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How young people describe the impact of living with and beyond a cancer diagnosis: feasibility of using social media as a research method

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Objective:

Young people with cancer exhibit unique needs. During a time of normal physical and psychological change, multiple disease and treatment related symptoms cause short and long-term physical and psychosocial effects. Little is known about how young people cope with the impact of cancer and its treatment on daily routines and their strategies to manage the challenges of cancer and treatments. We aimed to determine how young people describe these challenges through a social media site.

Methods:Using the principles of virtual ethnography and watching videos on a social media site we gathered data from young people describing their cancer experience. Qualitative content analysis was employed to analyse and interpret the narrative from longitudinal ‘video diaries’ by 18 young people equating to 156 films and 27 hours and 49 minutes of recording. Themes were described then organised and clustered into typologies grouping commonalities across themes.

Results:

Four typologies emerged reflective of the cancer trajectory:treatment and relenting side effects;rehabilitation and getting on with life;relapse; facing more treatment and coming to terms with dying.

Conclusions:

This study confirms the need for young people to strive towards normality and creating a new normal, even where uncertainty prevailed. Strategies young people used to gain mastery over their illness, and the types of stories they choose to tell provides the focus of the main narrative. This social media site can be examined as a source of data, to supplement or instead of more traditional routes of data collection known to be practically challenging with this population.

Keywords: cancer; oncology; social media; teenagers/young adults

Background

A cancer diagnosis can be traumatic and life changing at any age. In young people it carries extra significance, being unexpected and accompanied by perceptions of devastating consequences on the future [1]. Anxiety about treatment, side effects, negative attitudes towards cancer and longer-term prognosis are likely to be the most immediate concerns [2 3]. The array of symptoms resulting from the disease and its treatment cause short and long-term physical and psychosocial effects that impact on daily living [2 4 5] Cancer challenges their sense of self-esteem, leading to feelings of loss of control at a time when self-image and gaining autonomy is pivotal to normal development [6]. Transition to adulthood is often disrupted where the focus is on managing normative developmental tasks at the same time as coping with the challenges of their diagnosis[7] .

As a result, relationships with family members and friends can be disrupted reducing the development of social skills, family functioning and social support so critical to life with and beyond cancer [2 8 9]. Families of young people with cancer integrate illness and treatment into everyday living by reconstructing a new ‘normal’ view of their world and how to manage it [10]. Young people also value their personal resources and peer-group social support [11 12]. It is not surprising that maintaining engagement in school, with education, employment, and managing the shifting roles within the family, with partner and peers have been prioritised by young people with cancer [13] . In particular they describe networking online as critical to their life, facilitating real-time communication and connection with peers and those in the same situation [8].

Aided by the convenience and constant access provided by mobile devices, in particular Smartphones, 92% of young people have reported going online daily, including 24% who say they go online “almost constantly” [14]. Social media has become young people’s preferred mode for information gathering, communication, and support [15 16 17]. What has been described as ‘naturally occurring’ peer support, has revealed new avenues for the way in which researchers gather personal stories [18]. It increases our capacity to approach primary data collection in different ways, as well as access a vast and ever-growing repository of information and data that already exists[19].

This study sought to address two main issues:

1. How is a social media site for young people with cancer being used to share illness narratives: what kinds of stories are told, and what information, in terms of practical advice, technical or supportive information about treatment, young people choose to share with others.
2. Is it possible to collect and analyse these narratives: can this social media site provide quality data, and could it either replace or enhance other data sources known to be more practically challenging to collect from this population.

Methods

Young people report describing their cancer experience more freely using new technologies; self-filming provides the privacy to explore concerns and intimate worries [20 21]. JTV Cancer Support (JTV; https://jtvcancersupport.com/) is an online community for young people with cancer. Its origins are in the United Kingdom but now is host to international films. Patients are approached around the time of their diagnosis and admission to a hospital by a JTV 'champion' and invited to participate. They are offered a camcorder, which they keep and use to make a film about their experiences. At the time of this study, the site included over 1,620 films and receives 2,000-4,000 unique visits monthly. It was this rich source of naturally occurring 'data' we examined, seeking new ways to gather insights into patients' perspectives.

