-up				<ul style="list-style-type: none"> Any insurance coverage change associated with decreased probability of recent cancer related follow-up care (–5 ppt, SE 0.02 for those who gained coverage; –15 ppt, SE 0.04 for those who lost coverage) 	
Sadak et al ⁵⁵ (2019) USA	97 medical institutions	Institution reported barriers	Overall follow-up	<ul style="list-style-type: none"> Provider not willing to “let go” of survivor (11%) 		<ul style="list-style-type: none"> Lack of available adult providers to partner with (55%) 		<ul style="list-style-type: none"> Available adult providers lack knowledge in childhood cancer survivorship (58%) Adult models of care cannot accommodate influx of new patients (11%)

Sadak et al ⁵⁶ (2013) USA	103 survivors, diagnosed <16	Survivor reported facilitators [Percentages represent the proportion of survivors who perceive facilitators as (very important, important or very important)]	Transition to adult based care	<ul style="list-style-type: none"> Perceiving provider to be knowledgeable in childhood cancer (66%, 80%) 	<ul style="list-style-type: none"> Networking opportunities (13%, 58%) Feeling of "readiness" (16%, 60%) 	<ul style="list-style-type: none"> Flexible scheduling (58%, 99%) 	<ul style="list-style-type: none"> Insurance acceptability (78%, 97%) Opportunity to get insurance counselling (53%, 89%) 	<ul style="list-style-type: none"> Offer comprehensive care (58%, 98%) Address both health and lifestyle issues (43%, 88%) Access to other sub-specialists (51%, 96%) Access to PCP (34%, 76%) Access to mental health providers (24%, 67%) Access to vocational training (18%, 54%) A single identified contact person for transition (54%, 94%) Gradual transition (13%, 60%) Promote independence/personal responsibility (42%, 97%) Include parents (43%, 80%) Include significant others (34%, 77%)
Signorelli et al ⁵⁷ (2019) Australia	57 survivors diagnosed <16 years, 63 parents, 51 primary care providers	Survivor, parent and PCP reported barriers	PCP-led follow-up	<ul style="list-style-type: none"> Low confidence in PCP ability to deliver survivorship care (48%) Low perceived PCP knowledge about cancer history and long-term survivorship needs (38%) Perceiving PCPs as too busy (18%) 	<ul style="list-style-type: none"> Aversion to doctors after treatment (7%) 		<ul style="list-style-type: none"> Out-of-pocket expenses (5%) 	<ul style="list-style-type: none"> Unmet information needs about their patients' risk of developing late effects (94%), recommended surveillance schedule (77%) and general CCS information (76%)

(Continued)

Table 1 (Continued).

Author, (Year) Country	Participant Type, Number of Participants	Outcome Measure	Care Type	Dimension 1: Approachability/ Ability to Perceive	Dimension 2: Acceptability/Ability to Seek	Dimension 3: Availability and Accommodation/ Ability to Reach	Dimension 4: Affordability/ Ability to Pay	Dimension 5: Appropriateness/ Ability to Engage
Signorelli et al ⁵⁸ (2020) Australia	27 survivors, diagnosed <16	Survivor reported barriers	Overall follow-up	<ul style="list-style-type: none"> • Low perceived need to attend (30%) • Unaware of clinic (10%) 	<ul style="list-style-type: none"> • Prefer not to return to treating hospital (7%) • Prefer not to be seen in children's Hospital (4%) 	<ul style="list-style-type: none"> • Distance to clinic (30%) 		<ul style="list-style-type: none"> • Lack of reminders to return (7%)
Signorelli et al ⁵⁹ (2017) Australia	19 pediatric medical directors and clinical nurse directors from all ANZ pediatric oncology units	Provider/Institution reported barriers	Overall follow-up		<ul style="list-style-type: none"> • Lack of recognition of survivor needs in the adult sector (16%) • Oncologist engagement and recognition (11%) 	<ul style="list-style-type: none"> • Staff shortages (37%) • No dedicated patient PCPs (26%) 	<ul style="list-style-type: none"> • Limited space and resources (21%) • Lack of funding (37%) • Instability or loss of funding (42%) 	<ul style="list-style-type: none"> • Inadequacy of pediatric setting (42%) • Lack of patient and referral feedback (32%) • Lack of wider cooperation and support (16%) • Lack of referral pathways (26%) • Undefined transition process (84%)
Signorelli et al ²³ (2019) Australia	633 survivors, diagnosed <16, parents represented younger survivors (<16)	Survivor reported barriers	Overall follow-up	<ul style="list-style-type: none"> • Unaware of follow-up clinic • Do not like/trust health professionals • Prefer PCP • Low perceived control of cancer/late effects • No perceived need for follow-up care 	<ul style="list-style-type: none"> • Returning to hospital brings up memories • Would rather just get on with life 	<ul style="list-style-type: none"> • Unable to travel without assistance • Clinic too far away • Unable/reluctant to use leave • Cannot miss work • Difficult to find childcare • Appointments are inconvenient 	<ul style="list-style-type: none"> • Cannot afford loss of wages • Costs too much to attend 	<ul style="list-style-type: none"> • Did not have any reminders

