

Transition from pediatric to adult follow-up care in childhood cancer survivors – a systematic review

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Abstract

Purpose: The successful transition of childhood cancer survivors from pediatric- to adult-focused long-term follow-up care is crucial and can be a critical period. Knowledge of current transition practices, especially regarding barriers and facilitators perceived by survivors and health care professionals, is important to develop sustainable transition processes and implement them into daily clinical practice. We performed a systematic review with the aim of assessing transition practices, readiness tools, and barriers and facilitators.

Methods: We searched three databases (PubMed, Embase/Ovid, CINAHL) and included studies published between January 2000 and January 2020. We performed this review according to the PRISMA guidelines and registered the study protocol on PROSPERO; two reviewers independently extracted the content of the included studies.

Results: We included 26 studies: six studies described current transition practices, six assessed transition readiness tools, and 15 assessed barriers and facilitators to transition.

Conclusion: The current literature describing transition practices is limited and overlooks adherence to follow-up care as a surrogate marker of transition success. However, the literature provides deep insight into barriers and facilitators to transition and theoretical considerations for the assessment of transition readiness. We showed that knowledge and education are key facilitators to transition that should be integrated into transition practices tailored to the individual needs of each survivor and the possibilities and limitations of each country's health care system.

Implications for Cancer Survivors: The current knowledge on barriers and facilitators on transition should be implemented in clinical practice to support sustainable transition processes.

Keywords

Childhood cancer survivors; transition; long-term follow-up care; adolescents and young adults

1. Background

1 Most children and adolescents diagnosed with cancer will become long-term survivors. There is a broad
2 international consensus that most of these childhood cancer survivors (CCSs) need life-long follow-up care, as
3 the majority experience one or more late effects due to the cancer treatment received [1, 2]. The goal of long-
4 term follow-up (LTFU) care is to reduce the burden of late effects among CCSs by prevention, early detection
5 or adequate treatment, which ultimately leads to an overall improvement in the CCSs' quality of life. Today,
6 many adolescent and adult CCSs discontinue regular follow-up care once they have left the pediatric setting,
7 with a steady drop off over time after treatment completion [3-5]. The change in LTFU care from the pediatric
8 to adult setting is referred to as a transition, and it has been generally defined as an "active, planned,
9 coordinated, comprehensive, multidisciplinary process to enable childhood and adolescent cancer survivors to
10 effectively and harmoniously transfer from child-centered to adult-oriented healthcare systems" [6]. The
11 transition process itself is closely linked to the following LTFU care models, which can be implemented in
12 different ways [7-10]. In the cancer-center-based model, CCSs either transition directly from pediatric to adult
13 oncology or internal medicine as a one-step process or undergo a stepwise transition carried out by a mixed
14 team of pediatric and adult health care professionals (HCPs) before finally switching to adult care. Variants of
15 this model involve specialized LTFU clinics with multidisciplinary teams that provide life-long LTFU care. In
16 primary care models, CCSs transition to general practitioners with adult specialist consultations as needed (e.g.,
17 cardiologist). In shared-care models, LTFU care is provided by primary care physicians in collaboration with a
18 cancer center.

19 Many obstacles can hinder the practical implementation of these transition processes, such as barriers at the
20 levels of the survivor, family, providers and health care system. The ideal transition would overcome barriers at
21 all levels and would take facilitators and needs into account.

22 Many publications have reported on different LTFU care models, but the literature on the actual transition
23 process, including barriers and facilitators and measures of the success of different transition processes, is
24 scarce. This systematic review aims to close this knowledge gap. We aim to provide comprehensive insight into
25 current transition practices for CCSs from pediatric to adult LTFU care; to describe tools used in transitional
26 care; to summarize barriers and facilitators to the transition process from CCSs', parents' and health care
27 professionals' points of view; and to assess loss to follow-up in relation to different transition practices.

2. Methods

We performed this review according to the PRISMA guidelines for reporting systematic reviews and meta-analyses [11] and registered the protocol on PROSPERO (ID: CRD42019132786).

