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How and why school is important to teenagers with cancer: outcomes from a photo-elicitation study

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Abstract

Background

Being diagnosed with cancer during the teenage years can be significant given young people are at a key developmental, educational and future-planning stage. Little is known about young people's attitude to and engagement with school post-diagnosis, nor how this changes over time. We adopted a novel qualitative approach to examine accounts over time of young people recently diagnosed with cancer.

Methods

Twelve teenagers (13-16y), recently diagnosed with cancer, participated in photo-elicitation interviews at 3 time points (approximately 2, 6 and 9 months post- diagnosis), generating 30 interviews in total. Photo-elicitation interviews centre around images which participants bring to represent key experiences and issues that matter to them. Transcripts were analysed using Interpretative Phenomenological Analysis.

Results

Seven themes were generated, representing experiences over time. Themes convey how significant school was to the young people post-diagnosis, principally because it mattered to them to maintain a normative educational pathway. Young people felt tension between wanting to be the same as their peers but feeling distinctly changed. Keeping ownership and control of their cancer story within school was challenging. Survivorship brought, for some, a legacy of missed schooling.

Conclusion

Support for young people and reintegration plans for school need to be tailored to the young person's emerging way of understanding their cancer and recovery, and their orientation to coping. Young people need help to understand that schoolwork exemptions/ extensions do not

implicate academic deficiency, and how they could accept a ‘same but different’ position as they continue to develop personally and educationally with their peers.

1 INTRODUCTION

In the United Kingdom, approximately 2000 adolescents (13-24y) are diagnosed with cancer annually [1]. Whilst many adolescents cope well with cancer [2], some experience more posttraumatic stress symptoms than children [3]. This may be because cancer during adolescence is a “double penalty” (p. 49) [4], given the young person’s developmental stage, their advancement towards independence [5, 6] and because they are at important stage in their education and future-planning.

Only a few studies have examined how cancer affects school experiences for adolescents with cancer. Teenagers are at particular risk of school absences compared to younger children and these absences have been shown to be longer in duration and continue further into survivorship [7-9]. These school absences are a concern for young people even at the point of diagnosis, and many want to remain engaged with their education and minimise the impact of cancer [10, 11]. Peers have been established as an important element in the school lives of teenagers and absences from school can have a negative impact on peer relationships [10, 12-24]. In fact, education engagement and peer group dynamics appear linked to the extent that a clear cause and effect is difficult to establish [24]. Returning to school was rated the top concern of newly diagnosed adolescents [13], particularly with concerns about how others will perceive and react to changes in their appearance and how they will fit back into peer groups [10].

Teenagers have also been shown to have concerns about falling behind academically and the impact this could have on their educational and vocational attainment [25]. In addition to this, teenagers have reported low levels of satisfaction with hospital education and difficulties with support from their regular school [9, 10, 15, 26]. Compared to children with cancer, keeping up with schoolwork is particularly important to teenagers [27], as is good communication between their school and hospital [24, 28]. However, the impact of cancer on outcomes for adolescents appears variable. When assessing outcomes using quantitative measures there are reports that compared to healthy peers, educational and vocational outcomes are worse [7], no different [29] or better [30, 31].

Beyond these findings, little is known about the qualitative nature of school-related experiences for this group, potentially prohibiting effective support or continuing with poor practices not aligned with user service-user needs. Drawing upon the novel, participant-led method of photo-elicitation, the present study examined the school experiences of teenagers recently diagnosed with cancer. For a detailed examination of this method please see [32]. The aim of this paper is to present participant generated accounts of school related experiences of teenagers following a diagnosis of cancer, and to highlight areas that are important to teenagers beyond quantitative academic measures.

2 METHODS

2.1 Participant Recruitment

Ethical approval was granted in 2012 by Leeds Central NRES Committee Yorkshire & the Humber (12/YH/0387). Young people were recruited from paediatric and teenage outpatient clinics and inpatient wards within a cancer centre in the north of England. They were eligible if: they had been diagnosed within the last two months with leukaemia, lymphoma, soft tissue sarcoma or bone tumour; were 13-16 years of age; and were being treated with curative intent as defined by their clinician. Exclusion criteria included brain cancers and / or teenagers receiving palliative care, due to distinct educational experiences and outcomes for these groups [29, 33-35]. Twenty young people were approached and twelve consented to participate (six male and six female).

