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A narrative review of the late effects of paediatric cancer treatment within an educational setting: Existing evidence and where do we go from here?

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Abstract

Objectives: The late effects of paediatric cancer treatment within an educational context are an area that is relatively under researched within the United Kingdom.

Methods: To support this narrative review, systematic searches were conducted in key scientific databases between May and December 2020.

Results: Upon reviewing literature within this field, there are key considerations that should be addressed to provide clear and concise findings. These key considerations include clarification on whether the research undertaken focuses on the late or long term effects of paediatric cancer treatment, taking a consistent approach to data analysis with the aim to improve the validity of the study findings, utilising a mixed methodology to gain further depth to the findings as well as increasing the number of studies that focus on a specific tumour type rather than numerous types to allow a detailed study to be undertaken into the potential late effects a treatment for a specific tumour may elicit.

Discussion: If these key considerations are taken into account when conducting further research within this field, it would enable consistent findings to be utilised in providing the optimum educational provision for survivors of paediatric cancer who remain within the education system.

Keywords

Paediatric, education, support, wellbeing, mental health

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Introduction

Current statistics estimate that around 1900 new cases of paediatric cancers are diagnosed every year in the United Kingdom (UK),[1] representing an increase in the incidence of

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around 15% since the mid-1990s.[1] Despite this rise, data also indicate that the number of children surviving cancer in the UK has increased to a point where five-year survival rates can be expected to reach 80%.[2] This figure has steadily risen over the years, from around 65% in the 1990s to 80% in 2015.[3] This positive increase in survival can be attributed to the intensive research strategies applied to the development of effective treatments[4] and a personalised medicine approach.[5]

Whilst there has been considerable investment in the clinical management of paediatric cancer patients, the focus is slowly moving towards the trajectory of these patients upon cessation of their cancer treatment and what may lie ahead.[6] Cancer has been identified by the World Health Organisation (WHO) as one of the four most common chronic diseases,[7] suggesting that the effects of cancer and its subsequent treatments may be felt long after the acute phase of diagnosis and treatment has passed. Cancer treatment often involves invasive and arduous clinical procedures that take place over a prolonged period, and when treatment is successful at removing or halting the spread of cancerous tissue, patients are usually discharged from continued care. However, it is well documented that the impact of cancer treatment can persist, causing lasting impact on physical and psychological functioning. The late effects of cancer treatment are an active area of research for both paediatric[8] and adult cancer survivors.[9,10] Within the UK, research focuses on the impact that cancer treatment has on the survivor's health status,[10] physical disabilities,[11] prevalence of secondary cancers[12] and the psychological effects of undergoing treatment.[13]

However, despite this existing literature, there appears to be limited research investigating the impact of cancer treatment on the educational progression and achievement of paediatric patients,[14] particularly within UK educational institutions.[15] Given the statistics on the increase in five-year survival rates, there is likely to be an increasing number of children who return to, or continue with, their education once their treatment has finished, and yet it is unclear what additional support they may require. To gain an understanding of the potential impacts that paediatric cancer treatment may have on childhood survivors' academic education, knowledge must be drawn from other countries, particularly Canada and the United States.[16,17] This represents a gap in the evidence base for the UK context of support for paediatric cancer patients, which merits further research given the increasing priority of this policy area. In support of this, in 2018 the National Cancer Research Institute (NCRI) proposed its UK 'top 10 living with and beyond cancer initiatives'.[18] Within these priorities, educational outcomes were considered under themes addressing survivors with complex needs and support mechanisms to help survivors maintain their usual activities, due to education being a key activity for paediatric patients.[18]

Educational implications of cancer and cancer treatments

The existing literature indicates some key factors that are implicated when investigating links between paediatric cancer treatment and educational achievement. The first key factor is the influence of gender on educational outcomes in cancer survivors. Mitby et al.[16] established that female survivors had poorer educational achievement and cognitive skills after treatment compared to their male counterparts. Explanations for this centred on the effects of irradiation being more marked in females, as well as the finding that girls displayed higher-order cognitive skills, such as verbal reasoning, earlier in development meaning that deficits to these functions were more detectable in female patients. In addition, Dumas et al.[19] identified that females were more likely to have increased absenteeism as a result of undergoing cancer treatment and upon cessation of treatment, females reported

higher levels of distress compared to males. Both factors have been associated with poorer educational achievement.[20]

A second key factor which underlies the association between poor educational achievement and cancer survivorship is the age at diagnosis. Dumas et al.[19] affiliates a younger age at diagnosis with poorer academic achievement. Similarly, research conducted by Harila-Saari et al.[21] observed that female Leukaemia survivors who were diagnosed before the age of seven years of age, had poorer academic performance compared to controls. It is suggested that younger age at diagnosis exerts a greater impact on educational outcomes for two reasons; firstly because the child will likely miss more formal schooling with an earlier diagnosis, and secondly because cancer treatments may cause greater neurological impairment to the developing brain in a younger child.

