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**'Life then', 'life interrupted', 'life reclaimed': The fluctuation of agency in teenagers
and young adults with cancer**

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Nursing***

1. Introduction

Teenagers and young adults (TYA) face multiple challenges as they make the transition to adulthood. These challenges for example, may be associated with risk taking (Kelly, 2003; Scoles-Balog et al., 2013) and commonly involve peer group issues (Davis, 2012). Moreover, family difficulties can emerge (Kelly and Emery, 2003). Alongside these experiences TYA are also in the process of gaining increased independence and autonomy. Generally TYA will begin to engage independent decision making, they may of course be guided by others such as peers, parents or other important people in their lives (Bednar and Fisher, 2003). Nevertheless, they begin a process of navigating their paths through decision making including, for example, whether they will continue with formal education or which career they might pursue. They also begin to take control of lifestyle choices which may involve differing levels of risk as well as relationship decisions. It is argued that adolescent development is centrally dependent on being able to make such choices successfully (Downs and Fischhoff, 2009).

TYA with cancer are also in the midst of these same experiences. Their individual circumstances will inevitably differ depending on their stage of development and family background, nevertheless each individual has to negotiate the path towards adulthood. Cancer is uncommon in the 16 to 24 year age group (Cancer Research UK, 2016). However,

for those affected the disease has a significant impact on their lives as they encounter this transition to adulthood.

This paper presents findings from a study with the purpose of exploring how control over treatment and everyday decisions fluctuates in TYA with cancer. The findings result from a three-year research study involving TYA aged between 16 and 24 years who had developed cancer, their families, those closest to them and the healthcare professionals who participated in their care.

2. Background

The freedom with which TYA are able to engage in all types of decision making is governed by a number of individual variables. One perspective from social theory, agency, provided a theoretical framework to situate the findings from this study. Agency is concerned with the ability to make free and independent choices (Bryant and Jary, 1991; Emirbayer and Mische, 1998; Giddens, 1984). The use of agency was helpful in determining the levels of control that TYA had in all aspects of decision making set against social structures such as the family, healthcare teams and the treatment protocol that could result in restricted freedom. This provided interplay between the theory of agency and the young people's experience. Agency was chosen particularly because of the changing nature of the focus of this theory, which is identified as moving between personal, proxy and collective contexts.

'Personal agency' is identified as individuals acting independently and making free choices (Bungay et al., 2011). 'Proxy agency' is demonstrated when decisions are made on behalf of another person or people (Bjerke, 2011). Finally 'collective agency' is illuminated when actions are chosen which are shared between individuals (Kippax et al., 2013). These different types of agency in decision making provided the backdrop for demonstrating the fluctuation in personal agency for TYA during their cancer experience.

Independence, autonomy and choice, which are also important in decision making, are implicit in representations of agency and have featured much more prominently as valuable features of healthcare settings, particularly during the last decade. Moreover, there is also evidence from the general literature focusing on healthcare issues and TYA (Adams et al., 2014; Hutton, 2005; Schaeuble et al., 2010; Young, 2012). Consequently, there are particular aspects of agency and the ways in which it is relevant that serve to illuminate the TYA cancer experience.

A limited number of studies have explored the issues of control in decision making in this age group. Some of these studies are not confined to the TYA age group, and instead draw on a much wider age range, including younger children (Coyne et al., 2013; Dunsmore and Quine, 1995). The paucity of background evidence presented particular challenges, therefore, in terms of the age group selected for the study. A study undertaken by Hokkanen et al. (2004) identified six categories of decision making. These included:

'Joint decision making, inadequate chances for decision making, independent decision making, illusion of decision making, reluctant to make decisions, and excluded from decision making' (pg. 325).

The number of categories identified in Hokkanen's study mirrors the ideas presented in the introduction to this paper and supports differing levels of control in decision making.

