

Psychosocial experiences of child & adolescent cancer survivors

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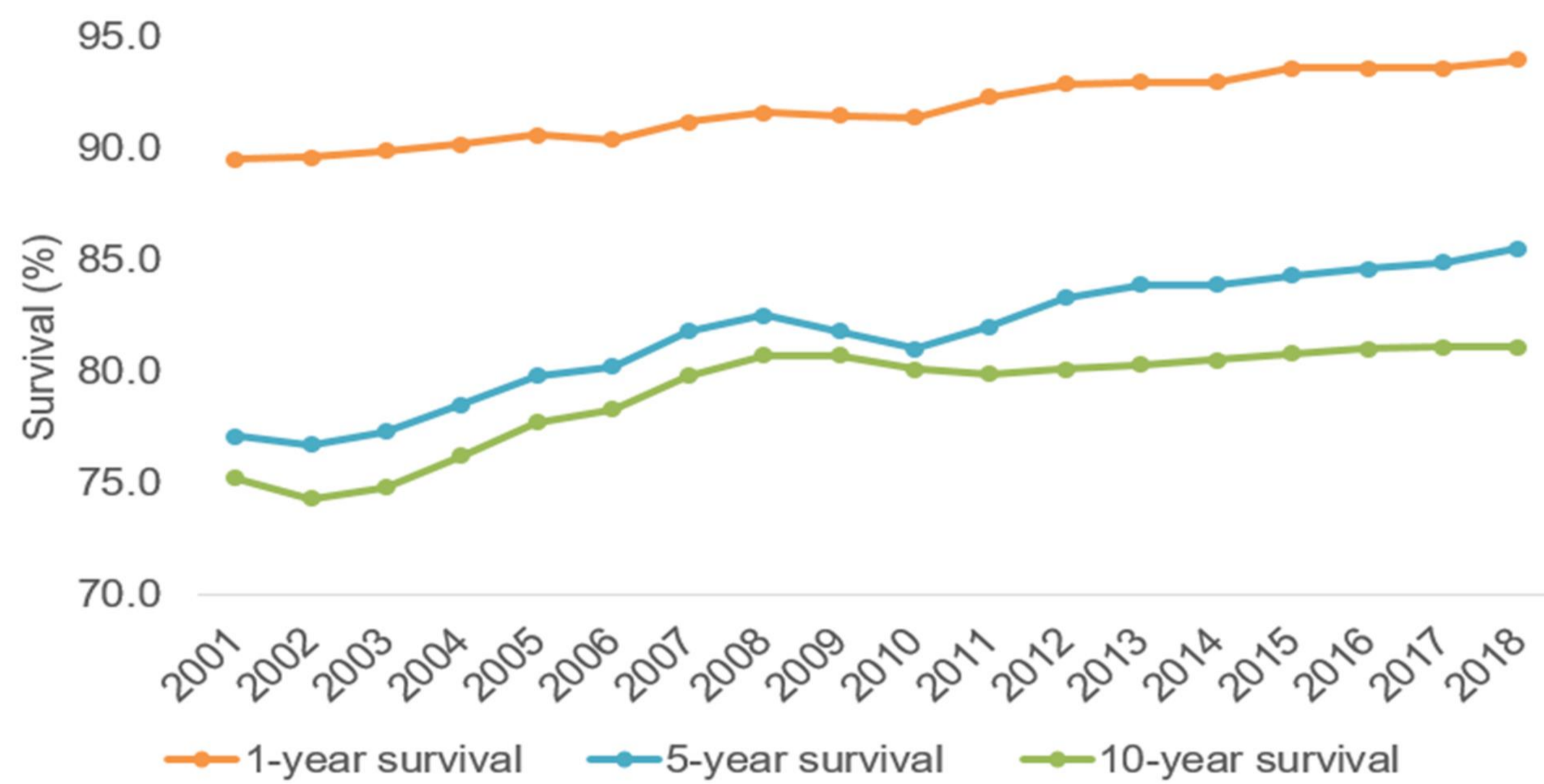
Introduction

Background: Treatment advances have led to an increase in children and adolescents living with and beyond cancer. In Great Britain, 84% of children survive for five or more years after a cancer diagnosis (1). Psychosocial implications are a common consequence, which can have lasting effects. Without addressing them, they can significantly impact quality of life (QOL).

Methods: Multiple databases were searched: CINAHL, Medline, and PsycInfo. Eligibility criteria were outlined prior to conducting searches. Data were coded and thematically synthesised to identify commonalities and differences, and highlight any gaps within the literature.

