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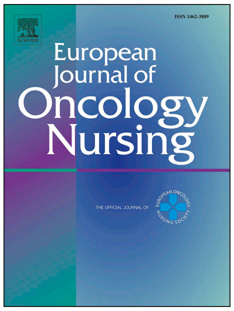

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'What are you crying for? I don't even know you' – The experiences of teenagers communicating with their peers when returning to school

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Purpose: Young people (YP) returning to school after a cancer diagnosis and treatment have to decide who has the right to know about their cancer experiences and how to distribute this information to peers. Young people face unique challenges in this area because of their life stage, their need to reintegrate with peers, and their own approach to their disease and treatment. This paper explores the perspectives of young people as they return to school during and after curative cancer treatment.

Method: 12 young people (6 females, 6 males) from the north of England (aged 13-16 years at time of recruitment) took part in photo elicitation interviews conducted at three time points during the year following a diagnosis of lymphoma, Hodgkin's lymphoma, osteosarcoma, A-plastic anaemia or acute lymphoblastic leukaemia. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA).

Results: Three main themes emerged: 'approaches to telling', 'lives becoming public property'; and 'owning the story'. Within these themes participants experienced stressors related to altered peer group dynamics, being propelled into the foreground of the school environment, being responsible for the feelings and needs of others, and conflicts between their perception of coping and the reactions of others.

Conclusions: Re-entering school following a diagnosis of cancer can result in challenging dynamics for a young person, which they are not always equipped to manage. Participants displayed individual differences in their approaches and preferences, but inevitably all had to cope with their lives becoming public property and managing the narrative of their cancer experience.

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Introduction

Cancer and treatments during teenage years often result in significant absences from school, which can pose complex psychological, social and educational challenges for young people (Abrams, 2007; Hedstrom et al., 2005; Lombard et al., 2013; Morgan et al., 2010; Pini, 2009; Pini, 2012; Pini et al., 2012, 2016; Searle, 2003) and includes the fear of being left behind or isolated from friends and peers (Decker, 2004; Grinyer, 2007; Mattsson, 2007; Palmer, 2000; Searle, 2003). In a longitudinal study of 176 adolescent and young adults with cancer, health-related quality of life mental component scores were found to be significantly lower when the individual was not involved in school, independent of prognosis for survival (Husson et al., 2017).

In the U.K. teenagers are often cared for by age-appropriate specialised services and have professionals and same-age patients around them who *"just know"* what it is like to have cancer (Cassano et al., 2008). When returning to school, young people emerge from the safety of talking to other others who *"just know"* and have to interact with their long-standing peer group (Jones et al., 2011). Soejima et al highlighted how important peer relationships were when a young person with cancer reintegrates into school (Soejima et al., 2015). They showed that peers being educated about the long term recovery process following cancer improved levels of peer support, as well as helping the young person to feel part of the school community. This was further facilitated by home visits by peers before the young person returned to school. Post-traumatic growth can be a positive psychological change following the experience of cancer, however survivors sometimes report feeling more mature than other people of the same age and being uncomfortable discussing cancer (Wong et al., 2017). Wicks reported how young people with cancer often felt 'out of kilter', with the values and behaviour of their contemporaries (Wicks and Mitchell, 2010). Similarly, Compere showed that peers did not know how to respond to details of a young person's cancer diagnosis or cancer related experiences, creating a potential barrier to support from their regular peer group (Compere, 2002).

When assessing experiences of young people with cancer it is useful to consider whether these experiences are distinct from findings within adult oncology and therefore perhaps unique to this developmental stage. Deciding how and when to "tell the truth" about cancer

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experiences when returning to previous environments can be a complicated issue for adult survivors (Surbone, 2006). In focus group interviews with 23 women following breast cancer surgery (Nilsson et al., 2013), disclosure upon returning to work was described as a *"worrying aspect"*, and worries about demotion prevented some women from disclosing their diagnosis. Other participants who felt obliged to disclose due to changes in their appearance felt awkward or shameful. Similarly, (Robinson et al., 2015) interviewed 19 breast cancer survivors following their return to the workplace and found that cancer communication was a burden on those already struggling to manage their diagnosis and treatment, and maintaining control over how information regarding their cancer is shared in the workplace was considered a challenge. Telling colleagues about their diagnosis could elicit emotional support and tangible help, however, for the majority of women all aspects of telling were associated with significant distress.