2.1. Literature search

We conducted a systematic literature search with the aid of an experienced information specialist in February 2020 and searched three databases (PubMed, Embase/Ovid, CINAHL) (**Supplemental S1**). We restricted the search to studies published from January 2000 to January 2020 and studies available in English or German. We built the search strategy for all three databases around four concepts. We identified MeSH terms and free text words for each concept, which we finally combined. For the population of interest, we included the concepts of “cancer” (including different types of childhood cancers), “children and adolescents” and “survivors”. For the outcome, we chose terms related to “transition”. In addition to the three bibliographic databases, we searched Google Scholar in English (“childhood cancer | childhood cancer survivor AND aftercare | follow-up”) and German (“Kinderkrebs transition| Nachsorge”). For each review article identified with our search, we screened the reference list for relevant original articles.

2.2. Inclusion and exclusion criteria

To be included in this review, the studies had to report on cancer survivors who were diagnosed during childhood or adolescence, who completed their cancer treatment and were in the process of transition or had finished transition when included in the respective study. The term “transition” in the context of this review only refers to the change from pediatric- to adult-focused LTFU care. For a study cohort to be considered “children or adolescents”, at least 75% of participants had to be aged less than 18 years at the time of the cancer diagnosis. We excluded studies that did not fulfill the inclusion criteria, case reports, case series ($n \leq 14$), commentaries, editorial letters, poster abstracts and review articles.

2.3. Outcomes

The primary outcomes of this review were current transition practices and care needs during transition. The assessment of current transition practices also included information on transition readiness tools, as these tools can be part of transition practices. Care needs included barriers and facilitators to transition and could be

1 reported by CSSs, parents or health care professionals. Loss to follow-up during transition was assessed as a
2 secondary outcome, as this might be an indirect marker of whether a transition practice is successful.
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5 6 *2.4. Data extraction and quality assessment*

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8 Two reviewers (MO and SD) screened all titles and abstracts separately and excluded those not fulfilling the
9 inclusion criteria. Any disagreements were discussed and resolved by a third reviewer (KS). The same reviewers
10 (MO and SD) independently checked all retrieved full texts for adherence. In case of disagreement or doubts, a
11 third reviewer (KS) was approached. Data from the eligible studies were extracted to a standard sheet including
12 the first author, year of publication, CCSs' age at diagnosis and time of the study, follow-up time, sample size,
13 role of the study participants (survivor, parent, or health care professional), study design, type of transition
14 model, barriers and facilitators to transition, perception of transition, and loss to follow-up. To summarize
15 barriers and facilitators, we first listed all of them in their original wording and subsequently grouped them
16 based on content. We assessed the quality, relevance and reliability of each included study on barriers and
17 facilitators by using the appropriate critical appraisal tool from the Joanna Briggs Institute [12], including the
18 checklists for qualitative research and cross-sectional studies (**Supplemental S2**). Since these tools do not use
19 any categorization, we made a classification with three categories. If all criteria of the respective checklist were
20 fulfilled, we assigned the study to "Quality 1". If a qualitative study did not include a statement locating the
21 researcher culturally and theoretically or a summary of the influence of the researcher on the research and vice
22 versa, we assigned the study to "Quality 2". If a cross-sectional study did not assess confounders or did not
23 clearly state how confounders were selected and used in the analysis, the study was assigned to "Quality 2". If
24 an additional point from the checklist for both types of studies was insufficiently covered, we assigned the study
25 to "Quality 3".
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46 **3. Results**

47 48 *3.1. Literature search result*

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50 Our search identified 6156 records. After screening the titles and abstracts, we excluded 5951 records. Finally,
51 we included 26 studies, one of which reported on two of the assessed outcomes [13] (**Supplemental 3**).
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3.2. Study findings

3.2.1 Current transition practices

We identified six studies describing the transition process in detail, one of which described two processes (**Table 1**). Three studies discussed transition processes that ultimately reflected shared-care models including the involvement of general practitioners [14-16]. Three studies described the transition to adult LTFU clinics [13, 17, 18], and one of these studies additionally discussed the transition to LTFU care provided by a combination of pediatric and adult HCPs [13]. We included six studies outlining five different tools, such as scales, questionnaires, and models, used to assess transition readiness among CCSs (**Table 2**) [19-24]. Although the applicability of four of the tools has been validated, these tools have not yet been implemented in daily clinical practice [19-21, 24].

