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# Renegotiation of identity in young adults with cancer: a longitudinal narrative study

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## Abstract:

**Background:** Despite increasing international awareness of the impact of cancer on young adults, to date there has been limited in-depth research to understand their experiences following a diagnosis using a qualitative and longitudinal perspective.

**Objectives:** To explore the impact of cancer on young adults' evolving sense of self and identity over one year from the time of diagnosis. In addition, to contribute further to an understanding of innovative research methods used to examine this experience.

**Design:** This was a longitudinal narrative study using visual methods and a psychosocial lens. Narrative was used to re-present experiences over time.

**Setting and Sample:** Recruitment was from a Principal Treatment Centre for Teenagers and Young Adults with Cancer and a Cancer Centre for Adults in the United Kingdom. Total population sampling was used over a six-month period, recruiting 18 young adults aged between 16 and 30, one to three months from a diagnosis of bone cancer, lymphoma or leukaemia.

**Methods:** In depth, free association narrative interviews at three-time points over a year were undertaken. Photographs were used to help with story-telling. Extensive reflexive field notes, debriefing and the use of a psychosocial research group, also formed data sources. Forty interviews were conducted with 18 participants: eight took part in three interviews, six in two interviews and four in one interview. Analysis focused on the holistic 'case' of the individual temporally. In-depth, visual images were analysed from discussion in the narrative text. Through memoing, coding and comparison, themes were developed across all cases and a conceptual framework developed.

**Results:** The conceptual framework illustrates the renegotiation of self over time through narrative. This was 'biographically' during young adult development and across 'cancer time'; through the core components of: the inner world, (psyche, emotion and coping); self as embodied; self as relating to others, and self as relating to place. Stories indicated that there was a constant inter-relationship over time between the renegotiation of identity and adaption of biography.

**Conclusions:** The focus in this paper is on 'the temporality of cancer' through the first year from diagnosis, and the juxtaposed process of managing biographical and developmental milestones. The importance of developing health care and research which enables narrative and the patient's voice has been highlighted. It emphasizes the need for professionals to 'be

with' and 'walk alongside' through the intensity of a biographically and identity changing illness.

Key words: biography; cancer; identity; longitudinal study; narrative; young adults

Tweetable abstract

A longitudinal narrative study exploring the impact of cancer on young adults' evolving sense of self and identity over one year from the time of diagnosis.

Contributions of the paper:

What is already known?

- Cancer that occurs in young adulthood is biographically and developmentally challenging
- There are reported poorer outcomes, such as, survival and quality of life for young adults in some cancers, when compared with children and older adults
- Supportive and psychosocial care have been identified as important and areas of unmet need by young adults

What does this paper add?

- New temporal, visual and psychosocial understandings of the cancer experience for young adults
- Insights into the impact of cancer and its treatment, juxtaposed on this developmental stage of the renegotiation of identity
- Importance of narrative, in the context of an intervention in nursing practice, and in research

## 1. Background

Globally there are 350,000 new diagnoses of cancer in the 15-29 age range (Barr, 2011), with double the number of diagnoses in the 24-29 age group than those aged 15-24 (Bleyer et al., 2006). Notably, there has been less improvement in survival rates for this age group than in children; particularly in acute lymphoblastic and myeloid leukaemia, bone and soft tissue sarcomas (Barr, 2011, Ries et al., 2017). The superimposition of developmental issues of young adulthood onto a diagnosis of cancer and the impact of illness and treatment suggests that cancer in this age group is particularly challenging. The recent growth of research describing the experience of young adults with cancer has begun to evidence this (for example, Kenten et al. 2019, Korsvold et al., 2017, Knox et al., 2017).

When referring to 'young adulthood' age varies widely, and this has implications for comparability of research globally. In Europe and Australia, the definition incorporates an age range from 16 to 29 or 30 years, the United States (US) utilises a wider spectrum, up to 39 years of age with some research groups now increasing to 45 or 50 years (Bleyer et al., 2017). In a recent European Delphi Study with teenagers and young adults with cancer, Pini et al., (2017), were unable to reach a consensus on the definition of age. An upper age limit, up to and beyond 30, was however accepted by most but not all Delphi panel members. In the United Kingdom (UK) the Improving Outcomes Guidelines (NICE, 2005), developed from expert consensus, stipulated 15-24 years as the age range for the provision of specialist Teenage and Young Adult [TYA] services, and most UK studies cut-off at 24 years. There has been a move to embrace an increase in upper age limit for research in the UK, in response to the wider societal context where there has been a lengthening of the period between childhood and adulthood (Briggs, 2008, Henderson et al., 2007). For this study, young adults were defined as being between the ages of 16 and 30.

This 16-30 age range has been defined as a period of liminality, removed from the direction and certainties of childhood and moving into a period where little has yet been decided about the future (Arnett, 2000, 2004). This period can be described as full and demanding. It involves the transition from family life to independence, to finding and establishing identity, developing the capacity to manage separation, loss, choice and independence, and the navigation of increasing commitment to occupational and relationship pathways (Wadell, 2002, Briggs, 2008, Arnett, 2004). Henderson et al. (2007) have termed this transition to adulthood, which is increasingly considered as fluid and multidimensional, as a 'project of self'. This consists of a 'constant questioning and reconstruction of the self' (Giddens, 1991, p.2); considered essential during biographical change, such as young adulthood, and during chronic or life-threatening illness, which is also identity and biography disrupting (Mathieson

and Stam, 1995, Williams, 2002, Bury, 1992). The theoretical framework underpinning this study emphasizes the importance of biographical continuity and the importance of language, through narrative, for conveying 'ours' and 'others' experience in the world (Ricoeur, 1991).