A survey of Japanese (n=362) and US (n=350) paediatric oncologists found mutual agreement that knowledge of a child's cancer diagnosis and treatment within their community would facilitate psychosocial support, but highlighted cultural differences in approaches to "telling the truth" about cancer when young people return to school. The majority of US oncologists (84.5%) advocated telling all staff and classmates about the child's diagnosis and treatment to facilitate the transition back into school, whilst the majority of Japanese oncologists (74.1%) disagreed with this approach. This could be linked to wider societal attitudes about cancer and to what extent young people are told about their cancer and treatment (Mayer et al., 2005). Young people may face unique challenges when talking about cancer because of their life stage, their need to reintegrate with a large number of peers in the school environment and the importance of maintaining the education trajectory. How young people tell others about their cancer was examined in a qualitative study of 37 young adults (aged 18-34) (Hilton et al., 2009). Hilton et al found young adults were very open about their diagnosis with family and friends, but would conceal their own distress in order to protect the feelings of their relatives. They found a significant gender difference in that young men were more likely than young women to be secretive about their diagnosis, be worried about how they were perceived by peers, and use humour to relieve tension with friends and colleagues. To date there has been little exploration of how communication about cancer within a public and exposed environment like school affects young people. In the period of "fame" that teenagers experience upon returning to school after completing cancer treatment (Choquette et al., 2016), YP have to decide who has the right to know about their cancer experiences and

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how to distribute this information to peers. This negotiation of "telling" may vary depending on their understanding of their own disease (Compere, 2002) and be an ongoing process depending on the nature of their disease and treatment, and the frequency of their return visits to school.

This paper aims to explore these dynamics from the perspective of young people as they return to school during and after treatment. The qualitative experiences of this group of young people adds an important first-hand perspective to the literature, which is distinct from using parents or professionals as proxies or from assessing the quantitative markers of engagement with school life. The aspects of the participants' experiences detailed in this article reflect secondary analysis of an important sub-theme within a wider analysis of their education experiences (Pini et al., 2016; Pini et al., 2018).

Method

Ethical approval was granted in 2012 by Leeds Central NRES Committee Yorkshire & the Humber (12/YH/0387).

Design: This study used photo elicitation interviews at three time points during the year following diagnosis.

Participants:

Twenty young people were approached over a year period, which resulted in 12 being recruited to the study (aged 13-16 years at recruitment). Participants were introduced to the researcher by a member of the clinical team whilst attending an outpatient clinic within a cancer centre in the north of England (Table 1). Teenagers were eligible if they were within two months of diagnosis and were being treated with curative intent. Those whose cancer involved the brain and / or who were receiving palliative care, were excluded due to distinct educational experiences and outcomes for these groups (Barrera, 2005; Freyer, 2004; Koch, 2004; Langeveld, 2002). Nine participants completed all three time points, eight provided visual images and eight had a parent present for at least one interview. Two participants completed the first time-point interview only. The first had returned to school by time-point two and did not want to revisit or reflect upon their cancer experiences any further. The second became very unwell by time-point two and did not feel able to carry on with the study. The remaining participant only participated in the final time-point interview. They

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initially delayed their participation because of difficulties with the methodology. Once the need to record images was removed from the process the participant was happy to be interviewed and provided a valuable account of their cancer experience.

All participants returned to their original year group after treatment.

