A Qualitative Systematic Review exploring the literature on Teenage and Young Adult and Adolescent and Young Adult cancer patients' experiences of survivorship and Late-Effects clinics.

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Abstract

Background

Adolescents and Young Adults (AYA) and Teenage and Young Adults (TYA) represent a patient population group with complex care needs. Post cancer treatment the patient is confronted by unique physical, psychological and social challenges. Survivorship care aims to address these needs.

Project design

A qualitative systematic review was conducted exploring TYA/AYA cancer survivors' experiences of survivorship and late effects clinics. Four electronic databases were searched CINAHL, Medline, Scopus, Web of Science. The CASP tool was used to appraise the studies methodological rigour.

Findings

Four themes were identified; Lack of knowledge and preparation for late-effects; Barriers in accessing and engaging with survivorship care services; Unmet holistic care needs in survivorship; Poor communication, coordination and transition of care.

Conclusion

AYA and TYA cancer survivors identified limited information regarding survivorship services and late effects risks. Survivorship Care Plans (SCPs) were valuable for information on late effects risks and follow-up schedules. However, it was highlighted that there was limited SCP availability together with fragmented services. The continuity of holistic care that focused on psychosocial well-being, peer support and use of digital tools and programs were vital in the ongoing care of the AYA and TYA population.

Introduction

This dissertation is a qualitative systematic review (SR) exploring AYA and TYA cancer survivor's experiences with survivorship and late effects clinics.

Background

TYA and AYAs are a patient population with unique biological, psychosocial and developmental needs (Carpenter *et al*., 2023). Cancer during this developmental period disrupts physical health, psychosocial wellbeing and key milestones; education, career progression, and relationships (May *et al*., 2018; Ke *et al*., 2020).

Internationally, approximately 1.2 million AYAs are diagnosed with cancer annually (Janssen *et al*., 2021a). AYAs represent a growing cancer survivor population, with five-year survival rates exceeding 80% (May *et al*., 2018).However, survival advances in AYAs are compromised compared to the paediatric and older adult populations (Fidler *et al*., 2019). Treatment for cancer places AYAs at increased risk of late effects and early morbidity compared with the general population, highlighting the need for structured long-term follow-up care (Gianinazzi *et al*., 2022).

Survivors experience prolonged health and quality of life concerns that can persist well into survivorship (Collaço *et al*., 2025). These may include cognitive difficulties, fatigue, reduced physical capacity, body deformity and psychological or sexual distress (Aagesen *et al*., 2024). Survivorship is multidimensional providing long-term monitoring, psychological care and health promotion (Viola *et al*., 2017). Brauer *et al*. (2019) highlights survivorship as a priority, however follow–up remains inconsistent and poorly tailored (Carpenter *et al*., 2025; Janssen *et al*., 2023b).

Rationale

Working as a CNS for this patient group, it was evident that there were limited services locally for AYA/TYA cancer survivors. From an initial literature review it was identified that AYA/TYAs remain an under researched population (Viola *et al*., 2017; Fidler *et al*., 2019). Due to recruitment challenges and anonymity concerns on a small island population a SR was selected as the most appropriate research design to explore the research question.

Research Question

What is known about teenage and young adult/adolescent and young adult cancer survivors' experiences with late effects or survivorship clinics after treatment?

Aims and Objectives

Aim:
To systematically identify, appraise, and synthesise existing qualitative, research exploring TYA/ AYA cancer survivors' experiences, of late effects and survivorship clinics post-treatment.

Objectives:
1. To examine through qualitative studies the impact of survivorship and late effects clinics upon TYA/AYA cancer survivors.
2. To critically appraise the research and synthesise the findings on how TYAs/AYAs perceive the role of survivorship and late effects clinics in addressing their physical and psychological well-being.
3.To identify the reported benefits and areas for improvement reported by TYAs in relation to their experience of survivorship and late effects clinic.