Although psychosocial, and support needs around the first year from diagnosis have been highlighted as important (Kwak et al., 2013, Zebrack et al., 2014), there has been limited in-depth research to understand the experiences of young adults over the year from initial diagnosis from a qualitative longitudinal perspective. Qualitative research focussing on young adults with cancer is a relatively recent addition to the body of evidence to inform care, with few including participants over the age of 24. So far studies have centred on specific points in time including: diagnosis (Korsvold et al., 2017, Soanes and Gibson, 2017); clinical trial participation (Pearce et al., 2016); supportive care and survivorship (e.g. Innaroino et al., 2017, Robinson et al., 2014); and advanced cancer (Knox et al., 2017, Kenten et al., 2019).

In this paper, temporal themes over one year for young adults with cancer will be examined from a study that sought to explore the renegotiation of identity and self from the time of diagnosis. In addition, this paper contributes further to our understanding of innovative research methods used to examine patient experience. The methodological value of a study such as this, which attempts to 'get beneath the surface' (Clarke and Hoggett, 2008 p.2) and beyond text, is vital to both research and practice, and helps to fill a gap in what is already known.

## 2. Methods

### 2.1 Design

Narrative in this study was used as a method to re-present experience (both expressing and reconstituting it); and thus able to display transformation and change (Squire, 2008, Ricoeur, 1984, 1991). Visual methods were incorporated from the outset to support both 'seeing', and the facilitation of a participant-led approach. It was hoped that this would allow for embodied symbolic, contextual meaning (Radley and Taylor, 2003), and the communication of difficult experiences (Padfield, 2011). A psychosocial lens developed as data emerged and the depth of data became apparent. This provided a route to verbally examine un-representable meaning (Frosh, 2002) and became a 'tool' for getting close to experience (Cooper, 2009), within the reflexivity of the research process (Frosh and Barraister, 2008).

### 2.2 Sample and setting

The setting for this study was a hospital which was both a Principal Treatment Centre for the care of Teenagers and Young Adults with Cancer and a Cancer Centre for Adults in the UK.

Total population sampling was used, this meant that everyone who was eligible during the recruitment period of six months were provided with written information about the study. Young adults were eligible if they were 12 weeks from a diagnosis (of lymphoma, leukaemia or sarcoma), between the ages of 16 and 30, were cognitively able to participate and for whom the gatekeepers, (clinical nurse specialists (CNS) and medical consultants), felt it to be appropriate. It was important to provide equity of opportunity rather than approaching only the easiest to reach and the most eager to participate. Table 1 presents the process of recruitment.

[Table 1. Recruitment of participants goes here]

## 2.3 Data Collection

### 2.3.1 The methods of data collection

Three methods were used to collect data. The first was interviews, which were open, conversational and unstructured to allow participants to tell their story in their own way (Hollway and Jefferson's 2013; Mischler, 1986). Probes were available to guide the researcher if needed. With permission, interviews were digitally recorded and transcribed.

The second was visual narratives. Participants were given the opportunity to take photographs, a medium that provided a window into everyday life, through which they could express feelings and communicate the impact of illness and treatment (Hanna and Jacobs, 1993; Lorenz, 2011; Williams, 1987). A guide was provided, although this was not restrictive. Where they were used by participants, photographs were explored during the second and third interviews as a prompt for them to tell their story (Frith and Harcourt, 2007).

Finally, researcher-related data were collected through a hand-written research diary which documented thoughts and experiences. This provided an audit trail of decisions, inferences, ethical challenges and reflections, as well as field notes of informal conversations. Monthly de-briefing with a psychotherapist and a bi-weekly seminar group focusing on psychosocial research at the Tavistock Clinic ( <http://www.tavi-port.org>) created another space to contain, reflect, digest, process, and provide a group perspective (Bion,1962): adding to the rigour and trustworthiness of this study.

### 2.3.2 The process of data collection

Data were collected over one year (Figure 1) by SP an experienced nurse and qualitative researcher undertaking doctoral research. SP was known to the research setting but not the participants prior to the study. Interviews took place two to three months after diagnosis,

and at six months and twelve months. Interviews were conducted where the participant preferred, most frequently in the ambulatory, outpatient or inpatient setting, with a smaller number in their home. All interviews, except for one, were conducted with the participant on their own. Informal conversations between interviews were a reciprocal part of the relational reflexive nature of this study, and an essential component of longitudinal research (Patrick, 2012). Contact in person, by text, or telephone took place before and after every interview. Health professionals were consulted to ensure it was an appropriate time to be in contact with participants. If any further support was needed by the participant during the study as a result of taking part, and the participant agreed, the CNS was contacted to provide this support.