3.2.2. Barriers and facilitators

Fifteen studies reported on barriers and facilitators encountered when CCSs transitioned from pediatric to adult LTFU care (**Table 3**). Seven studies included survivors' perspectives [13, 25-30], five included HCPs' perspectives [31-35], two included survivors' and parents' perspectives [36, 37], and one included survivors', parents', and HCPs' perspectives [38]. The term "HCP" was used to refer to professionals from different disciplines, such as pediatric oncologists, primary care physicians, health care practitioners, nurses, nurse practitioners, psychologists, and social workers. Overall, 523 survivors, 48 parents and 523 HCPs participated in these 15 studies. After the systematic collection of all mentioned barriers and facilitators, we grouped the barriers and facilitators into eight categories (**Table 4**):

1. CCSs' self-management skills, including knowledge, education and empowerment
2. Social environment, including family, friends, and peers
3. CCSs' personal feelings and emotions
4. Pediatric setting
5. Adult setting
6. Financial issues and insurance
7. Communication
8. Structural circumstances including organization of transition

Barriers and facilitators in the "CCSs' self-management skills" category were the most frequently reported.

Certain factors, such as fear and anxiety, were reported to act as facilitators for some CCSs and as barriers for

1 other CCSs. Fear of cancer relapse could motivate one CCS to attend LTFU care but hinder another CCS from
2 doing so. The impact of family, and especially parents, was mentioned in a similar way; while some CCSs
3 wanted to gain independence in the process of transition, others needed their families' support even as young
4 adults.
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7 8 9 10 *3.2.3. Impact of transition programs on loss-to follow-up*

11 We could not identify any study that evaluated the transition process and its success longitudinally through an
12 assessment of the proportion of CCSs not successfully transitioned and lost to follow-up as a surrogate marker.
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18 19 **4. Discussion**

20 21 *4.1. Transition practices and barriers and facilitators to transition*

22 Our review shows that the literature describing transition processes is limited and lacks evaluation of transition
23 success. In contrast, the literature provides deep insight into barriers and facilitators to transition and theoretical
24 considerations for the assessment of transition readiness.
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28 Transition is crucial not only for the CCS population but also for adolescents and young adults with other
29 chronic diseases, such as inflammatory bowel disease [39], diabetes [40, 41] and rheumatic diseases [42]. One
30 study including adolescents with type 1 diabetes compared an unstructured transition to adult care with a
31 structured transfer planned together with adult physicians. The authors showed that adolescents with a structured
32 transfer had higher clinical attendance, lower HbA1c and a more positive opinion of the transition process after
33 one year than those with an unstructured transition [40]. The structured transfer included a transition
34 coordinator, clear explanations about the process and clinical implications at each visit, and two joint
35 consultations with pediatric and adult endocrinologists. In accordance, the factors "transition coordinator" and
36 "knowing the adult setting before actual transfer" were frequently reported facilitators from the CCSs'
37 perspective. "Clear explanation/education" was also frequently mentioned by HCPs in the reviewed articles.
38 In this review, factors related to "CCSs' self-management skills, including knowledge", the setting of LTFU
39 care ("pediatric setting" or "adult setting"), "communication", and "structural circumstances" were identified as
40 key factors for successful transition. CCSs' knowledge deficits related to cancer history, risk of late effects and
41 importance of LTFU care were identified as major barriers that were mentioned by CCSs themselves and by
42 HCPs. In addition, adult HCPs' lack of knowledge regarding late effects and caring for CCSs was also
43 mentioned repeatedly as a barrier. The finding on the importance of the knowledge and education of CCSs and
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1 HCPs about transition is in accordance with that of other reviews assessing adolescents with other chronic
2 diseases [43, 44]. Therefore, education and empowerment of CCSs must be an important part of transition
3 preparation. The second most frequently mentioned factor was related to the setting of LTFU care (pediatric vs
4 adult) and confidence in the setting. CCSs' and families' attachment to the pediatric team and concerns about
5 terminating that relationship can act as a barrier. On the other hand, building a relationship with and having
6 confidence in the new provider can act as a facilitator. Building a new relationship takes time and in most cases
7 cannot be established during one consultation hour. Therefore, survivors wish to start this new relationship with
8 adult providers towards the end of their pediatric care, but when they are still in the pediatric setting.. During the
9 transfer from pediatric to adult care, communication is a third key factor. Good and clear communication
10 between HCPs and survivors, between HCPs and parents, and between pediatric and adult HCPs act as
11 facilitators. Finally, the structure and organization of the transition can either facilitate or hinder transition. Both
12 CCSs and HCPs report that the transition should be well prepared for and planned within an established
13 transition concept,, that the timing should be individualized and that there should be assistance and flexibility in
14 (re)scheduling appointments and having consultations combined on one day if multiple examinations are
15 needed.