In another study findings specifically documented a loss of control in decision making during cancer treatment and detailed some of the frustration that this caused for TYA (Wicks and Mitchell, 2010). This study related almost exclusively to treatment decisions. However, the results also suggest 'benefit finding'; reflecting positive experiences from cancer which enabled TYA to make decisions about their future lives. This was a useful account of the presence of independent decision making prior to a cancer diagnosis, compared to a lack of control whilst having treatment. Despite this, positive effects were illuminated which reflected a renewed independence as a result of cancer. Additionally, there is evidence of decision making prior to achieving a cancer diagnosis (Gibson et al., 2013). Overall, however, this research base remains limited. An exploration of shared decision making from the

perspectives of children, adolescents, parents and healthcare professionals (Coyne et al., 2014) provide some useful findings in relation to older children who expressed frustration at limitations on decision making as they saw them; leading to a loss of control.

Treatment decision making may be specific to a particular procedure and this issue has been examined in the literature. This includes clinical trials and decision making, parental decision making, survivorship and decision making and fertility and decision making (Barakat et al., 2014; Barnett et al., 2014; Fern et al., 2013; Kilicarslan-Toruner and Akgun-Citak, 2013; Scherer et al., 2013; Stein et al., 2014; Wakefield et al., 2011). Time frames in relation to the cancer trajectory include; during and following the completion of treatment and, in a more limited way, the decision making experience prior to diagnosis (Gibson et al., 2013). However, gaps remain in the literature in terms of non-treatment or everyday decision making in this age group across the cancer experience. The aims of the study therefore were to elucidate:

- The experiences of choice and control in decision making for a group of teenagers and young adults during their cancer journey.
- The experiences of parents or carers, health or social care professionals, partners and friends relating to TYA choice and control in decision making during the cancer experience.
- The nature of interactions involving decision making taking place in oncology outpatient settings where the TYA were receiving care.
- The evidence within written medical notes from each of the TYA, which records, and thus contributes to, insights into choice and control in the decision making process.

3. Design

A longitudinal multiple exploratory case study design was used in this research. This enabled, as is common in this design, the selection of a small number of individual contemporary cases to be studied in depth using a range of data collection methods.

Traditionally in individual case studies sample sizes do not normally reach double figures and commonly between five and seven cases are selected for study (Yin, 2009). An important facet of case study research is the opportunity to study the lives of participants in some depth, with the aim of eliciting rich accounts of individual experience. Case study research, because of the small samples required also allows for information to be collected over a period of time, from a range of sources and using a number of different data collection methods. Carrying out the study over a relatively lengthy period, also meant that interviews undertaken at different time points provided the potential to explore further the degree of agency TYA had encountered at different times during their treatment. The geographical area adopted for this study provided only a small number of potential participants who were in the selected age group. Thus the use of case study was a pragmatic attempt to ensure that participants could indeed be recruited. Full ethical approval was sought and granted from the University and the NHS sites being utilised for the study.

3.1 Participants

The sample were TYA between the ages of 16 and 24 who were selected based on the common application of these age parameters in UK service provision. This helped to provide a benchmark, especially given the recent debate relating to the age range of TYA with some commentators suggesting in terms of young adulthood, this can be as wide as 15-39 years (Geiger and Castellino, 2011). Participants were not interviewed during the first three months following diagnosis as this would have been taking place at a time when they would be managing a great deal of information and change. Other inclusion criteria further limited recruitment in this small population. These included, only TYA who were undergoing curative treatment at the time of recruitment, and those who had been diagnosed for three months or more. Those receiving palliative care were excluded as were those who did not have the capacity to consent to participation. This approach also provided the opportunity to begin by involving the young person and acknowledge them as central to the study. Following the exploration of their initial individual experience, perspectives were gathered from others who

were known or related to the TYA in some way. This could include either partners or friends or who had cared for them during their cancer trajectory (Gillham, 2000; Stake, 1995; Yin, 2009).

Characteristics relating to each of the five case studies can be seen in Table. 1. Maximum variation was used as much as possible in recruitment of the sample to allow for potential differences in the variability of agency with reference to disease type and other variables, which included family background, whether the TYA was living independently and whether they were in employment or education.

