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Barriers and facilitators associated with long-term follow-up care for childhood, adolescent, and young adult cancer survivors: a systematic review

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Abstract

Background Optimal long-term follow-up (LTFU) care for survivors of childhood, adolescent and young adult (CAYA) cancer can improve or maintain their quality of life by prevention and early treatment of late effects. However, optimal LTFU care is not provided to all CAYA cancer survivors. This systematic review sought to identify associated barriers, facilitators and other factors of LTFU care for CAYA cancer survivors worldwide.

Methods We included barriers and facilitators from a previously published guideline in 2017, and performed a systematic search using PubMed/Medline to identify studies between 1-1-2017 and 5-6-2025 examining barriers, facilitators and other factors associated with LTFU care from the perspectives of CAYA cancer survivors, diagnosed with cancer ≤25 years of age, healthcare providers (HCPs), and hospital managers involved in the provision of LTFU care for CAYA cancer survivors. Qualitative and (semi)quantitative (survey) studies with multivariable analyses were eligible for inclusion. Standardised evidence tables were made independently by one author and checked by another author to extract relevant information.

Results The search yielded 4,677 unique records, of which 230 were selected for full-text screening and 51 articles were included in this systematic review. Twenty-two studies were qualitative, twenty-two were quantitative and seven used a mixed methods design. The previous published guideline provided 19 barriers and 5 facilitators until 2017. Within the current review, 85 barriers, 63 facilitators, and 23 other factors were reported. Main barriers included lack of knowledge, information and awareness of LTFU care, lack of resources, poor transition from paediatric to adult care, and the lack of national/regional LTFU care programmes or clinics. Main facilitators included a treatment summary/survivorship care plan, involvement of multidisciplinary specialists, education to improve late effects knowledge, a

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clear contact/information point, and improved communication. Regarding other factors, treatment with radiation only, older attained age, age at diagnosis, and non-white descent were most frequently associated with less LTFU care. The main factor associated with more LTFU care by survivors was the number of late effects.

Conclusions We encourage raising awareness, provision of appropriate information, treatment summaries and survivorship care plans, and advocacy for supportive policies and funding in order to optimise LTFU care and facilitate engagement for CAYA cancer survivors.

Keywords Paediatric oncology, Long-term follow up care, Survivorship, Aftercare, Cancer survivors, Barriers and facilitators, Factors

Introduction

Advances in childhood, adolescent and young adult (CAYA) cancer treatment have led to a large increase in the number of CAYA cancer survivors, with over 500,000 survivors currently reported in Europe [1, 2]. However, these survivors are at high risk of potential late effects of cancer diagnosis and treatment that can affect their quality of life [3, 4]. For example, late effects can include endocrine or metabolic dysfunction, adverse psychosocial events, cardiovascular complications, and chronic fatigue [5–9]. Late effects can occur immediately after treatment or many years later as the CAYA cancer survivor ages [10]. Evidence has shown that prevention, early intervention and appropriate management of these late effects can improve or maintain the quality of life of CAYA cancer survivors and even reduce premature mortality [11]. Therefore, it is essential to provide long-term follow-up (LTFU) care, where all these issues are addressed, for CAYA cancer survivors.

The development of different models of LTFU care and implementation tools is progressing rapidly worldwide [12, 13]. However, despite these advances, comprehensive, continuous and effective survivorship programmes are often lacking in LTFU care systems [14]. To provide well-coordinated and timely LTFU care in a multidisciplinary setting, identification of barriers and facilitators associated with the implementation, optimalisation of, and attendance to LTFU care is essential. While Michel et al. provided evidence-based recommendations for the organisation of LTFU care [14], including literature up to 2017, optimal LTFU care structures are still lacking in many countries.

Therefore, this systematic review sought to identify barriers, facilitators and other factors of LTFU care for CAYA cancer survivors worldwide by summarizing the barriers and facilitators identified by Michel et al. and by conducting a systematic search for new articles published since 2017. Specifically, we sought to reflect the complexity of LTFU care across different roles and responsibilities by incorporating perspectives from CAYA survivors, healthcare providers (HCPs), hospital managers and policymakers.

Methods

Identification of previously identified barriers and facilitators

First, we extracted the barriers and facilitators associated with LTFU care from the guideline published by Michel et al. [14] and listed them in a table (Table 1).

Identification of recent barriers and facilitators

Second, we conducted a systematic literature review of articles published after 2017. Details of this review are described below.

Eligibility criteria

As a continuation of the previous search until 2017 [14], all original studies published between 1-1-2017 and 5-6-2025 were eligible for inclusion. We included qualitative, semi-quantitative (survey) and quantitative study designs. For quantitative studies, we only included those that reported multivariable analyses. Systematic reviews and narrative reviews were excluded, but eligible studies reported in such reviews were included.

Information sources and search strategy for identification of studies

We searched PubMed/Medline using a combination of terms for 'children, adolescents and young adults', 'cancer', 'survivors', 'care' and 'barriers, facilitators and factors' (Appendix 1). No language or geography limits were applied. Furthermore, the references of the included papers and relevant reviews were screened for potentially additional eligible studies.

