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What effect does a cancer diagnosis have on the educational engagement and school life of teenagers? - A systematic review

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Objectives A diagnosis of cancer during the teenage years arrives at an important stage of development, where issues of normality, identity and independence are crucial. Education provides opportunity for peer contact, achievement and development for teenagers. This systematic review examined how a diagnosis of cancer impacts on the educational engagement and school life of teenagers.

Method Five electronic databases were searched, returning a total of 3209 articles. Inclusion criteria were broad to allow for the range of literature within this area. Following screening, 22 articles (inclusive of both quantitative and qualitative methodologies) were retained and subjected to independent review and quality assessment.

Results Key areas involved in the impact of a cancer diagnosis on teenagers' educational engagement include; school attendance, reintegration, peer relationships and long term effects on education and employment.

Conclusion School absences are a concern for teenagers, but do not necessarily lead to a reduction in educational and vocational attainment. It is important to involve healthcare and education professionals, as well as parents and teenagers themselves in school reintegration if it is to be successful. Peer groups and body image are two areas that could mediate education engagement for teenagers. Further research needs to be undertaken to determine the overall impact of successfully maintaining education engagement specifically for teenagers, the role that peer groups play in this process and how education engagement contributes to the overall coping and wellbeing of teenage cancer patients.

Keywords: adolescence, cancer, education, oncology, systematic review

Introduction

Cancer is the most common cause of non-accidental death amongst teenagers and young adults worldwide and every year approximately 2000 teenagers are diagnosed with cancer in the UK alone [1]. Experiencing cancer and curative treatments during

adolescence can trigger a range of psycho-social difficulties [2]. Some of these difficulties reflect a compounding of normative developmental concerns, such as those relating to body image [3], peer relationships [4] and developing a sense of self [5]. Teenagers with cancer may also face non-normative psycho-social issues, such as those relating to an illness identity [6], an altered experience of time, the impact of illness on romantic and sexual intimacy and the effects of reduced engagement with school life and education [7]. This paper focuses on this latter issue and examines how a diagnosis of cancer impacts teenagers' involvement with their education and school community.

Previous research has shown that teenagers with cancer are more likely than healthy peers to have school absences [8] [9] and repeat a year at school [10] [8]. A cancer diagnosis leads to more absences than other chronic diseases [9] and absences are a particular problem in the year after diagnosis [9]. Teenagers with cancer are also more likely to require some form of special education [10] [11] [12].

Education attainment is a significant predictor of future employment for cancer survivors [13] and teenagers with cancer are identified as a group with a greater chance of future unemployment [11] [12]. The precise impact of a cancer diagnosis on future employment has however been shown to be mediated by age at diagnosis, with the career maturity of younger teenagers with cancer significantly less developed than healthy comparators, whereas older teenagers show tendencies to prematurely foreclose on career decisions [14].

In addition to the impact on school attendance and employment prospects, an extensive body of research has examined the psychosocial outcomes of continued engagement or non-engagement with schooling following a diagnosis of cancer. For example, sustaining regular involvement with school appears important for well-being [15] and global self-worth [16], whilst limited engagement can lead to feelings of social isolation [10] [15] and difficulties with peer interactions [10], especially among teenagers who require extended periods of home schooling [15]. However, considerable individual variation exists in what promotes or constrains teenagers' sustained engagement with education and their school community following a diagnosis of cancer [17], [18] and to date, there has been no systematic review of this literature. Thus, the aim of this paper is to conduct a systematic review to evaluate the

evidence on the ways in which a cancer diagnosis impacts on the educational engagement of teenagers. The term ‘education engagement’, as used in this article, refers to the extent to which teenagers remain in contact with school and/or receive educational support whilst undergoing treatment or during recovery. Currently the literature concerning education engagement for teenage cancer patients is focussed on specific aspects of education or overarching views of psychosocial care that include education as a small sub-section. Alternatively literature focuses on the education outcomes for survivors of childhood cancer and it is unclear how much research specifically focuses on education engagement for those individuals diagnosed as teenagers. This article attempts to identify the primary issues involved in education engagement for this group and bring them together in one place. Such a review is needed to assist healthcare providers in ensuring teenagers with cancer are not ‘lost’ in the transition to adult services, but are appropriately supported in sustaining a relationship with school and education if that is shown to have strong links with good psychosocial outcomes [19] [20] [7].