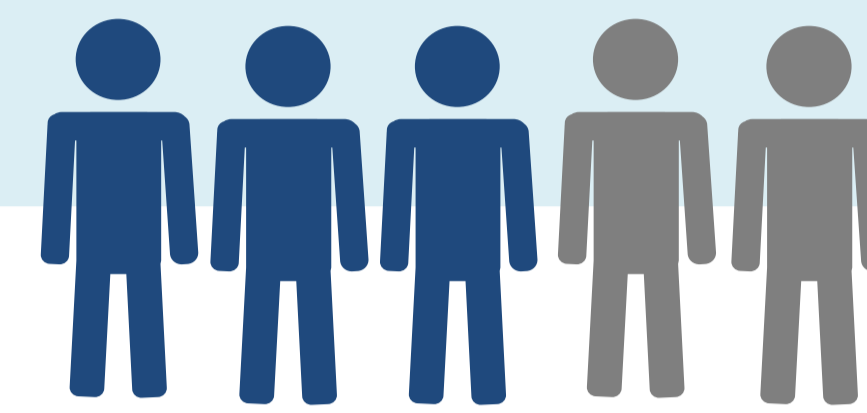


Figure 1: Survival for children (0-14 years) diagnosed with cancer in England between 2001 and 2018 (2)



Survivorship

Increases in survival have resulted in recognition of a distinct 'survivorship' phase. The National Cancer Institute define 'survivorship' as encompassing the physical, mental, emotional, social, and financial wellbeing of a person that has cancer from their point of diagnosis, throughout their treatment, and beyond (3). In this context, it encompasses any difficulties experienced during follow-up care, adaptation to life following cancer, and any late effects experienced by patients.



Psychosocial issues

Three in five childhood cancer survivors develop problems after completing treatment, such as chronic pain, school-absence, emotional struggles, and fertility issues (1). These effects can lead to children being disengaged during social activities or questioning their self-worth. Childhood cancer survivors must deal with the physical, emotional, and social stresses, whilst also trying to manage developmental changes and experiences associated with preparation for adulthood (4; 5).

Policy

The importance of the psychosocial implications of childhood cancer have been recognised in policies which aim to improve care (10). The European Society for Paediatric Oncology developed a set of recommendations around psychological support (11).

In England and Wales, the National Cancer Survivorship Initiative was developed after the introduction of The Cancer Reform Strategy. However, this initiative heavily focused on clinical long-term side effects, and the provision of psychosocial support was not emphasised, despite it being highlighted as one of the main aims. This lack of psychosocial consideration was due to the limited evidence of the needs of cancer survivors, which led MacMillan and NHS Improvement to gather intelligence on patient experiences' and create an updated [survivorship initiative in 2013](#).

Current literature

Reviews conducted in recent decades on psychosocial interventions, largely focus on young adults and there is a clear lack of reviews with children as the main focus. Two reviews found psychosocial interventions are beneficial to help young adults cope with cancer and its psychosocial effects (6; 7). However, a recently conducted meta-analysis contrasts these findings, concluding that the effects of psychosocial interventions were non-significant (8). Another recent meta-analysis suggested inadequate psychosocial support for childhood cancer survivors, due to a lack of personalisation (9).

Methods

A systematic review was conducted, following the recommended principles outlined in the Cochrane Handbook for Systematic Reviews of Interventions (12). Qualitative synthesis methods helped provide in-depth insights into experiences, helping to understand the unique circumstances and needs of childhood cancer survivors, while also identifying potential gaps in current services - this is especially important because psychosocial needs and experiences are likely to continuously change as services and the social environment adapts.

Table 1: Example of themes and codes for thematic analysis

Theme	Code	Sub-code
Physical experiences	Body image	<ul style="list-style-type: none">Physically different from othersFeeling differentBeing set apart from peers, by peersSelf-consciousVictimisedJudged on attempt to fit inPerceptions of selfImage alignment with social context/expectationsFemininityEmbarrassment
	Cognitive	<ul style="list-style-type: none">Memory lossCognitive impairment (due to treatment effects) affects learningCompare to former self (pre-diagnosis/ pre-treatment)Change in personality

Results

Eight studies were included and five themes identified:

1) Social experience

"Your life's put on hold for a bit and you're missing out on memories and you're missing out on, learning, and being with your friends" (Magrath et al, 2021)

2) Emotional experiences

"I do still have those days where I just feel really down...After the treatment I was just really sad, because it was just kind of hard for me to deal with." (Walker et al, 2019)

3) Physical experiences

"When I went back, I had no hair, and they treated me like I was somebody else." (Choquette et al, 2016)

4) Coping

"I watch a video on YouTube and then worries goes away. Maybe I'll go on Vine or Instagram." (Walker et al, 2019)

5) Getting back to 'normal'

"He just wanted to be treated like everyone else, although something had happened. He talked very openly about that, but wanted no different treatment and made that immediately clear." (teacher) (Vanclooster et al, 2017)

Some experiences reflect what individuals have overcome, such as reintegration, and others around what individuals fear for their futures, such as cancer journey preventing future opportunities. Coping mechanisms highlighted include the use of social media, to stay connected with peers, and group social skills interventions.

Practice implications

Findings can be used to inform practice and/ or policy change. By adapting current services, and potentially creating new ones, better life chances can be achieved.

Conclusions

Psychosocial experiences, such as feelings of a decreased self-worth and increased vulnerability, are likely to be deep rooted and therefore require attention to prevent psychosocial implications from becoming a lasting long-term effect.

The current lack of qualitative research exploring childhood cancer survivors' experiences is of concern, and more research is required to strengthen the evidence base.

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