Aside from gender and age-specific findings, research has also identified that paediatric cancer survivors were more likely to have difficulty maintaining concentration and have lower intelligence quotient (IQ) scores[22] than controls, both of which are key factors linked to educational achievement.[20] Furthermore, there is evidence that social and emotional difficulties are known to exist in the paediatric cancer survivor population, these factors are also consistently linked with poorer educational achievement.[23,24]

Whilst it is clear from existing literature that paediatric patients undergoing cancer treatment experience a negative impact upon their educational achievement and academic trajectory, findings relevant to the education system within the UK are limited. There are also areas of variation within the existing literature in this field of research that currently hinder the effective synthesis of data and conclusions. Examples of this are variations in terminology, variable study designs and patient classification, all of which make systematic review or meta-analysis unfeasible. These areas of contention need to be addressed for research that is conducted to be rigorous and relevant to the UK. This narrative review seeks to assess the current literature on educational impacts from childhood cancer survival and to address the key areas of debate within this field of research, including; defining the use of the terms late and long term effects, optimal study design, participant recruitment and tumour classifications. It also aims to make recommendations for future research focus, to provide clarity for this field going forwards.

Method

In this narrative review, systematic searches were conducted through Medline, PubMed, Science Direct and Google Scholar between May and December 2020. The key words and phrases utilised in the search included, but were not limited to; childhood cancer, cancer survivor, paediatric cancer, survivor and educational support, paediatric cancer and educational achievement, diagnosis, age and gender. To further refine the search criteria, additional filters were applied, these included; full text only, English language and a date range between 2000 and 2020 was used. Articles were selected for consideration to be included within the narrative review if they contained details relevant to the key words in the title and/or abstract. Reference lists of key studies identified through these mechanisms were also utilised to locate relevant literature, given the niche field being investigated.

Discussion

Long term versus late effects

As a result of increased awareness of the ongoing effects of cancer treatment brought about by many articles measuring specific late or long term effects, attention should be drawn initially to the definitions of these terms. As defined by Peter Mac;[25] 'Long term effects are those which begin during treatment and last for years after and late effects are side

effects that do not appear until years after treatment'. This distinction is critical when considering educational outcomes for cancer survivors, as late effects may be less predictable or detectable during formal schooling, thus may result in fewer strategies to provide additional academic support.

The majority of studies reviewed tended to focus on the late effects of cancer treatment. However, very few of these studies actually provide specific statements to indicate that it is in fact late effects that are being measured, as opposed to long term effects. For example, in questionnaires used in Mitby et al.,[16] Barrera et al.,[26] Boman et al.,[27] Koch et al.[6] and Hudson et al.[28] there is no mention of questions regarding when the survivor first experienced the perceived late/long term effect of interest. By not asking this information it is difficult to ascertain the time of onset of the late/long term effect and thereby attribute this to the impact of cancer treatment.

One of the potential reasons for this lack of distinction in the terminology used is that there is currently no consensus on how long it will take for survivors to develop late effects, and also whether each specific late effect has a time-dependent trajectory for its development. Throughout the literature, there are different stipulations surrounding time since diagnosis and/or time since treatment cessation. Some studies have only included survivors who had survived at least five years,[15,16,27,29] others provide an average based on time since diagnosis, examples of these are Halvorsen et al.[20] and Hudson,[28] who included survivors with an average time since diagnosis of 9.21 years. Consequently, some could be longer or shorter than this duration, with a lack of consistency in approach or in reporting. Alternatively, there were examples of good practice, with one study[30] considering both time from diagnosis as well as time since cessation of treatment. The threshold for this was set at survivors having completed treatment a minimum of two years before inclusion in the study and also having been at least five years from diagnosis. The inclusion criteria of the study may prove beneficial in distinguishing a late effect from a long term effect and also if any specific effects are time dependant in their development. This is particularly important as there is limited evidence of the time taken for a survivor to develop late effects of cancer treatment in the literature, with some sources specifying five years[15,16,29] and others speculating a 'few' years.