[Figure 1. The process of data collection goes here]

#### 2.4 Ethics

National Health Service Ethical approval (REC Reference 12/LO/0183) and local site approval for the study were secured. Consent was processual and relational, bound within the context of building a relationship of trust and rapport (Dewing, 2002, Holland et al., 2006). Participants were provided with study information, this included information about the purpose of the photographs, and what this would mean to them in terms of participating. Written informed consent was obtained before the first interview. Participants were supported if they wanted to withdraw at any time. If photographs were taken and discussed in the interviews, written consent for the use of each image was obtained from each participant after the interview. Written consent from any of the people captured in the image was also obtained by the participant, if an image was to be used in the study. Pseudonyms are used throughout.

#### 2.5 Data analysis

A longitudinal approach to qualitative analysis was undertaken. This involved developing narratives of the individual over time and narratives of community (Thomson and Holland, 2003). Analysis focused on the diachronic – over time (rather than synchronic- cross sectional analysis) with priority placed on a holistic analysis of the ‘case’ of the individual temporally (Clarke and Hoggett, 2008). These were then, as Thomson (2007) describes, brought into conversation with each other.

The data from participants who had taken part in more than one interview over one year from diagnosis were analysed initially. This involved tracing individuals' trajectories over time and identifying any dilemmas, conflicts, turning points, loose ends, repetitions, fixations or resolutions in the narrative. This was achieved through reading, and re-reading, memoing and coding and the writing of data summaries (Figure 2).

[Figure 2, The Process of analysis goes here]

Data were then analysed in two ways. Not reported in this paper was the writing of longitudinal case stories for the eight participants had taken part in all three interviews. The focus here is on the higher order themes initially from those fourteen participants who took part in more than one interview (Figure 2). For each participant it was possible to both develop a longitudinal table supporting the synthesis of change over time and a framework of themes for each individual illustrated in a thematic map (Figure 3). Using memoing, mapping and constant comparison, higher order themes across all 18 participants were then developed in order to inform an integrated conceptual framework for the collective narrative of young adults with cancer. This was then cross checked across all data sets until saturation of the higher order themes occurred.

[Figure 3. Example of a thematic map goes here]

Data analysis was primarily undertaken by SP with themes and processes checked and developed in analysis meetings with FG, DK, JW. Visual images were only analysed for their contribution to the narrative text. Anonymised sections of data were taken to the psychosocial research group at the Tavistock Clinic, and free association techniques were used to suggest and test additional questions within the data. This process provided an opportunity to maximise a group of 'thinking minds' (Price and Cooper, 2008 p. 64) when exploring and analysing data and introduced higher levels of reflexivity and rigour.

### 3 Findings

#### 3.1 Introducing the participants and the data

Eighteen young adults participated, 40 interviews were undertaken in total. The interviews were on average 69 minutes. Five participants took photographs which were used in the study. Eight participants took part in three interviews, six in two and four participants in one.

Two participants died before the third interview took place. Fourteen participants were male and the average age was 22. These young adults had a variety of experiences that included being at school to just having left school, to early career, second career and attending university, and two participants were supporting families. A number of participants moved back home with their families after their diagnosis. While many had partners, only six participants lived with their partner. Eight of the participants with either a lymphoma or a form of acute myeloid leukaemia had shorter treatment periods with a high chance of cure at the outset. Participants with some types of bone or soft tissue sarcoma had a poor prognosis when diagnosed. Their treatment often included a year of chemotherapy and surgical treatment including either amputation or extensive but limb salvaging surgery, or radiotherapy.

For the participants, it appeared that (whether managed and articulated consciously, or indicated unconsciously through affect and transference) their inner world (including the psyche, emotion and coping) became the central component to how self was externally expressed in terms of the body, in relation to others or place. Figure 4, the conceptual framework developed from all data sets illustrates the complexity of this interrelationship. Situated within a context of the different pathways of disease and treatment, the sense of renegotiation of identity and biography was expressed over time (one year) through narrative.

[Figure 4. The conceptual framework goes here]

### 3.2 Narrative, identity and the temporality of cancer

#### 3.2.1 Facing cancer

Stories of diagnosis were the first point of confrontation with cancer, for some participants this was described in detail, for others it was initially too difficult or something they came back to. Christopher, like others, indicated it was after chemotherapy that the reality of a cancer diagnosis became apparent.

He explained:

*You know and it didn't hit me until treatment started that you've got cancer, life is going to be a bit different for a little while. You know, hearing the doctor say, 'This is what you've got,' you just sort of take it on board. . . . I was just like, 'Okay, let's get on with it.' And then sort of had the three days' treatment, came home, didn't know*

*what to do, didn't know how to eat, didn't know how to get up, didn't know how to lay down. . . I think that's when it really hit me, the cancer thing, that's when it really hit me, you know, 'You've got cancer.'* Christopher, Interview 1

Hair loss was the most noticeable symbol of becoming a cancer patient and this bothered most participants. For some, the attachment to their hair in terms of a view of self, made it devastating. Jason hid beneath his very large hat worn at all times. He explained:

*Everything else, you know, you get over. . . . Maybe it's sort of something that you attach everything else to, because it's so visible. .... That can be the beacon of irritability!" Now my new identity is my hat.* Jason, Interview 1.