Data collection

We employed the principles of virtual ethnography online, a participant-observation approach using computer-mediated communications as the data source [22]. Studying 'at a distance' allowed us to enter more fully the world of young people through observations 'in the field': we learnt through immersion, supported by systematic enquiry of our observations. To enhance our insights our research team included a young person with a previous cancer diagnosis, a second young person with a previous cancer diagnosis also assisted with data collection.

Participants and procedure

At the time of our study there were approximately 490 films on the site, ten minutes in length, divided into a range of different genres, such as music, drama, video diaries, written stories as well as the spoken word: a search engine was available to search on a particular topic. We selected ‘video diaries’ for analysis due to their longitudinal nature this would allow us to follow young people telling their story over time rather than a cross sectional sample of diaries of different young people at different points in their journey. Additionally, the ‘video diaries’ captured how young people used the camera in different ways, including documentary, expression through animation and music, as well as conversations and interviews with professionals.

A proforma was developed by paired researchers independently viewing two films each directly from the website (FG/TG; LF/SH). Discussion was followed by refinement of the proforma. Two researchers independently watched each video at least twice.

Data analysis

Each video diary was analysed using qualitative content analysis [23] [22]. Narrative materials were broken down into smaller units of content on the proforma to capture the essence of the patient’s narrative (*coding and noting*). Data analysis and interpretation proceeded in tandem. Through a process of dialogue significant statements were identified and further transformed into mind maps (*abstracting and comparing*). The team returned to the website to re-watch videos as required (*checking and refinement*). Patterns and meanings implicit within patient’s stories were explored further, mind maps were further refined and expanded: supportive salient quotes were highlighted on each mind map. Themes were identified, organised and clustered into typologies (*generalising*).

Ethics

Ethical standards specific to online communities were adhered to [24] . Written consent is taken prior to young people making film(s) and edited films are approved by young people before posting on JTV. All quotes are anonymised.

Findings and discussion

Available for analysis were, 18 video diaries recorded longitudinally by 18 young people aged 11 -25 years (yrs) with cancer (Table 1). Diaries held 156 films totalling 27 hours and 49 minutes. Films averaged 10.42 minutes (range 1.42-38.02). Filming was in a range of locations including hospital and outpatients, young people’s homes, at special events and key social events.

Six themes emerged which were organised into four typologies reflecting an unfolding journey: treatment and un-relenting side effects, rehabilitation and getting on with life, relapse and facing more treatment and coming to terms with dying. We use this typology to address our first question: how is a social media site for young people with cancer being used to share illness narratives, to reflect on our perceptions of the kinds of stories being told and include salient quotes that best illustrate our typology. We present findings and discussion together so that we might best illuminate what this narrative adds to an emerging story of ‘what it means to live with cancer’?

Treatment and un-relenting side-effects

The most consistently discussed elements were side effects of therapy, symptoms and emotional issues and in particular advice for managing them (Table 2). Progressive fatigue and exhaustion featured prominently, compounded by nausea, vomiting and pain. One young person described three types of fatigue: *I’m so tired and I don’t know why...this is not a normal tired, it’s something to do with the treatment [radiotherapy]. It feels like chemo-tired but on a lesser scale. It’s not as bad...nowhere near as bad as chemo tiredness, which is interesting…not nice...no energy’ (Female, 16yrs).* Advice was offered for others: ‘*You can mix and match your anti sickness…keep speaking with the hospital and nurses and they’ll let you know what to do’ (Female, 22yrs).* Practical advice was also offered: *‘Celebrate your baldness, make it your fashion statement...I wanted to take control and didn’t want to find hair on my pillow, and I wanted to say OK cancer you can’t control me’ (Female, 17yrs).* Even those facing the last few weeks of life offered symptom control advice: ‘*Heat is the best thing, sod morphine just get something hot’ (Male, 20yrs).*

Boredom featured in many videos. This included endless waiting and hanging around for treatment, investigations or waiting for permission to return home. Those cared for in teenage and young adult units were appreciative of the facilities that helped relieve boredom, while a few, cared for in children’s units, valued the greater freedom these offered but felt too old to be there, and the ‘*playroom was rubbish’*.