Methodology

Ethical approval was not required for this systematic review, which was conducted in 2009. The following databases were searched electronically; MEDLINE, EMBASE, PsycINFO, CINAHL and ASSIA. The search strategy involved using the MeSH terms for the patient age group (‘teenage’, ‘adolescent’, ‘young adult’). Age groups are not consistently defined within the literature and these three terms were used to capture any articles that could include teenagers (13-19 year olds). This group was then combined with the MeSH terms for cancer (usually ‘neoplasm’). This ‘teenage cancer’ group was then combined with MeSH terms relating to education (‘education’, ‘school’, ‘mentoring’, ‘teaching’) and an additional group relating to psychosocial support (‘social support’, ‘psychosocial’). Psychosocial and social support were included due to the fact that some psychosocial research includes education as a sub-section and has the potential to contribute relevant findings. Alongside the MeSH terms, a truncated keyword search (educat*, teenage* etc.) was also carried out to maximise inclusion. An additional search of PsycINFO was conducted using ‘academic self-concept’ in place of ‘education’ as this is a term often used in research within education and would maximise inclusion at this stage.

Inclusion criteria

Studies were included in the review if they focussed on any aspect of the education of teenagers diagnosed with cancer between 13 and 19 years of age, regardless of the time since diagnosis. To be included, the study sample could extend beyond these age parameters provided the results for our target age range were clearly identifiable. Papers must have reported empirical studies, in peer reviewed journals and be available in English. Studies with non-English samples were included with acknowledgment that education and support systems vary by country.

Exclusion criteria

Studies were excluded if they failed to meet any one of the inclusion criteria. Hence, studies were not included if they involved a sample who were not between 13-19 years at the time of diagnosis. Studies which focused solely on the impact of having a teenager with cancer on the family were excluded. Studies concerned with educating teenagers about cancer were returned in the search given the selected keywords; following initial screening these were excluded due to lack of relevance. Systematic and other review articles were also excluded as they do not directly report empirical studies. Studies focussing on teenagers with brain tumours were excluded due to the well defined specific education implications of this diagnostic group [21, 22].

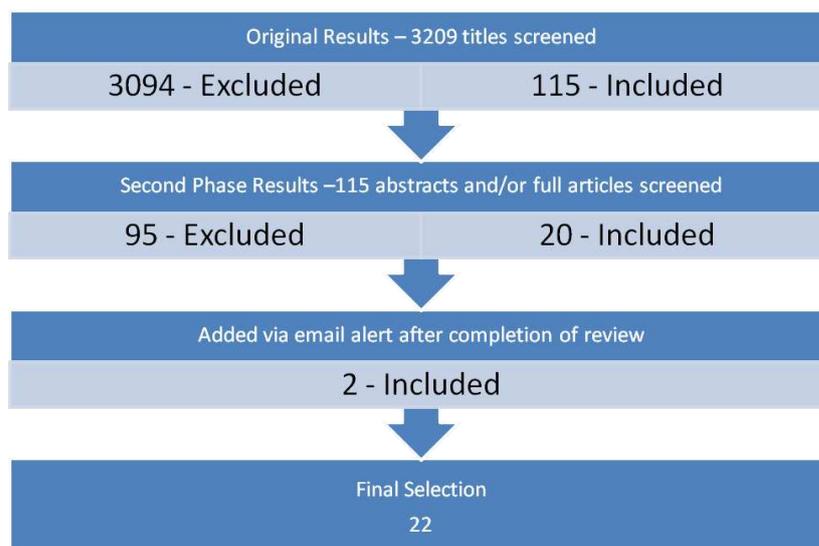
Quality Assessment

To assess the methodological quality of the 22 studies in this review, a new validated quality assessment tool was used [23]. The tool allows equitable comparison of empirical studies that utilise quantitative or qualitative methodologies. Each paper is rated on a scale of 0-4 on; aims, theoretical framework, sampling, data collection, recruitment, measures, analysis, user involvement, strengths and limitations [23]. Using this method each paper was assessed by the first author (SP) and allocated a quality score, with a maximum score of 42 and a minimum of zero (see study table). The total quality score of papers in this review ranged from 6 to 34. Despite the absence of an official 'cut-off' score for the quality assessment tool, the lowest scoring paper [18] was subsequently removed from the review as it was significantly lower than the other articles. Scores of the remaining articles ranged from 22-34 and

received high ratings for study design, sampling and appropriate analytical methods. However, some papers scored less well on explicit justification for the measures chosen for data collection and the method of analysis chosen and there was often a lack of user involvement in the research process, with 16 studies demonstrating no patient involvement.