2.2 Procedure

Photo-elicitation interviews [36] were planned for 2, 6 and 9 months post- diagnosis. The majority of the interviews were held in rooms within oncology outpatient clinics. Following guidance on the method [37] participants were asked, two weeks prior to each interview, to take photographs of objects, places or people which represented current school experiences. Photo-elicitation offers a number of benefits over traditional interviews including: the ability for the participants to plan what they want to convey; the capacity of images to stimulate and sharpen participants' memories in interview [38]; and supporting the communication of complex experiences [39]. Children and adolescents engage well in photo-elicitation interviews and it may also engage those who feel disempowered by their illness and / or by the colonisation of their experience by the medical world [40-42]. Participant images were discussed in interview using the SHOWeD technique [43, 44], which asks participants to: tell me why you chose this picture; what do you see in this picture?; what is happening in this picture?; how does this relate to your life?; what is missing from this picture?; how does this picture make you feel?. Further discussion emerged from these questions, led by the participant. Participants were given the option to have a parent or other appropriate adult present if it would make them feel more comfortable.

For those participants who did not provide images the interview proceeded using an open structure. Participants were initially asked to describe their recent experiences with school and the interviewer would ask them to expand on or give examples of any points they raised. The participant-centred approach of photo-elicitation remained the underpinning philosophy of these interviews and the researcher allowed the participant to lead the interviews as far as possible.

2.3 Data analysis

In line with many photo-elicitation studies, image content was not analysed as their purpose here was to support engagement and data generation only [45-47]. Data were analysed using interpretative phenomenological analysis (IPA), following guidelines by [48] and [49]. Step one involved multiple, detailed readings of each transcript followed by open coding, i.e. descriptive labels capturing the meaning of text. Step two involved clustering similar codes, analysing them for any conceptual connection, and grouping them into provisional themes per transcript. In step three, themes across all transcripts were analysed for any conceptual similarities and differences, following which overarching themes were generated to capture the key elements of individual level themes (e.g. "explaining" became "controlling the story" to better reflect the complexity across the sample). The lead analyst (SP) engaged in depth with steps 1-3. In line with good practice in IPA, in Step 4, the second and third authors provided supervision, discussion of themes, reviewed the evidence and the team reached consensus on final themes. Data saturation was assessed throughout the analysis and new themes ceased to emerge after nine interviews. The three time points were used to create an account of the individual experiences of participants throughout the first year of diagnosis and were not analysed or compared as discreet cohort time points.

3 RESUTS

Table 1 shows participants' (under pseudonyms) diagnoses and ages at three data collection points. Nine participants completed three interviews, whilst three participants completed one interview (Faisal withdrew due to illness; Matt withdrew as he did not want to reflect on his cancer; Alanna completed only T3 due to illness and logistics). Eight participants had a parent present for at least one interview and four chose not to bring images to the interview. This sample size was appropriate for IPA [50, 51]. Interviews lasted approximately 40 minutes (range 9 - 105 minutes). Data was also collected from participants at time points two and three reporting how often they had attended school, what other support they had accessed in-between interviews and whether they had attended other school activities (Table 2).

Our analysis generated seven themes and reflected changes over time (Table 3). The themes convey how school and education mattered to the young people, the trade-offs they made between health and education and the psychosocial challenges of being in school with cancer. Specific longitudinal analysis was not conducted, however the themes presented in an initial temporal order reflecting when they were most prominent in participants' accounts overall. Selected transcript extracts and participants' images are presented to support communication of data.

Theme 1: Falling behind

As early as diagnosis, school was a major concern for interviewees, specifically coping with pain and life altering treatments alongside maintaining educational progress. They reported concerns about school absence and missing examinations and coursework deadlines, even when exceptions and extensions had been granted. Falling behind their peers and expected or personal milestones mattered to the young people: *"I'm just missing that exam now and I've passed all the theory exams and the practical P.E exam I can't even do because I'm not going to be there"* (Faisal). Cancer and treatments meant some young people felt they were regressing rather than progressing on the usual course towards independence. Family, friends and professionals were relied on for assistance in everyday life, and participants were less able to attend school or to socialise independently. For many, this enforced dependency resulted in frustration and "feeling helpless" (Alanna).

