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Untellable tales and uncertain futures: The unfolding narratives of young adults with cancer

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Abstract

In this paper we examine the use of creative methods for understanding the experience of young adults aged between 16 and 30 years over a year following a cancer diagnosis. Exploring the renegotiation of identity, the narrative, longitudinal research design of the study demonstrated the unfolding process of the narrative work between these participants and researcher. We used a combination of visual, spoken and reflexive psychosocial approaches to understand emergent narratives, many of which do not always find symbolization in language. Our methodological approach focused on the difficult and sometimes 'unspeakable' nature of the young adults' narratives, demonstrating the importance of different modes of communication in articulating complicated relations with uncertain futures. In this respect the links between narrative, social action and the imagining of possible futures is precarious. In this paper we explore how untellable issues were explored, and the challenges of doing so.

Key words

Narrative, longitudinal, visual, psychosocial, cancer

Introduction

You spend your life thinking about the past and worrying about the future, and being on autopilot. But what you do now determines what happens in the future'. (Max aged 30, cancer diagnosis; Burkitts Lymphoma)

Ricoeur (1991) suggests that the self is best understood as unfolding through episodes which both express and constitute its nature. As such, an examined life is one understood through the stories that we tell about it (Ricoeur, 1991), and identity is a construction of the self, reflexively understood by individuals via biography and an ongoing process of narrative reconstruction (Giddens, 1991). The impact of a life-threatening illness, such as cancer, is likely to be especially disruptive during young adulthood, a time associated with intensive identity work (Harris, 1969; Erickson, 1968). This includes the assertion of independence from family and the development of capacity to manage separation, choice and independence. This biographical phase can also demand the capacity to both depend on, but also to be depended on, by others and, importantly, the development and testing of intimate relationships (Wadell, 2002; Briggs, 2008).

Kleinman (1988) suggests that illness narrative is the form through which the individual and their significant others can shape, and give coherence and voice to their suffering. Narrative can also help create order, explore emotions, and allow for a search for meaning and connection with others (Riessman, 2008). Illnesses, particularly those that are chronic or life-threatening, are experiences that can contribute to disruption (Bury, 1982), with a need for biographical revision (Williams, 2000) and the making of new narratives. Mathieson and Stam (1995) found that storytelling during the disruption caused by a cancer diagnosis, took on renewed urgency. This was seen in the quest for a new and renegotiated sense of personal identity when former meanings and assumptions no longer seemed relevant.

In this paper narrative is bound closely to a sense of self and identity experienced across time. Here we use examples from a longitudinal study with young adults diagnosed with cancer using visual, temporal and psychosocial narrative methods to provide insights into this particular situation and experience. The methods used sought to get close to these young adults' subjective experiences, getting 'underneath the surface' (Clarke and Hoggett, 2008, p.2) and accessing material that may be hard or sometimes impossible to articulate. The methods allowed the researchers to go beyond the text in order to capture something of the context and the practices that characterised it (Mischler, 1986). Cooper (2009) describes the use of psychosocial methods as practice-near research in evocative and multi-sensory terms: for example as methods that enable us to 'hear the grass grow' (Cooper, 2009, p.429) and 'smell the real' (Cooper, 2009, p.432). The methodological breadth of this study supported understanding of the complexity of narrative and meaning across different time points and for linking narrative meaning to action. It is this process that will be examined in this paper using data extracts to illustrate the methodological contribution of visual, longitudinal and psychosocial methods. Before outlining the study itself, we begin by exploring more generally the contribution of such methods in narrative research.

Visual and psychosocial methods in longitudinal, narrative research

Longitudinal or narrative research is relevant in applied research that seeks to explore human experience over time. Henwood and Shirani (2012, p1) suggest that 'everything people do is embedded and extended in time'. Indeed, it can be argued that time and temporality are the ontological entities which shape all of the life course (Adam, 1995; Adam, 2004; Uprichard, 2012). Storytelling can illuminate shifting identities through life's transitions and is a valuable method to re-present experience (both by expression and reconstitution), and thus, as both Squire (2008) and Ricoeur (1984, 1991) suggest, to reveal the nuanced nature of transformation and change. Interviewing over time helps us to understand the iterative relationship between individual biography and its social context as the past is brought into line with a changing present, scaffolding an emergent future. Narrative is central to this process, operating as a hinge between multiple futures and a reinterpretable past (Uprichard, 2012).