31 *4.2. Cultural and country-specific differences*

32 Transition practices are not uniform across the globe. Transitional care depends upon the possibilities of each
33 country's health care system. In many studies from the US, one major barrier to transition was a lack of health
34 insurance. In contrast to the US, where health insurance is often dependent on employment, Canada and many
35 European countries have compulsory health insurance. Countries also differ to a great extent in the distribution
36 of and distance to health care facilities, which might also affect the transition models used and the willingness of
37 CCSs to attend LTFU care. In larger countries, shared-care models with the involvement of primary care
38 physicians might be more convenient. In smaller countries, one or more centralized LTFU clinics can easily be
39 reached by CCSs. This model of centralized LTFU care was presented in the Slovenian study by Jereb et al. [17]
40 as a successful example. Acceptance of travel distances seems to be variable. The study by Granek et al.
41 reported the use of transition and LTFU care models in Ontario with centralized LTFU clinics, and the survivors
42 seemed to accept long travel distances [13]. All studies included in this review were conducted in first-world
43 countries. The implementation of transition and LTFU care for CCSs in countries with limited resources needs
44 to be investigated in the future. In addition to structures established by the state, such as health insurance, HCPs
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1 need to take the cultural background of the survivor and his or her family into account, as it might also affect the
2 transition. The study by Casillas et al. provided insight into the needs of Latino CCSs and their parents [36].
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4 Cancer stigma and its negative effect on the wider family was a barrier to transition. The involvement and
5 support of the nuclear family, even for young adults, was highlighted as a facilitator. This finding was in
6 contrast to those of other studies that emphasized the survivor's independence and self-management skills as a
7 requirement for successful transition.
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11 12 13 14 *4.3 Transition tools*

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16 Transition tools can be a helpful additional element in the preparation of CCSs to transition. They can help to
17 detect knowledge gaps, fears or uncertainties but also areas where the CCSs have their strength and resources.
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19 Through education to address knowledge gaps, psychological support to address fears, and reinforcement where
20 strengths already exist, CCSs can be supported in their independence. Information on helpful resources and
21 toolkits for transition of adolescents and young adults with chronic diseases for physicians and patients are also
22 available online, but most of these tools are not specific for CCS. One site is "GotTransition" from the US [45],
23 which provides information for young adults, parents and caregivers, and health care professionals. More
24 focused on health care providers is the initiative from the American College of Physicians (ACP), which
25 provides disease-specific toolkits (e.g. congenital heart disease or hemophilia) [46]. In other countries, specific
26 guidelines are in preparation, such as the AWMF guideline for transition in Germany [47] or exist already, such
27 as the NICE guideline in the UK [48]. In addition to these examples of overarching sources, there are many
28 national, disease-specific transition programs, for example from the British Diabetic Association [49], programs
29 linked to a specific clinic, such as for congenital heart defects in Bern [50] or links specifically for adolescents
30 or young adults, as an example the page "la suite" from Paris [51].
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46 *4.4. Main features of the ideal transition*