Selection process

We included studies with CAYA cancer survivors (diagnosed with any cancer type ≤ 25 years of age, irrespective of treatment, and after completion of treatment for their primary cancer), HCPs, and hospital managers and policy makers involved in the provision of LTFU care for CAYA cancer survivors. For mixed populations of eligible and ineligible participants, such as CAYA cancer survivors and survivors of adult cancer, a study was only included if at least 75% of the study population consisted of eligible

Table 1 Barriers and facilitators to LTFU care by survivors and HCPs from the previously published study by Michel et al. [1]

Barriers (n identified in included studies)	Facilitators (n identified in included studies)
• Lack of experience and inadequate preparation/formal training about survivorship (n=26) • Lack of knowledge or awareness about late effects, survivorship issues and needs (n=20) • Lack of time/high workload (n=9) • Lack of adequate insurance or funding for LTFU care (n=7) • Lack of knowledge and familiarity of LTFU guidelines (n=6) • Lack of support and staff to provide LTFU care (n=4) • Lack of staff to provide LTFU care (n=2) • Lack of communication between primary care physician and paediatric oncologists (n=4) • Lack of knowledge about late effects among survivors and parents (n=4) • Lack of a LTFU programme (n=3) • Confusion about role of survivorship programs, oncologists and primary care providers (n=3) • Distance to clinic for survivors (n=2) • Inability to locate adult survivors (n=2) • Survivor-related psychosocial barriers (fear, avoidance) (n=2) • Inadequate access to survivors' cancer treatment history (n=2) • Limited access to refer survivors to specialist care (n=1) • Low confidence in managing their survivorship care among survivors (n=1) • Difficulties organising an appointment (time, distance, scheduling) (n=1) or finding the right place to go (n=1) • Lack of a transition program from paediatric to adult healthcare (n=1)	• Access to support information, medical education seminars, courses or online tools regarding LTFU care (n=14) • Access to LTFU care, including access to cancer survivor specialists, access to support services, like social work and psychology, ability to telephone or email specialist for advice, and more medical/support staff in primary care office (n=11) • Survivorship care plan (n=8) • Evidence-based LTFU guidelines (n=5) • Adequate insurance (n=1)

Abbreviations: LTFU, long-term follow-up

participants or if separate results for the eligible participants were provided.

Data collection process

Two independent authors screened study titles and abstracts to identify studies that potentially met the inclusion criteria using Rayyan (https://rayyan.ai) [15]. For studies that were likely to meet the criteria, the full text was screened by two independent reviewers. In cases of disagreement, a discussion was held to determine whether the paper should be included or not, and third-party arbitration was used when necessary.

Outcomes

To be included, a study must have described barriers, facilitators and other factors related to all aspects of LTFU care, such as implementation of LTFU care, adherence to LTFU care, attendance at LTFU care, engagement with LTFU care and receipt of LTFU care. Barriers and facilitators were interpreted as potentially modifiable, whereas other factors were considered non-modifiable or very difficult to modify, i.e. socio-demographic and clinical characteristics. We included barriers and facilitators from both qualitative and (semi-)quantitative survey studies and other factors from quantitative studies, including observational or (semi) experimental studies with measures of association as outcomes. Barriers, facilitators, and other factors associated with a successful transition (from short-term follow-up care to long-term survivorship care and from paediatric to adult LTFU care services) are outside the scope of this review.

Data extraction

To ensure accuracy and consistency of data collection, we created standardised evidence tables (Supplementary File A) to extract relevant information from the included studies. These tables recorded the study design, participant characteristics, results, and any additional comments on study design components. The evidence tables were prepared independently by one author and checked by another author to ensure accuracy and completeness. In cases of discrepancy or disagreement, the authors discussed the matter until consensus was reached. Third party arbitration to resolve disagreements was not required.

Data synthesis

We distinguished between barriers and facilitators associated with LTFU care from the perspectives of CAYA cancer survivors, HCPs, hospital management and policy makers. Other factors concerned only the perspective of CAYA cancer survivors. Barriers, facilitators, and other factors are presented separately in the results. We categorised the barriers, facilitators, and other factors into overarching themes reflecting their content (e.g., "Communication and Information") and ranked from most to least frequently mentioned in the included studies. These themes were conceptual labels developed by the authors after synthesising all the findings.

Risk of bias criteria

We did not include a risk of bias assessment, because we decided to include all barriers and facilitators mentioned in the included papers independently of the level of quality of the overall methods of the papers as we considered them all relevant.

Results

Previously identified barriers and facilitators associated with LTFU care

Michel et al. [14] reported a total of 19 barriers and 5 facilitators associated with LTFU care from the opinions of survivors and healthcare providers (Table 1). Their

most frequently identified barrier was a lack of experience and inadequate preparation/formal training about survivorship ($n=26$), followed by a lack of knowledge or awareness about late effects, survivorship issues and needs ($n=20$), and lack of time/high workload ($n=9$). Their most frequently identified facilitator was access to support information, medical education seminars, courses or online tools regarding LTFU care ($n=14$), followed by access to LTFU care, including access to cancer survivor specialists, access to support services, like social work and psychology, ability to telephone or email specialist for advice, and more medical/support staff in primary care office ($n=11$), and a survivorship care plan ($n=8$).