Results

A large number of articles were returned due to the wide search terminology used. Non-English language articles and studies relating to animals were used as exclusion criteria from the outset. The titles of all remaining articles were initially screened by the first author (SP), using the defined inclusion criteria, who subsequently screened abstracts and full articles to refine the final selection by reviewing and establishing further exclusion criteria. The literature search produced a total of 3209 articles, including duplicates (PsycINFO – 200, Medline – 2440, Embase – 90, CINAHL – 213, ASSIA – 127, PsycINFO – 139). This number was reduced to 115 after screening the titles for suitability using the specified inclusion and exclusion criteria. The abstracts of these papers were examined and, where relevance was indicated, the full paper was reviewed. Only 20 articles remained for inclusion within the review at this stage (see Study Table). The original completion date of the literature search was 30/11/2009 and since this date 2 further articles have been included in the review after being identified through monthly email alerts from the OVID databases, bringing the final inclusion total to 22 articles.



Of the 95 articles excluded in the second phase, 35 included age ranges beyond the target parameters or were unclear about the age of the sample at diagnosis; 27 were not related to education; 17 were not published in peer review journals; 7 involved a sample of patients with brain tumours; 8 did not focus on the experiences of the teenagers themselves and 1 was excluded following quality assessment (detailed below).

Out of a possible 3209 articles returned in the search, only 22 articles met the criteria for full review. The number of initially returned articles was large because of the very open search criteria used to enable the detection of any papers discussing education engagement for teenage cancer patients. That only 22 articles remained after the application of inclusion and exclusion criteria suggests that there is a scarcity of research focussing specifically on teenagers with cancer and their engagement with education. This would appear to be due to the fact that education issues for teenagers tend to appear in the literature as a subsection of psychosocial care needs or are combined into reviews of education for children with cancer. There is a wealth of literature discussing the specific needs of this age group and therefore any aspect of their care, including education, needs to be addressed independent of the needs of children and adults. Had articles focussing on other psychosocial or information needs of teenagers with cancer, or the education of paediatric cancer patients been included, then the number of articles eligible for the review would have been considerably higher.

Study details (see Study Table for more details)

Of the studies included in this review, 10 were conducted in the United States, 3 in Sweden, 2 in the U.K, 2 in Canada and 1 each in Germany, France, Finland, Denmark and Australia. A range of methodological approaches were taken; 9 used quantitative methods, 7 qualitative and 6 used a mixed methods approach.

Qualitative studies included semi-structured interviews, grounded theory interviews, focus groups, written narratives and group therapy sessions; quantitative studies utilised standardised measures and questionnaires (detailed in Table 2) and mixed methods studies were typically a combination of interviews and standardised measures.

Table 2 – Standardised measures and questionnaires utilised in 7 studies that adopted quantitative paradigms
The Information Preferences for Adolescents [24]
Life Situation Scale for Adolescents [25]
HADS and SF-36 [26]
‘Peer comparison’, ‘Self-Perception Profile for Adolescents’, ‘Children’s Loneliness’ and ‘Social Satisfaction Questionnaire’ [4]
Vocational Rating Scale (VRS), Career Planning scale (CPS), Career developmental task scale (CDTS), Tendency to Foreclose scale (TTF), Career development assessment inventory (CDAI), Offer Self-image Questionnaire (OSIQ), Social Provision Scale (SPS) [14]
Study-specific Questionnaire [27-29]

Measures and questionnaires were completed from the perspective of different groups. For example, Moore [30] invited parents, school personnel and nurses to provide an assessment of barriers to education, whereas Stern [14] used a range of questionnaires completed by teenagers alone to assess the impact of cancer on career progression.

There were also considerable differences in sample size within the studies. Qualitative studies ranged in number of participants from 11 [31] to 35 [32]; quantitative from 34 [4] to 14,054 [13] and mixed method studies from 10 [15] to 76 [33].

