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

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

26

27 **Abstract**

28 In this paper we examine the use of creative methods for understanding the experience of  
29 young adults aged between 16 and 30 years over a year following a cancer diagnosis.

30 Exploring the renegotiation of identity, the narrative, longitudinal research design of the  
31 study demonstrated the unfolding process of the narrative work between these participants

32 and researcher. We used a combination of visual, spoken and reflexive psychosocial  
33 approaches to understand emergent narratives, many of which do not always find

34 symbolization in language. Our methodological approach focused on the difficult and

35 sometimes ‘unspeakable’ nature of the young adults’ narratives, demonstrating the

36 importance of different modes of communication in articulating complicated relations with

37 uncertain futures. In this respect the links between narrative, social action and the imagining

38 of possible futures is precarious. In this paper we explore how untellable issues were

39 explored, and the challenges of doing so.

40

41 **Key words**

42 **Narrative, longitudinal, visual, psychosocial, cancer**

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## 49 **Introduction**

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

53

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

65 Kleinman (1988) suggests that illness narrative is the form through which the  
66 individual and their significant others can shape, and give coherence and voice to their  
67 suffering. Narrative can also help create order, explore emotions, and allow for a search for  
68 meaning and connection with others (Riessman, 2008). Illnesses, particularly those that are  
69 chronic or life-threatening, are experiences that can contribute to disruption (Bury, 1982),  
70 with a need for biographical revision (Williams, 2000) and the making of new narratives.  
71 Mathieson and Stam (1995) found that storytelling during the disruption caused by a cancer

72 diagnosis, took on renewed urgency. This was seen in the quest for a new and renegotiated  
73 sense of personal identity when former meanings and assumptions no longer seemed relevant.

74 In this paper narrative is bound closely to a sense of self and identity experienced  
75 across time. Here we use examples from a longitudinal study with young adults diagnosed  
76 with cancer using visual, temporal and psychosocial narrative methods to provide insights  
77 into this particular situation and experience. The methods used sought to get close to these  
78 young adults' subjective experiences, getting 'underneath the surface' (Clarke and Hoggett,  
79 2008, p.2) and accessing material that may be hard or sometimes impossible to articulate. The  
80 methods allowed the researchers to go beyond the text in order to capture something of the  
81 context and the practices that characterised it (Mischler, 1986). Cooper (2009) describes the  
82 use of psychosocial methods as practice-near research in evocative and multi-sensory terms:  
83 for example as methods that enable us to 'hear the grass grow' (Cooper, 2009, p.429) and  
84 'smell the real' (Cooper, 2009, p.432). The methodological breadth of this study supported  
85 understanding of the complexity of narrative and meaning across different time points and for  
86 linking narrative meaning to action. It is this process that will be examined in this paper using  
87 data extracts to illustrate the methodological contribution of visual, longitudinal and  
88 psychosocial methods. Before outlining the study itself, we begin by exploring more  
89 generally the contribution of such methods in narrative research.

## 90 **Visual and psychosocial methods in longitudinal, narrative research**

91

92 Longitudinal or narrative research is relevant in applied research that seeks to explore  
93 human experience over time. Henwood and Shirani (2012, p1) suggest that 'everything  
94 people do is embedded and extended in time'. Indeed, it can be argued that time and  
95 temporality are the ontological entities which shape all of the life course (Adam, 1995;  
96 Adam, 2004; Uprichard, 2012). Storytelling can illuminate shifting identities through life's

97 transitions and is a valuable method to re-present experience (both by expression and  
98 reconstitution), and thus, as both Squire (2008) and Ricoeur (1984, 1991) suggest, to reveal  
99 the nuanced nature of transformation and change. Interviewing over time helps us to  
100 understand the iterative relationship between individual biography and its social context as  
101 the past is brought into line with a changing present, scaffolding an emergent future.  
102 Narrative is central to this process, operating as a hinge between multiple futures and a  
103 reinterpretable past (Uprichard, 2012).

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

117         Psychosocial research methods attempt to bridge inner and outer worlds, promoting  
118 the expression of subjective experience including material that has not yet found  
119 symbolisation in words or well-worn stories (Frosh and Barraister, 2008). Hollway and  
120 Jefferson refer to ‘a ‘thickening’ or enrichment of interpretative experience-based research  
121 (Hollway and Jefferson, 2013). This is associated with the willingness to engage with un-

122 representable and unconscious meaning (Frosh, 2002); or when the words are too difficult to  
123 find.