Although we may think of narrative as primarily verbal or written, it is possible to conceptualise narrative more holistically by including visual and non verbal dimensions (Riessmann, 2008). Harper has argued that ‘visual narrative’ provides a link between social science and the visual arts (Harper, 2002). This supports 'seeing' and embodied symbolic and contextual meaning within the research process (Radley and Taylor, 2003). Indeed, an expanded understanding of narrative is vital when we are interested in the communication of ‘difficult’ experiences that can be hard to put into words (Padfield, 2011). More generally visual creative methods have been championed in research with children and young people (Weller, 2012; Barker and Smith, 2012; Robinson and Gillies, 2012): where they may struggle with or resist invitations to ‘explain’ themselves. Importantly these kinds of methods have helped to challenge unequal power relations, and have facilitated communication for those who may otherwise be marginalised as well as those whose stories are hard to tell or to hear.

Psychosocial research methods attempt to bridge inner and outer worlds, promoting the expression of subjective experience including material that has not yet found symbolisation in words or well-worn stories (Frosh and Barraister, 2008). Hollway and Jefferson refer to ‘a ‘thickening’ or enrichment of interpretative experience-based research (Hollway and Jefferson, 2013). This is associated with the willingness to engage with unrepresentable and unconscious meaning (Frosh, 2002); or when the words are too difficult to find.

The use of free association as part of interviews and the analysis of interview material is a distinctive characteristic of the psychosocial research tradition. The assumption, borrowed from psychoanalysis, is that through free association we may secure insight into a person's *Gestalt* with access to their concerns which may not be accessable with more traditional methods (Hollway and Jefferson, 2013). Other tools of psychoanalysis used in psychosocial research, include ideas of containment (Bion, 1962) defence, transference and countertransference (Klein, 1952). There has been a strong debate as to how and whether such clinical ideas can find a place in social research. For Frosh and Barraister (2008) these are 'tools' for tentative understandings that may involve a reflexivity about the research process and the nature of the researcher /researched relationship.

Methods and data

In this paper we present an account of using visual, longitudinal and psychosocial methods in the exploration of cancer with a group of young adults with cancer aged between 16 and 30 (Pearce et al., 2019). They were all recently diagnosed with either lymphoma, leukaemia or bone cancer, and data were collected between April 2011 and December 2012. We recruited participants from one United Kingdom Cancer Centre for the care of adults, adolescents and young adults with cancer. Over the period of recruitment, 59 young adults were eligible, with 43 being approached. Eighteen of these consented to participate in the study, 14 of whom were male. Forty- interviews averaging 69 minutes in length were conducted, eight of the participants took part in three interviews over a year, with six participants taking part in two.

Longitudinal data collection spanned a period of 12 months. This was important when considering the temporal rhythms of young adulthood and the progression of cancer and its sometimes lengthy treatment. Indeed, the first year after diagnosis has been suggested to be the most difficult (Kwak et al., 2013). Methods included in-depth, free association narrative interviews at three points in time, photographs taken by participants were also discussed through a process of photo elicitation in the second and third interview; and extensive reflexive field notes were collected. The interviews became a process of joint construction between narrative and meaning (Mischler, 1986), and were participant-led, with some interview probes guiding the interaction (Hollway and Jefferson, 2013). This way of interviewing has also been termed a form of subjectivity in a historical context (Wengraf, 2009), with a focus on subjective experience across the individual, their context and history.

Visual data were collected by the participants in the study using mobile phone cameras. A framework was provided for the taking of pictures or events that reflected the impact of cancer on the person's sense of self, and on their daily lives, although the focus was not intended to be overly restrictive. Photographs were then explored during the second and third interviews in different ways; first, by including them in the development of a chronology of events; second as a way of developing any categories that were meaningful for the young person; and thirdly by inviting the participants to describe and discuss their favourite and least favourite images. The discussion of why a photograph was taken was often more meaningful than the content itself, which in itself could sometimes be hard to appreciate (Barker and Smith, 2012). The absence of photographs and discussion of events where photographs had not been taken were also revealing. For example, photographs were often not taken on days the participants felt at their worst physically or mentally, and this opened up opportunities to explore how such times might escape narration. Participants who did not take photographs also discussed images they *might* have taken and sometimes discussed the reasons for their decision. Thus, the discussion of visual context was part of most interviews to some degree.