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48 There is no uniform and ideal transition practice that fits each CCS and that can be applied similarly in every
49 country. This review highlights several key features. The transition from pediatric- to adult-focused LTFU care
50 should be individually adapted to the needs of each survivor. These needs and knowledge gaps can be identified
51 by using transition tools. The transition should be a gradual process rather than a one-step change. Pediatric
52 HCPs should start to prepare CCSs for transition well in advance and educate them on their cancer history,
53 future risks and need for LTFU care. The transition process should be well structured and organized, ideally
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1 involving collaboration between the pediatric and adult HCPs. Finally, good communication between HCPs and
2 survivors as well as between pediatric and adult HCPs is paramount to enable a smooth transfer.
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5 6 *4.5. Strengths and limitations*

7 The key strength of this study lies in the thorough application of the systematic review methodology, including
8 the performance of all steps of the review by two reviewers. The majority of included studies were qualitative
9 studies, which led to small numbers of preselected CCSs. Therefore, the included studies might have been
10 affected by participation and response bias. We assume that survivors who participated in these qualitative
11 studies were generally more interested in LTFU care than those who did not participate. Therefore, we might
12 have lacked the input of survivors who were less motivated in LTFU care and who were more at risk for loss to
13 follow-up. Our review is limited by the lack of reporting on loss to follow-up, and therefore, a clear judgment on
14 the performance of different transition practices is not possible.
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26 **5. Conclusion**

27 Our systematic review highlights important aspects of the transition of CCSs from pediatric- to adult-focused
28 LTFU care. To date, there is no single-best model of transitional care, and the current literature describing
29 transition practices is limited and does not evaluate adherence to follow-up care as a surrogate marker of
30 transition success. We showed that good knowledge, education, and communication among CCSs and HCPs are
31 key facilitators to transition that must be integrated into transition practices and tailored to the individual needs
32 of each survivor and the framework of each country's health care system.
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42 **Conflict of interest statement**

43 None declared.
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Table 1: Summary of studies describing transition processes (n=6)

First Author, Year, Country	
Berger, 2017, France [15]	<u>Shared-care model</u> - SALTO consultation: joint consultation with a pediatric oncologist and internist in addition to general practitioner follow-up care
Blaauwbroek, 2008, Netherlands [14]	<u>Shared-care model</u> - collaboration of pediatric oncologist and on-site family doctor at LTFU clinic at the University Medical Centre Groningen with local family doctor - collaboration with other specialists as needed
Costello, 2017, USA [16]	<u>Shared-care model</u> - collaboration of pediatric oncologist and primary care provider - joint consultation using telemedicine
Granek, 2012, Canada [13]	<u>Pediatric and adult LTFU care provided in a common clinic</u> - specialized LTFU clinic for pediatric and adult CCS - multidisciplinary team - referral to specialists as needed <u>Transition to adult LTFU clinic</u> - transition at age 18 - specialized LTFU clinic for adult CCS - multidisciplinary team - referral to specialists as needed
Jereb, 2000, Slovenia [17]	<u>Transition to adolescent/adult LTFU clinic</u> - transition at age 16 - multidisciplinary team lead by adult oncologist - collaboration with specialists as needed - monthly meetings for survivors offered
McClellan, 2015, USA [18]	<u>Survivorship transition clinic</u> - transition from pediatric LTFU clinic to specialized LTFU clinic within an outpatient Internal Medicine Clinic - transition nurse navigator - multidisciplinary team - possibility for shared-care with primary care physician - referral to subspecialists as needed

Table 2: Summary of studies describing transition tools (n=5)