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

## 134 **Methods and data**

135

136           In this paper we present an account of using visual, longitudinal and psychosocial  
137 methods in the exploration of cancer with a group of young adults with cancer aged between  
138 16 and 30 (Pearce et al., 2019). They were all recently diagnosed with either lymphoma,  
139 leukaemia or bone cancer, and data were collected between April 2011 and December 2012.  
140 We recruited participants from one United Kingdom Cancer Centre for the care of adults,  
141 adolescents and young adults with cancer. Over the period of recruitment, 59 young adults  
142 were eligible, with 43 being approached. Eighteen of these consented to participate in the  
143 study, 14 of whom were male. Forty- interviews averaging 69 minutes in length were  
144 conducted, eight of the participants took part in three interviews over a year, with six  
145 participants taking part in two.

146 Longitudinal data collection spanned a period of 12 months. This was important when  
147 considering the temporal rhythms of young adulthood and the progression of cancer and its  
148 sometimes lengthy treatment. Indeed, the first year after diagnosis has been suggested to be  
149 the most difficult (Kwak et al., 2013). Methods included in-depth, free association narrative  
150 interviews at three points in time, photographs taken by participants were also discussed  
151 through a process of photo elicitation in the second and third interview; and extensive  
152 reflexive field notes were collected. The interviews became a process of joint construction  
153 between narrative and meaning (Mischler, 1986), and were participant-led, with some  
154 interview probes guiding the interaction (Hollway and Jefferson, 2013). This way of  
155 interviewing has also been termed a form of subjectivity in a historical context (Wengraf,  
156 2009), with a focus on subjective experience across the individual, their context and history.

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



171 discussed the reasons for their decision. Thus, the discussion of visual context was part of  
172 most interviews to some degree.

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

186           Ethical approval for conducting the study was obtained in advance (REC Reference  
187 12/LO/0183). Written consent was sought before the first interview, consent was then  
188 processual and relational, bound within an ethics of personhood and the context of building a  
189 relationship of trust and rapport between participant and researcher (Dewing, 2002; Holland  
190 et al., 2006). Consent for the use of images took place on an individual basis from the  
191 participants and from anyone else captured in the photograph.

192           A balance was found between assurances of confidentiality and the intimacy produced  
193 by combining visual, longitudinal and visual methods. Giving a voice, going beyond text with  
194 visual, temporal and psychosocial sources created a sense of fragility in the anonymization of

195 identities (Thomson and Mcleod, 2015; Taylor 2015). Reflexive and flexible ethical  
196 engagement, together with a rigorous methodological process (Wiles et al., 2008; Taylor  
197 2015), were essential to manage this process. The challenges for maintaining anonymity  
198 during dissemination are critical. In this paper revealing images of individuals have not been  
199 used, with pseudonyms used in place of real names.

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

210

211           Data analysis involved a holistic analysis of each individual’s experience across time  
212 as well as connections between the accounts of different participants. The focus was initially  
213 on the eight participants who had taken part in all three interviews. The data for each  
214 participant were analysed intensively, with themes and changes mapped resulting in in a ‘case  
215 history’ for each participant where different kinds of data were synthesised. Visual images  
216 were not used in isolation but analysed against their discussion in the narrative text (Wiles et  
217 al., 2008). Case histories were then, as Thomson (2007) describes, brought ‘into  
218 conversation’ so that commonalities, differences and that higher order themes could be  
219 identified across the sample. Throughout, it was important to stay close to the data, rather

220 than searching for preconceived categories (Hollway and Jefferson, 2013) and allowing for  
221 individual motifs meanings and ‘gestalt’ to emerge. In keeping with a psychosocial approach  
222 to analysis, sections of anonymized data which the researcher was struggling to interpret,  
223 were taken to the psychosocial research group which used free association techniques to  
224 suggest insights and possible interpretations. This use of group analysis has been called ‘the  
225 power of the third’ (Clarke and Hoggett, 2008); or ‘thinking minds’ (Price and Cooper, 2008,  
226 p. 64). It follows the assumption that challenging and/unconscious material may need more  
227 than one mind to think about its meaning. In this study the psychosocial group became a  
228 place to discuss ethical and methodological issues as well as facilitating the analysis of the  
229 data (Thomson, 2012; Clarke and Hoggett, 2008).