Newly identified barriers and facilitators associated with LTFU care

Included studies

The PubMed search of articles published after 2017 and reference lists of relevant studies yielded 4,677 unique records, of which 230 were selected for full-text screening and 51 articles were ultimately included in this systematic literature review (Fig. 1). Supplementary Table 1 provides detailed demographic information for all included studies [16–65], which had a total of 16,248 participants. Twenty-two studies were qualitative, twenty-two were quantitative and seven used a mixed methods design. There was no overlap in the use of identical data sets or participant cohorts between the included studies.

Barriers and facilitators associated with LTFU care by stakeholder group

CAYA cancer survivors (n = 35 studies, Supplementary Table 2) Out of 34 barriers to LTFU care, the main barrier reported by CAYA cancer survivors was a lack of knowledge, information and awareness regarding late effects and need for follow-up care ($n=12$ [16, 17, 19, 20, 22, 23, 25–30]). Other frequently reported barriers were distance to the LTFU care clinic ($n=8$ [16, 17, 22, 23, 28, 34, 35, 42]), financial constraints ($n=7$ [16, 19, 27, 31–34]), time constraints/competing responsibilities ($n=7$ [16, 18, 22, 23, 27, 29, 31]), and GPs/PCPs perceived as unfamiliar with specific cancer and follow-up care ($n=7$ [21, 24, 28, 29, 31, 33, 34]). In addition, survivors reported poor/difficult transition from paediatric to adult services ($n=5$ [23, 25, 28, 31, 34]), lack of health insurance ($n=5$ [23, 34, 36, 37, 64]), emotional distress, fear, or motivational barriers ($n=4$ [17, 18, 21, 27]), and difficulty with navigating the health care system ($n=4$ [20, 26, 29, 34]). Other barriers were reported in three or fewer studies.

Furthermore, CAYA cancer survivors reported 27 facilitators for LTFU care, of which having a treatment summary and/or survivorship care plan (SCP) was the most frequently reported ($n=6$ [20, 24, 29, 38–40]). Other