Quillen et al ⁶⁰ (2016) USA	48 survivors, diagnosed <21	Survivor reported barriers	Transition to adult based care	<ul style="list-style-type: none"> • Positive association between seeing an adult primary care provider on a yearly basis and believing in the importance of a yearly checkup ($r = 0.35$; $P = 0.018$) 	<ul style="list-style-type: none"> • Not “ready” for adult healthcare (10%) 	<ul style="list-style-type: none"> • Transportation (2/48) • Location (1/48) • Scheduling conflicts (1/48) 	<ul style="list-style-type: none"> • Medical costs (4/48) 	
Zebrack et al ⁶¹ (2004) USA	19 CAYA survivors diagnosed under 30 years, 1 parent of deceased cancer patient	Survivor reported barriers [Measures of importance, 1–7, where 7 is critically important]	Overall follow-up	<ul style="list-style-type: none"> • Survivors lack knowledge about late effects and risks (5.47) • Survivors do not know details of their disease and treatments (5.47) • Lack of information about appropriate follow-up programs (6.06) 	<ul style="list-style-type: none"> • Anxiety or fear of being diagnosed with cancer again (6.47) • Survivor desire to “move on” (5.94) • Anxiety or fear of being diagnosed with a late effect (5.94) • Lack of medical community’s interest in providing survivorship care (5.25) 	<ul style="list-style-type: none"> • Limited number of adult providers equipped to deal with survivors (6.29) • Lack of follow-up programs (6.18) 	<ul style="list-style-type: none"> • Lack of personal finances (5.35) • Concerns about losing insurance if late effects are diagnosed (5.12) • Lack of insurance (6.59) 	<ul style="list-style-type: none"> • Lack of training/education of PCPs about health problems of survivors (6.47) • Lack of training/education of specialists about health problems of survivors (6.47) • Physicians fail to differentiate if health issues are related to previous cancer (5.81) • Lack of communication among specialists (5.71) • Lack of support for transition (5.35) • Lack of consensus about what tests and when they need to be done (5.18) • Difficulty locating medical records (5.35)

Supply-Side Factors: Professional Values and Norms

Healthcare professionals including oncologists, healthcare policy experts and representatives from Children's Oncology Group institutions identified a general lack of interest and support from healthcare organizations to provide long-term follow-up care for childhood cancer survivors.^{41,49,61} Survivorship issues were reported to be underappreciated in the healthcare system with organizational values prioritizing treatment first and providing the care of chronic illnesses within the remit of other non-oncology specialists. However, primary care providers (PCPs) reported numerous barriers to providing childhood cancer survivorship care, including a lack of confidence and understanding about the potential risks associated with treatments, the long-term effects they may have, inadequate funding, and time constraints.⁵⁷ Providers in three studies also noted the culture of some oncologists not wanting to "let go" of patients as they transitioned from pediatric to adult care, which was perceived as a barrier to providing ongoing survivorship care outside of the pediatric and/or tertiary setting.^{43,45,55}

Demand-Side Factors: Personal and Social Values, Autonomy and Survivor Demographics