Table 1 – Details of participants

	Females	Males
N	6	6
Age at recruitment	Mean 14 (range 13-16)	Mean 14.7 (range 13-16)
Lymphoma	1	2
Hodgkin's Lymphoma	1	2
Osteosarcoma	2	1
Blood disorders	2	1
Parent present at interview	5	3
Visual images provided for interview	4	4

Data collection:

Three interviews were planned: one within the first two months of the patient's diagnosis, one at six months post-diagnosis, and a final one at nine months post-diagnosis. Interviews lasted approximately 40 minutes (range 9-105 minutes) and used a photo elicitation technique (Harper, 2002) in which photographs taken by participants were used as a stimulus to elicit accounts during the interviews. Participants were asked, two weeks prior to each interview, to take photographs of objects, places or people which represented their experience of engaging with school. Ethical considerations were explained, as standard in photo-elicitation studies (see (Wiles et al., 2008) for discussion). Images produced were discussed using a SHOWeD approach (e.g. (Johnson et al., 2011; Keller et al., 2007)) which utilises the following questions to explore participants' choice of images (Radley and Taylor, 2003): 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?. The interviewer followed participant's responses to these questions with probes intended to elicit more detail and context, such as: can you give me an example of this in relation to school?; could you tell me about a time when this was not the

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case?; how do you think this might have been different if you did not have cancer?; how do the people around you react to, or support you with, this?

Data analysis:

The interviews were transcribed and all identifiable data amended or removed, and pseudonyms were used throughout. The images themselves were not analysed, and are therefore not included in this paper, because their function was to engage participants, stimulate discussion and structure the interviews (Mandleco, 2013; Walton and Niblett, 2013; Wells et al., 2012).

The transcripts were subjected to IPA, which has been increasingly used in health psychology research (see, for example, (Beestin et al., 2014; Hearn et al., 2015)). IPA is well suited to capturing the interpreted and constructed nature of health, illness, and life transforming events (Brocki and Wearden, 2006; Smith, 2004; Smith et al., 2009), as well as understanding the complexity and processes of lives in particular contexts (Smith et al., 2003). The aim of IPA is to assess patterns in the data whilst retaining and paying attention to the individuals in the sample (Smith, 1996; Smith et al., 2009; Smith et al., 2003). Standard IPA practices were followed (Smith et al., 2003) (Smith et al., 2009) and included: multiple, detailed readings of transcripts; making descriptive notes; generating first stage interpretive notes; developing conceptual themes; refining emergent themes and exploring connections between them, firstly ideographically, and then at the group level. The data was then organised into a thematic framework of higher order themes and associate sub-themes. To provide ongoing sensitivity to context and potential bias, and in line with good practice in IPA, the lead analyst (SP) engaged in depth with the process described above, with the second and third authors providing supervision, discussion of the appropriateness of thematic development and exploration of emerging models to represent the data. This process was also present during the interview process, as the interpretation of previous interviews could be incorporated into subsequent interviews so that participants would have the opportunity to verify or contradict interpretations. At the conclusion of the study, the results were fed back to participants who then had the opportunity to comment on the outcomes of the research.

Results

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The dynamics of telling and knowing were a key part of the experiences of participants. Leading up to their cancer diagnosis, participants were aware that family, peers and others in their lives had been worrying about their health and the outcome of investigations. Following their diagnosis, participants felt responsible for deciding how to tell others this sensitive and personal information. Rather than being a single event where participants finish treatment and reintegrate into school, many participants described multiple visits and short periods of time in school throughout their treatment. This meant sharing information about their cancer was an ongoing dynamic process, rather a one-off disclosure. The following sections describe the dynamics of telling and knowing as discussed by participants within three main themes: ‘approaches to telling’, ‘lives becoming public property’; and ‘owning the story’. The names used throughout the following sections are pseudonyms given to the participants.

Approaches to telling

Participants varied in their method of telling, but the majority engaged in the process to some extent. Parents often provided guidance or helped to tell family members. Education and health professionals helped some participants tell peers and staff at school initially. Many participants, like Nicola, decided first to tell close family and close friends and let the information spread naturally throughout the network of people surrounding them.

> *“Well at first we kept it like low key but, and I just told my close friends” - Nicola*

Participants often took responsibility for telling friends and peers, and this process was intensified in the school environment where they encountered the majority of their peers. One of the approaches often described by participants was systematically working through a hierarchical list of people to tell. This was more difficult for participants who were attending school, as their peers tended to all be present in one place at one time, making it more difficult to be systematic. Alanna decided to be open and communicative about her experiences. She described telling small groups of peers in turn and seemed to use the process of telling to reinforce a positive outlook.