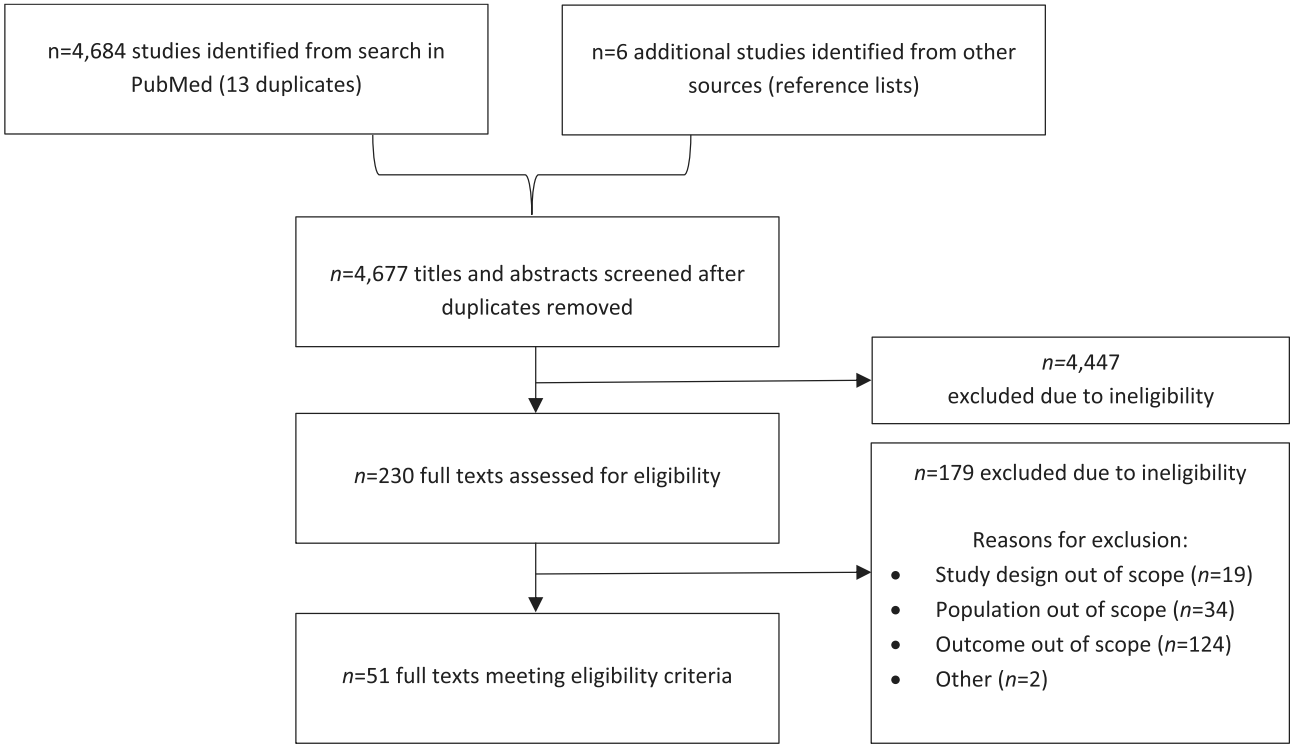

Fig. 1 Flowchart of included studies

facilitators that were reported three times were having a clear contact/information point regarding survivorship care [29, 31, 40], knowledge/information about late effects and the need for long-term follow-up [20, 31, 39]; routine follow-up [16, 29, 31]; communication and/or care via mobile phones or digital applications [25, 29, 31]; developmentally appropriate survivorship services [25, 27, 49]. Finally, automatic reminders of surveillance appointments and having health insurance [39, 62] were identified twice as a facilitator [26, 31]. Other facilitators were reported only once.

HCPs (n = 19 studies; Supplementary Table 3) We identified 40 barriers to LTFU care from the perspective of HCPs. The main barrier was the lack of resources/financial cost ($n = 12$ [28, 31, 43–50, 59, 60]), followed by a lack of knowledge about survivorship care among general practitioners (GPs) and primary care physicians (PCPs) ($n = 9$ [24, 28, 31, 33, 43, 48–50, 59]). The poor or inconsistent transition from paediatric to adult health care ($n = 7$ [28, 31, 34, 43, 45, 50, 60]), the lack of communication and collaboration between GPs and oncologists ($n = 7$ [31, 43, 44, 48, 49, 51, 60], and a perceived lack of patient communication, motivation to seek follow-up, and compliance [24, 46–48, 51, 60, 63] ranked third. In addition, time constraints [28, 44, 46, 47, 50, 59] were found in six studies, while lack of (access to) comprehensive medical records [31, 46, 59, 60, 63] was found in five studies. Both lack of support for CAYA cancer survivors [20, 31, 51, 59] and lack of experience and/or expertise [33, 46, 50, 60] were found in four studies. Other barriers were reported in three or less studies. HCPs identified 32 facilitators for LTFU care. Involvement of multidisciplinary medical specialists ($n = 6$ [34, 43, 45, 49, 52, 59]) and having a standardised follow-up program for survivors ($n = 6$ [44, 50–53, 59]) were mentioned most frequently. Three facilitators were reported in five studies, namely improved communication and closing the "feedback loop" between specialists and GPs [31, 33, 43, 50, 51]; a treatment summary or SCP [20, 24, 33, 44, 54]; and (centralised) education materials/training on treatment and late effects [43, 45, 47, 50, 52]. Follow-up care guidelines [44, 45, 50, 59] were reported in four studies. Other facilitators were found in two or less studies.

Hospital managers and policy makers (n = 2 studies, Supplementary Table 4) In total, eleven barriers and four facilitators from the perspective of hospital managers and policy makers were identified. The lack of a national/regional LTFU care programme and/or clinics was identified as a barrier in both studies [53, 55]. Other barriers were reported in only one study, i.e. childhood cancer not discussed openly in the country of residence [55], lack of a dedicated LTFU care clinic [55], lack of use of survivorship care guidelines [55], lack of HCPs [55], lack of time to dedicate to care and transport [55], financial problems of the centre [55], lack of health insurance (after 18 years of age) [55], difficult transition problems of survivors from paediatric to adult clinics [56], lack of patient education [55], and insufficient education about LTFU care [55]. Facilitators included the existence of a national/regional LTFU care programme [53], open discussion of childhood cancer in the country of residence [54], use of a treatment summary/SCP [53], and availability of survivorship care training programmes [53].

Barriers and facilitators associated with LTFU care by category (Table 2)

Across all stakeholder groups, we identified 85 barriers and 63 facilitators related to LTFU care. For CAYA cancer survivors, the largest category of barriers and facilitators involved Communication and Information, followed by Logistics and Accessibility and Care Characteristics. Similarly, for HCPs, the largest category was Communication and Information, followed by Care Characteristics and Logistics and Accessibility. For managers and policy makers, the largest category was Care Characteristics, followed by Communication and Information. Financial and Insurance factors, Community and Support, and Logistics and Accessibility all tied for third place.

Other factors associated with LTFU care (n = 12 studies, Table 3, Supplementary Table 5)

We identified 9 other factors associated with less LTFU care and 14 other factors associated with more LTFU care. Treatment with radiation only [35, 36], older age at cancer diagnosis [36, 42], and black or other descent (vs. white descent) [35, 36] were most frequently associated with less LTFU care. Higher risk or number of late effects [38, 39, 41] was most frequently associated with more LTFU care. Of note, older age at study was associated with more LTFU care in three studies [17, 32, 35], but also with less LTFU care in two studies [39, 56]. Additional other factors were reported only once. As gender was significant in one study [65] but not in six others [17, 32, 35, 39, 42, 56], it was left out from Table 3 and Supplementary Table 5. Overall, the largest category of other factors involved Patient Characteristics, followed by Cancer Treatment Characteristics.