One limitation of this approach to reaching consensus in terminology use, is that it is difficult to differentiate between what is a late or long term effect, as a patient may have survived five years but still be undergoing treatment. This ongoing treatment, in some circumstances, has the potential to cause long term effects rather than late effects and this could be misleading if the article is reporting the measurement of late effects.[31] Future research within this field should aim to take a consistent approach in determining thresholds for time since diagnosis/cessation of treatment as an initial step to providing consistency in the literature between a late and/or long term effect of cancer treatment.

Participant recruitment and data collection methods

A key theme that became apparent during this review was the high level of variation in approaches to participant recruitment and study design in this field.[6,15,20,28] These differences in aspects of study design could be attributed to some of the inconsistencies in the research field as a whole, as suggested by Ioannidis.[32] For example, in research undertaken by Halvorsen et al.[20] the Cancer Registry of Norway was used as a source of participants. Here, all participants were at least 18 years of age and had received a cancer diagnosis prior to their 21st birthday. Controls were age matched and recruited from a local university. Koch et al.[6] took a similar approach to obtaining participants by

recruiting them through the Danish Cancer Registry. Controls, however, were matched on age and gender from a national statistics record programme. This approach was also undertaken by Lancashire et al.[15] who used data available from the British Childhood Cancer Survivor Study (CCSS) to obtain information regarding survivors, with controls being matched from the general household survey on age and gender. The method of data collection was self-reported questionnaires, which is in concordance with other studies in the field.[6,20] For example, Koch et al.[6] and Halvorsen et al.[20] both used this methodological approach, as well as utilising national statistics programmes to obtain their participants. On the contrary to studies undertaken by Koch et al.,[6] Halvorsen et al.[20] and Lancashire et al.[15] one study[28] used siblings as a control, but this appears to be in the minority as an approach, with most other studies favouring general population controls when analysing the effects of paediatric cancer treatment.

The method of age-matched control recruitment (from the general population) may be the favoured approach to study design to limit the introduction of bias. For example, Halvorsen et al.[20] used university students as age-matched controls, but this does not remove all potential for confounds when considering parity in educational attainment, given firstly, that university students will have already achieved a certain level of qualification and secondly, due to the link between socioeconomic class and participation in higher education there could be a skew in the control matching. This suggests that any research undertaken using only university students as controls is not representative of a broad socioeconomic status and therefore not always fully compatible as controls for paediatric cancer survivors.[33,34] Moreover, university students may also be under a higher level of stress and/or anxiety due to undertaking higher education studies and the requirements to complete coursework and exams that this requires.[35] This could be particularly relevant when considering the most frequent data collection method in this field is self-report questionnaires. University controls may perceive themselves to have increased stress and/or anxiety levels as a result of their current environment, which could increase the reporting incidence against these factors resulting in control data which may not be representative of the general population, and may create a confound when comparing the experiences of cancer survivors in education.

This concern regarding self-reporting in questionnaires extends to both respondents who are survivors and also to parents/guardians who may be completing the questionnaire on behalf of a survivor (in cases where they are a minor). In this situation, it is possible that the survivor or their parent/guardian may over emphasise factors addressed by the questionnaire, such as educational achievement, which may introduce bias when analysing grades attained. There may also be differences within data obtained from parent/guardian questionnaires when asking for reports of any cognitive problems (such as memory loss) in the cancer survivor, compared to the responses given by/or perceived by the survivor themselves.[36,37] Research has identified discrepancies between the academic scores given by the student compared to the scores given by a teacher,[38] a further example of how the respondent may overestimate their academic ability and as a result introduce error into the study.

Some studies took the approach of using siblings as a control to assess educational attainment in cancer survivors,[20] however, this could potentially introduce confounds as a result of the shared lived experiences of siblings.[14] Specifically, the siblings of paediatric cancer survivors may also have poor school attendance due to the negative impact of their sibling's cancer diagnosis, or logistical issues to do with accessing treatment. This suggests that using siblings as a control to compare the academic achievement of survivors may bring about inaccuracies due to the fact that they

may also have been negatively affected academically, and therefore would not be a reliable representation of the general population.[14]