Project Design

Methodology

A qualitative SR was selected over mixed-methods or quantitative approaches due to the nature of the phenomena of interest; exploring TYA/AYA cancer survivors' experiences with late effects and survivorship clinics. Cresswell and Cresswell (2018). Identify that qualitative research explores how individuals or groups interpret and give meaning to social or human issues. SRs are regarded as one of the most rigorous research methodologies for identifying, collecting, critically appraising, and synthesising high-quality evidence related to a specific research question (Munn *et al*., 2018; Randels and Finnegan, 2023).

Qualitative research within healthcare seeks to gather and interpret individual experiences and social interaction to explain the phenomena of interest (Lockwood, Munn and Porritt, 2015; Lim, 2024). An advantage of qualitative research is its ability to understand the complex human behaviours and processes that are challenging to capture through quantitative research (Tenny, Brannan and Brannan, 2022). The review will follow PRISMA 2020 guidelines, ensuring methodological rigour, transparency and reproducibility (Page *et al*., 2021).

Inclusion Criteria

TYA/AYA cancer survivors aged 13-39 years old; Studies published within the last 10 years; Focus on patient experiences; Perceptions of survivorship or late effects clinics post-treatment.

Exclusion Criteria

Paediatric-only populations (<13 years); Studies published more than 10 years ago; Studies focusing exclusively on adult (>39 years) survivors; Articles not available in English; Grey literature, conference abstracts, systematic reviews, mixed-methods studies.

Database searching

The electronic databases searched were: CINAHL, Medline, Web of Science, Scopus. These databases were selected for their relevance to healthcare and extensive coverage of peer-reviewed literature.

Data Reduction and Analysis Methods

The CASP tool was selected due to its structured and transparent checklist to assessing credibility, relevance and rigour across a range of qualitative methodologies (CASP, 2018). The CASP tool for qualitative analysis aligns with Lincoln and Guba's (1985) criteria for trustworthiness, which include credibility, transferability, dependability and confirmability. 15 qualitative studies were selected for this SR. A narrative synthesis was employed to analyse findings across studies. Lisa and Porritt (2016) identify that this method extends beyond describing or summarising the main features of the studies. They highlight that it supports comparison across studies, identification of relationships within the data and assessment of the overall strength of the evidence.

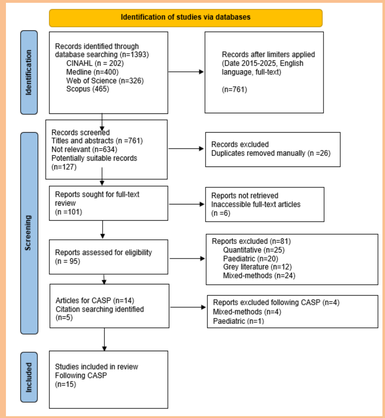
Ethical considerations

In a SR, ethical considerations include accurately representing studies, acknowledging their limitations, and avoiding bias (Prime, 2024).This proposal was submitted for scientific review to the University School of Health Ethics Review Panel (SERP). The proposal was approved, and as a SR, formal ethical approval was not required. In line with the NHS HRA Decision Tool (HRA, no date), this study did not require formal ethical approval from the Jersey Health Research Ethics Committee.

Reflexivity is an important ethical consideration within qualitative research, requiring the researcher to recognise how their background, beliefs and professional experience may influence the research process and interpretation of findings (Gerrish and Lathlean, 2015). As a CNS working with TYA cancer survivors, it was acknowledged the potential for preconceptions that could influence the analysis of this review. To minimise personal bias and ensure transparency, key findings were extracted multiple times into Excel, and each study was appraised using CASP. Lincoln and Guba's (1985) framework supported my judgements to ensure credible and transparent interpretation.

Findings

PRISMA flow



Data Extraction

The following standardised data were extracted from each study:
- Author(s), year, country
- Study aim, design, sample size, ethical approval, consent
- Participant characteristics
- Setting
- Findings

Themes identified

Theme 1	Theme 2	Theme 3	Theme 4
Lack of knowledge, understanding and being prepared for late effects	**Barriers to accessing and engaging with survivorship care services**	**Holistic care needs in survivorship**	**Communication, coordination and transition of care**
Identified in eleven studies.	Identified in ten studies.	Identified in eight studies.	Identified in ten studies.