Non-significant results of quantitative studies

The included quantitative studies also reported non-significant results (Supplementary Table 6). Other non-significant results were most frequently found for treatment intensity ($n = 3$ [39, 56, 62] out of 3 studies), type of cancer diagnosis with leukaemia as reference group ($n = 2$ [17, 56] out of 2 studies), educational level ($n = 2$ [17, 56] out of 2 studies), socioeconomic status ($n = 2$ [39,

Table 2 Barriers and facilitators associated with LTFU care by stakeholder group

Stakeholder group	Themes	Barriers (n identified in included studies)	Facilitators (n identified in included studies)
CAYA cancer survivors	Communication and Information	• Lack of knowledge/information and awareness regarding late effects and need for follow-up care (*n*=13) [16, 17, 19, 20, 22, 23, 25–30] • Uncoordinated/unclear information provision (*n*=2) [26, 29] • Lack of communication between HCPs (*n*=1) [31] • No reminders to attend appointments (*n*=1) [27]	• Having a written treatment summary and/or survivorship care plan (*n*=6) [20, 24, 29, 38–40] • A clear contact/information point regarding survivorship care (*n*=3) [29, 31, 40] • Knowledge/information regarding late effects and the need for long-term follow-up care (*n*=3) [20, 31, 39] • Communication and/or care using mobile phones or digital applications (*n*=3) [25, 29, 31] • Surveillance appointments and reminders automatically se(n)t (*n*=2) [26, 31] • Discussion of required follow-up care with a physician (*n*=1) [39] • Tracking phone calls (*n*=1) [54] • Direct communication between HCPs and CCS (without parents) (*n*=1) [26]
	• Logistics and Accessibility	• Distance to clinic (*n*=8) [16, 17, 22, 23, 28, 33, 34, 42] • Time constraints/competing responsibilities (*n*=7) [16, 18, 22, 23, 27, 29, 31] • Healthcare system difficult to navigate (*n*=4) [20, 26, 29, 34] • Unable to travel without assistance (*n*=2) [19, 27] • Difficulty with electronic medical records (*n*=1) [31] • Crowded waiting room (*n*=1) [26] • Need for parental permission to access health records (*n*=1) [26] • Medical follow-up terminated by the HCP (*n*=1) [20] • Difficult to find childcare (*n*=1) [27] • Coming from large towns (vs. urban areas) (*n*=1) [58]	• LTFU care outside of normal hours to increase attendance (*n*=1) [27] • GP-led long-term follow-up care consultations (*n*=1) [29]
	• Patient Characteristics	• Survivor felt well (*n*=1) [19] • Being ill (*n*=1) [19]	• Having medical problems (*n*=1) [54]
	• Financial and Insurance Factors	• Financial constraints (*n*=7) [16, 19, 27, 31–34] • No health insurance (*n*=5) [23, 34, 36, 37, 64] • Insurance change (vs. stable coverage) (*n*=1) [57]	• Having health insurance (*n*=2) [39, 62] • Public insurance (vs. private insurance) (*n*=1) [57]
	• Care Provider-related Issues	• GPs/PCPs perceived as unfamiliar with specific cancer and follow-up care (*n*=7) [21, 24, 28, 29, 31, 33, 34] • HCPs perceived as having too little time (*n*=3) [28, 31, 33] • Lack of trust in HCPs (*n*=2) [32, 33] • Difficulties talking to new doctors (*n*=1) [26] • Shifting patient-HCP relationships (*n*=1) [28] • Having a newer relationship with the main LTFU care provider (*n*=1) [61]	• Endorsing greater confidence in physicians' abilities to address questions and concerns (*n*=1) [38] • Having a cancer specialist as the main LTFU care provider (*n*=1) [61]
	• Psychological and Emotional Factors	• Emotional distress, fear, or motivational barriers (*n*=4) [17, 18, 21, 27] • Low priority given to follow-up care (*n*=2) [19, 23] • Fear that providers would not understand them (*n*=1) [20] • Having an aversion to doctors after treatment (*n*=1) [33] • Unwilling to come (*n*=1) [19]	• Perceived greater susceptibility to cancer-related health problems (*n*=1) [38] • Assigning greater importance to follow-up visits (*n*=1) [38] • Higher health-care self-efficacy (*n*=1) [39] • Having more painful treatment memories (*n*=1) [38] • Higher reported number of motivating factors (*n*=1) [27]
	• Community and Support	• Unawareness of social environment (*n*=1) [19] • Social stigma	• Meeting other people in a similar situation (*n*=1) [29] • Highest income neighbourhood (*n*=1) [65]

Table 2 (continued)