> *“So telling them I’d just say... I wouldn’t tell them in front of everybody else, I’d tell them sort of like two or three people at a time and things and just say ‘look I’ve got cancer and I will tell you everything that I could’ and they were like ‘oh right... are you going to beat it?’, ‘yeah, of course I am! What do you think?!’ - Alanna*

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Others, like Robert, wanted to tell larger groups of school peers in an attempt to avoid repetition, which unlike Alanna, he found frustrating:

> *"I made a decision with my head of year and form tutor to go to my form room, just my form room, not assembly or something like that, and I went in and I said 'right, I haven't been to school for the past couple of days because I noticed a lump on my neck' and everyone went like 'oh!' and I said 'and basically what it is it's a cancer'" - Robert*

Interestingly, Robert still had a hierarchy of telling and felt the responsibility to tell his cousin personally and individually. It seemed that he wanted to contain the experience for his cousin and be able to personally attend to his reaction.

> *"They were all obviously shocked at first and my cousin, he took it quite hard, I didn't want his dad... I didn't want his mum and dad to tell him, I wanted to tell him personally and like I knew straight away as soon as I told him it hit him because he went from like 'you alright?' to like being blank..." - Robert*

Robert demonstrated an understanding that different relationships required different types of telling. The group approach he took with his class form seemed to be more focussed on what was important to him i.e. not having to repeat his story, whereas the individualised approach he chose for his cousin involved more empathy for the impact the news might have on the other person.

The above extracts are from participants who were happy, in principle, to discuss their health with their peers. However, some participants, like Patricia, did not really want to talk to friends, which seemed to be because she wanted to keep her cancer separate from her experiences with others.

> *Interviewer: They ask you lots. What kind of questions do they ask you?*
> *Patricia: Like 'are you alright?' 'are you fit?' 'how are you doing?' things like that.*
> *Interviewer: Yeah, and what do you say to them?*
> *Patricia: I just say 'I'm OK, what about you?'!*

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> *Interviewer: Right so you’re still worried about whether they’re OK as well! So you said they treat you just as normal really?*
> *Patricia: Yeah.*
> *Interviewer: And do you talk to your friends at home about things that happen?*
> *Patricia: Not much." – Patricia*

This approach seemed to help her with her desire to maintain normality when returning to school, but risked a lack of understanding from her peer group as to what her cancer experiences entailed.

Lives becoming public property

Being diagnosed with cancer placed participants in a unique position within their school because they were very often the only young person with cancer in this environment. Being known as *“the person with cancer”* invited a lot of attention and questions from peers and staff whenever they visited or returned to school. In the extract below, Georgie was worried about feeling exposed when returning to school because of the attention she might receive from school peers with whom she had no relationship. In her interviews Georgie repeatedly referred to wanting to “*be the same”* as her friends at school, so having the attention of many distant peers was a challenge to her desire for normality and a change to her previous peer group dynamic.

> *Georgie: Everybody might come and ask me, everybody, it might be a bit awkward maybe.*
> *Interviewer: What kind of things do you think they might ask you?*
> *Georgie: I’m not sure. They might just like come and talk to me even if I don’t know them.”*
> *- Georgie*

Hayley also experienced this extra attention from peers when she returned to school and was annoyed by the emotional response from peers who would not normally interact with her. Hayley perceived their reaction as an inappropriate level of involvement with her personal experiences:

> *“So... yeah that first day back... people that I didn’t even talk to normally they just started crying, and it was like ‘what are you crying for? I don’t even know you’.” - Hayley*

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In this way, Hayley shows that being affected by someone else's experience of cancer is only legitimate under certain relationship conditions, i.e. being 'known'. Participants regularly reported receiving a flurry of questions and comments from peers when visiting school after their diagnosis. Participants sometimes felt "*bombarded*" with this flurry of questioning. It was more difficult for participants to maintain a sense of normality in school than in hospital or at home. Their periods of absence provided a before and after that allowed peers to compare two versions of the participant. Changes to their appearance, mobility and abilities, were signs that propelled them into the foreground in a way that was more glaring in the school environment. Fielding questions from other people was a challenge for those participants who were trying to simply be a normal pupil and did not want to talk about cancer in this context. Sometimes for these participants having to field questions highlighted the limitations of their knowledge about their cancer experiences and led to frustration and vulnerability. Robert found this flurry of attention and questioning had a cumulative frustrating and draining effect on him.