Theme 1 - Lack of knowledge, understanding and being prepared for late effects

Participants were unaware of late effects believing they would resume normality post-treatment (Aase, Ingebretsen and Hauken, 2022; Murnane *et al*., 2025). Survivors lacked knowledge of risks of late effects and understanding of what long-term follow-up entailed (May *et al*. 2018; Psihogios *et al*., 2019). Survivors preferred follow-up care with their oncologist than general practitioners (GP) due to concerns of GP knowledge and interest in late effects and surveillance for secondary cancers (Ramsay *et al*., 2018). Survivors felt their late effects were dismissed or attributed to psychological causes, causing frustration and feelings of burdening their GP (Aase, Ingebretsen and Hauken. 2022).The absence of structured survivorship education and planning heightened these challenges. Studies reported limited awareness and absence of SCPs (Hydeman *et al*., 2019; Aase, Ingebretsen and Hauken, 2022). Information was described as insufficient or developmentally inappropriate, predominantly in relation to fertility, health promotion, disease prevention and surveillance for recurrence or secondary malignancies (Smith *et al*., 2022a; Figueroa Gray *et al*., 2024). Age-appropriate communication and resources were highlighted as essential, as general adult-focused services and support groups did not meet the AYAs specific needs.

Theme 2: Barriers to accessing and engaging with survivorship care services

Psychosocial and emotional barriers were a common theme for disengagement with survivorship and follow-up services post-treatment. Fear and uncertainty regarding future health, fear of cancer recurrence and late effects were persistent among AYAs following completion of treatment (Psihogios *et al*., 2019). AYAs wanted to distance themselves from cancer ultimately leading to disengagement with ongoing care (Psihogios *et al*., 2019). Participants experienced mental health challenges including depression and anxiety, loss of control and isolation (Figueroa Gray *et al*., 2024). Survivors described a lonely and unsupported transition to survivorship (Aase, Ingebretsen and Hauken, 2022). AYA cancer survivors experienced challenges related to education, employment, relocation and competing life demands which limited their ability to attend follow-up appointments or survivorship programmes (Psihogios *et al*., 2019; Ke *et al*., 2020). Financial burden was a recurring obstacle across studies conducted within the USA. Survivors described lack of insurance, mounting debt and the cost of attending community-based or supportive services as unaffordable, despite perceiving these services as beneficial (Vollmer Dahlke *et al*., 2017; Figueroa Gray *et al*., 2024). Survivors described challenges understanding how to access follow-up care and navigating fragmented healthcare systems (Hydeman *et al*., 2019; Ke *et al*., 2020). Vollmer Dahlke *et al*. (2017) reported that those with access to a specialised AYA program (after cancer care ends survivorship starts [ACCESS]), survivors had an improved understanding of survivorship care, late effects and healthy lifestyle behaviours. Survivors who had a negative relationship with their healthcare provider desired to change providers or failed to attend follow- up appointments (Ramsay *et al*., 2018).

One participant described "*feeling abandoned and alone*" (Aase, Ingebretsen and Hauken, 2022)

Theme 3: Holistic care needs in survivorship

TYA/AYA survivors conveyed the need for holistic multi-professional care in Survivorship that extended beyond disease surveillance and addressed the physical, psychosocial and practical aspects of life post-treatment. Psychosocial needs were a focal component of holistic care. Survivors reported anxiety, depression, identity disruption and difficulties with social reintegration, relationships and returning to education and employment (Walsh *et al*., 2019; Figueroa Gray *et al*., 2024).Mental health support was described as insufficient or inaccessible despite being perceived as one of the most unmet needs during survivorship (Psihogios *et al*., 2019; Figueroa Gray *et al*., 2024). Peer support was emphasised as a key element of holistic survivorship care and vital for reducing isolation, normalising late effects and supporting identity restoration during survivorship. General adult support groups were recognised as being developmentally inappropriate for this cohort of patients (Hydeman *et al*., 2019; Figueroa Gray *et al*., 2024). TYAs favoured peer support over counselling (Collaço *et. al*, 2025). An effective holistic care model identified was the ACCESS AYA program (Vollmer Dahlke *et al*., 2017).