Conducting research during cancer therapy means that the research itself can become part of the treatment experience. Some of the participants appeared to use the research relationship as a containing space where the researcher helped them to process their distress, thus making it more tolerable (Bion, 1962). As part of a commitment to safe psychosocial methods, the provision of both a boundaried space and assurance in facing the potential for inadvertent harm or exploitation (Malcolm, 2012), were firmly embedded in the study. The researcher had regular supervision with a psychotherapist, wrote exhaustive detailed reflexive notes and became a member of psychosocial research group for peer support and collective analysis. These methods supported psychoanalytic forms of noticing oneself, being aware of and separating discomfort to that of the participant and of staying engaged emotionally (Elliott et al., 2012). This in turn promoted reflexivity, transparency, trustworthiness and the ability to pick up the cues of whether communication, contact or data collection was or was not appropriate at a particular time (Pearce et al, .2019).

Ethical approval for conducting the study was obtained in advance (REC Reference 12/LO/0183). Written consent was sought before the first interview, consent was then processual and relational, bound within an ethics of personhood and the context of building a relationship of trust and rapport between participant and researcher (Dewing, 2002; Holland et al., 2006). Consent for the use of images took place on an individual basis from the participants and from anyone else captured in the photograph.

A balance was found between assurances of confidentiality and the intimacy produced by combining visual, longitudinal and visual methods. Giving a voice, going beyond text with visual, temporal and psychosocial sources created a sense of fragility in the anonymization of identities (Thomson and Mcleod, 2015; Taylor 2015). Reflexive and flexible ethical engagement, together with a rigorous methodological process (Wiles et al., 2008; Taylor 2015), were essential to manage this process. The challenges for maintaining anonymity during dissemination are critical. In this paper revealing images of individuals have not been used, with pseudonyms used in place of real names.

Researching with seriously ill participants amplifies the ethical commitment to do no harm. Participants were supported if at any time they felt they would like to withdraw from the study. Two participants died before their third interview. Others found it hard to find a good time for the second or third interview. This could have been due to illness but it could also have been due to recovery and the challenges of returning to ‘normal’ life. Others may have withdrawn when the costs of participating began to outweigh the benefits, often this happened at the end of treatment. The researcher met the participants informally once more after the final interview if they were visiting the cancer clinic. If this was not possible a text message was sent; to ensure that their contribution was recognised and to mark the end of the project (De Laine, 2000).

Data analysis involved a holistic analysis of each individual’s experience across time as well as connections between the accounts of different participants. The focus was initially on the eight participants who had taken part in all three interviews. The data for each participant were analysed intensively, with themes and changes mapped resulting in in a ‘case history’ for each participant where different kinds of data were synthesised. Visual images were not used in isolation but analysed against their discussion in the narrative text (Wiles et al., 2008). Case histories were then, as Thomson (2007) describes, brought ‘into conversation’ so that commonalities, differences and that higher order themes could be identified across the sample. Throughout, it was important to stay close to the data, rather than searching for preconceived categories (Hollway and Jefferson, 2013) and allowing for individual motifs meanings and ‘gestalt’ to emerge. In keeping with a psychosocial approach to analysis, sections of anonymized data which the researcher was struggling to interpret, were taken to the psychosocial research group which used free association techniques to suggest insights and possible interpretations. This use of group analysis has been called ‘the power of the third’ (Clarke and Hoggett, 2008); or ‘thinking minds’ (Price and Cooper, 2008, p. 64). It follows the assumption that challenging and/unconscious material may need more than one mind to think about its meaning. In this study the psychosocial group became a place to discuss ethical and methodological issues as well as facilitating the analysis of the data (Thomson, 2012; Clarke and Hoggett, 2008).