First Author, Year, Country	
Bashore, 2016, USA [19]	<u>Transition workbook</u> - method of preparing survivors to transition to adult care
Klassen, 2014, Canada [20]	<u>Transition scales</u> - development and evaluation of cancer worry scale, self-management skills scale, expectations scale
Klassen, 2014, Canada [24]	<u>Transition-Q</u> - development and validation of self-management skill scale for adolescents with chronic health conditions (further development of scale developed for childhood cancer patients)
Schwartz, 2011, USA [22]	<u>SMART</u> - development of SMART model - social-ecological model of readiness for transition to adult-oriented care for adolescents and adults with chronic health conditions
Schwartz, 2013, USA [21]	<u>SMART</u> - further validate SMART for survivors of childhood cancer
Schwartz, 2017, USA [23]	<u>Transition Readiness Inventory (TRI) Item Pool</u> - development and validation of TRI Item Pool based on SMART

Table 3: Characteristics of studies reporting on barriers and facilitators in the context of childhood cancer survivors' transition from pediatric to adult long-term follow-up care

First Author, Year, Country	Study design	Sample size	Age at diagnosis [years]	Age at study [years]	Time point of transition at study	Type of transition	Quality Assessment
Casillas, 2010, USA [36]	Qualitative, interview with survivors, focus group with parents	Survivors: n=27 Parents: n=21	Mean 12 (range 2 – 18)	Mean 20 (range 15 – 39)	Not mentioned	To adult care (not further specified)	QR: Quality 2
Frederick, 2017, USA [25]	Qualitative, semi-structured focus groups	Survivor: n=16	Mean 8.6 (range 1-17)	Mean 27.5 (range 22 - 39)	Before and after transition	Not mentioned	QR: Quality 2
Granek, 2012, Canada [13]	Qualitative, semi-structured interview	Survivors: n=38	Range 0 – 17	Range 15 – 26	Pre-transition (n=10), successful transition (n=11), failed transition (n=7), dropped out of transition (n=10)	- Pediatric LTFU clinic to adult LTFU clinic - Remaining in same LTFU clinic	QR: Quality 2
Kenney, 2017, USA [31]	Observational, cross-sectional, survey	HCP (COG members): n=347	NA	NA	NA	Not mentioned	CS: Quality 2
McCann, 2014, Scotland [38]	Qualitative, semi-structured interview	Dyads survivors/parents: n=12 HCP: n=11	Range 1 – 11	Range 17 – 25	n=6 dyads before transition n=6 dyads after transition	To adult care (not further specified)	QR: Quality 2
Mouw, 2017, USA [32]	Qualitative, semi-structured interview	HCP (COG affiliated institutions) n=20	NA	NA	NA	Not mentioned	QR: Quality 3
Nandakumar, 2018, Australia and New Zealand [37]	Qualitative, semi-structured telephone interview	Parents: n=15 Survivor: n=18	Parents: Mean 2.5 (SD 1.6) Survivors: Mean 6.8 (SD 5.1)	Parents: Mean 15 (SD 1.9) Survivors: Mean 26 (SD 6.3)	Parents: n=4 after transition Survivors: n=11 after transition	To primary care provider (n=15)	QR: Quality 2
Quillen, 2017, USA [26]	Observational, cross-sectional, survey	Survivors: n=48	<21 years	Mean 23.3 (range 20 - 25)	All transitioned to adult facility	Adult oncologist, adult primary care provider	CS: Quality 1

