



The impact of a cancer diagnosis on the education engagement of teenagers – Patient and staff perspective

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A B S T R A C T

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Purpose: Engagement with education during treatment is an important and complex issue for practitioners and an important psychosocial need of teenagers with cancer. There is limited research currently available specifically concerning the education of teenagers with cancer. This paper reports the outcomes from a patient and a practitioner questionnaire study which explore prominent issues and experiences in educational engagement for this population.

Method: Eighty-eight teenage cancer patients completed a questionnaire about their education experiences since diagnosis. Forty oncology practitioners completed an online questionnaire on experiences of education engagement of teenage patients. Questionnaires were developed from a systematic research review conducted by the authors and included; peer relationships, school attendance, reintegration and long term effects of cancer on attainment.

Results: Among teenagers there was a significant relationship between successful maintenance of peer groups, successful reintegration into school and positive ratings of the education support. Teenagers who reported school as their primary source of support had significantly more successfully maintained peer groups. Practitioners rated peer support as the most important factor in education satisfaction for patients and stressed the need for collaborative planning between hospital, school and home.

Conclusions: Collaborative education planning should be initiated on diagnosis and aim to include non-academic variables, such as peer groups, which can influence successful maintenance of education. Further research is needed to understand the relationship between education engagement and teenagers' cancer experiences as a whole, as well as gaining a more in depth understanding of how teenagers experience their education after a diagnosis of cancer.

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Introduction

Every year approximately 2000 teenagers are diagnosed with cancer in the UK (Brierley et al., 2009). Preliminary studies suggest that the successful, ongoing engagement with education and school life of child and teenage cancer patients impacts substantially on their quality of life (Searle et al., 2003) and global self-worth (Seitzman et al., 2004). Cancer survivors, more so than those with other chronic conditions (Eiser and Vance, 2002), have been shown to be up to four times more likely to experience school related difficulties when compared to healthy controls (Roberts et al., 1998). Supporting ongoing educational engagement post-diagnosis can be complex for practitioners, families and teenagers alike, as issues

related to school attendance, reintegration, peer relationships and long term effects on attainment and employment are encountered (Pini et al., 2011). In addition, maintaining contact with school offers a normalising environment that can provide respite from the sick role (Whyte and Smith, 1997).

Difficulties associated with school absence remain prominent for many teenagers with cancer (Manne and Miller, 1998), despite more successful management of side effects and a greater emphasis on care in outpatient settings. Teenagers are a particularly high risk group for extended school absence (Bonneau et al., 2011) and they themselves identify potential school absence as a major concern even at the point of diagnosis (Hedstrom et al., 2005). Central nervous system tumours, bone marrow transplants and relapses provide the most significant treatment risk factors for school absences (Eiser and Vance, 2002; Abrams et al., 2007). Absences can also be increased/exacerbated by parental factors, with some families finding alternative ways to address academic concerns (e.g. private tutoring, or home schooling) to allow them to spend more

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time with their child (Haase, 2004), or by becoming overprotective with regard to the risks of bullying and/or infection associated with school reintegration (Roberts et al., 1998). Studies indicate that in the year following diagnosis, teenagers with cancer are absent from school for an average of 40–60 days (Moore et al., 2009), although this decreases over time (Eiser and Vance, 2002; Abrams et al., 2007). Absences from school caused by cancer and treatment can require some teenagers to repeat an entire school year on their return (Sorgen and Manne, 2002; Bonneau et al., 2011) and school attendance can continue to be irregular for up to 3 years post-diagnosis (Moore et al., 2009). When teenagers resume regular school attendance, difficulties related to missed school work can still affect some teenagers up to 2 years later (Mattsson et al., 2007).

Reintegration into school after a period of absence can be a significant challenge for patients and staff (Koch et al., 2004) and is a primary concern for patients as early as diagnosis (Decker et al., 2004). Reintegrating into existing peer groups and forming new friendships are prominent worries for teenagers with cancer (Decker et al., 2004; Duffey-Lind et al., 2006), which can be exacerbated by concerns about being teased or bullied given hair and weight loss (Drew, 2007). In addition, teenagers who have been in hospital schools may be concerned about disparities in academic standards and their future ability to cope with their normal school work (Searle et al., 2003). Despite these concerns, Searle found that the majority of patients who had been in hospital schools did successfully reintegrate into mainstream schooling (Searle et al., 2003). Some teenagers have reported low levels of satisfaction with the support they received from their regular/mainstream school teachers (Enskar and von Essen, 2007), identifying negative staff attitude (Hokkanen et al., 2004), low academic expectations (Grinyer, 2007) and the ignoring of health plans (Moore et al., 2009) as key issues. Other studies, however, report that teenagers found school personnel to be flexible and supportive (Mitchell et al., 2006).