> *"I just go 'I'm fine, it's a little bit bad but don't worry, it's... I'm fine, I will get better' and then they'll just go 'oh, good, good, good' and then another person will come up and ask the same question and like 'I'm fine!'" – Robert*

Thus, possibly authentic concern for a young person with, or recovering from, cancer could become a relentless burden within a school context. Nathaniel described this cumulative effect of questioning from peers had already begun before his diagnosis and in subsequent interviews he continued to struggle during times of questioning from peers.

> *"Yeah, because it just gets a bit annoying. Like when I had the operation just on the massive lump I had, it went really big and they all just asked, everybody asked me, what's that, what is it and I didn't know so I just said, I don't know but everybody asked me it, virtually everybody and it just got really irritating and annoying, you know." – Nathaniel*

Nathaniel's irritation at having to explain changes in his appearance to others is apparent. He paints a picture of a certain type of school experience where he is noticed, observed, talked about, and interrogated, in ways that are not helpful to him, nor experienced as caring. Participants rarely talked about perceived public / private boundaries that were understood

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and respected by peers or staff. It was more common for participants to feel exposed and on display.

There was sometimes a sense from participants that neither they nor their peers really knew how to talk about cancer. It seemed they had a shared normality with their peers, where they had built up a gradual understanding of the rules of interaction over time and this was altered when participants introduced cancer into the dynamic. After the initial flurry of concern and questions, participants reported they and their peers often reverted back to previous dynamics, and in most cases this seemed desirable to participants. Peers were perceived often not to know how or when to ask questions, nor the acceptability of broaching the subject. The extract below from Mario demonstrated the confusion within his peer group. They shared activities and time together, but he perceived them to be "*scared*" to ask him about his health. He did not say he knew this to be true, which implied they had not openly discussed it. He said he was happy for them to ask him questions and it appeared that if somebody had broached the subject they would all have been willing to discuss it.

> *"Mario: No, we don't usually talk about it, it's usually just playing on games or watching TV or whatever, just chilling really.*
> *Interviewer: And have you spoken to any of them or have they asked you questions about your operation and things like that?*
> *Mario: Not really, I don't know, I think they must be quite like... a bit scared to ask. But I'm not bothered if they did ask.*
> *Interviewer: So do you not sort of tell them anything about it unless they ask?*
> *Mario: No." - Mario*

In the extract below from Nicola, it seemed some of her peers avoided this issue by addressing questions to friends rather than directly to her. She did not explain the *"don't want"* in this extract, but it seemed she was referring to her perception that peers did not want to upset her or say the wrong thing, and it was safer and more diffused when talking to her friends.

> *"I guess some people like they don't want to ask questions because they don't want, so then they ask like closer friends kind of thing so they go around me." - Nicola*

Owning the story

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Within the school environment the dissemination of information about their cancer mainly happened through their peer groups. Both Hayley and William, in the extracts below, were concerned about their peers *"wondering"* what had happened to them and why their appearance had changed. They both approached this concern by trying to ensure their peers had the correct information. In context of other sections of interviews with Hayley, it seemed this was something she thought *"people have got to know"*, but was complicated by her contrasting desire not to draw attention to herself in school.

> *"Yeah, so, but people have got to know haven't they really, it's like better... like when I've got this [Hickman line] like hanging out and stuff they're not going to be like asking me 'why have you got that? Why are you wearing a wig?' and all that so... It is better that they know." - Hayley*

> *"No, I think it's alright. It's better that kind of they know what's going on than just wondering what's happened." – William*

For some participants, as demonstrated by the extract from Alanna below, having ownership over their story was a way for them to reinforce their own beliefs about this story. Alanna repeats that she is *"not going to die"* as a reassurance to her peer group within school when telling them about her diagnosis, but this repetition of a version of the story that she owned and was comfortable with also seemed as though it reinforced her conviction in this belief. Alanna also seems to be addressing the fear and association her peers may have about cancer and mortality, so that she can move past this difficult subject at an early stage.