Stakeholder group	Themes	Barriers (n identified in included studies)	Facilitators (n identified in included studies)
	• Care Characteristics	• Poor/difficult transition from paediatric to adult services (*n*=5) [23, 25, 28, 31, 34] • Interventional/painful procedures (*n*=1) [26]	• Routine follow-up care (*n*=4) [16, 29, 31, 62] • Developmentally appropriate survivorship services (*n*=3) [25, 27, 49] • Having a regular doctor for non-cancer care (*n*=1) [39] • Seeing a primary care provider for a cancer-related problem (*n*=1) [38] • Having more primary care provider visits (*n*=1) [65]
• HCPs	• Communication and Information	• Knowledge gap of survivorship care in GPs/PCPs (*n*=9) [24, 28, 31, 33, 43, 48–50, 59] • Lack of communication and collaboration between GPs and oncologists (*n*=8) [31, 43, 44, 48, 49, 51, 60] • Perceived lack of patient communication, motivation to seek follow-up, and compliance (*n*=7) [24, 46–48, 50, 60, 63] • Uncertainty about whose responsibility it is to provide different aspects of survivorship care (*n*=3) [31, 48, 51] • Patients unclear who to approach for health issues (*n*=1) [44] • Overdue and insufficient late effects communication with CAYA cancer survivors (*n*=1) [28] • Anxiety/distress that survivors may experience when returning to the medical setting in which they were treated for cancer (*n*=1) [63]	• Improved communication and closure of the "feedback loop" between specialists and GPs (*n*=5) [31, 33, 43, 50, 51] • (Centralised) education materials/training on treatment and late effects (*n*=5) [43, 45, 47, 50, 52] • Informational resources covering diverse aspects of the survivorship experience (*n*=1) [49] • Knowledge and awareness about LTFU care among survivors and important stakeholders (*n*=1) [59] • Reported results of LTFU care (*n*=1) [59]
	• Care Characteristics	• Poor or inconsistent transition from paediatric to adult health care (*n*=7) [28, 31, 34, 43, 45, 50, 60] • Labour intensity of survivorship care plans (*n*=3) [43, 49, 54] • Lack of standardized LTFU care program (*n*=3) [46, 51, 53] • Complex healthcare systems which are difficult to navigate (*n*=3) [46, 49, 51] • Lack of standardized guidelines (*n*=1) [46] • Incomplete or unclear SCPs (*n*=1) [48] • Inequities in care available between states and cancer types, as well as between paediatric and adult settings (*n*=1) [49] • Lack of specialised nurses (*n*=1) [50] • Lack of skills regarding late effects among HCPs outside LTFU care team (*n*=1) [59] • Survivor no shows (*n*=1) [59] • Low trust in GPs and local care clinics (*n*=1) [59] • Lack of collaboration with psychosocial care facilities (*n*=1) [59] • Lack of (access to) psychosocial care facilities (*n*=1) [59] • Uncertainty about which to use (*n*=1) [60]	• Involvement of multidisciplinary medical specialists (*n*=6) [34, 44, 45, 49, 52, 59] • Having a standardised follow-up program for survivors (*n*=6) [44, 50–53, 59] • A written treatment summary or survivorship care plan (*n*=5) [20, 24, 33, 44, 54] • Follow-up care guidelines (*n*=4) [44, 45, 50, 59] • Nurse-led survivorship care (*n*=2) [43, 51] • Involvement of GPs and local care facilities (*n*=2) [43, 59] • Risk-stratification of survivors (*n*=1) [43] • GP-led care including the traditional family model (*n*=1) [43] • Smaller patient numbers (*n*=1) [45] • Equitable and sustainable care systems (*n*=1) [49] • Routine follow-up consultations (*n*=1) [51] • A more systematic involvement of already-existing local care services (*n*=1) [51] • Care coordination and continuity (*n*=1) [31] • Availability of psychosocial support services (*n*=1) [63]

Table 2 (continued)