Decker reported that amongst newly diagnosed teenagers, peer relationship concerns were second only to worries about coping with treatments (Decker et al., 2004). Teenagers with cancer often express feelings of not being understood by their pre-diagnosis peer group (Palmer et al., 2000) and of being left behind as their peers move on with their lives (Grinyer, 2007). Although maintaining contact with peers is important, sometimes teenagers state that being reminded of the activities they are missing out on can be painful (Searle et al., 2003). In this situation, teenagers can intentionally prohibit friends from visiting while they are unwell (Searle et al., 2003). Woodgate noted the potential importance of a 'special friend' [p. 125] in maintaining overall contact with school peers and that this was usually a lifelong friend (Woodgate, 2006). It has been suggested that maintaining peer relationships at school can improve the reintegration of teenagers with cancer by providing a 'peer-shield' (Abrams et al., 2007) to unwanted questions and attention. Problems with school can be predictive of future social difficulties and life satisfaction (Enskar and von Essen, 2007) and those teenagers experiencing social isolation during treatment can continue this into longer term survivorship (Drew, 2007). Social isolation, which has been shown to be exacerbated by school absence, can be problematic for this group in the long term, because of the direct positive relationships that exist between social support, self-esteem and health-related quality of life (Cantrell and Lupinacci, 2008).

Planning for careers and further/higher education can be affected by a diagnosis of cancer during the teenage years (Drew, 2007). This effect varies between individuals and can be moderated by the stage of career exploration they are in when diagnosed (Stern et al., 1991). 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, such as increased confidence in career success and a sharper focus when assessing options (Stern et al., 1991). Stern showed that teenagers with cancer are more inclined to foreclose early on career choices. Survivors of teenage cancer are often older when they are first employed, but this does not necessarily lead to lower levels of vocational achievement compared to healthy controls (Dieluweit et al., 2011).

Survivors of central nervous system cancers are the only group of teenagers with cancer who are consistently reported in the literature as differing significantly from healthy controls in academic attainment (Mitby et al., 2003; Koch et al., 2004; Bonneau et al., 2011; TCT, 2011) and employment (Dieluweit et al., 2011). Although the results are not always differentiated for the teenage population, research has shown that survivors of childhood and teenage cancer are more likely than siblings to access special educational services (Mitby et al., 2003) and have lower academic attainment than the general population in the U.K. (TCT, 2011). Survivors of leukaemia, central nervous system tumours, non-Hodgkin lymphoma, and neuroblastoma have all been shown to be significantly less likely to finish high school compared to siblings (Mitby et al., 2003; TCT, 2011).

Currently, teenagers with cancer have variable access to education support depending on where they are treated within the U.K. The majority of Teenage Cancer Trust (TCT) units have access to a hospital school or hospital based education teams, as well as home tuition services that are in place through local education authorities. Only the TCT units in Leeds, Birmingham and the South West have a specialist education practitioner specifically for teenagers with cancer and this person does not always have education as the sole focus of their role. Hospital school services can offer good education support, but only when teenagers are inpatients and often only for limited periods of time. Continuity of education achieved through multi-disciplinary working throughout the teenagers' cancer journey is difficult within restricted timeframes and requires individual tailoring of care, which a specialist educational practitioner is in a better position to achieve (Harris, 2009; Pini, 2009).

For teenagers with cancer there are multiple vulnerabilities which can both lead to, and be caused by, disengagement from education. In order to support such teenagers more effectively, we need to know more about the contemporary concerns that they have, and the factors which seem crucial to both maintaining contact with school and reintegration when appropriate. There is limited research focussing solely on the education engagement of teenagers with cancer, especially the experiences they have and challenges they face during treatment. In light of this we conducted (via questionnaires) an extended exploration of teenagers' experiences of education and the services available to them. Through practitioner networks, we also sought the perspective of teenage oncology practitioners and allied healthcare staff. This paper reports the findings of the questionnaire study and discusses the implications for improving service provision and care for this group.

Find Your Sense of Tumour Conference

Questionnaires were distributed to teenagers at the 2010 'Find Your Sense of Tumour Conference' (FYSOT) conference, organised by the TCT. Education issues have not previously been explored in depth at this conference. However, education was briefly addressed at the 2004 FYSOT conference, with 36% of patients reporting difficulties in communicating with others and returning to school, and 81% reporting that no healthcare

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