Theme 2: Controlling the story

An early challenge for participants involved informing family, friends, peers and school of their diagnosis. Participants found it difficult to decide who and how to tell, and how to retain control of their story when their lives often felt like public property even though “They [healthy *peers] don’t know what it’s like and they don’t know what pain you go through” (Alanna).* Many described school as the most distressing context in which they had to manage this information as it was difficult to keep control of the story of their illness and limit rumours. Robert was troubled by his school’s reaction to his diagnosis, as he stated he had had *‘moved on’* from the drama of the diagnosis himself: *‘when I told the whole school it spread like* wildfire, it went around the whole school like so quickly, mostly the whole school or my whole *year just like was so depressed and so quiet, I wasn’t there, but I heard* it was very bad place *to be’*. The dynamics of this theme have been explored in more detail elsewhere [52].

Theme 3: Conflicting priorities

Young people described two lines of progress that mattered to them – recovery from cancer and educational milestones. It was difficult, if not overwhelming, for young people to manage and tolerate the impact of one on the other. Treatment often resulted in setbacks in education (*“I ended up missing my last exam because I just wouldn’t have been able to go in”, Hayley)*, whilst attending school sometimes meant missing hospital appointments or risking infection, raised by Mario via his picture of a door handle (Figure 1). That educational progress continued for their peers, but not for them, gave rise to a sense that something important was carrying on without them. However, some participants found it straightforward to prioritise recovery over education. By Mario’s second interview, he had undergone a leg amputation, intensive chemotherapy and considerable periods of hospitalisation but accepted the effect of this on his schooling: *“I’ve not been able to go to school or anything because of...I can’t walk yet properly* but besides that everything is going well with chemo and everything.”

Theme 4: Maintaining educational pace

Participants diagnosed during the final year of high school were concerned about final examinations, and impacts on subsequent educational options. All participants had been given guarantees by their schools that they would be able to progress without having to take formal examinations. However, it appeared difficult for the young people to opt out of these, and all participants who were due to sit formal examinations wanted to, and managed to, take the majority of these. Young people also valued the calibration which schooling affords, helping them to judge their progress compared to their peers. Georgie brought a picture of pens (Figure 2) to highlight her educational motivation, and explained she would rather do work from her own school than hospital tutor work; *"then I know where I'm up to and then I can d*o it the same as everybody else, kept like on the same lines and then when I go back I *know I'm doing the same thing"*. Having cancer did not negate her academic goals, and it mattered to be part of a collective, progressing through education at a matched pace. She wanted to be *"the same"* as her peers, to be along *"the same lines"* and do *"the same things"*.

Although Mario prioritised his recovery over educational progress, his academic achievements still mattered to him. He had not been upset during discussions about his cancer or treatment, but became distressed when reporting his disappointment with his final examination results. He stated *"I always thought I'd do better"*, and his distress as he discussed this revealed tough personal expectations and raw disappointment that he could not demonstrate his true ability in these milestone examinations.

Theme 5: A paused life?

Actively managing and driving forward both cancer recovery and educational progress were important for most interviewees. For example, Nicola was highly informed and interested in her treatment plan (*"so I've got ten weeks of chemo, this is my last week now, and then I've got* surgery like next week hopefully to completely replace the femur with titanium from hip ball *and sockets, and then I'll be in a wheelchair for like six weeks or so and like it'll be intense physio to get my legs on the go"*) and Robert was motivated for physiotherapy to *"get* my body *how I want it to be"*. Others like Alanna, Hayley and Mario were heavily involved in trying to manage the maintenance of their education and engaged in planning. However, some young people seemed to temporarily 'pause' their lives, only engaging minimally in education, socialising or medical decisions. For example, Nathaniel and Patricia described not wanting, or feeling able, to engage with school, social activities or treatment decisions. They wanted to 'pause' their life, exist through cancer, and then resume life as it was before. Patricia explained that she did not want cancer to permeate her broader life; when asked whether she talked to her friends about what she had been going through: *"No, not much, no, it never comes to my mind"*. Nathaniel said he wanted to *"forget it [cancer]"* post-treatment and found it difficult when peers and professionals at school asked him about his cancer.