Stakeholder group	Themes	Barriers (n identified in included studies)	Facilitators (n identified in included studies)
	• Logistics and Accessibility	• Time constraints (*n*=6) [28, 44, 46, 47, 50, 59] • Lack of (access to) comprehensive medical records (*n*=5) [31, 46, 59, 60, 63] • LTFU care too far away or too expensive for survivors (*n*=3) [59, 60, 63] • Lack of administrative staff and data managers (*n*=1) [43] • Large patient volumes seen by GP services act as a competing interest to furthering childhood cancer survivorship care education (*n*=1) [43] • Concerns about privacy issues (*n*=1) [46] • Lack of access to specialists who provide specific elements of survivorship care (*n*=1) [48] • Lack of capacity to treat both acute cancer patients and survivors (*n*=1) [59] • Lack of LTFU care staff (*n*=1) [59] • Organizational issues with planning multiple examinations on same day (*n*=1) [59] • Care appointments unavailable outside of normal business hours (*n*=1) [63] • Limited size of survivorship clinic (*n*=1) [63]	• Availability of a national database to hold survivor information (*n*=2) [43, 45] • Leveraging on existing adult survivorship care infrastructure (*n*=1) [43] • (Intelligent) IT system that is sharable between different care facilities (*n*=1) [59]
	• Financial and Insurance Factors	• Lack of resources/financial cost (*n*=12) [28, 31, 43–50, 59, 60] • Dealing with insurance (*n*=2) [20, 63] • Convincing hospital managers to allocate resources for LTFU care is a time-consuming process (*n*=1) [59]	
	• Community and Support	• Lack of support for CAYA cancer survivors (*n*=4) [20, 31, 51, 59] • Childhood cancer not talked about openly in country of residence (*n*=1) [53] • Lack of leadership support (*n*=1) [46]	• (Inter-)national network for LTFU care strengthens argumentation for LTFU care (*n*=1) [59] • Understanding of hospital management (*n*=1) [59] • Attention for diversity, equity, and inclusion (*n*=1) [63] • Survivors' trust in their healthcare system (*n*=1) [63]
	• Care Provider-related Issues	• Lack of experience and/or expertise (*n*=4) [33, 46, 50, 60]	• Motivated and committed HCPs to take care of survivors (*n*=2) [59, 63] • Motivated HCPs to convince stakeholders for LTFU care (*n*=1) [59] • Positive interpersonal relationships between survivors and healthcare providers (*n*=1) [59]
• Managers	• Financial and Insurance Factors	• Financial problems of centre (*n*=1) [55] • Lack of health insurance (after 18 years of age) (*n*=1) [55]	
	• Care Characteristics	• No national/regional LTFU care program and/or clinics (*n*=2) [53, 55] • Lack of HCPs (*n*=1) [55] • Difficult transition problems of survivors from paediatric to adult clinics (*n*=1) [55]	• A national/regional LTFU care program (*n*=1) [53] • Use of a treatment summary/survivorship care plan (*n*=1) [53]
	• Community and Support	• Childhood cancer not talked about openly in country of residence (*n*=1) [53]	• Open discussion of childhood cancer in country of residence (*n*=1) [53]
	• Logistics and Accessibility	• Having no separate LTFU care clinic (*n*=1) [55] • Lack of time to dedicate to care provision and transport provision (*n*=1) [55]	• Ongoing advocacy to direct resources toward the systematic development of comprehensive survivorship initiatives (*n*=1) [49] • Continuous financial support and commitment (*n*=1) [59] • Financial aid for survivors to participate in LTFU care (e.g., reimbursement for survivors living far away) (*n*=1) [59]
	• Communication and Information	• Not using survivorship care guidelines (*n*=1) [55] • Lack of providing knowledge to patients (*n*=1) [55] • Insufficient education about LTFU care (*n*=1) [55]	• Availability of survivorship care training programs (*n*=1) [53]

• Abbreviations: *CAYA* Childhood, Adolescent, and Young Adult, *CNS* Central nervous system, *GPs* General practitioners, *HCPs* Healthcare providers, *LTFU* Long-term follow-up, *PCPs* Primary care physicians

Table 3 Other factors significantly associated with LTFU care

Themes	Factors significantly associated with less LTFU care	Factors significantly associated with more LTFU care
Patient Characteristics	• Older age at cancer diagnosis (*n*=3) [36, 42] • Black or other descent (vs. white descent) (*n*=2) [35, 36] • Older age at study (*n*=2) [39, 56] • Longer time since cancer diagnosis (*n*=1) [39] • Hispanic and other descent (vs. non-Hispanic white) (*n*=1) [39]	• Being at high risk for late effects/higher number of late effects (*n*=3) [38, 39, 41] • Older age at study (*n*=3) [17, 32, 35] • Previous relapse (*n*=1) [42] • Hispanic descent (vs. white descent) (*n*=1) [36] • Less time since cancer diagnosis (*n*=1) [56] • History of leukaemia, lymphoma, or solid tumour (vs. CNS tumours) (*n*=1) [42] • Earlier year of cancer diagnosis (*n*=1) [64] • More recent period of diagnosis (*n*=1) [65] • High morbidity (*n*=1) [65] • Older age at cancer diagnosis (*n*=1) [65]* • Younger age at cancer diagnosis (*n*=1) [65]*
Cancer Treatment Characteristics	• Treatment with radiation only (*n*=2) [35, 36] • Lack of history of stem cell transplantation (*n*=1) [36] • Treatment with radiation and surgery (*n*=1) [36] • Treatment with surgery only (*n*=1) [35]	• Lack of history of stem cell transplantation (*n*=1)[65] • Treatment with radiation (*n*=1)[65] • Treatment with anthracyclines (*n*=1)[65]

Note: The numbers in parentheses indicate the frequency of the factor across the included studies.

Abbreviations:*CNS* Central nervous system, *LTFU* Long-term follow-up

* In this study, older age at cancer diagnosis was associated with greater adherence to colorectal cancer adherence and younger age at cancer diagnosis was associated with greater adherence to cardiomyopathy adherence.

62] out of 2 studies), and income ($n = 2$ [42, 56] out of 2 studies). With the exception of gender, none of the significant findings identified in the included studies were outweighed by a greater number of non-significant findings. In other words, the results described in Tables 2 and 3 were all found to be statistically significant more often than they were statistically non-significant.

Discussion

This systematic review sought to identify barriers, facilitators, and other factors related to LTFU care. The previous guideline provided 19 barriers and 5 facilitators until 2017 [14]. The current study also included articles published after 2017 and identified 85 barriers and 63 facilitators reported by CAYA cancer survivors, HCPs, and hospital managers/policy makers involved in the organisation of LTFU care. Communication and information was the most important category of barriers and facilitators for survivors and HCPs, while managers mainly identified barriers and facilitators related to care characteristics. In addition, we found 9 other factors associated with less LTFU care and 14 factors associated with more LTFU care, consisting mainly of patient characteristics such as age at diagnosis, attained age, descent and treatment with radiation.

