Re-finding the Path: An Exploration of the Illness Narratives of Young Adults with Cancer

Laura Jane Curry

Supervised by: Christine Horrocks

March 2013
Re-finding the Path: An Exploration of the Illness Narratives of Young Adults with Cancer

ABSTRACT

In the U.K., six young adults per day receive a diagnosis of cancer. However, treatment provisions differ between Great Britain, where there are a range of Teenage Cancer Trust (TCT) units and Northern Ireland (NI), where currently young adults are treated on either child or adult wards. This is in spite of growing literature for the need of specialised units, and the continuing vocalisation by young people of their discomfort with non-specialised wards. This research had four objectives. To explore the treatment variations for young adults, to look at the process of affiliation, to explore how cancer impacts on the life story and the feelings associated with post-treatment.

Frank (1995) argued that in order to understand an illness experience an illness narrative is needed. By using narrative methods, these aims were explored by interviewing one young adult from NI about her cancer experience, by speaking to TCT service providers, and by analysing 3 stories available online from young adults who were treated in specialised units. The analysis found that the most significant difference between Britain and NI was support post-treatment. Survivorship becomes a key issue for young adults finishing treatment, and may aid with the re-establishment of a ‘path’ forward.

KEY WORDS: CANCER YOUNG ADULTS NARRATIVE ILLNESS RECOVERY
This Journal Report is dedicated to four amazing women:

Julie Elphick, for taking time to talk to me.
Lorraine Wright, for being so inspirational and supportive.
Christine Horrocks, for her unwavering patience and humour.

and E, my extraordinary friend.
Thank you for your story. I’ve tried my best to do it justice.
BACKGROUND

Sontag (1991) compares health and illness as akin to two separate countries. If we are lucky, we spend the majority of our time in the land of health, however at some point, most of us end up holding passports for both. Our understanding and experiences of illness, in particular severe illness such as cancer, can be diverse. The discovery of cancer can be a life altering event. Within the United Kingdom (U.K.), six young adults aged 13 to 24 per day receive a diagnosis of cancer, this amounts to around 2,100 per year (Teenage Cancer Trust, 2013a).

History of Hospitalised Children and Young Adults

Traditionally considered as purely biological units and nothing more (Hunt, 1974), the Platt Report of 1959 focused on making “a special study of the arrangements made in hospitals for the welfare of ill children” (Ministry of Health, 1959, p.1). Moving away from a medical perspective that a child's health is dependent upon their physical needs, the Platt Report encouraged a more humanitarian approach by attending to psychological and emotional needs also. This was achieved through several steps, including allocating separate wards for children and adolescents, allowing parents regular visiting hours and actively encouraging them to participate in the care of the child (Davies, 2010).

It wasn’t until 1995 with the publication of the Calman-Hine Report that the treatment options for cancer patients within the U.K. was evaluated. This included issues faced by young adults within the system. The Teenage Cancer Trust was set up in 1990 and aimed to ensure that cancer care and treatment was to the best possible standard for those between childhood and adulthood; a group of people who “too often, remain at risk of missing out on the best possible holistic care when diagnosed with cancer” (Smith et al., 2012, p.4). As it currently stands, young child and adult cancer patients in Britain are now treated as part of a multidisciplinary approach (Smith et al., 2012).

Whiteson (2003) believed that young adults undergoing cancer treatment are at risk of being a neglected group due to the gap they find themselves in between paediatric and adult services. The Teenage Cancer Trust has tried to subvert this by aiming to fill the gap by providing the best possible age appropriate care to those affected (Smith et al., 2012). This involves giving young adults the option to be treated together, separate from child and adult wards, as well as offering “comprehensive psychosocial support, a network of peers and entry into clinical trials, all coordinated by a multidisciplinary team with expertise in the management of this patient group” (Smith et al., 2012, p.7).