Participant Age	Diagnosis	Time since diagnosis	Gender
Case one 20yr	Acute Lymphoblastic Leukaemia	8 months	Female
Case two 19yr	Hodgkin's Lymphoma (relapse)	18 months	Male
Case three 19yr	Osteosarcoma	9 months	Male
Case four 16yr	Neuroblastoma	3 months	Female
Case five 24 yr	Acute Promyelocytic Leukaemia	3 months	Female

Table.1. Characteristics of the five case studies

3.2 Methods

The application of multiple methods including interviews, observations and documentary analysis enabled the experiences of TYA, and those closest to them, to be examined from a number of perspectives. The application of multiple approaches enabled the triangulation of data. Data managed in this way have the capacity to offer a broad data set (Casey and

Murphy, 2009; Halcomb and Andrew, 2005). As is common in this approach purposive sampling was utilised to recruit participants to the study.

All but one participant was interviewed three times over an approximate six month period.

Case four out of the five participants had a more protracted period of interviewing over eight months. This was because this participant was unwell for a period of time during the study and was unable to take part on a couple of occasions.

Three face to face interviews were undertaken with five TYA who were all recruited from a single geographic site (Gill et al., 2008; Kvale, 2015). Each young person also gave permission for parents or carers to be interviewed once following their consent. Only one set of parents were interviewed together and one set of parents chose to be interviewed separately, the remaining participants were all parents who were interviewed alone.

Additionally, one interview took place with a healthcare professional involved in each participants care and one with another person close to the participant, for example, a partner or friend. Both of these groups were nominated by each participant. Non-participant observations of consultations were undertaken in oncology outpatients settings on two negotiated occasions during the data collection period with each participant, although for one participant, only one observation was possible. Two observations were carried out in a second site (which required ethical approval). Therefore, nine rather than ten observations could be completed due to one participant moving to a different part of the country, where research governance approval would have been required and this was judged to be impracticable for one observation.

(Hammersley and Atkinson, 2007). Documentary analysis was also undertaken through an in-depth examination of each TYAs' medical notes (Bowen, 2009) see table below in

Table.2.

Interviews with 5 TYA	15 (3 X 5)
Interviews with parents/carers	6 (two fathers, three mothers, one couple together).
Interviews with nominated participants	5 (one boyfriend, one girlfriend, two friends and one aunt).

Interviews with healthcare professionals	5 (four nurses and one oncology consultant)
Observations in outpatient clinics	9
Documentary analysis of medical notes	5
Total primary data sources	45

Table 2. Primary data sources resulting from data generation

3.3 Data analysis

In case study design it is important to be able to recognise the relevant themes both within individual cases and across cases. It is argued that this is central to data analysis in case studies (Ayres et al., 2003). It is crucial, Ayres further argues, that researchers are able to make clear the information that is relevant to all participants as well as being able to identify experiences that are limited to individual cases. These authors justify this by saying although these individual experiences may have limited value, there are aspects of the experience which are unique and thus help us to understand a particular person's story.

This study utilised a within case and cross case approach through the application of thematic analysis (Braun and Clarke, 2006). Thematic analysis is amongst one of the most popular approaches to making sense of qualitative data (Boyatzis, 1998) and as such provides a consistent pattern of experience amongst research participants. Braun and Clarke use a six step plan to achieving and reporting the identification of themes.

In this study these steps were followed closely. Each of the audio- taped interviews were listened to as soon as practical. Verbatim transcripts were then read and re-read once available. The transcripts amounted to 24 hours of interviewing and comprised 31 interviews in total. The length of interviews with the TYA varied and lasted between thirty minutes and one hour. The length of interview was similar for health care professionals and those nominated for interview. However, the interviews with parents were longer with one interview lasting one hour and twenty minutes. On reflection, this is perhaps not surprising given the

fact that they felt able to talk at length to a professional outside of their situation who was not part of the clinical team. Interestingly as data collection progressed each young person began to reveal more about their experience.

