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

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Abstract

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

Key words
Narrative, longitudinal, visual, psychosocial, cancer

Introduction

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

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

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

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.

Methods and data

134

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.

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 crticial 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).

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

Narrative when futures may end

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

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

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

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

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

14

untellable, beyond the defences of humour and stoicism which characterised his spoken

narrative.   This image was of the snow he had seen from the hospital window. He reflected

on happy times as a child in the snow which led to reflection on how things were for him

now: '*It's a bit dull really, my life. Yes, I wake up and go to sleep'*. He then described the

present situation as overwhelmingly depressing: '*A bleak unending nothingness'.* Later in

field notes the researcher recorded:

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

In his last interview some months after his amputation, and on the last day of his

treatment, a buoyant Jason spent time looking back on the whole experience from his cancer

diagnosis. In a different place emotionally to the previous interviews he said:

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

He seemed resolved that he would not be able to return to his career. Yet, this was now

framed more positively, with a new integration of the past and the future. A new sense of

purpose in returning to a high level of mobility was present; '*I can't run, although it's*

technically possible. It's something I intend to pursue'.

The Visual, image and metaphor

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
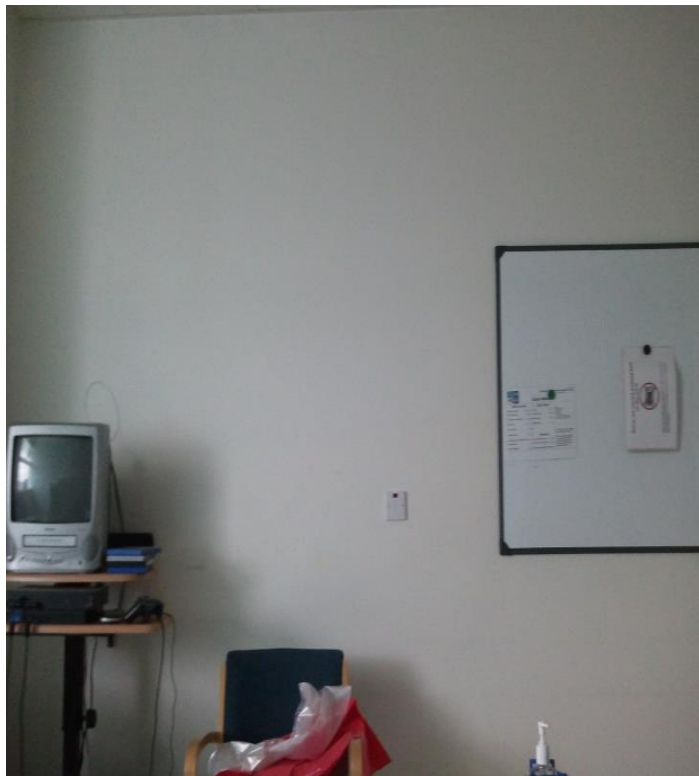
436   Photograph 2. The blank wall

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.

Discussion

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

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

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

558   **Declaration of Interest**

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

560   the research study reported in this paper

561

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