Some adolescent cancer survivors reported negative emotions, and having developed aversions to clinical settings, which impacted their ability to engage with survivorship care.^{24,42,57} Some survivors reported fear of discovering late effects, being diagnosed with a secondary or recurring cancer, and painful memories of cancer treatment as barriers to seeking care.^{44,61} Survivors also reported that returning to the hospital where they received painful and traumatic cancer treatments triggered distress, which they felt inhibited them from "moving on" from their cancer.^{23,58} By contrast, one study found that having health concerns was associated with an increased likelihood of having a cancer-related health visit.⁴⁴

Health-related self-efficacy – or the confidence to manage one's own healthcare – was also positively associated with follow-up care attendance.^{50,53} Patients also reported that feelings of "readiness" eased their transition from pediatric to adult-based care.^{40,56} Conversely, feelings of reluctance or hesitancy were associated with greater disengagement from survivorship care.⁶⁰

Seven studies assessed the correlation between survivor characteristics and survivorship care attendance. There was mixed evidence on the correlation between age and attendance. While most studies suggested that younger survivors were more likely to seek and attend follow-up care, Ernst et al's study reported a positive association between older age and follow-up care attendance.⁴² The influence of sex on attendance was found to be negligible, except for two studies that reported a lower likelihood of follow-up care attendance among male survivors. Two studies that analyzed patient data from the United States showed that non-Caucasian survivors were less likely to attend follow-up care than Caucasian survivors.

Dimension 3: Availability, Accommodation and the Ability to Reach

Fifteen studies identified barriers and facilitators associated with the availability of survivorship services. Ten provided the perspectives of the childhood cancer survivors, four on the perspectives of healthcare providers (eg, oncologists), and one of the perspectives of parents of survivors.

Supply-Side Factors: Availability of Resources and Providers, Geographic Location, Opening Hours and Appointment Mechanisms

The four studies involving healthcare providers highlighted that limited availability of healthcare resources and providers were significant barriers to the delivery of survivorship care. All four studies reported a lack of long-term follow-up programs, adult providers with childhood cancer and survivorship expertise, and subspecialty providers (eg, oncologists), which limited the availability of healthcare services.^{49,55,59,61} Many survivors reported that the limited availability of services and the fact that they are concentrated within urban, metropolitan centers was an obstacle to accessing follow-up care, particularly when they had relocated back to their home communities and services became too far away.^{24,48,58} Centers that limited appointments to within business hours only also restricted access, as there was no availability at times most preferred by survivors who worked full time, had schooling commitments or whose parents (who provided support and transportation) worked full time.^{23,56}

Demand-Side Factors: Living Environments, Social Support, Transportation and Mobility

Survivors reported logistical reasons as barriers to attending follow-up visits. An inability to reach follow-up services was primarily related to transportation problems or the inability to travel without the assistance of a parent/caregiver due to age and/or a patient's mobility needs.⁴⁶ Some young adult survivors reported that they disengaged from follow-up care because their parents did not prompt or remind them.²⁴ Other logistical barriers included the poor health of other family members, finding childcare, the inconvenience of attending appointments, and the inability or unwillingness to take leave from their workplace.

Dimension 4: Affordability and the Ability to Pay

Twenty studies assessed financial factors that affected the provision of survivorship care or access to these services. Out-of-pocket costs and funding challenges were commonly reported by survivors and providers, respectively.

Supply-Side Factors: Direct, Indirect and Opportunity Costs

Healthcare providers in four studies listed a lack of funding as a significant barrier to providing follow-up services. Providers reported that insufficient funding was linked to staff shortages in clinics,²³ with some also reporting limited physical space and other resources as impacting service provision. Survivors also reported that direct healthcare expenses and medical costs were also barriers to care.²³

Demand-Side Factors: Insurance, Out of Pocket Expenses and Lack of Financial Support

Insufficient insurance coverage was a significant barrier to obtaining survivorship care, as reported by several studies from the US. Additionally, four studies listed insurance acceptability and opportunity for insurance counselling as facilitators of follow-up care and transition from pediatric to adult care.^{38,40,56} Survivors expressed concerns that being diagnosed with late effects during follow-up care might cause them to lose their existing health insurance, which would impact their ability to pay for healthcare.⁶¹ Mertens et al noted that in some healthcare systems, insurance did not adequately cover preventative healthcare, negatively affecting a survivor's ability to afford and access care.⁴⁹ Any change in survivor health insurance was associated with a decreased likelihood of follow-up care attendance.⁵⁴ Survivors also identified opportunity costs from lost wages, lack of financial support, and high perceived cost of medical expenses such as screening examinations as obstacles to obtaining survivorship care.