The same principles were applied to field notes which were made following observations and the written documentation which was taken from the medical records. The observations amounted to a total of 3 hours. All of the observations took place during outpatient oncology appointments. Present at all, apart from one, were parents and sometimes partners with each consultation being medically led. The purpose of this source of data was to observe examples of agency being played out during events where face to face encounters took place outside of their treatment times and away from the home environment, thus adding another layer of data for interpretation and providing further depth to the research design.

A written ongoing reflective diary and continuous reflexivity helped with thinking about the identification of themes and personal learning and development more generally. This ran concurrently with reading of verbatim transcriptions. The identification of codes was achieved by working manually through each data item interpretively line by line. This was completed by using a hybrid approach of induction and deduction (Fereday and Muir-Cochrane, 2006). Initially there were a high number of words or phrases identified and subsequently minds maps containing the words and phrases were created to identify similarities. Ultimately six codes enabled an interpretive mapping of all data extracts against the most appropriate meaning. The six codes were: 'full control', 'no control', 'negotiation', 'helping', 'disagreement' and 'advice'.

Against these six codes, the complete data set was imported into the NVIVO 10 software programme and each data item mapped against the aforementioned codes, extracting relevant narrative items. Some extracts were lengthy but this was done in order not to miss the context of the conversation (Bryman, 2012). Comparisons were made, primarily within cases, and patterns were searched for which were common to a number of participants

within each case and/or with the interviews, observational data and medical notes. Where these patterns occurred themes were then established for an individual case. Each case was then fully written up separately and discussed with colleagues, where consideration was given to the resultant individual themes pertaining to each young person. Once each case had been themed, it was then possible to iteratively reconsider the whole data set again looking for patterns; this time across cases. The temporal nature of data collected over time provided the basis for the three overarching themes as choice and control in decision making seemed naturally to fit with the course of time. The types of decisions being made also could be categorised within the pre-diagnostic phase, 'life then' the earlier treatment phase, 'life interrupted' and the later phase including the completion of treatment, 'life reclaimed'. These three core categories formed the basis of the findings which illuminated the fluctuation of agency over time in TYA and suggested the influence of an adapted theory of decision making during cancer treatment.

4. Findings

Findings were divided into two distinct contexts, within case and across case, thus individual themes were identified for each case and themes which cut across either all of the majority of the cases were also illuminated. The three overarching themes of 'life then', 'life interrupted' and 'life reclaimed' formed the basis of further sub themes. Within each of these phases the levels of personal, proxy and collective agency fluctuated during the cancer experience. Across case findings will form the basis for the remainder of this paper.

4.1 Across case findings

Instances of similar experience related to cancer enabled cross case analysis to take place, with extracts being grouped together to provide cross cutting sub themes. This evidence of commonality between cases were categorised as described earlier into three overarching themes of 'life then', prior to the cancer diagnosis, 'life interrupted', during treatment and 'life reclaimed' as they came towards the end of treatment. Examples of data are presented to

illuminate these cross cutting themes. Importantly, TYA did not always move through stages in a linear way but there were similarities in their experiences when particular types and levels of agency were illuminated. At the outset it was envisaged that the TYA would only provide information on their experience of decision making that was happening at the time of interview. However this was not the case, participants wanted to recount their level of agency before their diagnosis and also wanted to 'look forward' and to discuss how personal agency might become stronger as they moved towards or completed treatment. Additionally, at the final interview stage some participants who had recently completed treatment were able to talk about their control around decision making in real time. The following sub themes were common amongst all five participants, see table below in Table.3.