Inadequacy of hospital food was frequently mentioned, many described it as '*crap*' and offer advice about bringing your own and spoke of essential food items needed to keep you going, such as energy drinks and '*Battenberg cake'*: many spoke about looking forward to eating out or a '*roast dinner with the family'*.

The extent to which side effects and treatment frustrated young people, was apparent in their dialogue. Treatment for many impinged upon all elements of social and educational life, destroying the creation of life plans. Young people consistently shared stories of multiple rather than single symptoms, similar to previous studies that have used reporting instruments [25 26]. In addition to seeking information from health professionals, young people used the Internet for advice and practical help, and turned to family members and friends to find support. Concern was often expressed about the impact their illness was having on family members, particularly parents and siblings, and many stressed the importance of returning home. Relationships with parents featured frequently, particularly worry about the burden family members might be experiencing in their role as carers. Strengthening of the family unit was often expressed. One young woman described how nice it was to get close to both of her separated parents: '*...is just so much stronger [relationship]...before we were really close but it's just brought us together' (Female, 16yrs).*

The frustration of disrupted daily routines was a significant thread. In alignment with the need to look forward not back, and knowledge, information and support aided this process. Although some young people reflected this buoyant view, for others the treatment was described as 'all consuming' and they were unable to focus on much more. A journey of moods was often witnessed. A positive effect of setting goals, seeking a new normality, and planning social events served to raise energy levels was evident and frequently given as advice. As was the advice to *'learn to be comfortable being ill, cherish little moments and take control, take each day as it comes, and don't be scared to open up' (Male, 19yrs).*

Rehabilitation and getting on with life

Regaining a sense of normality through everyday activities was considered important even for those with a poor prognosis. Rehabilitation was viewed as a means to assist with attaining goals. Retaining some normality was integral throughout all the video diaries. This included calendars counting down the day's left of treatment or towards holidays, or specific events or treats and often included aiming to be well enough to enjoy a celebration, getting back to school or seeing friends. The importance of keeping up with friends was not always explicitly articulated within the video diaries but was apparent through the dialogue. Young people often described positive experiences of peer support and forming close bonds with other young people with cancer. Friendship groups did not uniformly change after diagnosis, some friendships grew stronger while others weakened, but maintaining a relationship with friends was important: *'especially when you are a teenager…you don't want your parents there all the time and you do need friends to be normal with' (Female, 16yrs).*

Being normal included everyday activities such as attending school and sitting exams, resuming past activities, such as hobbies, driving or sports and often in the context of having difficulty doing so, or the pleasure/relief they experienced when achieved. To walk to school with their friends, which meant learning to walk less aided, or socialising when feeling unwell, which required more effort became even more important: *'Felt absolutely horrific before I went because I had been throwing up all day. But I got dressed, put my make up on and was determined to go, I took my sick bucket, even took it into the restaurant. The girls picked me up. Absolutely amazing if you get out of the house, it is a distraction and helps you feel better' (Female, 22yrs).*

The word 'normal' was used frequently and it was apparent it had come to signify something positive for some but elusive for others, for some positivity was tinged with fear and uncertainty, as they knew their disease had returned. The ambitiousness for life changed in relation to recovery or set-backs in treatment but the seeking of normality remained throughout, even when facing death. Several discussed or demonstrated the importance of hope and a positive outlook while others described feelings of claustrophobia or frustration at not being able to resume normal life: *'I feel the cancer has taken control of my life, no longer feel I can do things for myself, like go down in the morning to make myself a cup of tea without having someone to help me' (Female, 17yrs).*