Fern (Interview 1) stated: *"I was just concerned about my hair to be honest, I don't care about how much pain I am in. I don't want to lose my hair"*. In contrast, Simon and Richard coped by shaving off their hair in a symbolic ritual, which brought with it a sense of control. The importance of sharing this and then receiving support from others in their re-negotiation of self was part of this. For Simon, this was from a wider group through social media with the added benefit of raising money. For Richard, the recognition by his son of seeing him without hair for the first time, was a treasured 'moment' and his favourite photograph: *"Me and him together just after I'd shaved all my hair off, knowing that he accepted it and how happy he was."* Richard, Interview 2. For Christopher losing the hair on his head was: *"Okay, I can deal with it. But then like my eyebrows started falling out and everything else, and you're like, 'Now it's weird now!'"* The biggest effect was dealing with how these bodily changes made other people see him, which was a common concern for participants in this study. Christopher said:

*Yes, it's still me, yes. And you want people to know that as well you want people to know that I'm still me. But then you still have that struggle yourself like, you know, I know it's still me, but I don't look like me or I don't feel like me, yes.* Christopher, Interview 2.

Lucy discussed feeling, disconnected from herself and who she had been: *"The thing is I'm not in my usual me, you know. I'm not wearing clothes that I'm used to, so I've lost my identity really. And my hair, this isn't me. . . everything's changed."* Lucy Interview 1. When I asked her if she could describe what she felt like, Lucy said she felt like *"Cancer me."*

### 3.2.2 Managing Treatment

#### 3.2.2.1 Reflections of context and place

The first two cycles of chemotherapy were often the most intense. For some of the participants with lymphoma, treatment then ended. However, many participants spent months in hospital. As Paul suggested in his photograph (Photograph 1 in supplementary file), the drip-stand became a friend.

Lucy had strong reflections on the context of the hospital and its association with the intensity and the impact of treatment:

*When every time you walk through that door downstairs, you begin to hate the place. Like I hate this building and it's not because it's horrible, it's just associated ... And who wants to self-inflict all of that on themselves? You know, it's coming, I walk through that lift door knowing that I'm going to sit down and they're going to pump it into me. Lucy, Interview 1.*

Being away from home for five months had a significant impact on her internal world:

*I'd got to a point where I was really down ... just having my own room and my own space and my things around me. I know it sounds silly but when you're taken away from that it's horrible. Lucy, Interview 3.*

Several participants took photographs of blank walls (Photograph 2 in supplementary file).

Nick described the magnitude and extent of the impact of his boredom: *"have to find something to do because otherwise I would go crazy and I would end up killing someone or something."* Nick, Interview 2.

#### 3.2.2.2 The body

The intensity of the treatment on the body was discussed by all participants. With interviews often being held on the participants' 'better days', the visual brought 'seeing' to these times. This included an image of cranes (Photograph 3 supplementary file). After his bone marrow transplant, Nick indicated the degree of suffering many of the participants described at the height of treatment. All Nick could do for several days was to watch from his hospital window a crane repeatedly travel up and down. Photograph 4 illustrates the impact of chemotherapy on the body for one participant. Field notes noted the fragility of bodies and the horror in the eyes of participants at critically embodied times such as the height of their disease and treatment related symptoms. For example, Neal for days was desperate to talk and give voice to his experience, but had to wait to be able to open his mouth after a week of acute

mucositis. He described this as: *“the worst bit of it”* Neal, Interview 1. Some images were discussed after the event. Max stated:

*You always see the people on chemotherapy, . . . really sort of sunk into your bones and not very, you know, quite pale and no hair. I guess obviously I was like that towards the end, but I didn't really see myself as that, it's such a gradual progression. And it wasn't until I saw myself in this photograph and this video, that sort of, you know, oh thought, wow, 'I'm like that,' you know. I had sort of got to that point. That was a bit of a shock.* Max, Interview 2.

After the intensity of the first few months of treatment, Simon said:

*I'm starting to recognise bits of myself again, bits of my old self again ... My physical body has changed so much. It's only little bits that I recognise, but then in terms of mental and emotional things, it's like I'm realising that I had parts of me that I didn't know were there.* Simon, Interview 1

Internal processes were also viewed as a way of sustaining and maintaining some control over the body. Nutritional supplements and eating super foods were described by both Dan and Simon to support the recovery of their body and create some sense of control. Sleep was used as a means to escape and 'not remembering' was also frequently reported. Lucy stated:

*I can't remember it all. I think it must be some sort of like mechanism trying to protect yourself . . . I remember getting here in January, but then I don't really remember what happened next because I was so ill.* Lucy, Interview 2.

After the completion of his treatment Max used mindfulness techniques to help in his recovery: *“I sort of take a deep breath and think about a particular time during treatment, I just sort of feel . . . sadness to some extent . . . I think it's just my body sort of remembering what it went through”*. Max, Interview 2.

### 3.2.2.3 Managing uncertainty

Receiving or anticipating news on whether treatment was working, or regarding significant treatment decisions, had a profound effect on the participants. It was described as:

*. . . Panic attacks . . . Not sleeping ... heart was racing, I found it really scary. I thought I was losing my mind. I was just scared that I was going to get there and she*

*was going to say, 'The cancer is growing again and it's spread'* Christopher, Interview 1.