<p>'Life then'</p>	<ul style="list-style-type: none"> • High levels of personal agency in decision making. • Needing to maintain agency in order to achieve goals. • Help from others who are close however, decision making remains with the individual, utilising personal agency. • Diminishing levels of choice and control in agency relating to decision making as symptoms progress.
<p>'Life interrupted'</p>	<ul style="list-style-type: none"> • Personal agency severely restricted compared to 'life then' following diagnosis • Examples of proxy and collective agency in decision making changing the emphasis of choice and control. • Some evidence of personal agency relating to treatment decisions but with limitations on choice and control. • Loss of choice and control in relation to future aspirations. • Striving to maintain some personal agency in respect of everyday decision making.
<p>'Life reclaimed'</p>	<ul style="list-style-type: none"> • Regaining levels of personal agency as the recovery process continues and treatment nears completion.

	<ul style="list-style-type: none"> • Still a requirement sometimes for high levels of collective agency in planning the future. • Trying to reclaim full control but sometimes faced with challenges which limit this e.g. change in physical status in light of cancer treatment. • Looking forward to having higher levels of personal agency in pursuit of aspirations in work and education.
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Table 3. Sub themes common to all five participants

4.2 ‘Life then’

The lives of TYA prior to diagnosis were largely under their own control with aspects of work, education and social life being independently actioned. Once they had developed symptoms they practiced what was described as ‘holding on’ and in some cases moved beyond the ‘threshold points’ identified by (Gibson et al., 2013), in an attempt to keep control of their decision making and their lives. These are described by the authors above as; “when either the symptoms had intensified and could no longer be tolerated and/ or normalised or when they were interfering and intruding on the young person’s life to an unbearable extent” (pg 2585).

This form of agentic control was despite medical advice and sometimes in the absence of any professional help. Their actions which could be described as the ‘compulsion’ to continue with life in order to meet aspirational goals and targets was quite startling as they struggled sometimes without adjustment to ‘stay on track’.

Case five illuminated a clear assertion of personal agency as they tried to cope with the onset of symptoms prior to diagnosis. The level of personal agency in this case was significant in terms of the participant not wanting to surrender control in spite of worsening health. Although others such as friends and family tried to help and give advice, this whilst

accepted was not acted upon. The following extract details this assertion of personal agency:

I walk up to the train station and that was the worst it had ever been I actually got there and had to sit down and got on the train I mean these trains are packed and I think now, how I didn't pick anything up because I had no immune system at this point and I was still travelling on trains and tubes and slowly making my way into work... (interview one with case five)

This highlighted the need for the individual to 'hold on' to their agency by continuing with their daily life. This participant had a strong work ethic and was very rarely absent. Despite difficulties with fatigue and subsequent breathlessness she continued going to work every day. Despite advice from friends and family acting as proxy agents, there was evidence that this was not something the participant responded to; instead they decided to continue with their own decision making.

The involvement of TYAs' partners and friends in their lives at this time was central to them in terms of the value they placed on these relationships. However, this value was displaced by the fact that, despite their best intentions, friends and partners had minimal or no effect on the intent and strong personal agency of the TYA. The partner of case one described this as he tried in vain to help her when her symptoms progressed:

I can remember, I got a phone call from ... and I couldn't really make out what she was saying because she was in absolute agony. She was like screaming and I said ... we are going to come and get you and you can come and stay with us and my mum will look after you and she kept telling us please no, just stay on the phone with me and I was like, my mum was like, I am going to go and get her and I was like ok mum just wait you know, so ... really stubborn didn't want to impose (interview with partner of case one).

The youngest person in the study, case four was only just 16 years but was at a critical stage in her development; socially, emotionally and intellectually. Her impending examinations were her key priority and it was crucial that she was able to attend school in order to finish course work and prepare for assessments. As her symptoms progressed she would often experience vomiting and abdominal pain, which were serious enough that she could not stay in school. Rather than stay away from school completely she exerted her personal agency by negotiating her attendance with both of her parents. She persuaded her

mother to contact the school, demonstrating elements of requiring proxy agency and make arrangements on her behalf so that she could maintain some control over her situation:

So I started contact with the school trying to say look she's ill if she gets better in the next hour or two hours can she come to school, she wants to come to school if she is better, she knows she is in the middle of her exams she would like to come to school if she's able can she come to school (interview with mum of case four).