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

240         It is probably unsurprising that longitudinal qualitative research in such a highly  
241 sensitive area, and with a population often described as ‘hard to recruit’, was both  
242 challenging and time consuming. However, as Patrick (2012) suggests, extended time in the  
243 field and use of reflexive and creative methods provided a wealth of opportunities for the  
244 building of trust and rapport. Maintaining contact in a longitudinal design was essential, and

245 finding the ‘good moments’ for conversations had to be judged sensitively over time. This  
246 involved face to face communication where ever possible (Patrick, 2012), as well as the  
247 sending of text messages. When the researcher was in the field she would often ‘bump’ into  
248 participants and share informal conversations. In situations where the researcher had not seen  
249 the participant for some time it was important to talk with health care professionals to ensure  
250 it was good time to resume contact. Indeed, the uncertain nature of cancer made these touch  
251 points with professionals essential. The results of this process is highlighted in the  
252 participant’s data presented in the sections below.

### 253 **The longitudinal, time and experience**

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

#### 262 *An unforeseeable future*

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

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

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

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

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

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

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

291

292 *Narrative when futures may end*

293           Longitudinal methods have been used with elderly populations (Bornat & Blythway,  
294 2008) and are attuned to both the passage of life and its finality. Yet with these young adults,  
295 the prospect that life may end during the study was hard to articulate, and make sense of, for  
296 both the researcher and those being researched. Participants talked about the death of others,  
297 perhaps as a way of articulating and making sense of the possibility of their own. This was a  
298 preparation for a narrated future with an end point, and a moving between the temporal  
299 horizons of past, present and future. Simon and Richard, for example, both talked about dead  
300 loved ones (through a medium, or in dreams). This suggested the importance of creating a  
301 narrative space beyond death. Of course, participating in this study itself contributed to a  
302 sense of legacy and the leaving behind of a story. Hearing about continuity of life after the  
303 finality of death for others seemed to be immensely reassuring and became a vehicle through  
304 which to talk and think about their futures.

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

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

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

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

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

326

### 327    ***The reconstituted narrative***

328

329    Bruner suggests that we become who we are by telling stories about our lives (Bruner, 1990).

330    An affordance of the longitudinal design of this study was the opportunity to see this process  
331    in action during an intense challenge to biography. Jason, illustrated the potential for  
332    reconstituting the self through a process of narrative reflection, reconstitution and action.

333    Following a diagnosis of osteosarcoma Jason faced the amputation of his leg. Initially he had  
334    protected himself from communicating with the cancer world that he now found himself in,  
335    and slept most of the time with a hat over his head, *'I shut it out as it were. So it's not that*  
336    *bad'*.

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

340            In one interview, Jason reflected on images and a photograph that, looking back, he  
341    might have taken. Identifying this image seemed to help him move him towards the

342 untellable, beyond the defences of humour and stoicism which characterised his spoken  
343 narrative. This image was of the snow he had seen from the hospital window. He reflected  
344 on happy times as a child in the snow which led to reflection on how things were for him  
345 now: *'It's a bit dull really, my life. Yes, I wake up and go to sleep'*. He then described the  
346 present situation as overwhelmingly depressing: *'A bleak unending nothingness'*. Later in  
347 field notes the researcher recorded:

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

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

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

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

363

364 **The Visual, image and metaphor**

365



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

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

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

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

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

384 By displacing a definitive ending, hope endured, allowing for the endurance of  
385 discontinuity and trauma (Grotstein, 1981). Simon also used storytelling as a way to organise  
386 his thoughts and feelings and gain reassurance. As Grotstein suggests the text can then  
387 become a 'visual transformation of events in the internal world' (p.371). The discussion of  
388 images, symbol and metaphor helped us to explore what 'lies under the surface' This can be

389 described as an existence of ‘shared multi layered collage of images in the human  
390 unconscious’ which is a route into our strongest emotions and affect (Manley, 2008, p. 96).