An additional consideration when evaluating the study design of the existing literature is that a common inclusion requirement was for participants to be at least 18 years of age to complete the questionnaires. This is understandable in order to overcome methodological issues surrounding consent, as these are significantly reduced when including only adult participants and could have been a barrier to data collection. However, taking this approach requires participants to remember information and events from the past (sometimes many years have lapsed since diagnosis and/or cessation of treatment) and therefore could be a source of error.[39] Retrospective surveys are an approach that has been deemed unreliable in other specialisms.[40,41] To enhance data accuracy, questionnaires should ideally be completed a short time after cancer treatment ceased or within the time frame identified for the development of late effects, to reduce the likelihood of error and recall bias becoming a systematic flaw with the study design.[42]

Across this area of literature, it is noteworthy that the majority of the key studies investigating educational outcomes in paediatric cancer survivors[6,26] were conducted in the early 2000s, as most would now be considered historic as opposed to current research, given the range of years the data were collected over. Koch et al.[6] included survivors diagnosed between 1960 and 1996 and Barrera et al.[26] included survivors diagnosed between 1982 and 2001. Aside from the age of the published research, the timeframes of the survivors' diagnoses do not allow for the inclusion of survivors who were diagnosed and treated as a result of advancing treatments and personalised medicine approaches, one of the primary aims of which is to reduce the incidence and severity of side and late/long term effects. This is particularly relevant to central nervous system (CNS) tumour survivors as there is now an increased understanding of the molecular mechanisms underpinning CNS tumour growth and metastases, which will undoubtedly have an impact on the treatment regimens offered.[4] Thus, including paediatric cancer survivors who have experienced modern treatments could provide more relevant information regarding the effectiveness of personalised medical approaches in reducing late/long term effects and if these have any educational implications.

Tumour classification

There is consistent evidence, within the literature, that one group of survivors, in particular, are significantly affected by their tumour diagnosis and subsequent treatment; these are survivors of CNS malignancies.[16,28,31] Research by Hudson et al.[28] suggests that survivors who underwent radiotherapy to the brain as part of their treatment regimen had the highest percentage of functional impairment, the educational impact of which was determined in further research undertaken by Mitby et al.[16] This study found that survivors of CNS tumours were 13.3 times more likely to be in special education compared to sibling controls. Crucially this finding displayed a dose–response effect, whereby an increase in the dose of cranial radiotherapy coincided with an increase in the odds of the survivor requiring the support of special education services. Further supporting these data, Ness and Gurney[31] reported that survivors who sustained whole-brain irradiation during treatment were more likely to have deficits in intelligence, and that this was positively correlated with visual reductions in white matter within the brain, a link previously documented.[43] The same associations were made for survivors who received 24 h gray (gy) radiation, as they were found to report reduced levels of attendance and increased usage of special education services.

Taken together these findings indicate that whole-brain irradiation reduces the volume of white matter within the brain, which then

manifests in a decline of cognitive function. This links to the gender-specific differences in cognitive decline that have been reported earlier, in which female survivors are at an increased risk of underperformance and achievement academically. This has been attributed to the sexually dimorphic differences in fibre density and white matter of the female brain, which has been found to differ throughout childhood and adolescence.[44] This finding may have an impact upon the type and frequency of academic support that is required and provided, thus, is another area requiring further investigation.

Deficits in intelligence and cognitive function amongst survivors of CNS tumours are also evident from other research which shows that CNS survivors are more likely to perform poorly academically, as well as being less likely to obtain a degree or teaching qualification.[15] Similarly, Koch et al.[6] found that upon comparison, the educational level completed by CNS survivors was disproportionately lower than non-CNS survivors and controls, however, the odds ratio of requiring support from special education services decreased as the year the survivor underwent treatment in moves nearer to the present day.[37] This may provide some support for the advancements in medical techniques and a move towards personalised medicine.[45]

To examine these findings in detail it is important to consider further factors that may contribute to poorer educational achievement and progression. One of these is increased absence from school due to undergoing treatment, which for CNS survivors is often lengthier in duration than other tumour types. The use of chemotherapeutics as part of a survivor's treatment has been associated with a decline in intelligence and thus academic ability, particularly in the case of cisplatin and carboplatin[46] and this is reportedly due to their effects in the reorganisation of white matter,[43] a theory that provides support to previous research on this factor.[31] In reality, it would be likely that the tumour type as well as the treatment regimen both contribute to the adverse effect on academic achievement and progression. There are, however, questions arising from these findings regarding tumour and treatment type. These include outstanding data on why survivors of CNS tumours are less likely to complete the same level of education and have poorer educational outcomes compared to controls, even when they are supported with the provision of special education services in many cases. It is possible that this difference could be due to the anatomical changes found in the white matter as a result of radiotherapy and some chemotherapeutics, which cannot be compensated for by additional academic support. Alternatively, it could be that these differences can be attributed to the effectiveness of special education services and the support that is offered to survivors. There is limited data within the literature to answer these questions, as this is not a focus for most studies within the field, including those undertaken by Mitby et al.,[16] Koch et al.,[6] Halvorsen et al.[20] and Lancashire et al.[15] This indicates the requirement for further research within this area that may highlight positive and negative aspects of special educational support services, as well as identify areas of enhancement to benefit cancer survivors.