Rosenberg-Yunger, 2013, Canada [27]	Qualitative Semi-structured interview	Survivors: n=38	Range 0-18	Range 16 – 26	Pre-transition (n=10), successful transition (n=11), failed transition (n=7), dropped out of transition (n=10)	- Pediatric LTFU clinic to adult LTFU clinic - Remaining in same LTFU clinic	QR: Quality 2
Sadak 2013, USA [28]	Cross-sectional survey	Survivors: n=103	NA	16 - >35	All before transition	NA	CS: Quality 1
Sadak, 2017, USA [33]	Qualitative, semi-structured telephone interview	HCP: n=29 (key informants involved in transition)	NA	NA	NA	Three cancer center including pediatric and adult facilities	QR: Quality 2
Sadak, 2019, USA [34]	Cross-sectional survey	COG members: n=97	NA	NA	NA	- Adult-centered care in pediatric cancer clinic - Adult cancer clinic - Pediatric/adult non-cancer clinic - Adolescent and young adult cancer clinic	CS: Quality 2
Signorelli, 2017, Australia and New Zealand [35]	Qualitative, semi-structured telephone interview	HCP: n=19	NA	NA	NA	Different between clinics, risk-based, some to general practitioner	QR: Quality 2
Szalda, 2017, USA [29]	Observational, cross-sectional, survey	Survivors: n=80	Mean 10.4 (range 0.5-22)	Mean 27.7 (range 23-36)	After transition	From children's hospital to adult care/ provider	CS: Quality 1
Van Laar, 2013, UK [30]	Observational, cross-sectional, survey	Survivors: n=143	Pediatric: Median 9 (IQR 5.7-12.9) Adult: Median 10.2 (IQR 4.5-13.4)	Pediatric: Median 24 (IQR 21-27) Adult: Median 24 (21.7 - 32)	Pediatric setting: n=69 Adult setting: n=74	From children's hospital to adult cancer center (trained in pediatrics and adult medicine)	CS: Quality 2

CS, cross-sectional study; GP, general practitioner; HCP, health care professionals; LTFU, lung-term follow-up; NA, not applicable; QR, qualitative research; SD, standard deviation

Table 4: Summary of barriers and facilitators reported in the eligible studies (n=15)

Barriers	
CCS' self-management skills , including knowledge and empowerment	<ul style="list-style-type: none"> - CCS knowledge deficits or incorrect information on: <ul style="list-style-type: none"> - disease and treatment history [25] - long-term complications [25] - importance of health care screening / LTFU care [26, 27, 32] - navigation of the adult medical system [25] - preventive and healthy lifestyle [32] - CCS cognitive delay / impaired development [31, 32, 37] - Knowing that cancer had a good prognosis for survival, minimal rates of relapse and late effects [27]
Social environment , including family, friends, and peers	<ul style="list-style-type: none"> - Parental factors <ul style="list-style-type: none"> - conversations about risks for late effects is avoided by parents [36] - anxiety, loss of control, fear of the unknown hinder independence of their child and change from doctor-patient-parent triad to doctor-patient dyad [25, 33, 36] - Cancer seen as contagious and incurable illness, leading to stigmatization [36] - Unstable social situation [31] - CCS living further away from the clinic [27, 32]
CCS' personal feelings and emotions	<ul style="list-style-type: none"> - "Cancer a thing of the past" [13] - Medical transition coincide with other changes in life [38] - Believing there is no point to attend LTFU [27] - Not willing to take time to attend LTFU [27] - Believing LTFU appointments are redundant [27] - Having no late effects and concerns about health [27] - Hearing only good news at appointments [27] - Fear/ anxiety of relapse, new cancer, late effects, of dying of cancer, and fearful memories [13, 27]
Pediatric setting , including CCSs perception	<ul style="list-style-type: none"> - Attachment of patient/parent to provider and vice versa and concerns about terminating the relationship [27, 31, 34, 37] - Unstable medical condition in CCS [31] - Survivors not ready for adult-centered care from a psychosocial or medical standpoint [34]
Adult setting , including CCSs perception	<ul style="list-style-type: none"> - (Lack of) adult providers familiar/ comfortable with CCS and SCP [25, 31, 32, 34, 35] - Adult models of care cannot accommodate influx of new patients [34] - Concerns of pediatric oncologists that adult providers' lack knowledge to care for CCS [31, 32] - Concerns of CCS that new providers do not understand healthcare needs [27] - Environment in adult hospital <ul style="list-style-type: none"> - perceived as rushed and impersonal by CCS [27, 37] - makes CCS think about cancer and death [27] - perceived harder to navigate for CCS and families [32]
Financial issues and insurance	<ul style="list-style-type: none"> - Health insurance issues [31, 32, 34] - Financial barriers, medical costs [26, 31]
Communication	<ul style="list-style-type: none"> - Inadequate communication between CCS, pediatric and adult HCP [37] - Miscommunication about LTFU care [27]
Structural circumstances , including organization of transition	<ul style="list-style-type: none"> - CCS have little/ no information about adult hospital before transfer [38] - CCS experience difficulties to organize or reschedule appointments at adult provider [26, 27] - Lack of coordination between multiple appointments [27] - Undefined transition process [35]
Facilitators	
CCS' self-management skills , including knowledge and empowerment	<ul style="list-style-type: none"> - CCS knowledge on: <ul style="list-style-type: none"> - disease and treatment history [32] - long-term complications/ risk for late effects [25, 26, 32]