In regards to this treatment process, research has suggested that shared stress or affiliation is thought to be beneficial so those who are ill can ‘place’ themselves and their situation alongside others, similar to themselves with similar circumstances (Heckhausen, 1999; Molleman, et al., 1986). Conversely, the importance of social affiliation in a health context has been debated in previous research. Rofe, Lewin and Hoffman (1987) found that on the majority cancer patients wish to be alone with their condition. Yet, research has also shown the benefits of parallel comparisons, wherein those who have similar conditions and
are at a similar level of treatment find that this comparison aids emotional health (Bellizzi et al., 2006).

These findings were originally developed and proposed by Schachter (1959) whose theory of shared stress, when applied to this situation, would suggest that young adults diagnosed with cancer would have benefitted from being with others of a similar age going through the same experience. This has been noted in some research (Geehan, 2003; Mulhall, Kelly & Pearce, 2001). Gravelle and Bertram (1986) further argue that examples of ex-patients doing well can help current adolescent patients believe recovery is possible for them also. Notwithstanding, research within this area of affiliation and cancer patients has been considered to mostly feature artificially derived research designs (Bellizzi et al., 2006).

While the Teenager Cancer Trust is growing in terms of the number of specialised units currently available, these units are not part of a coordinated health procedure for teenagers and young adults within cancer care, they remain primarily part of local initiatives (Whelan, 2003). This is in spite of growing literature in regards to the needs of teenagers and young adults undergoing cancer treatment (Barr, 2001; Bleyer, 2002; Hollis & Morgan, 2001; Reaman, et al., 1993), and the continuing vocalisation by young people of their discomfort and alienation within paediatric and adult wards (Whelan, 2003). While no concrete evidence exists to suggest that these units increase survival rates, it can be argued that they aid psychological wellbeing and psychosocial support (Geehan, 2003; Whiteson, 2003) and may also be beneficial as to the greater likelihood of being included in clinical trials (McTiernan, 2003).

Storying of Illness

Frank (1995) describes the diagnosis of a serious illness, such as cancer, as a loss of a “map that had previously guided the ill person’s life” (p.1). Bury (1982) referred to this process as ‘biographical disruption’, wherein the illness unsettles not only the body but the whole trajectory of a person’s life. In young adults, this is heightened due to the already unstable nature of adolescence. Meeks and Bernet (2001) wrote of the developmental process during late adolescence, which includes, “autonomy from parents; emotional investment in a significant relationship with another person; and commitment to a general career area” (p.7). However while receiving treatment for conditions such as cancer, these developmental stages are difficult to achieve.

In particular the ‘autonomy from parents’ becomes problematic. At a time where a young individual should be moving away from the dependant environment their parents have created, they find themselves returning to a situation of acute dependence upon adults (Gravelle & Bertram, 1986). Further aggravating this situation is bearing witness to parents or guardians becoming dependant on medical staff, where they traditionally, in the eyes of their children, are ‘in charge’ (Gravelle & Bertram, 1986).

Although normative developmental theories are of interest when looking at young adults who have had their development disrupted by cancer, Sunmi Lee (2001) argued that normative developmental theories are detrimental to young cancer patients. Their experiences are non-normative to traditional healthy development;
therefore, developmental theories only serve to give a limited understanding of a cancer experience within this situation (Frank, 1992). Independence however is not a unique situation to teenagers and young adults. In regards to a diagnosis of illness or disability Galvin (2005) states that one of the key areas of identity affected by illness are those concerning independence.

The story of illness is far more than just the medical dialogue. Frank (1995), an ill person is more than just a body of aches, pains and symptoms. Recovery from illness brings about its own separate issues, in particular for young adults, who face further issues such as of a loss of support, loss of comfort in future planning, possible infertility and a mistrust of their own body (Odo & Potter, 2009). The differences between cancer care for young adults within Great Britain and Northern Ireland¹ is of interest due to issues of support, affiliation and general care. In order to gain a greater understanding of this subjective experience, this research aims to use narrative methods to understand this non-normative experience.