> *"then they'd all come and say 'so why've you been off? What's wrong? What's wrong?' and I'd go 'they're 95% sure I've got cancer, but I'm not going to die' and they'd go 'are you sure? Are you sure?' and I'd go 'yeah, I'm not going to die'" - Alanna*

Owning the story also meant being able to shape it in the way they wanted others to perceive it, rather than necessarily reflecting what was really happening. Alanna thought that if others perceived she was coping well then it would be easier for them to support her. For her, telling her story became a cycle of reinforcing a positive attitude in her and in others.

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> *"Alanna: I didn't say there's a chance I could, I just said 'no I'm going to beat it' so they didn't worry about it.*
> *Interviewer: Oh OK, so did you want to give off that impression to them so that they'd feel better about it or was that how you were feeling?*
> *Alanna: Both. It's how I felt about it and... because if everybody else thinks that I'm going to beat it then they're all going to support me to help me beat it, if everybody thinks that I could die from it then they're going to be... they're minds would be all over the place about what to do and everything so..." - Alanna*

In the extract below, Nicola discussed her irritation that somebody she had never spoken to did not have the *"proper"* version of her story. As this person was not known to her she could have been unaffected by this inaccuracy, but the impact was intensified through the combination of her life becoming 'public property' and a lack of control over the shaping of this process.

> *"I'm alright, really, because I prefer people to ask questions rather than to like talk about me behind my back and like enquire through word of mouth. Like this guy who I went to primary school with, he messaged me the other week, and he was, like, "Oh, I heard that you had to have your leg amputated", and like so I was explaining it to him, and I was like "So who did you hear it off?", and it was this guy that I'd never heard of, and I was like "Well, how does he know, like the proper story if I've never spoken to him", and it really annoys me. So I'd rather people ask me personally so I can like tell them, like the actual story" - Nicola*

Participants all seemed to be aware that their cancer diagnosis was the beginning of a story for them and in the minds of the people around them. To a greater or lesser extent all participants wanted to ensure this story was *their* story as far as possible. The extracts below from Robert show that the timing and manner in which he conveyed his status as a young person with cancer within school altered the dynamic of his relationships within education. It seemed that asserting power was important to Robert as he reintegrated into school because he wanted to feel some ownership of his status as a young person with cancer and that he was in control of his story. Robert mainly used his status as a young person with cancer to attempt to put his peers at ease, by using humour, as in the extract below where he jokes that they cannot deny him anything.

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> *"Myself making fun of this bad situation, putting a light twist on it, so like I'd go to school and Wayne, one of my friends, would like... I'd trick my friend by saying 'oh can I have your dessert?' and he'd say 'no' and I'd say 'you can't say no to a cancer patient!' or I'd just try and get out of everything by saying 'I'm a cancer patient, you can't do that!" – Robert*

Regardless of the amount they engaged with the process, knowing how and when to reveal the presence of cancer in their lives was a difficult and ongoing challenge for the young people in this study. Different people had different approaches and experiences, but all had to cope with their lives becoming public property and managing the narrative of their cancer experience.

Discussion

The experiences of participants reported in this paper show re-entering school following a diagnosis of cancer can result in challenging dynamics for a young person, which they are not always equipped to manage. Having cancer propels young people into the foreground within school, introduces new variables into their existing relationship dynamics and can make their lives seem like public property. Absences from school and altered physical appearances create a 'before-and-after' which draw attention, intrigue and concern from peers and staff members. These are inevitable consequences of the situation and therefore something young people are forced to confront to some extent, regardless of their wishes and preferences.