Discussion

The studies included in this review were designed to examine specific aspects of education engagement for teenage cancer patients. Owing to the methodology used in individual studies and variation in research questions and focus, no meta-analysis of studies was possible. Therefore, prominent issues addressed by the studies were identified and are reported here. The core issues across studies were school absence, reintegration, peer interactions and long term impact will be discussed in terms of their effect on the education engagement of teenagers. The articles identified in this review will provide the information and context for the discussion of these themes.

School absence

A diagnosis of cancer and subsequent treatment mean significant absences from regular schooling for teenagers [28, 30, 34, 35] with absences during the first year after diagnosis averaging 40 to 60 days [30]. Sometimes the ill teenager needs to repeat an entire school year [33, 35]. Teenagers have been shown to be a particularly high risk group for extended school absence compared to younger children with cancer [35]. Attendance can continue to be irregular for up to 3 years after diagnosis [30] and difficulties in catching up with work missed can be experienced by some teenagers up to two years later [34]. Bonneau showed that, as well as being in secondary education, other risk factors for repeating a year of education included; the education level of parents, bone marrow transplant, cerebral surgery and enduring physical difficulties [35]. Despite the increased likelihood of school absences presented by a diagnosis of cancer, Manne reports that through more successful management of side effects and a greater emphasis on outpatient care, the extent of school absences by teenagers with cancer is being addressed [28].

Teenage patients experience the possibility of school absence as a primary concern as early as at the point of diagnosis; along with concerns about not getting well, mucositis, nausea and painful procedures and treatments, these anxieties reached the cut off scores for potential clinical anxiety in 12% of the sample and in 21% for potential clinical depression [26]. Teenagers report that increased school absence can be for numerous reasons including; decreased energy and concentration [34], decreased cognitive ability [34] and sometimes the 'intolerant attitude' [p270] of school staff regarding their reintegration [32]. However, this does not necessarily equate to long-term poorer academic outcomes. Moore [30] reports no significant relationship between perceived academic performance / ability and days absent from school when using parental perception as an indicator. Dieluweit [36] showed in a sample of German survivors of teenage cancer that survivors actually achieved higher educational and vocational levels than healthy controls, even though the survivors did not enter higher education or employment until later in life.

Reintegration

Reintegration appears to be an important issue in this area and can be discussed in terms of (i) teenagers' concerns, (ii) facilitation, (iii) support from healthcare professionals and (iv) support from school

(i) Teenagers' concerns:

Returning to school after a diagnosis of cancer has been shown to be a major challenge for the ill teenager and school staff [21] and a primary concern for teenagers as early as diagnosis [24]. This concern can stem from teenagers fears about being accepted back into their peer group and having to build new friendships [24, 37], alongside worry about being teased or bullied about their appearance due to hair and weight loss [27]. Grinyer [32] reports that 'hair loss was the single most commonly experienced effect on appearance, and could threaten self-belief and self-esteem to a perhaps surprising extent' [p271]. Teenagers have reported that hair loss affects their confidence and reduces willingness to engage in social activities, including attending school during treatment [28]. Palmer [38] found that, out of all the possible pains associated with having cancer, 'being teased about their appearance when returning to school' [p50] was rated by teenagers as the worst. This negative effect has been shown in other studies where teenagers have expressed being bullied at school [39] due to negative body image. Searle [15] reports that this negative body image can lead teenage patients to request home or hospital schooling during treatment, which can be very beneficial to patients in this group, especially if restricted to the short-term. However, many patients find that the reality of returning to school is not as difficult as they had imagined [15] and that some education staff can be understanding and will facilitate their return [29].

As well as concerns about peers and body image, research shows there can be specific academic concerns [15]. Teenage patients who have been in hospital schools may be concerned that the work in those settings is 'too easy' [p352] and worry about their ability to catch up with their regular school curriculum [15]. Despite these concerns, Searle found that the majority of patients who had been enrolled in hospital schools successfully reintegrated into their regular schools [15], although the article does not include data relating to the length of absence as a mediating factor.