Simon described the unexpected suggestion of a colostomy being like: *"hitting, a marathon runner's wall. I said to mum I didn't want to wake up, but not like I wanted to be dead. I wanted to just stay asleep and just sleep because I just didn't see the point of waking up"*. Simon, Interview 3.

Simon went on to use myth and metaphor as he described uncertainty but also the opportunity to move between treatment paths. Having no endings or finality allowed the maintenance of hope. Simon said:

*And the surgery one seems very straight, very right there. 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 now not there.' It's still there. I sort of like to visualise it in that way.* Simon, Interview 2.

Other mechanisms for managing the intensity of these times included psychic retreats, meaning processes which were developed to protect against mental pain, for example Simon stated: *"You just need to go, 'Right, no I've accepted that, . . . I've thought about it and now I can put it away and just, you know, bring it back whenever I want. . ."*. Simon, Interview 2. A number of participants found distraction helpful, for example with a new puppy. This was a different kind of retreat, a way of focusing on the everyday experience of - dog walking, clearing up dog accidents, puppy antics- rather than focus on their own more complex lives.

Defences were also important in managing uncertainty. Jason gave some examples of using defences when discussing a pending amputation of his leg. When the researcher asked him if he felt worried he used humour: *"A little bit. I worry that I'm going to be disappointed if they don't cut off my leg,"* and then using logic he continued: *"If it's more radical, it must be because either it's spread, which it doesn't look like it has or because it would affect limb function. So it [amputation] will be the smart choice. I say I try not to make assumptions based on facts that I don't have."* Jason, Interview 2.

Keeping cancer in a box with a definite sense of separation of cancer and self was central to these, perhaps at times, more defended narratives. Paul discussed how he saw treatment

like a day's work and would come home and forget that it ever happened. Martin stated: *"I've never really thought about it.' But things in a box, moved on don't really want to think about it again."* Martin, Interview 3. It was perhaps less easy to keep within this defence if cure was no longer likely.

### 3.2.3 Breaks in treatment- finding biographical opportunity

For all the participants in this study, finishing or having a break from treatment was critical. Escaping, for a period at least, the debilitating effect of fatigue was a significant part of this. Christopher emphasised this when he described his body's tiredness in terms of age: *"Like I'm 22, but I felt like 82."* Christopher, Interview 2. For those whose disease progressed and treatment would be ongoing, these gaps in treatment became even more important.

Christopher and Andrew, who both accepted the fact that at some point that they would die as a result of their cancer, relaxed once they stopped treatment. Enhanced physical strength, by not having chemotherapy, was linked to an internal calmness. Andrew was: *"Grateful for the break they gave me, as soon as it stopped, I started getting myself back together again and feeling normal"*. He continued: *"You always know it's going to end. But it was like it was good"*. Andrew, Interview 3. Christopher explained: *"I'm more relaxed, I'm more happy, think it's all linked to feeling physically much better and stronger. . .it would be a different case if the chemo was going to cure it. . .But it's not so – I was happy to end it."* Christopher, Interview 2. Having some 'well time' to meet some of their developmental goals while they could, was vitally important, Christopher stated: *"I should just make the most of this time, however long it lasts"*. Christopher, Interview 2.

### 3.2.4 Looking forward reflecting back

At the last interview, twelve months following diagnosis, Max, Martin, Nick and Lucy had all had six months since their last treatment. This is often referred to as survivorship, however neither a sense of 'surviving' nor 'survivorship' were mentioned by the participants. Many who reached the end of treatment experienced this time as challenging. This was initially in terms of needing to recuperate; to re-orientate to a world away from the regimented structure and pace of treatment, the clinic and the body. Then to reintegrate socially and renegotiate back into their life priorities once again. Lucy stated: *"I can't believe how well I feel compared to how I was"*. Lucy also talked about feeling: *"a new me now"*. This was symbolised by wanting to now keep her hair short: *"I don't think I'll ever be that person"*

*before again, like with the long hair and – everything's changed so much, I don't think I'll ever go back to that if you see what I mean."* Lucy, Interview 3.

### 3.3 Temporal landscapes: managing developmental milestones

#### 3.3.1. The juxtaposition

Juxtaposed on the temporal landscape of cancer is the individual and socially structured developmental process of young adulthood. These two processes bring together, or indeed perhaps clash, the thrust for life typical of young adulthood with the sense of death that a cancer diagnosis brings. This can create conflict, which may make the diagnosis of cancer at this time harder to bear, and may have implications for all those concerned, young adults, families and professionals.

A cancer diagnosis on the threshold of new lives, such as going to university for Neal and Simon, emphasized this juxtaposition. Simon started treatment the day he should have been at University fresher's week. Neal stated: *"I was moving out of home . . . It was quite upsetting that I had to stop everything, I was like the closing chapter before going to university and I didn't really get to have it."* Neal, Interview 1. Andrew had his diagnosis weeks before he would have finished his nursing degree with first class honours, a second career he had been working towards for seven years. He stated:

*...not the year I expected. I didn't expect to be in this position this time back then , . . . I expected to be in a job and doing what they're doing [looking at the nurses]".*  
*"It just seems a bit of a waste, it's seven years, it will be seven years wasted, you know.* Andrew, Interview 2.