Young people described strategies employed in order to continue with schoolwork, such as making sure treatments were scheduled around important calendar dates and conserving energy for important events. Visits to school and time with friends at school appeared frequently as images as well as in discussion. Setting goals was a strategy used with education such as being able to sit exams. Education is known to provide a safe and familiar structure, opportunity for peer contact, achievement and development [27]. Our work further supports the need to provide for young people to continue education and to keep in contact with friends [27]. Acknowledging what was described by participants in a previous study as 'I have this other life' [28], health care teams need to offer advice on both practical and emotional strategies that enable young people to maintain a 'normal life'

Relapse and facing more treatment

A constant companion for some was the thought of relapse; one young person reported a sense of relief, as they had been so preoccupied by when this might happen. Uncertainty shadowed remission for some young people. For those who relapsed, some expressed anger as they felt they had kept their side of the deal and were back at square one, their body having let them down. The fear of going back into hospital due to relapse was evident including describing the feeling that they did not belong in hospital anymore.

Determination about new treatments working (when healthcare professionals (HCP) were explicit this may not be the case) were apparent in some stories, as was the converse; HCP assuming that young people would want 'experimental' treatments which compromised quality of life led to adamant refusal.

Fear of relapse is reported in the adult literature and by young people [29] , adult data suggest that fear of recurrence is related to quality-of-life and psychological well-being [30]. Interventions to improve communication about relapse risk and helping young people manage their fear of reoccurrence may improve quality-of-life for young people where fear and anxiety about relapse persist. In turn, this may help confidence building, adoption of healthy lifestyles, engagement with healthcare services and transition back to 'normality'. Joint decision making and realistic expectations from HCP and young people about the probability of treatment success during relapse are required. Interventions are necessary to manage hope and realism between HCP and patients during discussions around relapse and experimental treatments. Miller et al., demonstrated that adolescents consenting to Phase I (experimental) studies did so based on expectations of prolongation of life and during consultations HCP often use language which would infer hope that this may be the case [31].

Coming to terms with dying

The description of provision of care in the voice of the young person dying with cancer is incomplete [32]. Stories were often optimistic, even when prognosis was poor. For patients with a terminal diagnosis nearing the last few weeks of life, an attempt to retain a sense of normality often featured – this included everyday things (school, exams) and goals (holiday planning) but as a mechanism to come to terms with their imminent death. In the diaries where death was inevitable the descriptions of what was important to young people were similar to those receiving curative therapy: hospital environment, peer support and being in control of treatment and care choices. Our study highlights the need for more research examining the needs of young people and their carers facing the end of life. This will allow health care professionals to best empower choice in young people and provide them with appropriate services to support them and their families when facing death.

Reflections on the method and limitations of the study

In undertaking this study we sought to answer our second question and find out if it is possible to collect and analyse narratives shared on a social media site. Initial selection of narratives was based on the nature of the posting, in this case video diary. We acknowledge this as a limitation resulting in stories from across a broad range of ages; however we might suggest these were in fact similar stories just told in different ways. Analysing personal narratives recorded by young people has facilitated new ways to gather insights into the experiences of young people with cancer. The video diaries allowed a sense of being ‘up close’ and intimate with the participant, for some the camera was used as a ‘*friend*’ to express thoughts and feelings they could not express directly with others: *‘Helps me much (sic) talking to the camera. I find it harder talking to other people…easier to just let it all out in one* *place...just say it...this is how I'm feeling...yeh...definitely easier. I feel I can never hide stuff with the camera...which is nice'* (Female, 16yrs). The video diaries facilitated the freedom to express themselves in a range of formats rather than being confined to structured questionnaires or interviews, young people therefore choosing to share what was important to them, not to us as researchers, using language they seemed more comfortable with. Thus, the data is more like a 'natural data' source, where participants behave as they would without the influence of researchers: a definite strength of the method where we hear something close to their authentic voice.