(ii) Facilitation

A mediating factor for reintegration is the ability for education staff to make adjustments and facilitate reintegration of teenage patients back into school through collaborative planning with medical staff [15, 29]. However, when this collaboration is not successful it has been shown to be a major barrier to effective education services for teenage patients [30]. Both families and professionals identify the need for a designated co-ordinator of education for teenage cancer patients. [29, 30]. The application of this co-ordinating position appears to vary considerably between institutions regarding the responsibility of the staff involved, the length and execution of the planning and the involvement of the patient, parents and peers. Increased knowledge of the teenager's situation has been shown to encourage education staff to make more time for the returning student, which appears to be highly valued by the teenage patients [29]. Parents have reported the desire for more information about their child's cancer to be given to teachers and peers [29] and parents themselves seem to have an important influence on successful multi-disciplinary working [30, 35]. Moore reported unsuccessful communication between parents and staff was a major barrier to successful reintegration and that staff were often uncertain how to help parents negotiate school systems [30]. This appears to place the emphasis on parents being in control and healthcare staff supporting, whereas it has been shown elsewhere [18] that a specialist co-ordinator can relieve some of the pressure on parents to organise their child's education and reintegration.

(iii) Support from Healthcare Professionals:

As well as providing medical information to school staff, peers and the school community, healthcare professionals have been shown to have an important role in encouraging teenagers to engage in education where possible [15]. It has also been shown that a significant role for healthcare professionals is in helping to decide the most appropriate environment for education considering the medical and health needs of the teenager. This can be homebound, hospital or community based education and healthcare professionals should take into account 'social, emotional and academic, as well as health factors' [p383] [15] when making these recommendations. The precise solution to the correct education environment for a teenager needs to be individually tailored, as Searle showed that a teenager's engagement in education prior to

diagnosis was an important mediating factor affecting teenagers' reaction to changing education environments [15].

The absence of specialist teenage oncology staff from education co-ordination has been shown to increase the stress experienced by teenagers going through treatment, through a lack of understanding of their needs [32]. However, Moore [30] reports that nursing staff perform 'few services to facilitate re-entry' [p90], that these services were 'moderately helpful' [p92] and that additional services including technology, educational support and hospital tuition would improve services.

(iv) Support from school

Patients have reported low levels of satisfaction with the support they received from teachers [25]. The reasons for this include; negative staff attitude [39], that school staff did not think the patient could pass their courses [32] or that teachers ignored health plans [30]. Moore [30] found that parents felt that teachers were not willing to help 'one child when they have so many others' [p95]. Other studies, however, have found that school personnel were flexible and supportive within their capabilities [29]. From the teachers perspective, it has been found that they do not always rate the support they give as particularly helpful [30] and have been shown to know what services would support patients, but were not clear who had responsibility for implementing this support when so many people are involved in the teenager's care [30].

Perhaps as a result of incomplete knowledge of the cancer experience, teachers have been shown to have lower expectations of the academic ability of patients compared with healthy controls [21]. Collaborative planning and information sharing clearly increase the understanding of the ability of teenage patients to engage in education activities [29, 39]. Ongoing education planning and collaboration has an important implicit message to the teenage patients; that planning for the future remains important and appropriate.

Peer Relationships

The importance of peer relationships as a mediating factor in the ability of teenagers to engage in education was reported in 12 papers [4, 15, 24, 28, 29, 31, 32, 34, 37-40]. Peer relationships can therefore be discussed as an important issue in this area and can be considered in terms of; (i) level of contact with pre-diagnosis peers and (ii) peer support from other patients.

(i) Level of contact with pre-diagnosis peers

Findings suggest that a diagnosis of cancer leading to absence from school can adversely affect a teenager's interaction with their peer group [4, 15, 24, 28, 29, 32, 34, 38-40], although this situation is improving in some areas through increased emphasis on outpatient care and side effect management [28]. Decker [24] found that 'relationships with friends' [p331] was second only to 'dealing with procedures' [p331] in the concerns of newly diagnosed teenagers. Manne [28] reported that teenagers diagnosed with cancer have, on average, smaller social networks compared to healthy controls. Teenage patients can find it demoralising if repeated attempts to engage with their peer group are thwarted by their illness and treatment [32]. Illness related differences between patients and their pre-diagnosis peer group can also contribute to the patient feeling socially isolated [34] and teenagers who feel different from their pre-diagnosis peer group have been shown to report more loneliness, reduced social acceptance and lower self worth, as well as being less satisfied with their physical appearance [4].

Teenage patients often express feelings of not being understood by their pre-diagnosis peer group [38] and of being 'left-behind' [p220] as their peers move on with their lives [32]. Although maintaining contact with peers is important, sometimes patients state that it can 'hurt to be reminded' [15] of the activities they are missing out on. In this situation, teenage patients can intentionally 'cut off relationships' [p382] by not allowing friends to visit while they are unwell [15]. Woodgate [40] noted the potential importance of a 'special friend' [p125] in maintaining this contact with peers at school, which was usually a lifelong friend.