Because cancer is rare amongst YP, participants sometimes found themselves unprepared to handle situations and experiences arising from their diagnosis and treatment, and equally their peers often did not have experience of providing cancer support or how best to respond to YP (Compere and Compere, 2002). The majority of participants reported some examples of altered peer group dynamics, some of which provided significant challenges, whereas others resulted in positive experiences such as increased closeness and care from others (Pini et al., 2016). Overall participants did not report isolation from peers when reintegrating into school, but did discuss anxiety, awkwardness and pressure related to handling their cancer story when returning to this environment. Responsibility and concern for the feelings of others depended on closeness; family members and close friends were often told first and separately so participants could personally attend to their reaction. As with the findings of

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Hilton (Hilton et al., 2009), some participants projected a more positive image of their experiences and feelings in order to protect their friends and relatives. Peers and mutual friends were often told in groups such as form classes, or participants would wait for the news to spread through the peer network. The use of humour in the YP group is compelling, and also reported in the adult literature for the purpose of expressing empathy (Wilson and Luker, 2006) and keeping online discussions about cancer optimistic (Myrick et al., 2016). Perhaps for YP, humour allows survivors to revert back to their pre-diagnosis peer dynamics, tapping into their desire to feel normal whilst also relieving tension and talking about their illness in a non-direct way (Hilton et al., 2009).

Controlling the narrative of their illness was important to participants, but sometimes difficult to manage. For some, being confident and knowledgeable when answering questions from peers enabled them to shape their story to convey the message that they will “beat” cancer. Retelling their own experiences of cancer in a way that reinforced the belief they wouldn’t die served as a coping strategy, as well as eliciting support from peers and protecting the feelings of others. For participants who were less confident, having agency in deciding who to tell and when could be difficult if physical changes provided obvious external signs for any peers to see and react to. ‘Mismatches’ between the story projected by participants and the reactions of those around them in school could be distressing. The feelings of tertiary peer groups became a source of stress when their reaction seemed too strong for the closeness of the relationship or they had the wrong information about the YP’s diagnosis or treatment. This is because attention from distant peers can make young people feel more exposed and conflicts with their desire to feel ‘normal’. The pursuit of ‘normal’ has been shown to be more of a concern amongst YP than adults (Iannarino et al., 2017), but there can also be tension between the desire for this normality and the variable need for special consideration (Pini et al., 2016). Our findings are consistent with existing knowledge that communication about cancer experiences is fundamentally important for YP survivors and that advice related to disclosure could be beneficial to survivors (Wong et al., 2017).

Limitations and implications

This paper adds an important young person voice to the literature in this area and highlights dynamics of information sharing that can be further investigated and used to inform the development of support, services and information. A limitation of this research

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was that telling and knowing were not the specific focus of the original interviews. Therefore, a more targeted investigation of the process of telling and knowing experienced by YP would be beneficial, including an assessment of these experiences in different environments (school, hospital, home and community). It would also be useful to investigate the current ways in which young people are supported with telling in these environments. A more detailed assessment of this kind could then be used to inform the development of guidelines to best support young people with this process.

The James Lind Alliance Priority Setting Partnership for Teenage and Young Adult Cancer identified the question "What interventions are most effective in supporting young people when returning to education or work?" as number 7 in their list of Top 10 priorities (James Lind Alliance, 2018. Retrieved from: http://www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer/the-top-10-priorities.htm). The self-reported experiences of young people captured in this paper are key to developing supportive interventions.

Conclusion

The dynamics of telling and knowing were an important part of re-entering school for participants in this study. New responsibilities, handling sensitive personal information and being brought more into the foreground, all combined to make re-entering school a challenging and potentially distressing part of the cancer journey for young people. More focussed research is needed to more comprehensively understand these experiences and inform the development or refinement of support for young people at this time.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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Highlights

- Participants described the process of telling as an ongoing dynamic process marked by multiple school visits and short periods of time in school throughout their treatment, rather than a one-off disclosure.
- Agency in deciding who to tell and when was lost if changes to their appearance, mobility and abilities propelled them into the foreground and invited questions from a large number of peers.
- Having the attention of many distant peers in school was a challenge to participants' desire for normality.
- Sometimes questioning from peers on their return to school highlighted the limitations of their knowledge about their cancer and led to frustration and vulnerability.
- Owning their cancer story by providing a knowledgeable and confident narrative allowed participants to shape their experiences to reinforce their belief that they will survive cancer and elicit social support.

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Conflict of interest statement

Manuscript title: *'What are you crying for? I don't even know you'* – The experiences of teenagers communicating with their peers when returning to school

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