It should be noted that although survivors have been found to utilise special education services more frequently than controls, those who are diagnosed at a younger age remain there for the longest duration Mitby et al.[16] This could be due to the ongoing need for additional support due to factors previously described or, unfortunately, this could also be due to additional funding available for special education students[47] resulting in a beneficial financial situation for the educational establishment in which the survivor is attending. The reason for such an extended duration could also be due to the survivor becoming reliant on this additional support and then struggling to adapt to inclusion within mainstream educational pathways. Literature on this topic

suggests that there is currently no data available to identify the number of students who re-enter mainstream education but cannot manage academically and therefore they return to special education services. This is an area requiring further investigation.

Conclusions: where do we go from here?

Considering the topics discussed in this review, future research within this field should aim to address the following issues with the goal being to improve outcomes for paediatric cancer survivors, particularly within an educational context. Firstly, a clear definition within future studies as to whether late or long term effects are being measured would avoid misinterpretation of research findings and allow for clearer conclusions to be drawn regarding the educational impacts. This may help improve predications relating to the provision of academic support. For research specifically measuring late effects, then justification should be given for the selected time duration since the cessation of treatment within the methodology, as presently this is study-dependant with limited consistency. Inclusion of questions relating to the onset of the late/long term effects may also assist in determining a late effect from a long term effect, thereby, improving the reliability of any findings.

Secondly, focusing on a single source for accessing survivor's information within the UK would remove variations in data collection methods and make comparability between studies undertaken in the UK less complicated. An example is the CCSS[48] that has been used as a source of information in the Lancashire et al.[15] study; having further studies using this information source would improve the consistency of findings allowing for a more robust practical application. Lancashire et al.[15] also uses general population controls, which, if applied to further studies within the UK, could remove systematic bias that is introduced by using sibling and other student controls. Alongside this consideration for future research, using a mixed-methods approach to data collection may be beneficial in acquiring information relating to recent treatment advances. Questionnaires or pre-collected survey data such as the CCSS could be combined with focused interviews to gain a deeper understanding of the impact of cancer treatment on the survivors' education and help to answer questions regarding educational impacts of the cancer treatment that are possibly not included in surveys such as the CCSS.

Problems introduced as a result of recall bias, as discussed earlier in cases where survivors or their parents/carers are completing retrospective questionnaires, could be addressed in future research by seeking to find out the specific treatment regimen the survivor underwent. This data could be obtained from medical records (providing the appropriate consent, data protection and ethical issues had been considered) alongside confirmation of their educational achievement, which could be seen on certificates or through contact with the student's educational establishment. Adopting this type of mixed-methods approach in future study designs could be pragmatic, as such information could be obtained prior to or during an interview as well as obtaining the necessary consent for the researchers to access this information.

Finally, focusing on distinct tumour types within studies could provide a greater understanding of how the specific treatment mechanisms related to different cancers impact on the survivor's educational attainment and experiences. In studies where multiple tumour types are analysed it can result in superficial outcome data, as the focus is on the number of tumour types included in the study as opposed to the specific effects of the clinical treatment for each tumour type independently. For example, in CNS tumour survivors, further research could address the specific radiation dosages that are used in treatment regimens to determine if any significant

differences exist between dose strengths, and the implications this has on the survivors learning and educational achievement. Findings from this type of research will also have clinical relevance as they can be used by the doctor, patient and family in treatment decision making to ensure that if dosages of radiation are required that have been found to negatively affect the patient's ability to learn, then educational support can be put in place promptly upon cessation of treatment, or even before treatment ends. Closer links between medical and educational professionals may help ensure a smooth transition from completion of medical treatment to returning to education, as well as ensuring suitable support is available for the patient's needs, which may help them return to full-time mainstream education and avoid over-reliance on additional support services. Taking these factors into consideration when undertaking future research into this area may contribute to improving both medical and educational outcomes for paediatric cancer survivors.

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