"it wasn't all based on the illness or the complications . . . it was based on having fun, being normal and moving on"

(Vollmer Dahlke *et al*., 2017)

Theme 4:Communication, coordination and transition of care

AYA survivors reported uncertainty of who was responsible for their care, how follow-up should be organised and accessing support for any ongoing concerns (Aase, Ingebretsen and Hauken, 2022; Murnane *et al*., 2025). Survivors reported not being spoken to by HCPs, inconsistent or absent SCPs, limited information and guidance regarding late effects and follow-up schedules and lack of available services (May *et al*., 2018; Psihogios *et al*., 2019). AYAs reported a lack of continuity of care, frequent changes in hospital clinicians and inconsistent handover between oncology teams and GPs. Survivors repeated cancer histories leading to frustration and reluctance to disclose challenges (Aase, Ingebretsen and Hauken, 2022; Collaço *et al*., 2025).Transitions in care were identified as challenging and although inevitable, AYAs felt unprepared and unsupported expressing fear of losing providers, they trusted which led to concerns regarding PCP knowledge of late effects and cancer specific follow-up (Walsh *et al*., 2019; Aase, Ingebretsen and Hauken, 2022). Young adult survivors identified digital communication and coordinated models of care as potential facilitators for improving survivorship services (Psihogios *et* al.,2019; Collaço *et al*., 2025). AYA survivors valued an educational program that supported navigation of life post-treatment and increased
their understanding of survivorship care (Vollmer Dahlke *et al*., 2017; Aagesen *et al*., 2024). The findings highlighted the need for centralised platforms to provide young survivors with up-to-date, relevant and reliable information on survivorship and late effects and the implementation of a care navigator role (Ke *et al*., 2020).

Discussion

This SR and wider literature highlight inconsistent survivorship care and information provision for late effects among AYA and TYA survivors (Figueroa Gray *et al*., 2024). Survivors value holistic, age-appropriate follow-up that prioritises psychosocial wellbeing beyond surveillance for recurrence (Košir *et al*., 2025). SCPs can support information provision and self-management, yet their use remains inconsistent despite guideline recommendations (NHS England, 2023). Barriers to survivorship care include competing responsibilities, service availability and financial challenges (Beauchemin *et al*., 2025). AYAs and TYAs report fragmented care, poor transitions, and emphasise the need for coordinated services, peer support and survivor connection (Carpenter *et al*., 2025; Košir *et al*., 2025).

Limitations

During the course of this SR limitations were identified. Firstly, professional experience and possible influence on study selection; secondly, independent researcher bias; Finally, time constraints and completing this SR in six months.

Recommendations

1. Training, education and awareness of HCPs supporting AYAs and TYAs. Education promoted through in-house training, weekly education sessions and adding an AYA specific module to the medical curricula.
2. The publication of this SR could encourage researchers to build upon these findings by expanding the search to include additional databases and addressing the gaps identified within this review.
3. The dissemination of the findings from this SR could be presented at conferences both locally and nationally to raise awareness of TYAs and AYAs survivorship and late effects needs.
4. The SR has acknowledged the need for primary research into the experiences of follow-up care for AYAs and TYAs post cancer treatment. As there is limited primary research within the UK it is acknowledged that research on post-treatment support is essential within the UK looking specifically at those aged 13-24.

Conclusion

This SR has provided an original insight into AYA and TYA survivorship. It has recognised the need for a standardised approach and terminology for survivorship and late effects care and the need for the implementation of policy and guidelines worldwide. Furthermore, identifying the need for more coordinated and developmentally appropriate survivorship services that support the multidimensional needs of AYA and TYA cancer survivors. The review emphasises the need for improved survivorship education for survivors, HCPs and parents.

"I somehow got this in my head that once I get into remission, I'll be immune from cancer forever. I don't know where I got that idea, but I never asked anyone about it" (Psihogios *et al*., 2019)

References

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