The thrust for life was maintained in different ways by participants. Simon for example worked hard in his last year of life, finding a place for himself, finding his voice. He said he had grown up much quicker than he ever could have done in one year of university:

*It was like, 'Damn, I'm going to have to put like a year of seeing my friends all with their new friends at uni', 'But I've sort of, I've got caught up with everything around here, like the fundraising and I've just sort of busied myself. And it hasn't been too bad". I feel a lot braver than I was, my sister says, I've grown up almost overnight'. Simon, Interview 2.*

For Paul, the important thread through treatment was a narrative of escape, independence and travelling. Meaning was found in the planning and discussion of a future orientated goal of a long trip on his own around Europe at the end of treatment. This was only partially lived with two short breaks before a return to treatment.

There was an impression of the 'adolescent thrust' and normative narratives of and getting much done as quickly as possible. This could be seen in Simon's story, where he raised a huge sum of money for charity in his last year of life. Lucy, Max, Martin and Nick, all propelled forward with life once they had finished treatment. Max stated: "*And there's no point waiting around really is there? You know, and what is one waiting for? You know, who knows what's going to happen?*" Max, Interview 3. Martin, who was on a junior doctor rotation, found he was reaching his goals despite the treatment: "*It's close enough, to be honest, I'm probably more ready now*". Martin, Interview 3.

### 3.3.2 Biography and loss

Loss and mourning pervaded all the interviews to some degree and included body and career changes. Jason, for example, connected to loss through the amputation of his leg and the subsequent loss of his chosen career and his associated identity. Jane in her second interview was fearful of an amputation: "*I was kind of hoping for a miracle; I just hope they can save my leg*" Jane Interview 2. There was mourning for friendships which did not survive diagnosis and treatment, however there was often an acknowledgement of new ones gained. Some intimate relationships also ended. Of course, loss and mourning were much greater for those who also had to come to terms with the loss of their own lives. Although in many ways an anathema to the thrust of life in this developmental stage, loss and morning is also normal as their lives were moving and shifting from parents, peers, schools, university, work places, geographical locations and early intimate relationships.

A number of participants told stories of significant people who had died. This was a way of experiencing grief and provided a vehicle for some participants to mourn for themselves, together with trying to make sense of existential concerns. It was in some ways helpful to make sense of death through someone and recording the absence of significant people in their narratives, visually (Photograph 5) and orally, provided the opportunity for some participants to understand their experiences and perhaps understand a sense of existence after death.

### 3.3.3. Narrative, biography and meaning

Coping and finding meaning with cancer in young adulthood was a large component of the stories told. Some of the participants expressed how beneficial this had been:

*I'm piecing together so many conversations I've had with so many other people, who haven't got the whole picture like I've put it for you. They've had little bits, little conversations. And I'm piecing together all those conversations into sort of one story almost, like now you've got the whole story.* Simon, Interview 3.

Neal expressed how important it was to share his experience: *"to show people you can go through this. It's tough, I'm not going to lie to them and say it is easy because it isn't but you can get through it."* Neal Interview 2.

Amongst the disruption of cancer and treatment, the tasks of managing uncertainty, moving through, or mourning the developmental goals of this period in life, there were a myriad of intense feelings to work through. There were several ways in which meaning was achieved, or sense made, for example, Christopher said:

*"Nobody wants to be told they've got cancer, but, you know, the amount I've learned in a short space of time is amazing really. And, and I suppose people talk about it, and it does give you a new perspective on life, and so this is a positive thing to come out of it, yes, yes. Fresh perspective on life".* Christopher, Interview 2.

Max had discovered meditation and mindfulness to manage: *"you know, just sort of listening to the morning, like lie in bed and listen to the birds singing, just appreciate that more."* Max felt something in life would have happened to inspire change. *"But this has happened and it has inspired change. And I'm grateful for that"*. Max, Interview, 3.

Paul discussed how cancer made him have to stop a life he felt he was not getting the most out of, he was enjoying life better now but was frustrated he was not now in the position to do the things he wanted. This was also felt by Christopher:

*. . .it does, you know, make you think about the way you're going, what you're doing with your life, you know, what you're going to do now, the whole thing does just give you a new way of seeing life, I suppose.. .it's balancing that with learning to live now with what you've got . . . cancer, so I need, you know, balance it with being patient.* Christopher, Interview 1.

#### 4 Discussion

This paper, by focusing on the temporal themes of a longitudinal narrative study with young adults following a diagnosis of cancer, contributes an understanding of the importance of experience and identity over time. Where events in the present are linked to the past and the future (Thomson et al., 2004), Ricoeur (1991) suggests, an examined life is only understood through the stories we tell. The findings reported here would indicate that having the opportunity for story telling is important at a time of biographical life change and identity formation, such as in young adulthood, particularly when juxtaposed with a diagnosis of cancer, its treatment and the repercussions of both.

Stories here, revealed that for some participants there was an intensity and variety of individual experience regarding this renegotiation over time regardless of age. There were shared higher order themes relating to issues in the developmental stage, these were broader and more individually articulated than might be expected, reflecting modern theories of young adulthood as a multidimensional, fluid and reflexive developmental stage (Briggs, 2008). This may challenge the traditional age delineations for young adults and the boundaries between children, teenagers and adults in the provision of health and care.