Dimension 5: Appropriateness and Ability to Engage

Fifteen studies assessed the appropriateness of existing services and survivors' ability to engage with survivorship care. Many factors were associated with the quality of services and the challenges of transitioning survivors from pediatric to adult care.

Supply Side Factors: Technical and Interpersonal Quality, Adequacy, Coordination and Continuity

Healthcare providers and survivors in several studies reported that existing primary care providers and non-oncology specialists did not appear to have sufficient knowledge about survivors of childhood and adolescent cancers.^{43,49,55,57} This included knowledge about late effects, recommended surveillance schedules and general survivorship information as well as an inability to differentiate if health problems were related to a previous cancer or cancer treatment or not. For example, Sadak et al found that the lack of knowledge in childhood cancer survivorship among available adult providers was the second most common barrier (55%) to providing survivorship care to adult childhood cancer survivors.⁵⁶ Access to comprehensive care, including other sub-specialists (eg, fertility and endocrinology), mental health professionals (eg, social workers and psychologists), and vocational training was considered a crucial aspect of survivorship care by the majority of childhood cancer survivors and parents of survivors in two studies.^{40,56}

Healthcare providers noted that poor coordination of care between pediatric and adult providers resulted in inadequate services for older survivors remaining in pediatric settings.²³ Coordination and continuity was reported to be an important factor in the ability to engage with follow-up care, particularly in the context of transitioning from pediatric to adult care.⁵² Poor communication was reported between providers in most of the studies, with one study reporting administrative pressure to transition or discharge patients from pediatric services over the age of 18.⁵⁹ Oncologists also

wanted to receive more feedback from primary care providers about their patients, while primary care providers expressed a preference for specific management plans to be prepared for them.⁵⁷ Providers in one study reported difficulties in identifying/reaching survivors, while providers and patients in three studies reported difficulties locating medical records across pediatrics and adult clinics.^{37,49,61}

Survivors expressed that they preferred to continue receiving care from the same doctor, rather than changing doctors with every visit. Patients in two studies identified that having a single identified contact person was an important facilitator during the transition to adult care.^{40,56} Providers in three studies also suggested that the undefined transition process and insufficient or conflicting follow-up guidelines were barriers to care engagement.^{23,43,49,59}

Demand-Side Factors: Empowerment, Information, Adherence and Caregiver Support

Few studies examined survivors' ability to engage in survivorship care. Survivors and parents in two studies perceived that it was important for adult-based services to promote independence and personal responsibility in survivors who were transitioning out of pediatric services.^{40,56}

Discussion

This scoping review used Levesque et al's conceptual framework of access to care, including dimensions of approachability, acceptability, availability and accommodation, affordability, and appropriateness to conceptualize factors affecting access to long-term follow-up care in CAYA survivors. We identified barriers across all dimensions of healthcare access, which we further organized into the Framework's demand side factors (relating to patient and parent factors) and supply side factors (relating to provider and health system barriers). Commonly reported barriers included practical concerns such as distance from available services, transportation issues, appointment reminders, out-of-pocket costs and lack of financial support. However, our review also revealed several barriers specific to adolescent and young adult survivors. These included, but were not limited to, a lack of CAYA cancer survivorship services and changes to living arrangements and social support as survivors transitioned from pediatric to adult care. Although several studies in our review acknowledged the significance of patient-provider relationships and survivors' self-efficacy in healthcare management, only a limited number of them addressed the facilitators that contribute to their development.

The distance survivors must travel to access survivorship services has consistently been reported within the literature as being too far, too expensive, and too inconvenient for survivors to manage on a regular basis.^{24,48,58} Greater involvement of PCPs may alleviate some of the challenges associated with accessing survivorship care by necessitating less patient travel, shorter wait times and by capitalizing on a patient's familiarity with their local doctor to facilitate regular care. However, the literature suggests that primary care physicians report insufficient education and training about childhood cancer survivorship, including the potential late effects of cancer and its treatment, leading to difficulties managing these patients.⁵⁷ Facilitating better communication between PCPs and oncologists may enable patients to fully benefit from community-based survivorship services while also ensuring that PCPs received the specialized education and training needed to deliver high-quality care.⁶²