The longitudinal nature of the study also allowed a series of narratives to emerge, including the synergies and dissonances between these, and communicated much about the young adults’ inner worlds. A psychosocial framework which allows for the self, the psyche, the social and the physical body (Pearce et al., 2019) as well as explicit and implicit modes of communication can help facilitate understanding of narratives over time (Craib, 2004, Bradbury and Day Sclater, 2004 Thomson, 2012). For all those involved in this study, there was a significant period of embodied, emotional, social and biographical disruption; and for most, particularly for those for whom cure was unlikely, there was the monumental task of making sense of their situation. Visual, psychosocial and longitudinal methods were intrinsic in capturing and understanding this process and our insights of it.

It is probably unsurprising that longitudinal qualitative research in such a highly sensitive area, and with a population often described as ‘hard to recruit’, was both challenging and time consuming. However, as Patrick (2012) suggests, extended time in the field and use of reflexive and creative methods provided a wealth of opportunities for the building of trust and rapport. Maintaining contact in a longitudinal design was essential, and finding the 'good moments' for conversations had to be judged sensitively over time. This involved face to face communication where ever possible (Patrick, 2012), as well as the sending of text messages. When the researcher was in the field she would often 'bump' into participants and share informal conversations. In situations where the researcher had not seen the participant for some time it was important to talk with health care professionals to ensure it was good time to resume contact. Indeed, the uncertain nature of cancer made these touch points with professionals essential. The results of this process is highlighted in the participant's data presented in the sections below.

The longitudinal, time and experience

Longitudinal studies with young adults have characterized this life stage as involving 'critical moments' where important changes give rise to new narratives and identifications (Thomson et al., 2004). This was also true of the young adults in this study during their treatment for cancer. These crticial moments occurred within the cancer and treatment trajectory; the biography of young adulthood; and reflected the time during which these data were collected. Narrative data collected over time facilitated reconstitution, linking the past present and future. This supported narrative as a way of constructing multiple and unforeseeable futures, helping to conceptualise the present and re-interpret the past (Uprichard, 2012).

An unforeseeable future

Paul, diagnosed with a metastatic Ewing's sarcoma, focused on going travelling during his first year of treatment. This was a projected future which would involve him regaining his freedom and independence – which in developmental terms has been described by Margot Wadell as being ready to 'take off and let go' (Waddell, 2000, p. 177). These plans were recounted, and adapted as his cancer treatment and situation changed:

> *I want to get a camper van you know, just go. I think maybe it is just a way of escaping. . . I just want to get out and have a bit of peace, from treatments and seeing doctors and even my mum.*

Although Paul was preoccupied with planning for his future, his narrative also communicated an ambiguity rooted in an awareness of the gravity of his situation and a hope that the disease would be controlled. The methods of this study supported the exploration of these tensions, here voiced by Paul:

> *At the moment the doctors have left it like, you know, 'We're not expecting to get rid of it all with the chemotherapy but we are just going to keep an eye on it'. Like it could, you know, and I always look at the positives. It could just stay stagnant and stay there and not do anything for the rest of my life sort of thing.*

During the study Paul explained that he was enjoying life more than he ever had before his diagnosis, communicating a sense of regret about choices made previously. It is also possible to understand his pleasure in the present as amplified by an emergent mourning of a lost future:

> *I wish I'd have done my Physics and the universe and something. But I always just wanted to get money. . . I still might, I might go like Open Uni.. At least I'd get into something that I really do want to do sort of thing.*

At the end of his year of treatment, Paul went to Amsterdam for five days on his own. This was a vastly reduced version of the trip to Europe that he had shared at the start of the study, yet it was an ambition expressed and fulfilled. Meaning had been found in future-orientated developmental goals which were partially fulfilled. The progression of disease, however, meant that new goals were harder to find.

Narrative when futures may end

Longitudinal methods have been used with elderly populations (Bornat & Blytheway, 2008) and are attuned to both the passage of life and its finality. Yet with these young adults, the prospect that life may end during the study was hard to articulate, and make sense of, for both the researcher and those being researched. Participants talked about the death of others, perhaps as a way of articulating and making sense of the possibility of their own. This was a preparation for a narrated future with an end point, and a moving between the temporal horizons of past, present and future. Simon and Richard, for example, both talked about dead loved ones (through a medium, or in dreams). This suggested the importance of creating a narrative space beyond death. Of course, participating in this study itself contributed to a sense of legacy and the leaving behind of a story. Hearing about continuity of life after the finality of death for others seemed to be immensely reassuring and became a vehicle through which to talk and think about their futures.