Context of Research and Development of Reflexivity

The foundations and reasoning of this research owe their existence to the background of the researcher and my experiences of young adults and cancer treatment in Northern Ireland. A personal approach to the creation of ideas is not uncommon within research projects (Holloway & Freshwater, 2007). As it stands, the Teenage Cancer Trust does not have a unit in Northern Ireland, although there are plans for one within the next 2 to 3 years (Teenage Cancer Trust, 2013b). Adolescents and young adults in Northern Ireland currently have limited options in how and where they are treated, and often it is dependent on their type of cancer to which ward they are placed. Although it is acknowledged that young adults in Northern Ireland need holistic care, there is currently no provision in training for those within this category (Safety, Quality and Standards Report, 2011).

At 19 years old, one of my close friends was diagnosed with cancer after a year of intense illness. This was followed by another 19 year old acquaintance being diagnosed, and my own social circle being expanded by other patients we met through Belfast City Hospital's Cancer Centre. In a short period of time, cancer went from being a foreign, adult concept to one that I found myself, and my immediate friendship group immersed in. While treatment processes and the aetiology of cancer were a difficult concept to comprehend, I also found myself noting the differences in treatment options for those in Northern Ireland and those who fell under the jurisdiction of the Teenage Cancer Trust.

Although Sontag (1991) would argue merely two islands exist of separate healthy and ill persons, Frank (1995) suggests that those who have recovered from cancer can never re-enter the land of the healthy but instead linger in a ‘remission society’. This further complicates the experiences of young adults who have had cancer treatment, as it suggests they never truly separate themselves and grow from their hospitalised history. It suggests that my friend will forever remain separate from normative healthy development as she enters remission and

¹ Great Britain – England, Wales, Scotland.
United Kingdom – England, Wales, Scotland & Northern Ireland
continues with her life story. Since a cancer diagnosis is a rare occurrence to undergo during young adulthood, narrative enables an in depth insight into experiences which others may not have personal knowledge of (Garro & Mattingly, 2000) as this research aims to achieve. In order to gain some understanding of this unique experience and all it entails, narrative methods best facilitated a research piece that would encompass all background issues raised.

Considering the existing research, and the current treatment options for young adults in Northern Ireland and Great Britain, this piece of research had several aims. Firstly, to explore cancer treatment experiences for young adults in both Great Britain and Northern Ireland. Secondly, to look at the process of affiliation and how this could influence treatment experiences and possible recovery. Thirdly, to understand how a cancer diagnosis can impact on the life story of a young adult, and finally, to explore the end of treatment and feelings associated with this process.

REFLEXIVE METHODOLOGY

Broyard (1992) explains our use of stories and narrative as a way of confining a catastrophe, such as illness in early life. Due to the personal nature of illness; it has been argued that the only possible way to understand an illness experience is through an illness narrative (Kleinman, 1988; Broyard, 1992; Frank, 1995). This is in part due to narrative being more than just a telling of a sequence of events but rather an aim to find meaning to experience (Martin, 2008). Within psychology, narrative theory focuses on human existence as “lived, experienced and interpreted” by each individual (Crossley, 2000, p.45).

In order to gain some understanding of this life event that I have no firsthand experience of, I interviewed one participant in depth who had been opportunistically sampled. My participant (Saoirse\(^2\)) was 22 and had been diagnosed with cancer at age 19 and underwent treatment in Northern Ireland, which she has now finished. I also explored three survivor stories that are available online through the Teenage Cancer Trust website (Teenage Cancer Trust, 2013c) (see appendices 4 - 6). The stories were selected from a host of others due to certain criteria. The story had to feature someone who was diagnosed between ages 18 – 25, they had to have completed treatment and their story had to have enough substance to engage with the research aims. I also spoke to people employed by the Trust in Manchester and Cardiff to gain a clearer understanding of the work that is carried out there and the facilities available for young adults through treatment and post treatment.

The reason for choosing just one person to interview and include in my research is twofold. Wengraf (2001) argued that within research such as this, small samples are not a disadvantage but instead can provide rich and informative data. Instead of performing five or six shorter interviews, I will be able to explore a vast range of issues and experiences within a longer timeframe. As Patton (2002) suggested, it is depth rather than breadth that is essential to biographical research.