Theme 6: Finding a way to be the same but changed

The final interview time point was usually characterised by treatment end and more regular school attendance. Many participants explained the tensions between wanting to be perceived and treated within school as they were pre-cancer, whilst also recognising that much had changed for them. Getting the balance right here was described as difficult for both the young person and their peers. Robert brought a representation of friends (Figure 3) to prompt talk about how he wanted his friends to engage with him, as the same Robert, not a new 'Robert who had cancer'. He was not ashamed of having cancer ("*I'm* proud to be bald"), but said cancer was an experience rather than a definition of him: *"I don't want people to pick me out* for being, *for what I've got, I just want to been seen as me being normal and remember me* with hair and stuff like that because *I don'*t want to be, *'oh be careful with him because he's got that.'"* Alanna also talked about trying to manage her peer relationships when returning to school, giving the example of their reaction to her hair loss overtaking her own, accepting perspective: *'I told them all, I went 'I'm going to take my hat off, if you want me to put it back on... if it... if you really want me to put it back on, I will, don't worry, it doesn't bother me but I just need to take it off' so I took it off and I saw some of my* friends crying, kind of like [Name], *who I was talking about, she was crying and I saw them crying and I went 'why are you crying? It's not you, it's my hair, I'm not bothered, it's just hair.'"* Many participants, like Alanna and Annabella, talked of having new life perspectives that were out of kilter with their peers. Hayley, who in the first interview, had described the difficulties of returning to school because of changes to her appearance, later rejected a performance of normality, and instead wanted to reveal the true impact of cancer on her. Her decision to be a 'normal young person' in her own, changed way was described by Hayley as "a good point": *"And I just thought 'right, just forget it, I'm just going to go in a hat instead of like having all that hair' because there's no point like wearing the wig and then people thinking it's actually real hair and then like a few months down the line just whipping it off one day and like 'oh you've got really short ginger hair! It's* not long br*own hair!' so yeah. That point was like, that was a good point for me because I had the confidence to actually go to school without my wig on."* Some changes were difficult for participants to avoid and the perceived certainty of this could be distressing. Mario brought an image of his leg amputation to the interview (Figure 4) and discussed how difficult he imagined it would be to go back into school in a wheelchair or with a walking stick, and the inevitability that people would stare at him and treat him differently.

Theme 7: Legacy of missed schooling

Several participants talked about the impact of time away from school. There were often ongoing and late effects of treatment for participants when they returned to school. Fatigue, reduced concentration, reduced immune function, sickness and sleep problems were a challenge to study. For example, Matt brought a picture of a sick bowl (Figure 5) to raise the issue of how nausea affected his ability to do school work and resulted in him having to catch up on entire sections of the syllabus. Some were anxious about anticipated challenges in concentrating. William explained that: *'I think maybe like the* concentration side of things. *I'm* a bit nervous about that actually, sort of sitting in a classroom listening for, working. I think it could be quite, n*ot difficult, but a challenge.'* Several participants moved into further education during the study. For some, this was a fresh start alongside peers all embarking on the next stage of their lives. However, the legacy of missed schooling remained for some. Mario felt unprepared for challenging academic work, feeling he had been "dropped straight into *it"*. Hayley, who had transitioned into her final two years of education (A-Levels), was frustrated at teachers' unrealistic expectations given her time away from school, and her felt responsibility to plug the gaps in her knowledge: *"I've missed a year of it so I've missed quite* a lot of the b*asic stuff that is needed like they're saying to me 'well you should know about this, you did it in GCSE' and it's like 'yeah well I wasn't there for a year... well I kept one of the biology books and I've looked through it and there's* nothing about it in there so, *it's like 'Oh God!'"*

4. DISCUSSION

Via multiple photo elicitation interviews, this study tracked newly diagnosed adolescents over approximately nine months to understand the impact of cancer on their individual school-related experiences. Their accounts reflect the interconnectedness of health, educational, developmental and social aspects of their lives. This is perhaps why quantitative research in this area can show inconsistent findings when trying to disentangle and pin-point measurable impact [53]. Participants' accounts overwhelmingly advocated the continued importance of schooling to them post-diagnosis, although school both created and magnified cancer related stressors. Maintaining educational progress mattered to the majority of participants, with only a few preferring a 'paused life' approach. School was perceived as a benchmark for progress, normality and how well one was coping with cancer.

In line with previous research, this study showed that participants had significant absences from school [7-9] and these absences were an early concern [10, 11], which was reflected in theme 1. The impact of cancer and treatment on education was reported by many, notably the effects of nausea, physical changes and poor concentration, and that maintaining recovery could mean compromising education (theme 3). The importance of peers reported in other research [10, 12-24] was also seen in this study, but the exact nature of the impact of cancer on interaction with peers varied across issues of calibration of progress (theme 1), controlling their cancer narrative (theme 2) and reintegrating into, or visiting, school (themes 5, 6 and 7). Offers of school examination exemptions were rarely taken as it mattered to young people to achieve previously held milestones, be as similar as possible to their peers, and to be calibrated against them.