Simon, who had been diagnosed with a rare soft tissue sarcoma, discussed the death of a close friend from the ward:

> *. . . they said he couldn't really feel any pain or anythin. . I was sort of, 'Okay, that's something I can hold on to.' …the main thing I can really think of, was, 'Am I going to wake up tomorrow morning?' . . . I'd sort of go to sleep and I'd lie in bed and I'd go, 'Is this it?'*

Within the containment of an interview space that continued over time, some participants were able to experience and communicate a sense of profound sadness and loss. Andrew, who was diagnosed with metastatic Ewing's sarcoma at the point of graduation from his university degree as a mature student, regretted that he had focused so much on the future: '. . *I just think I should have enjoyed myself a bit more*'. By the second interview, he was able to talk openly of his prognosis and time-limited future:

> *Well I think I've sort of come to terms with things now, so there's nothing you can do. I think everyone's just hoping it won't happen. But when it's happening to you, you know the eventuality.*

The sense of sadness and loss was also deeply felt within the interview space by the researcher. It was powerful to be a part of the participant's exploration of the essence of meaning of life and attempts to navigate an emotional and existential landscape. The emotional transference was often deeply uncomfortable and the writing of researcher thoughts and reflections were essential to manage emotional sequelae and make sense of what was taking place. This process of writing sometimes took days and if, at times, it was delayed or evaded it eventually became vital and unavoidable.

The reconstituted narrative

Bruner suggests that we become who we are by telling stories about our lives (Bruner, 1990). An affordance of the longitudinal design of this study was the opportunity to see this process in action during an intense challenge to biography. Jason, illustrated the potential for reconstituting the self through a process of narrative reflection, reconstitution and action. Following a diagnosis of osteosarcoma Jason faced the amputation of his leg. Initially he had protected himself from communicating with the cancer world that he now found himself in, and slept most of the time with a hat over his head, '*I shut it out as it were. So it's not that bad'*.

Near the end of each interview Jason was able to verbalise about more difficult subjects, including the prospect that his leg might be amputated: '*Well the terribly wishful part of me would like it to be as it was before I was diagnosed.'*

In one interview, Jason reflected on images and a photograph that, looking back, he might have taken. Identifying this image seemed to help him move him towards the untellable, beyond the defences of humour and stoicism which characterised his spoken narrative.   This image was of the snow he had seen from the hospital window. He reflected on happy times as a child in the snow which led to reflection on how things were for him now: '*It's a bit dull really, my life. Yes, I wake up and go to sleep'*. He then described the present situation as overwhelmingly depressing: '*A bleak unending nothingness'.* Later in field notes the researcher recorded:

Jason found it hard to leave the interview space and I had to bring it to a close, I knew he had a meeting with the surgeon. Later when checking he was OK post interview, Jason was not able to speak, he communicated through the fear and anguish in his eyes a sense of the sheer enormity of what was going to happen. This was something he was not able to directly verbalise in the interview.

In his last interview some months after his amputation, and on the last day of his treatment, a buoyant Jason spent time looking back on the whole experience from his cancer diagnosis. In a different place emotionally to the previous interviews he said:

> *At the beginning, you know, fourteen cycles of chemotherapy was, it's the longest thing in the world. It still feels like the longest thing ever, but it's actually gone quite smoothly and quite quickly.*

He seemed resolved that he would not be able to return to his career. Yet, this was now framed more positively, with a new integration of the past and the future. A new sense of purpose in returning to a high level of mobility was present; '*I can't run, although it's technically possible. It's something I intend to pursue'*.

The Visual, image and metaphor

Innovative methods for understanding difficult and complex individual human experience may challenge the dominant medical and social discourses (Bury, 2001) around cancer and death. Simon found comfort in communicating with a bigger audience during his illness, making the most of opportunities to be public about his diagnosis and situation:

> *Definitely I've got just stories to tell. Yes, and seeing people's reactions to it sort of builds my confidence back up after being knocked down by having to actually have the experience.*

However, by the second and third interview Simon was turning away from his external audience, wishing rather to explore his inner world. He used image and metaphor creatively to make sense of the growing cancer inside him: *'... you could almost describe it very much like ivy growing up a wall. . . And it sort of creeps up. . . And now that's shrunk right back'.*

The image in the metaphor was elaborated, providing a way to capture uncertainty and to envisage treatment paths.