\(^2\) Saoirse, pronounced ‘shear-sha’ Irish name meaning freedom
Secondly, regarding ethical considerations, I have known my participant for a number of years. She is familiar with me and the work I have been doing for my undergraduate degree therefore there is an element of trust, but also knowledge of what participation involves. This put me as a researcher in a position of occupying an ‘insider stance’. Insider research involves a researcher and participant who share an identity, or language, or culture, or a common experience (Asselin, 2003).

An insider status may enable participants to be more open and honest with researchers (Dwyer & Buckle, 2009). This phenomenon was observed with Talbot (1998-99) whose research involved bereaved mothers. She noted “at the end of their interviews, several mothers said they would never have shared certain aspects of their experience if I had not been a bereaved mother also” (p.172). Dwyer and Buckle (2009) have argued in opposition of insider status that participants may feel that they do not need to expand on certain issues or explain their experience fully as there is a level of similarity present. Although I did not fully occupy the experiences of an ex-patient I do have a greater understanding of young adults and cancer treatment than an outside researcher. This enabled me to occupy the middle ground between.

Interview Structure

Different researchers have approached illness narratives with different methods within a narrative framework. Williams (1984) used thematic methods to analyse interviews based on the simple question ‘Why do you think you got arthritis?’. Although this idea was appealing, similarly to the Biographic-Narrative Interpretive Method (Wengraf, 2001), this approach is based around the idea of asking one open ended question to the participant. McAdams (1993) argued, that “we do not discover ourselves in narrative, rather, we make or create ourselves through narrative” ( p12), while I hoped that my participant gained from telling her story, due to the sensitive nature of the topic being discussed, I believed the interview would be best conducted in a semi-structured manner. This allowed for the conversation to be contained, and protected my participant from any topics that could have made her uneasy. A semi-structured interview does not have to be rigidly structured, but merely a guide or outline for a conversation (Crossley, 2000). For this research I aimed to adapt McAdams (1993) approach to a personal narrative interview. McAdams incorporates seven questions into his narrative interview. The main themes are:

• Life chapters
• Key events
• Significant people
• Future script
• Stresses and problems
• Personal ideology
• Life theme
By following this structure the participant is able to discuss their whole life story within a semi-structured interview. The reasoning behind choosing this method over others as it focuses on past, present, and future events which I believe to be important to young adults who have completed treatment as they find themselves facing a future they may not have planned for. However, due to the nature of this research question, I wished to concentrate on a specific chapter of illness. The original approach was too wide for this question, therefore I adapted the questions to deal more specifically with the period of illness and the time afterward, yet still allowing room for talking about past life events (see appendix 1).

Although I believed a narrative approach would be useful in this context, narrative methods are not without criticism. Some criticisms are based on the idea that narrative goes against and ignores biomedical experiences (Atkinson, 1997). Charlton (1995) further argued that narrative enables a subjective interpretation to be taken as fact. However, it is not only the interviewee who becomes the focus of critique. Smythe and Murray (2000) focused on how the researcher can compromise the participating individual’s own experiences as they are interpreted by the research. They further argued that in this sense narrative research can become intrusive and subtly damaging. I do not believe that these points hindered this research investigation, but enhanced my understanding and aided my approach in subverting these possibilities.

Analysis

Following McAdams (1993), I also adapted his method of analysis for my interview and the three Teenage Cancer Trust narratives posted online (appendix 4 - 6). McAdams’ approach came in three stages. Firstly, by establishing a Narrative Tone to the transcript. McAdams (1993) described the narrative tone as reflecting “the extent to which a person dares to believe that the world can be good and that one’s place can be more or less secure within it” (p.48). Security with your place in the world and ultimately viewing that world as a good place is an interesting aspect to explore in the context of this research, wherein there has been a question mark on an individual’s own mortality for a period of time. Crossley (2000) used the example that narrative tone could be either predominantly pessimistic or optimistic.