Previously, Michel et al. [14] identified lack of experience and inadequate preparation/formal training in survivorship as the most common barrier to LTFU care. The most common barrier in the current study, which was the second most common barrier identified by Michel et al., concerned the widespread lack of knowledge, information and awareness of late effects and LTFU care. These barriers highlight the urgent need for targeted education and awareness initiatives to bridge this gap. An example of such an initiative are the Person-centered, Lay-language, Accessible, International, Navigable (PLAIN) summaries, started in the PanCare group and continued in the PanCareFollowUp (https://pancare.eu/plain-language-summaries/) [66] and EU-CAYAS-NET (https://beatcancer.eu/) projects. The PLAIN summaries provide information on late effects and recommendations for LTFU care and are based on the PanCareSurfUp, PanCareFollowUp, and International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG) late effects surveillance guidelines [14, 67–69]. The EU-CAYAS-NET project aims to establish a European network of young cancer survivors, a knowledge centre and interactive social networking platform that empowers cancer survivors to advocate for their needs and rights. Another useful initiative is the SCP, which was also found as a facilitator both in the current study and by Michel et al. [14]. SCPs, such as the North American Passport for Care [70] and the European PanCare Survivorship Passport [71, 72], can help HCPs to provide LTFU care more efficiently and increase knowledge about late effects and related LTFU care, thereby improving survivors' quality of life and long-term health outcomes. Lastly, with the help of institutions like Childhood Cancer International, local childhood cancer communities across the globe can be brought together to increase awareness, spread knowledge, and help survivors achieve a better quality of life (https://www.childhoodcancerinternational.org).

Inadequate resources, such as a lack of time and funds to travel to the survivorship clinic or to hire sufficient staff, emerged as another common challenge, also previously identified by Michel et al. [14]. In certain clinics, LTFU care is not available at all, which was identified as the main barrier by hospital managers and policy makers. On the other hand, access to late effects specialists and support services, such as social workers

and psychologists, and the ability to communicate with specialists for advice were identified as important facilitators for LTFU care. This highlights the importance of using digital solutions, such as online treatment summaries/SCPs and communication via mobile applications and video calls, which were also identified as facilitators in this review. In addition, there is a need to advocate for policies and funding to reduce the economic burden on both LTFU clinics and survivors seeking LTFU care. Transitional issues, particularly the difficulties of moving from paediatric to adult services, are another common concern that requires coordinated efforts to ensure smoother transitions and continuity of care.

Unlike Michel et al. [14], we also looked at sociodemographic and clinical factors associated with LTFU care. Older age at diagnosis (although not univocal in all studies), non-white descent and treatment with radiotherapy were most frequently associated with less LTFU care. A higher risk or number of late effects was most frequently associated with more LTFU care. Insights into these factors can help to increase awareness among HCPs and hospital managers/policy makers regarding which survivors are most at risk of suboptimal engagement in LTFU care and who may benefit most from targeted interventions to improve LTFU care. Furthermore, while we have distinguished between barriers and facilitators on the one hand and other factors on the other, these other factors can also act as barriers or facilitators. They influence how individuals engage with and participate in LTFU care and thus influence the effectiveness of LTFU care systems.

This review has several strengths, including the comprehensive global scope of LTFU care within our findings which represents different approaches and experiences of various care models. Secondly, the inclusion of barriers, facilitators and other factors as perceived by different stakeholders from qualitative, quantitative and mixed methods studies covers a wide range of relevant aspects of LTFU care. However, LTFU care was not always well defined in the included studies, which may have affected the consistency and comparability of the results. Furthermore, we did not assess the risk of bias in the included studies. However, we consider this to be appropriate given the exploratory nature of our analysis. Lastly, the generalizability of our findings is limited to the countries included in the review, which are over-represented by those from Western European and North American regions. Future research efforts should therefore include under-represented regions to ensure a more complete understanding of LTFU care on a global scale.

In conclusion, major challenges to LTFU care experienced by both survivors and HCPs include lack of awareness, knowledge and information about late effects, lack of financial resources and time constraints. We encourage the use of information and awareness initiatives such as PLAIN summaries, EU-CAYAS-NET, CCI, and PanCare/IGHG guidelines in order to overcome some of these barriers. In addition, the provision of (digital) treatment summaries or SCPs, coupled with online communication and advocacy for policies and funding opportunities, are essential to support the effective implementation of LTFU care. Insights into the socio-demographic and clinical characteristics associated with LTFU care can be used to raise awareness of which survivors are most at risk of suboptimal engagement in LTFU care. Ultimately, the implementation of LTFU care, tailored to the specific needs of survivors, HCPs and managers, will likely improve engagement and consequently the overall quality of life of CAYA cancer survivors worldwide.

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

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Authors' contributions
IdB, JT and SvdO wrote the main manuscript text. IdB and JT prepared all tables and figures. IdB, JT, SvdO, EvD, RM, LK, GL, SP and HvdP were involved in setting up the study methodology. SP and HvdP were the main supervisors of the project. All authors were included in the literature search and all authors reviewed the manuscript.

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