> *And the surgery one seems very straight. . The chemo one is also very straight. But it's a bit hard to go through. It's like lots of brambles and stuff, a bit overgrown. But I can always cross the path to surgery . . . so that's always good. It's like they haven't ever like cut that path off and said, 'No you've missed that one, that's now not there.' It's still there. I sort of like to visualise it in that way.*

By displacing a definitive ending, hope endured, allowing for the endurance of discontinuity and trauma (Grotstein, 1981). Simon also used storytelling as a way to organise his thoughts and feelings and gain reassurance. As Grotstein suggests the text can then become a 'visual transformation of events in the internal world' (p.371). The discussion of images, symbol and metaphor helped us to explore what 'lies under the surface' This can be described as an existence of ‘shared multi layered collage of images in the human unconscious’ which is a route into our strongest emotions and affect (Manley, 2008, p. 96).

Creative and visual methods allowed the opportunities for both flexibility and autonomy (Wang, 1999), and provided a vehicle for young people to tell their story in a way of their own choosing. The taking of photographs became a ‘tool’ for collaboration; and allowed active participant-led data collection and interpretation (Frith and Harcourt, 2007; Lorenz, 2011; Pink, 2001). Photography and talking about pictures gave participants a different medium through which to express feelings and ideas and through which to communicate the impact of illness and treatment (Williams, 1987; Hanna and Jacobs, 1993). Photographs were taken by those who already were used to taking them or for whom it might support their storytelling. For others this was not perceived as useful or manageable although images, actual or possible, were discussed by all of the participants to some extent.

Paul, for example, took many photographs, and this seemed to help him reflect, to facilitate recall, to connect to the past and the future and ultimately portray his new sense of self (Wang, 1999; Yi et al., 2010; Yi et al., 2016). Sharing his private experiences through photographs enabled Paul to control the interview and to mediate what Rollins (2005, p.220) has termed the ‘researcher gaze’; providing a safe focus, and at times a distraction from a focus on his cancer prognosis that was difficult to share or tell.

Some participants took many photographs over Christmas, providing a window onto family life. These photographs helped sustain a sense of continuity with the past during a time of intense change. Photographs of Christmas and family also represented something which was nurturing to retrieve from the past and to continue as a goal for the future. For Simon, Christmas was at a time when he was still adjusting to his diagnosis and first cancer treatments, this seemed to have spurred feelings of anger:

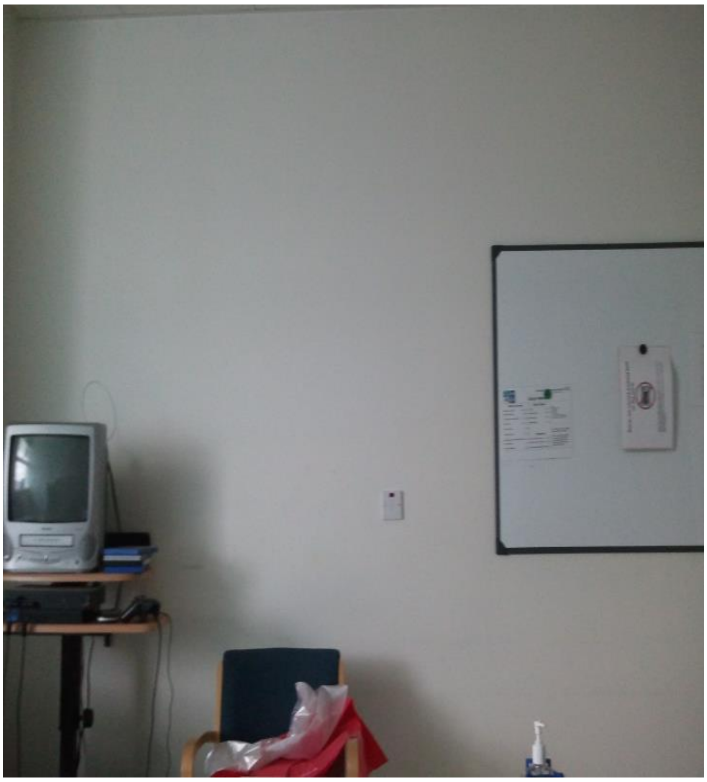
> *They've said 'Don't plan anything.' Why not? I want to plan, I want to plan Christmas. Christmas is a huge thing in our family. It is the best day ever. I . . . I really hated the fact that someone turned round and said, 'don't look to the future don't try and plan anything because you never know how you're going to feel.' And I'm like, '***NO...***'.*