Secondly, the stories were analysed for Imagery presented through the dialogue. This involved looking at the language used, or the images and metaphors utilised in storytelling. This enables a deeper understanding of how imagery was developed, either through family dynamics or the discourses of society. Thirdly, the main Themes within the dialogue are established. McAdams makes reference to themes of power and love as they tend to be typically dominant within stories. Interestingly, and relevant to this research, McAdams points out that these needs often become more noticeable in times of crisis such as illness. This could be due to the formation of new identities after such events, and the inconsistencies between who we were and who we now are (Crossley, 2000).

Ethical Considerations

Ethically, there are two areas to consider when conducting this research. Firstly, the three post-treatment stories published on the Teenage Cancer Trust website
The stories were originally published in an effort to elevate concerns of other young patients about their treatment in such specialised facilities. Due to the stories being online and publically available, in accordance with the ethical guidelines laid out by the British Psychological Society, I can use them as part of my analysis without consent from each individual. It was also felt that due to the nature in which they were posted on the website, they could only enrich the data available.

Secondly, the interview with my participant. Willig (2001) outlined several basic ethical considerations when conducting qualitative interviews. These were, informed consent, no deception, right to withdraw, debriefing and confidentiality. Each of these was observed during the interview process, with an information sheet and consent form (appendix 2 & 3) made available to the participant 48 hours before the interview took place. Due to the nature of the research, ‘process consent’ (Ramos, 1989) was utilised instead of informed consent, as this implied that consent was a one off process.

Process consent allowed consent to be constantly negotiated, it gave participants the right to withdraw from sections of the interview, or from all aspects. With my participant being over the age of 18, both mentally and psychically healthy and given all possible information about the research and their role in participation it was believed they could give full consent. Confidentiality was also problematic, as due to the nature of this research, complete anonymity could not be given. Names and identifying situations had to be shared with my dissertation supervisor and other relevant members of staff. Confidentiality was negotiated with my participant, a pseudonym was adopted, and any identifying information was removed to protect her.

ANALYSIS AND DISCUSSION

The analysis and discussion will be combined to analyse Saoirse’s narrative in comparison with Gabrielle, Faye and Joe’s stories (see appendix 4 -6) who completed treatment with the Teenage Cancer Trust (the ‘Trust’ narratives), and some evidence from the service providers of the specialised services. Firstly, narrative tone will be discussed, then imagery, and finally themes that exist within the stories.

Narrative Tone: The Optimistic Bubble

The first section of the interview, wherein Saoirse describes her treatment in Belfast Cancer Centre, the narrative tone appears to exist within an ‘optimistic bubble’. With frequent feelings of being lucky and appreciative in spite of having cancer and undergoing treatment, she frames her situation in comparison with others in a similar position but who are in her eyes less fortunate.

S: I was quite lucky as I was never sent home.

S: I met people who came in for chemo and had to go home because they didn’t have a bed for them, which I’m so grateful that never happened me.
Saoirse also, within the first section of the interview, insinuates that her life, while average before, is now extraordinary due to her experiences. She chapters the first segment of her life from age 0 to 16 as ‘The Average’.

*S: I wasn't overly extraordinary or anything. I wasn't! (Laughter) I was a really average person living in a single parent family. Went to school, had fun, had friends. Nothing really ever happened that was (Pause) amazing.

However after the cancer diagnosis she states that it “put my average life in a completely other direction”. The narrative tone of this extraordinary life in spite of original positivity changes whenever Saoirse finishes treatment. Her optimistic language and overall view of the world becomes somewhat negative, lost, and ‘anti climatic’.

*Interviewer: What happened when you finished treatment?
*S: Nothing. (Laughter). It was very anti climatic.

It could be argued that at this stage, she is completely abandoned by the institution that cared for her for the past year and is left to work out what a post-treatment world is supposed to consist of. There is an assumption that just because the cancer is no longer present that this constitutes a complete recovery, however Geehan (2003) argues that ex-patients have a price to pay for this status of remission, which is often ignored in biomedical discourses.