This study has emphasized critical times in the temporal landscapes of cancer and the importance of this first year from a cancer diagnosis in terms of negotiation of identity, shifting patterns of what identity means, together with story-telling, for making sense of the experience. The intensity of a first treatment, hospitalisation and their combined impact on the embodied, social and biographical self were pronounced as was the importance of having periods of time which are treatment, symptom, and hospital free. This allowed for self and identity negotiation, for making sense and for the accomplishment of biographical opportunities. For the participants who got to the end of treatment, the renegotiation of self, post cancer was challenging as developmental tasks were re- engaged with. This is a finding which has also been reported by others (for example Galan et al., 2017, Innarino et al., 2017, Lea et al., 2018, Husson et al., 2018).

For the participants, cancer seemed to become part of their transition to adulthood. Some participants maintained their pre- illness developmental goals, for others they were changed or adapted in response to what they had been experiencing and new insights gained. Those with shorter treatments seemed to have a developmental goal surge after the completion of treatment. Participants with long treatments and a lower likelihood of cure still focused on developmental future goals as an important way of articulating self and identity, while simultaneously having to manage degrees of loss, mourning, change and uncertainty in the

present. This has also been identified by Knox et al., (2017), and Lundquist and Berry (2019).

The conceptual framework developed from this study highlights the core components of self and identity articulated by these young adults. The centrality of the internal world, psyche and emotion, were core. This provides a platform for further research to translate these findings into practice.

#### 4.1 Implications for research and practice

These findings emphasize the value of longitudinal qualitative and psychosocially informed research and practice. This is important as UK health policy promotes pathways and trajectories of care, following the patient's journey over time, across integrated care delivery and within a framework for quality, safety and compassion (NHS England, 2014). Thomson et al., (2004) suggest there are critical moments or turning points in an individual's life course that have the potential to create and respond to new opportunities. The diagnosis of serious illness in young adulthood such as cancer is most likely to be a critical and life changing moment; and this study indicates there are other critical times along the cancer trajectory which have implications for care.

The criticality of the first experience of treatment and hospitalisation on identity and self is strongly emphasised. Narrative opportunity at critical times may have significant implications for coping and making sense and the study suggests the importance of such time being developed by nurses and the multidisciplinary team alongside other supportive interventions. This study suggests practitioners need to be aware on the importance of identity renegotiation and biographical opportunity away from the hospital, treatment and symptoms, and the creation of this time if treatment may not end.

This study illustrates particular importance for story-telling over the time of cancer illness, the co-construction of meaning, and the development of trusting, relational and reflexive relationships. The value of basing care on individual experience beyond age, but situated within biography and identity, is highlighted. Changrang (2017) argues similarly that modern nursing needs to transform from 'being there' at a distance to 'being with' patients over time, with a responsibility to listen (to stories of patients) as the basis of implementing patient focused care and comfort. This has implications for professional education, the implementation of co-designed narrative practice and simultaneous support mechanisms for staff. Professionals need to be working within a supported space to be able to be both open to people through the challenges of illness yet to some degree protected. This has

significance in view of recent findings that young adults with cancer, despite worries about death, do not feel able to discuss them (Holge and Hazelton et al., 2016).

A strength of this research is that it is situated very closely to the real world of practice and involved 'being with' young adults with cancer over a year of their lives. As Cooper suggests, 'practice-near research' is essential if knowledge that is helpful in the 'real' world of practice is to be created (Cooper, 2009, p. 432). The impact of a life-threatening illness and its treatment at this time, which are also identity and biography-disrupting, was shown by the participants to be a monumental task both in the internal/external or emotional, physical and social worlds. This has significant implications for other areas of health care where there is a juxtaposition of biographical and disease intensity.

#### 4.2 Limitations

This was a single site study, including young adults with a range of cancer diagnoses. Most of the participants recruited described themselves as white English. Although enormous efforts were made to approach everyone, a study such as this may only seem accessible to certain groups and indeed story-telling after a cancer diagnosis may be culturally bound because of language, or because of the potential stigma felt of talking about cancer so soon after diagnosis. However, there were a large proportion of males in this study, a group who are thought to be hard to reach in such studies. In all other respects, there was a range of biographical and cancer stages.

Only five participants actually collected photographs which were used in the study and this is a limitation. Clearly the method was not embraced by all participants, but where used, photographs did add depth and richness to the temporal context of young adults' lives. They portrayed the visual, contextual and social at critical times for different representations of self (Wang, 1999, Yi et al., 2010, Yi et al., 2016). The method seemed to help some participants find their voice, to reflect, to facilitate recall and indeed divert the researchers gaze (Rollins 2005). However, participants who did not take photographs also discussed images. Thus, in some sense visual was present in many interviews. However, similar to other studies (Yi et al., 2016), it was perhaps surprising that young adults did not use this medium more. Obtaining consent for each image and from everyone in each image maybe have contributed to a sense of bureaucracy, together with the fact that the young adults may have had other more pressing priorities. There are potential costs to participants in longitudinal and visual studies and people stopped participating when perhaps the costs to them began to outweigh the benefits. The inclusion of photography as a research method does need careful

consideration and needs to allow as much freedom, individuality and reflexivity of use within ethical parameters as is possible.