Those coming to terms with the meaning of their shortened lives, seemed to be particularly liberated using the camera, their discussion with the camera was both direct and composed. Recruitment to end of life studies are noted to be difficult, with the debates centering around the nature of vulnerability, moral appropriateness, consent, gate-keeping and inclusion and research culture [33]. The category of 'do not approach' has been applied to recruitment challenges [34]. The ethical issues around undertaking palliative and end-of life research with young people are of course considerable. We might suggest that analysis of patient stories available on social media sites might provide an avenue that will increase professionals knowledge of what it is like to be facing death at a young age: an approach that avoids some of the gatekeeper and bias complexities of research with this population[35]

We do however acknowledge film editing by JTV and young people prior to posting may have resulted in some adjustment to the story. For example, important areas of discussion, thoughts and emotions which the young people subsequently decided not to post. Despite this, we believe what we have analysed is the stories they wanted to tell others, similar to all research but perhaps with even higher levels of participant involvement in this approach, as the films are self edited.

There are noted gaps in the evidence base to support the care of young people with cancer, with calls for research to fill these gaps [36]. Social media and social networking platforms can provide a more acceptable avenue to engage, educate and improve the health of its users. Researching online is associated with a very specific set of skills and knowledge that must be learnt and refined similar to all other research methods. The method offers a wealth of opportunities including the potential to be effective, efficient, and more representative in recruiting samples for future studies[37] . In this study, researching online offered up patient stories that are accessible, personal, and reflective accounts of what is important for participants to tell others in a similar situation. This is a strength that requires further exploration in future studies.

Conclusions and further research

This is the first study to analyse how young people describe their cancer experience using self-directed films placed on a social media site for young people with cancer. Our findings revealed emotive and insightful stories. The narrative in the majority of films took the viewer on a very personal journey through episodes of treatment, recovery, rehabilitation, and relapse and for some preparing for death. The overriding sense from observing these accounts was of young people trying to make the best of their situation, finding ways to overcome what they and others were feeling and return to normal as soon as they could, even if it was a ‘new normal’.

For young people with cancer the films provide practical advice and emotional and social insights into dealing with cancer, the delivery of this information from another young person with cancer makes the information accessible, understandable, credible and potentially more powerful and informative than conventional formats such as patient information leaflets. For HCP we are exposed to more in-depth accounts than we may typically be privileged too, potentially, allowing us to tailor healthcare management and delivery of appropriate care and information more effectively.

We can be confident in suggesting this site as a source of Internet data that can reveal much about the lives of young people living with and beyond their cancer diagnosis, particularly where focused questions are used to interrogate the narratives and where visual data is maximized to complete the narrative being told. The positive impact of storytelling on patients has been reported. Young people have also reported benefits of creating digital stories to express personal and social impacts of illness on every-day life[38]. However, we know of no evaluation of the therapeutic benefits of posting online video diaries for young people with cancer and the personal creative journey this may lead to. Despite the expansion of social media and sites where patients share their stories [16 39], little research exists about the effects of watching and hearing other patient stories, particularly for young people. However research with adults with chronic conditions can help to inform future studies, where Internet use in relation to health was shown to have an impact described using five key themes: (1) information, (2) feeling supported, (3) relationships with others, (4) experiencing health services, and (5) affecting behaviour [40]. How these effects are both similar and different for young people with cancer is worthy of exploration.

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Table 1 Participant demographics

Characteristics	Number
Male	7
Female	11
Age at diagnosis (years)	
11-12	2
13-18	4
19-25	11
Unknown	1
Diagnosis	
Brain	3
Lymphoma	3
Leukaemia	5
Sarcoma	5
Unknown/carcinoma	2

Table 2. Symptoms, emotional issues and coping strategies described and/or observed

Symptoms: Pain; discomfort of intravenous cannula/Naso-Gastric tubes; headaches; insomnia; sore/peeling feet; steroidal side-effects; visual disturbances; constipation; haemorrhoids; oedema; bleeding; shaking/fever; leg weakness; stomach pain; losing nails; heightened sense of smell; restlessness; shingles; feeling physically/mentally overwhelmed; neuropathy; fatigue
Emotional issues: Determination; anger/annoyance; anxiety; inertia; loss of old life; sense of injustice; physical/emotional vulnerability; loss of independence/control; excitement about treatment finishing or events.
Strategies: Music; looking forward; set targets; complimentary therapies; take control; heat and regular painkillers; visit friends; take food into hospital; create sleep/rest routine; meet other young people with cancer.

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