*S: I remember getting very depressed because I didn't know what to do with my life now because for like the past year it had just been you go to hospital, you come out, you be sick for a while, try not to get an infection ...You usually feel a lot better especially if you've had a blood transfusion or something and maybe you're able to go out and do something with your friends ... put your best wig on (Laughter) and ... that all stopped ... It was like I'd been taken out of that bubble and left with the realisation that the world has to go on now and your life has to continue now and I didn't really know what that life was meant to be. I still don't really know what that life is meant to be.

For cancer patients who have completed treatment, the loss of support from healthcare staff can be traumatic as an ex-patient moves away from a process of ‘doing something’ into uncertainty. While it is mostly expected for the finishing of treatment to bring about feelings of joy and relief, the trauma of leaving the ‘bubble’ has been documented (Arnold, 1999; Atkins & Goodhart, 2011; Deshields, *et al*., 2005; Lethborg, *et al*., 2000; Wakefield, *et al*., 2010). In spite of a wealth of research indicating high levels of post-treatment mental health issues, Saoirse was offered no further help from healthcare professionals upon finishing treatment.

Geehan (2003) writes about this experience speaking as an ex-patient who has been treated within a Teenage Cancer Trust setting. She states that “with the right post-treatment support, the whole experience [of having cancer] can be turned into a positive one and can result in a very optimistic and 'live life to the full' attitude in the patient rather than leaving them with a fear of moving on” (p. 2683). This narrative of a ‘lost bubble’ is also noticeably absent from the Trust narratives.
Instead, the ending of their stories are framed in a positive, optimistic manner that often looks to the future.

Gabrielle: I am looking to return to university … hopefully I’ll be able to get back into the hectic life of university!

Joe: I live a very active and fun life following treatment. I have moved on and am working full time in finance.

Saoirse’s story, in contrast with the three Trust stories, would indicate that treatment within specialised units may help to aid this transition from patient to post-treatment and may have helped to secure a more optimistic attitude for continuing with the life story. While Saoirse’s cancer treatment was excellent within Belfast, her abandonment post-treatment has left her without a ‘live life to the full’ attitude.

S: Kind of stuck between that whole you only live once and you don’t know when your life is going to end and you don’t know what’s going to happen so you might as well do it, which is good! But in other ways it's really, shit, because you’re not really living properly like a normal person.

Imagery: The Path

Saoirse continually throughout her story makes reference to ‘a path’ or ‘road’.

S: Even though I did learn so much from it, it put me down the path I’m meant to go down.

S: It's so different from what everyone else is going through (Pause) I'm not saying it's like (Pause) it's just such a different kind of path.

In some instances she positions herself on this road, whereas in others she is searching for the correct path to follow now that she has finished treatment and is looking to continue her life journey. Bury (1982) spoke of the process of biographical disruption where illness upsets the trajectory of a person’s life. This disruption becomes evident through Saoirse’s sense of loss from the previous ‘road’ she travelled and the one she is yet to find.

S: I don't have a clue what to do now. I've just got better and I don't know what else there is to do with life because I was just concentrating on surviving for so long and I just have no idea. I'm completely lost now and I just kind of have to ... find whatever road I'm supposed to be on.

Through ‘concentrating on surviving for so long’, Saoirse has missed the developmental process associated with late adolescence, such as independence from parents, investment in a relationship outside of family and the planning and commitment to a future life path (such as career) (Meeks & Bernet, 2001).

S: I don't know what I want to do with my life anymore. I kind of feel like I've lost out in time in regards to qualifications and (Pause) I kind of feel like I've been left behind (Pause) I feel really lost.
While this feeling of a lack of direction after cancer treatment isn’t uncommon (Arnold, 1999; Brennan, 2004), this feeling of a loss of direction is again absent from Gabrille, Faye and Joe’s narratives. Some Teenage Cancer Trust units, including the Manchester branch currently offer a ‘Survivorship’ programme that consists of regular meetings of those in post-treatment, and a residential weekend (see appendix 9). When I spoke to Lorraine Wright, the Youth Support Coordinator for the Teenage Cancer Trust unit in Manchester (see appendix 7), she spoke of a residential weekend they run for those who have completed treatment. The programme consists of eight sessions held over two days. These sessions cover relationships, anxiety and stress management, post-treatment, late effects, fertility, back to education/employment, finances, and wellbeing. While is cannot be assumed that this type of programme would have aided Saoirse to find her path, Faye speaks highly of such services in her own narrative.