Our review identified several demand-side factors that impeded CAYA survivors' attendance at a survivorship clinic. These factors included moving away from home to pursue higher education and reduced parental involvement in their care, leading to a lack of appointment scheduling and attendance reminders. This reflects challenges explained in the literature, which shows how young survivors are increasingly expected to manage their own care while navigating personal and social challenges as well as challenges within their living environments.^{24,25,28} These survivors have also expressed the necessity for developmentally appropriate care that recognizes their need for autonomy while also recognizing the potential need for parental involvement.³⁵

Some novel survivorship care delivery models have emerged in recent years to address the dual challenges of the AYA developmental period, and the complexity of continuing to engage AYA survivors of child and adolescent cancer in the critical importance of ongoing surveillance for cancer-related late-effects, years after this seems most salient. For example, in Australia, the Engage program – a nurse-led e-health intervention involving a personalized follow-up care plan for survivors, has shown success in increasing survivor self-efficacy and engagement in follow-up care.⁵⁸ The program ensures multidisciplinary communication, seeking review from medical specialists such as pediatric oncologists, clinical psychologists, endocrinologists,

neurologists, and allied health. This may be particularly useful given how prevalent distance was as an identified barrier in this review. Additional research is necessary to identify potential enhancements to current care models and explore other viable methods of care delivery that can offer high-quality services to cancer survivors.

Despite the recognized need for childhood and adolescent specific services, there is an inadequate provision of services like Engage within Australia and overseas.^{63,64} Greater funding and support are needed to ensure survivors receive developmentally appropriate care. Considering the gaps in these services, promoting healthcare self-efficacy is necessary to ensure survivors have the confidence and abilities to engage with existing adult-oriented services.^{50,65} Interestingly, in our review, only seven of the 27 studies looked at CAYA survivor characteristics associated with engagement in survivorship care. This may suggest a gap in the literature in terms of understanding factors that may contribute to survivors' engagement in care – and individuals for whom survivorship care services currently work better, and less well, for. Understanding survivors' individual characteristics and related healthcare needs will also inform how multidisciplinary survivorship care can best address the unique physical and psychosocial needs of childhood and adolescent survivors. Depending on the needs of individual survivors, services that are likely to augment the impact and relevance of survivorship care are likely to include well-integrated mental health services, fertility preservation, education and vocational support.^{16,18}

Limitations and Future Directions

A key limitation of our review is the inclusion of only studies published in English, as it may exclude the additional challenges faced in different cultural and healthcare contexts and populations. Within the constraints of literature published in English to date, studies have only reported on barriers to survivorship care in high-income countries, where advances in survivorship have led to the need for, and empirical focus on, how survivorship care is delivered (and accessed); unfortunately, in the low-to-medium income setting, the burden of childhood cancer is greatest, yet survival rates also remain the poorest.⁶⁶ Indeed, two-thirds of our included papers were from the US, which has unique and specific financial considerations with regard to healthcare insurance. Another limitation could be whether the framework adequately captures all reported barriers. While no barriers were unable to fit within the model, future research can be guided by the lack of research published in certain dimensions. A strength of our review is its ability to provide a comprehensive summary and synthesis of the literature, across a myriad of countries and contexts. However, it should be acknowledged that the inherent complexity and uniqueness of healthcare settings may also limit how much each finding can be related to an individual country or clinical setting. To further build understanding of CAYA survivorship healthcare access in the literature, future work could build on the present analysis with qualitative data, which may add further insights as to how barriers to survivorship care are experienced from multiple perspectives.

Conclusion

This review provides a comprehensive overview of the barriers that survivors must overcome to receive adequate and appropriate survivorship care. To optimize survivorship healthcare services, each of the barriers within the Levesque framework needs to be overcome, with emphasis on the importance of patient-related factors such as personal values and perceptions of care. When developing future guidelines and survivorship programs, it is important to consider the intricate interplay between barriers and facilitators through the entire process from seeking to obtaining care. This includes addressing obstacles that may arise at various stages of a patient's healthcare journey, as well as identifying strategies to promote access and offer support to childhood cancer survivors.

Data Sharing Statement

Data are available on request from the authors.

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