Ultimately however, and despite coping with worsening symptoms, there was a point for each of the TYA where they surrendered personal agency. The word surrendered was applied here as in some cases they were still not keen to hand over control to others.

Despite the significant disruption to life and the lack of choice and control, TYA were then able to accept and indeed feel grateful that sometimes others acted on their behalf during the early stages of treatment.

4.3 'Life Interrupted'

In the evidence which follows, whilst the cancer journey was largely sequential in terms of each young person's treatment plan, there were many of what could be described as 'peaks and troughs' in their journey, which provided a complex set of events relating to their choice and control. Subsequently it appears that whilst their personal agency was severely disrupted on many occasions, there were glimpses of their need to take control of events by making decisions and managing some areas of their lives, despite the way in which the cancer severely limited their life journey.

At the point when the diagnoses were confirmed, for some the disruption to personal agency had already become more marked and parents made conscious decisions to withhold information for a variety of reasons. They, therefore, did not always provide choice to their children nevertheless, all those involved felt that this restriction was a good decision given the circumstances. Case two was in the middle of A level examinations, this was a crucial time for him in terms of his education and his mother was convinced that she had made the

right decision to act as a proxy agent in essence and not to tell him straightaway about his diagnosis:

And you know the way A levels are now they do them over such a long period of time and he happened to be doing two history subjects that couldn't be re taken in January he would have to wait... I just thought that's going to be really depressing... having whatever treatment you have... and then all you do then is turn round and... Yeah, so what I did was I didn't tell him at all the diagnosis for about three weeks (interview with mum of case two).

There were other examples of withholding information by parents as they viewed it to be in the best interests of their children and largely the participants agreed with this approach in supporting their role as proxy agents. One consultant who participated in the study expanded on this further as a collective approach and stated that, as far as he was concerned, the family were a 'constant' in all scenarios which discussed matters of the care and management process during treatment:

With the teenagers is to involve them as much as they want involvement in all the discussions and with ... I felt that at all times, I am trying to think if there ever has been a discussion where (young person) hasn't been present when I have spoken to her parents maybe there was one but in any case umm right from the word go whenever I have had a discussion with parents I have had it across the bed where you know I sit on one side,... on the bed and then either one or both parents on the other side and then we have this discussion (interview with consultant of case four).

Families and those close to them played an important role in this aspect of their treatment course. The TYA accepted the loss of personal agency and indeed sometimes they did not desire control; this was highlighted in conversation with some where they made reference to the notion that, in their view, they had 'no choice' in terms of decision making there was only one course of action for them. Case one was quite clear about this in her second interview:

I didn't have any options apart from treatment or dying...I didn't have any options...treatment wise they gave you a timetable of what they were going to give you on what day and you know have lots of lumbar punctures and bone marrow samples... and they put like chemo in my spine (interview one with case one).

Evidence in relation to other treatment issues however, resulted in some different responses from some as they struggled sometimes to accept their treatment. This culminated in their refusal, for example, to take some types of oral medication, although there was an

acceptance from staff that this decision should be acknowledged as was evident in the medical notes of case four:

Ongoing issues of not taking medication contravenes ward policy. Staff to remind 2-3 times then remove 15 minutes later if not taken (medical notes of case four).

Another example of the need for TYA to take control of decisions relating to their treatment was also linked to medication and again involved a decision not to take particular medicines. The mum of case two would have acted as a proxy agent here given the opportunity and the discussion was of a collective nature but ultimately case two utilised personal agency to make his own decision:

The consultant then asked what medication he was taking and at this point there seemed to be some confusion. He said that he was not taking antibiotics, he also said that he was no longer on magnesium, his mum added that he had decided that he wouldn't take these (second outpatient oncology consultation with case two).