Photograph 1. Christmas at home

Photographs seem to help Paul to project a narrative of young adulthood into the future, protecting his sense of self away from an identification with cancer and illness. Paul's photographs asserted well-being, special days out, meals cooked and eaten, hobbies, and holidays. Paul recognised this method of coping, and said:

> *I think I blanked cancer out. I don't think about things, I don't dwell on that. When I'm having my treatment, it's about that day, so then I go home. Like I forget that day's even happened.*

The work of acknowledging and integrating the split of cancer can be seen in the way he took and shared just two photographs representing illness: one of an intravenous drip stand to which he was connected for days at a time over a period of a year and who he called his ‘new friend’; as well as a photograph of the blank wall opposite his bed in his hospital room. To Paul this reflected the emptiness of life whilst on chemotherapy treatment. Nick took a similar photograph of his blank wall and describing a sense of boredom said: *“. . . he would have to find something to do otherwise I will go crazy and end up killing someone or something”.*



Photograph 2. The blank wall

For Nick, diagnosed with acute myeloid leukaemia, photographs documented his physical recuperation after weeks of isolation during high dose chemotherapy and a bone marrow transplant. His visual narrative provided insights into the times that otherwise might be difficult to articulate, or even observe. After his transplant Nick was very ill, and a photograph of a crane illustrated the extent of his incapacity, as watching the cranes go up and down was the only thing he could do for several days.

The recovery process, documented by Nick, provided the narrative basis for his emerging ability to be back in the world, after weeks and months of isolation. This growing capacity was visualised through social events captured in photographs. First, was a picture with his brother, his bone marrow donor, and second a small dinner with his friends. Attendance at a big stadium rugby game with tens of thousands of other people signified higher immune system strength and physical recovery. The series culminated with photographs of his engagement, and a fully recovered adult body. This visual narrative, over a period of one year, represents and performs the social action that propelled Nick forward with his new life.

Psychosocial Reflections

The psychosocial lens has been reflected on throughout this paper as it became inherently entwined with the co construction of narrative over time and the use of the visual image, symbol and metaphor. Possession of psychosocial sensibility is a useful tool when seeking to understand more deeply the relationship between narrative, meaning and personal or social action. Building rapport over time and bearing witness to suffering and sadness was not without personal cost and exhaustive writing of reflective notes were essential to capture and manage this process. Much reflection was necessary in the managing the endings of research participation, as well as, for some, the endings of life:

> *When I was informed Paul was gravely ill and most probably dying, I was actually listening to his interviews (with headphones on), in the first stage of analysis. The juxtaposition of hope and life in his interview with an awareness of the reality was*

> *powerful and I had to go outside and take a deep breath, the feeling was of total sadness.*

Similarly the transference and countertransference after some of these interviews could be very powerful. On a number of occasions there was an emotional response which seemed to come from nowhere, hours or sometimes days after the interview. For example after an interview with Lucy the researcher wrote:

> *I felt emotional, full of angst and deep heightened sadness following the interview and was exhausted the following day. At the end of the week I wept tears for two hours without knowing the cause or feeling sad. This was the same amount of time Lucy had wept with me.*

Time, reflective space and reflective writing became essential and the longitudinal design in some ways supported the necessary reflexive process of being able to sit alongside the participants despite the uncomfortable feelings that this evoked by doing so. In many ways each stage of the study, and the connection to these young adults and their stories through recruitment, data collection, analysis and report writing, required another layer of mourning to take place.