	<ul style="list-style-type: none"> - importance of health care screening / LTFU care also in adulthood [25, 26, 27, 30, 33, 38] - preventive and health lifestyle [32] - Adequate, appropriate, and early information [37] - Empowerment of CCS for independence and self-management skills [25, 26, 32, 35, 37] - CCS being able to advocate for themselves and navigate in health care system [32] - Ageing / getting older [37]
Social environment , including family, friends, and peers	<ul style="list-style-type: none"> - Parental/family factors - Involvement of parents/ family in health care decision-making and survivorship care [29, 36] - Parental worry [27] - Parents/family offering practical support (e.g. transportation to appointments [27]) - Parent/ family member for moral support at appointment [27] - Talking about importance of LTFU care / spending time with Friends and peers [27]
CCS' personal feelings and emotions	<ul style="list-style-type: none"> - Identification as "cancer survivor" [13] - Going to LTFU care to ensure health [27] - Having concern with health or cancer worries [13, 27] - Having symptoms or late effects [27] - Gratitude of being alive, sense of responsibility to attend follow-up care, help others by participating in research through attending LTFU [13, 27]
Pediatric setting	No study
Adult setting , including CCSs perception	<ul style="list-style-type: none"> - Good/ familiar relationship between HCP and CCS/ families [27, 32] - Confidence in physician who understands burden of late effects, needs for comprehensive care, and includes subspecialists [27, 28, 37] - Having a familiar and friendly adult environment [27]
Financial issues and insurance	<ul style="list-style-type: none"> - Having health insurance [28, 29] - Opportunity to get insurance counseling [28]
Communication	<ul style="list-style-type: none"> - Clear and developmentally appropriate communication between CCS/families and provider [25, 33, 36] - Good communication among past and future HCP [25, 33, 37] - Pediatric HCPs know PCPs [32]
Structural circumstances , including organization of transition	<ul style="list-style-type: none"> - Transition <ul style="list-style-type: none"> - Transition as a process and gradual transfer of care – planning, preparation and flexible time point of transition are key elements [25, 26, 31, 32, 38] - Transition process start in early adolescence [25, 33] - Talk repeatedly about (time point of) transition with CCS and parents [33, 38] - Meet adult oncology team before leaving pediatric hospital [38] - Appointment(s) <ul style="list-style-type: none"> - Receiving help to find appropriate adult provider [25] - Receiving next appointment at a scheduled visit, also when leaving pediatric setting [26, 27] - Receiving reminder calls about appointments [27] - Flexibility when booking or rescheduling appointments [27, 28] - Structural <ul style="list-style-type: none"> - Shorter distance CCS - cancer center [32, 37] - Provide specific information/ materials to CCS to be communicated to new provider, e.g. survivorship care plan [25, 32] - Coordinated appointments with multiple specialist [27, 28, 33] - Patient navigator [28, 33] - National or binational model of care [35]



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Supplementary material

Transition_Review_Supplemental_Revision.docx