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

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

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

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



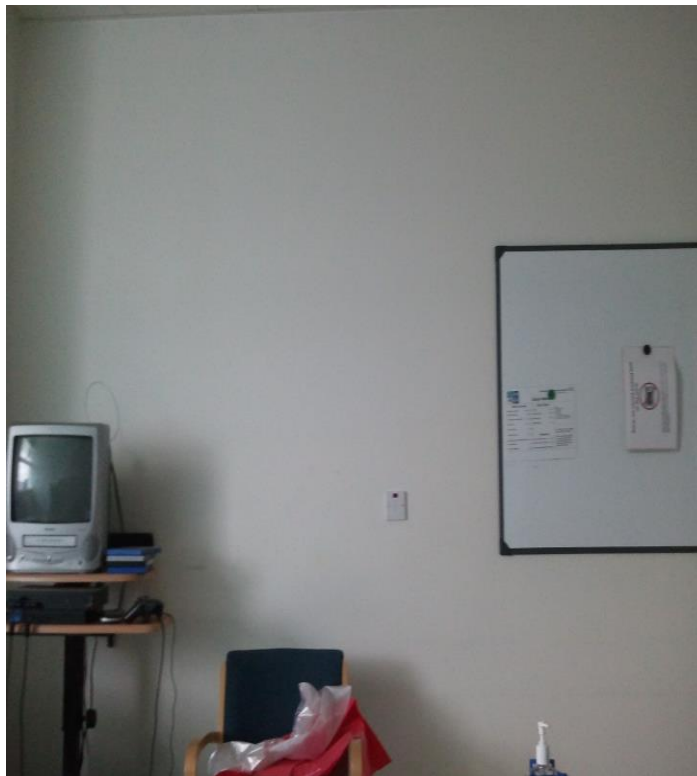
418

419 **Photograph 1. Christmas at home**

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

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

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



435

Photograph 2. The blank wall

436

437

438           For Nick, diagnosed with acute myeloid leukaemia, photographs documented his  
439 physical recuperation after weeks of isolation during high dose chemotherapy and a bone  
440 marrow transplant. His visual narrative provided insights into the times that otherwise might  
441 be difficult to articulate, or even observe. After his transplant Nick was very ill, and a

442 photograph of a crane illustrated the extent of his incapacity, as watching the cranes go up  
443 and down was the only thing he could do for several days.

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

### 453 *Psychosocial Reflections*

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

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

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

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

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

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

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

## 488 **Discussion**

489

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

506         Participants all faced uncertain futures with a need to re-interpret the past, and re-  
507 conceptualise or re-negotiate the present. Understanding this situation involved getting  
508 underneath the surface of everyday talk, facilitated by visual methods and a psychosocial  
509 sensibility, and also by a sense of walking alongside the participants over the year that they  
510 were part of this study. What these methods revealed was the profound and dynamic identity  
511 work involved in living with a cancer diagnosis and treatment so early in life; involving a  
512 circular and repeating relationship between reflection, reconstitution and action. These

513 young adults embodied a profound contradiction simultaneously facing death, loss and  
514 mourning while also seeking ways to thrust forward into an imagined future.

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

523

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

532

## 533 **Conclusion**

534 This paper has described a study that explored the difficult emotional terrain of young adults  
535 faced with cancer to illustrate the value of methods which allowed reflection, reflexivity and,  
536 over time the representation of experience through the collection of personal narratives.  
537 Narrative, longitudinal research designs have the potential to study the unfolding process of



538 meaning making and personal or social action. The illustration here, drawn from young adults  
539 with cancer may be particularly revealing as, both biographically and in terms of the cancer  
540 and its treatment, there was an added degree of urgency. Visual and psychosocial methods  
541 were essential for getting to the ‘untellable’ underneath surface and understanding the  
542 complexity, multi-directionality, multi-dimensionality and the inter-subjectivity of the human  
543 cancer experience. By so doing the analysis of these participants’ narratives help to develop  
544 our understandings of the link between the internal and external self (the body and the social)  
545 and the relationships between narrative to meaning, reconstitution and potential action. The  
546 exploration of these methods within their relational, ethical and situational contexts ensured  
547 that the study extended and deepened all our insights. The experiences of young adults with  
548 cancer were explored in ways that have not been achieved before. We trust that this paper  
549 helps to advance the potential of such innovative, creative methods to understand experience,  
550 especially human suffering, in all its complexity.

551

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553

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## 558 **Declaration of Interest**

559 There has been no financial interest of benefit that has arisen from the direct applications of  
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561

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