Interviewing participants across three time points allowed some preliminary temporal ordering of emergent themes across the first year of treatment. Discussion of the period following diagnosis was mainly underpinned by experiences related to falling behind in their education and controlling information about their cancer experiences (themes 1 and 2), which showed the participants trying to manage the initial impact of their diagnosis on their school trajectories and their dynamics within the school community. Interviews covering the period 2-6 months post-diagnosis showed participants balancing conflicting health, educational and social priorities (theme 3) and trying to maintain some degree of progress in their schooling (theme 4). However, some participants were also still coping with the pressure of falling behind and managing their own cancer narratives. Discussions in the 9-12 month period often saw participants encountering the first outcomes of their implicit approaches to coping and adjustment, by either trying to pick up where they had left off if they had adopted a more "paused life" approach (theme 5), or integrating a new version of themselves into their previous school environment (theme 6). In either scenario all participants were confronted with some degree of educational, personal or social impact of the time they had missed from school (theme 7).

For some, cancer experiences were part of their ongoing biographical flow constituting a form of enrichment, akin to descriptions in some adult oncology literature [54-56], but also presented the challenge of integrating a new version of themselves into a previous environment (theme 6). However, when reintegrating into school, psychosocial challenges were evident, spanning the owning and controlling of their cancer story and managing emergent differences in life perspective between the young person and their friends and teachers. Permeating the accounts of all participants was tension between wanting to be treated as if cancer had not happened, and needing special consideration (discussed in more detail elsewhere [24]). This reflects similar findings in adult oncology research where returning to previous personal norms in appearance, behaviour and health could be complicated by having to adapt to a "new normal" post cancer [57]. There were also individual differences within the realigning concept of normal which were challenging for young people, family, peers and professionals to understand and allow for.

5 CLINICAL IMPLICATIONS

Clinical and school support for young people and reintegration plans for school need to be individually tailored and sensitive to the young person's emerging way of making sense of their cancer and recovery and their sense of difference but need for normality. Schools should foster a respectful attitude to a young person's cancer experience, help peers to adopt helpful roles and ensure that later teachers of the young person are aware of any missed schooling. Young people may benefit from reassurance that accepting schoolwork exemptions and extensions will not have adverse consequences. Support services and schools should tailor their approach to the young person's way of coping and identify the relative importance to them of reaching certain educational milestones. For more detailed recommendations for practice see [24].

6 STUDY EVALUATON

Strengths of this study include the participatory approach, the use of three data collection points, and an in-depth method of analysis, which collectively generated rich data on the school related issues arising for young people from diagnosis through to reintegration. However four participants chose not to engage in the photo-elicitation aspect, showing that it is not attractive for all participants. Limitations include the possibility of sampling bias, as the participants were self-selecting and likely to be invested in sharing school related experiences (although how that would change for them over time was unknown at the point of recruitment). The presence of parents in some interviews had the potential to influence the way in which participants related their experiences and could have resulted in some withholding by the young people. In the majority of these interviews the parent provided prompts on dates or order of events, but did not regularly engage in the interviews when participants were discussing how they felt about their experiences, although the exact influence the parent had on the dynamic remains unclear. Personal experience are a valuable form of data, but retrospective accounts are subject to distortions. Life and illness narratives are never final [58]; had we followed the young people for longer we would likely have encountered new and different concerns about the legacy of missed schooling or how young people can compensate for that. The analysis used in this study aimed to identify individual experiences and was not explicitly longitudinal, so the emergence of themes across time points was preliminary and not based on thorough longitudinal analysis. The longitudinal nature of the interviews allowed the themes to be reported in a temporal order of how they presented across the interviews, but it was not possible to pin-point exact origins of these themes within the timeline and a larger longitudinal study would be an interesting avenue for future research.

7 CONCLUSION

School was a prominent issue for young people experiencing cancer. School provided important links to peers, the calibrated sense of self young people develop through interaction with peers and assessments, and the importance of reaching educational milestones to feel the same as one's peers and part of collective cohort. Cancer and treatment can significantly impact the way young people experience and conceptualise education and the school environment, although very often young people do not have prior experiences to help guide them through this challenging time. Sensitive, well-informed and individually tailored support that takes account of a young person's approach to coping with their cancer would help young people navigate the complexity of simultaneous treatment and educational progress.

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