Faye: Meeting with YOU’s [Young Oncology Unit in Manchester] social group really helped me, for the first time I was able to feel normal again ... it made such a change.

Gabrielle also suggests that meeting other young patients enabled her to rediscover her own path.

Gabrielle: It was very inspirational to see them carrying on with their lives... It helped me to think positively and encouraged me to want to go back to university which I was considering not doing

This prominent narrative of a path is of interest, as it contradicts Sontag’s (1991) observation of cancer being portrayed as a ‘battle’ or ‘war’ but instead supports Frank’s (1995) ‘map’ analogy. Military language is absent from all narratives, this is important, as it shows that the prominent battle analogy is not adopted by ex-patients, instead both treatment and post-treatment feelings are expressed as disrupted journey.

Themes: Relationships and Affiliation

Saoirse makes continual reference to her friends, family and loved ones throughout her telling, and has strong bonds in each of these categories. It is obvious that love and affiliation become driving factors during her period of illness and post-treatment. In particular, her mum becomes a source of enduring love yet some residual guilt.

S: I hate that I done that to her ... I don't like people having to worry about me. Especially her. I think she just needs to be happy. And I stopped that.

The urge for young adults in treatment to feel protective of their mothers has been previously noted (Whelan, 2003). While the guilt remains as she continues to believe she has halted her mother’s happiness, her experiences have somewhat altered her feelings towards her. She later states that while she didn’t have a hero before treatment, her mother is her hero now.

With other patients, Saoirse affiliates more with certain individuals. This affiliation is positive in some aspects, and there are some examples of ‘shared stress’
Schachter (1959), such as finding others who “understood what was going on”, Saoirse unfortunately experiences a lot of death which has an immensely negative impact upon her story. This contradicts other research that states death amongst other young adults with cancer is often seen as part of the journey, and rarely noted as a negative experience (Whelan, 2003).

S: I saw his pictures and stuff on facebook. I think it’s just cause looking at his pictures I was reminded of my life and my friends ... I really didn’t think he would die. He shouldn’t have died and I still can’t get my head around that.

While Saoirse did benefit in some areas meeting others of a similar age going through the same experience, her lack of exposure to those doing well post-treatment may have damaged her understanding and faith in recovery being possible. Geehan (2003) also noted the drawbacks of losing friends and the lack of exposure to those in post-treatment. It should also be made clear that Saoirse was not exposed to many other patients within Belfast Cancer Centre, but instead had to refer herself to an outside charity who in turn introduced her to other patients. She states however that some of these friendships felt forced and ‘pushed’. One death particularly hits her hard, and almost destroys her faith in forming new friendships within this context.

S: I don’t think they knew what to do with her ... they didn’t understand how she wasn’t in agony all the time ... It’s kind of sad because she was just so used to being in pain nothing really stood out for her ... After Jill died I just didn’t want to meet anyone anymore.

The Trust narratives speak of the importance of new and old friendships, yet their stories fail to mention death. The one friend Saoirse has left who completed treatment, she speaks highly of. Interestingly however, Saoirse frames her friend’s successful completion of treatment in regards to how well she has moved on with life and found her ‘new path’. “She’s doing really, really, really well. Yeah! She’s in England now doing her teaching”, the subtle implication remains that one hasn’t truly recovered until they’ve found something beyond cancer.

Themes: Death and Survivorship

S: I’d never had a friend who had died and I haven’t really experienced a lot of death (Pause) like my granddad died and that’s about it. Now I’ve experienced loads.