## 5. Conclusion

The study offers new insights into the experience of young adults with cancer, emphasising the value of basing care on individual experience, beyond age, situated within biography and identity. These stories have indicated a continuous inter-relationship of the renegotiation of identity and adaption of biography to narrative and story-telling over time. Across this study the temporal flow through the first year from diagnosis, the altered biography of young adulthood, and the shifting patterns of what identity means to them was illustrated. The intersection of the powerful effect of a serious life-threatening illness juxtaposed on an intense developmental stage, on self and identity, is well described by participants. There is now increasing evidence that more consideration must be afforded to translating this into practice, to develop both greater professional understanding and practice-based supportive interventions. The value of narrative as an intervention in health care should be considered to support sense making, identity renegotiation and revision; to give patients a voice and allow professionals to walk alongside.

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Tables and figures

<b>Total number of eligible patients</b>	<b>58</b>
<b>Number not approached by gatekeepers</b>	<b>13</b>
<b>Information given but researcher not able to follow up</b>	<b>3</b>
<b>Declined at time of initial contact</b>	<b>14</b>
<b>Declined after time for considering</b>	<b>4</b>
<b>Researcher stopped following up after time</b>	<b>6</b>
<b>Numbers consented</b>	<b>18</b>

Table 1. Recruitment of participants

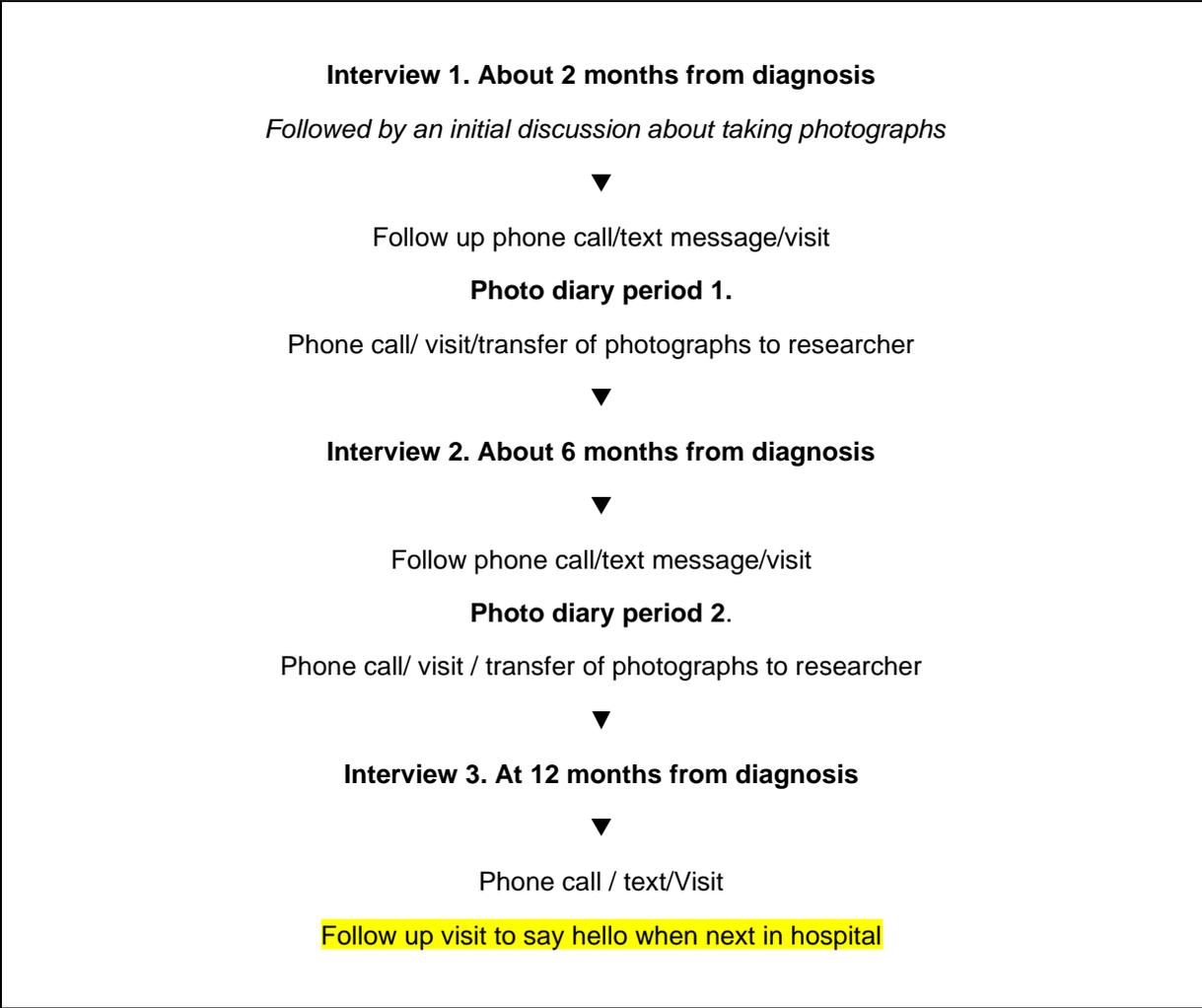


Figure 1. The process of data collection