Containment and providing a safe intersubjective space is central in studies such as this, both to the individual participant, and the researcher. In the interview the researcher's task was to 'hold' some of the participant's feelings a process that has been described as, 'the capacity for being in uncertainties, mysteries, doubts without reaching after fact and reason' [(Keats 1899 p. 212) in Clarke and Hogget (2008, p.16)]. Reflexivity, supervision, psychotherapeutic debriefing and the psychosocial research group provided contained spaces for the researcher and for the interpretation of these participant's data.

Discussion

In this paper we have highlighted the importance of longitudinal, visual and psychosocial methods in narrative research in the context of young adult cancer. As Polkinghorne (1988) suggests, through narrative configuration and the constant revising of what has been, and anticipation of what will be, it may be possible to accept a shifting sense of identity and a bearable concept of self. Bruner suggests that a life led is inseparable to a life told and that narrative organises the structure of human experience; we become who we are by telling the stories of our lives (Bruner, 1990). This relationship is complex, and as Craib (2004) and Bradbury and Day Sclater (2004) suggest, most narratives, if they have any worth, are multi-layered, multidirectional, and are contingent and transient within the nature of their meaning. The complexity of narrative mirrors the complexity of internal and external (social) aspects of life. As the stories within this study illustrate, things that are too difficult may be concealed within the narrative (Craib, 2004), separated from self (Bury, 1991) or remain under the surface (Clarke and Hoggett, 2008; Cooper, 2009). The methods used here were important for an understanding of the intricacy and individuality of narrative. This included the centrality of experience which changes over time, meaning-making and how this helped constitute and reconstitute the nature of living after cancer is diagnosed.

Participants all faced uncertain futures with a need to re-interprete the past, and re-conceptualise or re-negotiate the present. Understanding this situation involved getting underneath the surface of everyday talk, facilitated by visual methods and a psychosocial sensibility, and also by a sense of walking alongside the participants over the year that they were part of this study. What these methods revealed was the profound and dynamic identity work involved in living with a cancer diagnosis and treatment so early in life; involving a circular and repeating relationship between reflection, reconstitution and action. These young adults embodied a profound contradiction simultaneously facing death, loss and mourning while also seeking ways to thrust forward into an imagined future.

Such a contradiction creates conflict which is hard to bear, for all concerned. It can also explain the professional, academic and cultural defences that emerge in such situations (Katz and Johnson, 2006), protecting one (often cancer professionals) from confrontation with mortality, pain and suffering. In such a situation the felt emotional dimensions of our lives are often overlooked in the study of the social world (Craib, 2001). Catherine Riessman has encouraged courage among researchers arguing that ‘doing justice means we cannot look away' from emotions ‘too hard to bear’(Riessman, 2002 p. 194). The methods used in this study provide one way that this is painful to witness.

The research relationship, and the interview space, allowed a co-production of narrative, an event wherein, over time, the intolerable could be expressed and experienced. Some of the participants expressed how being part of this study, and the telling of their story, felt beneficial and was a unique opportunity for sense making and the building of a new identity through tumultuous change. It appeared to help some to cope and to make pathways into the future, irrespective of how truncated that now may be. One participant stated “*I’m piecing together all those conversations into sort of one story almost, like now you’ve got the whole story”*.

Conclusion

This paper has described a study that explored the difficult emotional terrain of young adults faced with cancer to illustrate the value of methods which allowed reflection, reflexivity and, over time the representation of experience through the collection of personal narratives. Narrative, longitudinal research designs have the potential to study the unfolding process of meaning making and personal or social action. The illustration here, drawn from young adults with cancer may be particularly revealing as, both biographically and in terms of the cancer and its treatment, there was an added degree of urgency. Visual and psychosocial methods were essential for getting to the ‘untellable’ underneath surface and understanding the complexity, multi-directionality, multi-dimensionality and the inter-subjectivity of the human cancer experience. By so doing the analysis of these participants’ narratives help to develop our understandings of the link between the internal and external self (the body and the social) and the relationships between narrative to meaning, reconstitution and potential action. The exploration of these methods within their relational, ethical and situational contexts ensured that the study extended and deepened all our insights. The experiences of young adults with cancer were explored in ways that have not been achieved before. We trust that this paper helps to advance the potential of such innovative, creative methods to understand experience, especially human suffering, in all its complexity.

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Declaration of Interest

There has been no financial interest of benefit that has arisen from the direct applications of the research study reported in this paper

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