(ii) Peer support from other teenage cancer patients:

Teenage cancer patients have been shown to provide important peer support to each other [31, 37, 38]. However, this contact with other teenage patients is still seen as an unmet need in some areas [29]. Teenage patients sometimes report feeling more mature than their pre-diagnosis peers [15, 34] and that can lead to a perceived lack of understanding and increased distance from this group. By developing peer relationships with other cancer patients, teenagers have been shown to make positive comparisons and have a more positive self-concept through placing their own situations in a more appropriate context [4]. This strengthened self-concept can lead patients to feel reduced social isolation and increased self-esteem [4]. This support between patients is important as it can increase the likelihood of successful interactions with other peers at school and in the community through reduced illness related anxiety and good relationship modelling [41]. As well as meeting other patients on wards and in clinics, support groups have been shown to provide environments where teenage patients can be understood [4, 38] and talk to others who ‘just know’ [p196] [31]. However, comparisons made between patients based on illness are not always reported to be helpful and are sometimes ‘conscientiously avoided’ [p382] [15], especially if the situation has normality as a focus, for example in a hospital school setting. Although there are benefits to encouraging peer relationships between teenage patients, difficulties have also been highlighted; predominantly dealing with the death of a group member [15, 31]. Despite these difficulties the potential benefit to engaging teenage patients with education through successfully maintaining and developing peer group relationships is an important area which requires further study.

Long term impact on education and employment

A diagnosis of cancer can be disruptive at any stage of life, but individuals in teenage and young adult years have been described as being on the ‘threshold of fundamental change in their circumstances’ [p269] [32]. Treatment and illness experiences can lead to chronic post-traumatic stress for patients extending into remission and affecting their subsequent experiences [32]. This ongoing ‘narrative wreckage’ [p282] [27] can make it difficult for patients to identify appropriate pathways and plan their future [27]. This effect in relation to employment varies between individuals and can be moderated by the stage of career exploration they are in when diagnosed [14].

Those at early stages of career exploration have been shown to be affected more negatively by a cancer diagnosis than those with more developed career plans, who can demonstrate a positive effect [14]. Survivors of teenage cancer are often older when they are first employed [36], but this does not lead to lower levels of vocational achievement compared to healthy controls [36].

With regard to effects of cancer and treatment in relation to long-term educational difficulties, it appears that survivors of CNS cancers are the only group reported as differing significantly from healthy controls in education attainment [21, 35] and employment [36]. Problems with school can be predictive of future social difficulties and life satisfaction [25] and those patients experiencing social isolation during treatment can continue this into longer term survivorship [27]. Social isolation, which has been shown to be exacerbated by school absence, is important for this group long term because it has been shown that a positive relationship exists between social support and self-esteem and HRQOL [42].

Conclusion

Emerging from this review are key issues surrounding teenagers' engagement with education after a diagnosis of cancer. Despite literature showing that school absences do not necessarily lead to a reduction in educational and vocational attainment, absence is clearly an issue felt acutely by some teenage patients. It is important to involve healthcare and education professionals, as well as parents and teenagers themselves in school reintegration if it is to be successful. This could be facilitated through encouraging maintenance of existing peer groups and interaction with other teenage cancer patients. Professionals also need to show sensitivity towards issues surrounding body image and the effect this can have on reintegration into school and peer groups. It is clear that the experiences teenagers have during their cancer journey can stay with them for the rest of their lives, with positive or negative outcomes. It is unclear from the literature whether successfully maintaining teenagers' engagement with education during treatment has a direct impact on their educational and vocational achievements. Further research needs to be undertaken to determine the overall impact of successfully maintaining education engagement specifically for teenagers, the role that peer groups play in this process and how education engagement contributes to the overall coping, wellbeing and quality of life of teenage

cancer patients. It has proved difficult for existing research to demonstrate any clear and consistent quantitative outcomes when analysing the relationship between a cancer diagnosis and education engagement. Future research in this area may benefit from utilising a qualitative and longitudinal approach to investigate in greater detail the intricacies of the interaction between cancer, education and coping. To provide a clearer and more valid view of this interaction it will also be important to have teenagers as the main focus of any future research.

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