Importantly, some of the decision making related to everyday life decisions and there was a clear determination here that TYA would attend social events and continue with their usual routines. Case four was undergoing a particularly intensive regime due to the nature and stage of cancer and spent most of her time in the treatment unit. From the outset of her treatment she had only spent a handful of days at home. Her school prom was planned to take place whilst she was having treatment. Both her mother and father were apprehensive about this and were very tentative in saying that she could only attend if she was well enough. She was discharged from hospital only 48 hours before the event and a decision was made jointly, through negotiation that she would attend, thus providing an example of collective agency. Staff in the unit were familiar with this type of occurrence and always tried to accommodate the wishes of the TYA in enabling them to fulfil their requests. However, the mother of case four found it incredibly difficult to relinquish control and although she did go to her prom there was a caveat in order for her mother to feel confident that she would be safe:

I was outside in the car but she had her phone I had my phone and obviously I was in contact with the teachers keeping an eye on her, she had a bit of blood dripping

down... she did because her haemoglobin was a little bit low... but no she said she was still fine and she was ok and she was staying and so in the end I said at 9 o'clock I said to her I said look are you OK yes mammy I'm enjoying , I'm dancing, I'm with all my friends, I'm here with my sister I said, is it ok if we go to the pub around the corner? We've been stuck in the car all this time (interview with mum of case four).

Furthermore, the simplest of everyday activities were also important to participants as they tried to keep control of their decision making through the use of personal agency as was highlighted by case five:

Oh yes absolutely, I mean I did, I found it quite strange do you know what it was actually a way of trying to keep control of things in that I would, I would wake up every morning not at a set time necessarily, I would wake up and I would... the first thing I would do was to get myself together, get all my wash stuff and go have a shower and change, I would get out of my pyjamas and put like lounge clothes on umm and then usually I wouldn't get back into bed, I would make the bed (laughter) I used to, I wouldn't get back into bed I would sit in my chair that I would sit in, I would only sit on the bed really if people were coming in and I had to give them the chair really (interview two with case five).

4.4 'Life reclaimed'

There was evidence in this theme of an optimistic picture of the future for the TYA involved; a time when they could reclaim their lives and a time for the full re-alignment of their agency. This was for all the TYA a time of intense reflection as they considered their future, re-evaluated each of their respective positions and took action to 'make things happen'. Crucial to the realignment of agency and wanting to 'reclaim' their lives was the recognition that increasingly, they wanted to lead the planning for life after completion of cancer treatment. Whilst support was vital independence was nevertheless something that proved very important. The positivity with which they were able to show signs of 'liberation' and of being 'different but determined' was an indication of the way that they wanted to mark the closing of a difficult chapter and to move on from cancer. All of the participants in the study had a strong need to return to work and education as soon as it was possible to do so. Their requirement for control in this context was also marked by their increasing autonomy in decision making as they recovered. During this time they continued with intimate

relationships, however there was sometimes a struggle, as there had been in the phase before diagnosis, when despite the best intentions of partners, TYA steered their own path towards the future.

Case five felt that it was crucial for her to make a fresh start as she associated her illness very much with the flat she lived in prior to her diagnosis. This marked the beginning of the rest of her life and she was keen that it was as far away from the memories of her illness as possible. She explained in detail her move back to her new flat:

So I came down here, packed everything up umm picked up the van in (city) and drove it up to (city of treatment) to, I had to pick up (mumbles) and things like that, that were at my mum's and I did that... umm but I suppose looking back on it now it is probably quite, like if I could see myself driving a van and lugging boxes in and out of a van two weeks after finishing chemotherapy it is a bit ridiculous really isn't it but that's it I, there comes a point where you have to get back to normality isn't there and you know you can I don't know you can carry on being cautious and just saying umming and ahing about stuff but there does come a point where you have to get on with it (interview three with case five).

This was only two weeks following the completion of chemotherapy and yet she asserted her personal agency. Case two was also keen to re- establish independent living. He made no secret of his desire to find an independent living space and had discussed this at length with his partner:

And he was like no I am going to move out and umm I know his mum was like I don't think you should but at the same time something she told my mum is that she doesn't want to say no all the time and she is like a mental health doctor as well so she understands that he has to grow up and stuff but yeah he is going to move out (interview with partner of case two).