Death becomes a prominent theme through Saoirse’s narrative. The majority of friends that Saoirse made who were also going through treatment have died though it should be noted that she was only introduced to a few individuals. These deaths however affect her deeply and she repeatedly states feelings of confusion, “I couldn’t really understand how he could have died and my treatment was going really well”, “I just didn’t understand”, and “it just didn’t make sense to me”. There are also aspects of survivor’s guilt which has been left unresolved in her narrative.

While death remains an unresolved issue for Saoirse, she states that the one issue that “annoys me most and always will annoy me till this day” is fertility.
S: It's the one thing that makes me wish I'd never had cancer. Even though I did learn so much from it [the cancer] ... I would give anything to be able to have children. And that's the one thing that will always annoy me and I don't think I'll ever get over it, because it feels like you've lost something. You're mourning (Pause) it feels like you're mourning for all the children you didn't have. You could've had.

Her survivorship is marred by what the cancer took from her. Fertility is an acknowledged problem for young adults post-treatment (Whelan, 2003; Whiteson, 2003; Zebrack, et al., 2004). She expresses a lack of information on the topic from healthcare providers. Her 'mourning' imagery of her fertility frames it almost like a death that she cannot move on from as she lacks the proper understanding and clings to the 'hope' of an anticipated future.

S: I was referred on to a specialist in gynaecology and she said 'No, this will kill your ovaries' ... she was just matter of fact. I mean in her head all she wanted to do was make sure, y'know, I didn't die. I guess ...Then I was referred up to the early menopause clinic ... I tried to talk to people there but the doctor wasn't really great and kept saying 'Oh you could talk to this network here, the DAISY network' like fuck that! ... No one really sat me down and spoke to me, so I don't have a clue. Part of me is always living in hope. Though that's a ridiculous fantasy.

Her fertility becomes another issue that places her solidly with the 'Remission Society' (Frank, 1995) and distances her from the future she anticipated before treatment to the one she faces today. This new future has not been adequately supported by healthcare staff, and leaves Saoirse in a limbo state between what once was, and what now must be.

Reflexive Summary: “I realised what life was more about”

While Saoirse’s experiences and construction of her story does take a more pessimistic turn after treatment, she finishes her story with what her journey has taught her.

S: I look back a lot and if I'm having a problem I always think what the cancer you would say to you right now. The cancer you. The one who was sick in hospital and couldn't eat and vowed never to complain ever again, what would their advice to you be? Or what would my advice be to me? Sick me person, because ... I realised what life was more about. She's very stern at times. She don't take no shit. (Laughter).

Quality of life concerns and the experiences of young adult patients are often overlooked (Whiteson, 2003). I initially believed that the gaps between treatment provisions in Great Britain and Northern Ireland would be the source of most distress for young adult patients. However, through Saoirse’s narrative, it became apparent that she views her treatment in Belfast Cancer Centre as exceptional thanks to the staff there. Issues only arose post-treatment, and it is here that the differences between services such as the Teenage Cancer Trust and standard hospitals become evident.
I found this dissertation incredibly difficult to write at points, as it became more and more apparent that a research base exists to support that young adults who finish treatment need more help. I felt like Saoirse had been let down by a system that should have supported her, and I wondered about the hundreds of others in the same position. Yet, I did enjoy the interview process, and I felt our friendship was somewhat strengthened. McAdams (1993) noted that such interviews often bring about intensification within a friendship. I left that interview appreciating just how extraordinary she really is, and how this path has moulded her into an extremely compassionate, generous and enlightened adult.

While Saoirse continues on her path with an accelerated maturity similar to other young ex-patients (Whelan, 2003; Whiteson, 2003), she is left with the same post-treatment issues and traumas that many other young adults face who are not given effective post-treatment support. As previously stated, there is a price to pay for those who survive (Geehan, 2003), and it is apparent through both Saoirse’s account and the three Trust narratives that just because treatment has finished, it does not mean that an individual is ‘better’. Survivorship becomes and remains a vital and crucial part of treatment, which for young adults, is all too often overlooked, and makes the path all that more harder to find.

References