This need to realign personal agency and taking control of decision making was evident in many aspects of life and included alongside the practical matters of accommodation, social pursuits. As case three commented:

Despite my disability I'm not going to stop playing sport and you know not do anything. It's a huge part of my life. I've played sport since I was about five, basketball, rugby, football, tennis you know so yeah I just want to stay involved with sport and hopefully career wise go into coaching or sports analysis you know something along those lines (interview three with case three).

The importance of returning to life and aspiring to a successful and fulfilling future should not be underestimated. This taking back of control was crucial to the recovery and the realisation of future aspirations in the lives of these TYA.

5. Discussion

There is a growing body of evidence that examines aspects of the cancer journey in this age group and this has contributed to the current knowledge base (Coyne et al., 2014; Hokkanen et al., 2004; Hollen et al., 2013; Wakefield et al., 2011). This evidence comprises elements of how decision making takes place, however some is related exclusively to when treatment is completed and is more specific in focus. For example, decisions being made about fertility choices. However evidence of decision making involving everyday aspects of life are minimal. Furthermore detailed examination of the period prior to diagnosis from the voice of the young person is sparse (Gibson et al., 2013).

The fluctuation of agency between the personal, proxy and collective perspectives, whilst not always a linear concept, appears to be part of the trajectory for young people as they experience cancer. This is the first study of its kind which has simultaneously considered the journey of cancer from the development of symptoms through diagnosis and coming to the end of treatment using the theoretical lens of agency. Trajectories in long terms conditions are recognised as being useful in understanding the changing nature of disease over time (Corbin and Strauss, 1985; Hannigan and Allen 2013).

The trajectories in this study were unique for two reasons. Firstly they concerned the temporal nature of agency in three phases, 'life then', 'life interrupted' and 'life reclaimed' in teenage and young adult cancer specifically. Additionally, they are situated at a time of development which is also different to any other in the life cycle. Similar work considers the cancer trajectory and recognises the significant constraints that are placed on the TYA over time and stresses the importance of how patient needs may vary both overtime and between individuals (Fern et al., 2013; Olsson et al., 2013).

The way in which TYA manage their symptoms and make decisions through the assertion of personal agency prior to diagnosis is striking as is the response to severely restricted agency both in treatment and in their lives more generally, where they still demonstrate small peaks in agency during treatment as they manage what decisions they can. Their ability to exercise agentic power in determining actions in difficult circumstances is strongly apparent. However there is evidence which reports there is frustration amongst adolescents who believe that shared decisions were not 'real' for them as they had no opportunity to refuse (Coyne et al., 2013). The need for the freedom to plan and make decisions about their future pathways as their health improves is apparent. Nevertheless proxy and collective agency is a feature throughout this part of their experiences, involving families, those close to the TYA and professional staff. Despite the need to plan evidence suggests that 24 months from diagnosis poor social functioning can be present (Husson et al., 2017). This may act as barrier to effective decision making and therefore a proxy or collective approach to decision making may in some cases be the most useful way to proceed.

The illumination of these trajectories gives the opportunity for those involved in the care of TYA to appreciate the 'peaks and troughs' of choice and control in decision making through the notion of agency. Early indications of the usefulness of agency in TYA cancer trajectories are encouraging. A variety of practitioners in the field provided feedback and made suggestions about how TYA could be assisted more effectively as a result of a clearer understanding of agency during the cancer experience. Their feedback, particularly in the life interrupted and the life reclaimed stages, suggest that the notion of being able to predict when TYA might benefit from being able to independently make choices and times when they needed support or guidance could be therapeutic as well as meeting their needs. Recent guidance supports the need for independence, choice and support throughout the cancer experience (Smith et al., 2016). Additionally studies recently undertaken such as 'BRIGHTLIGHT' in the UK will further report the importance of matters of choice in decision making following a cancer diagnosis.

The group also articulated the need to further consider the period prior to diagnosis in thinking about what is currently available in terms of education, particularly in those over 16 years. The use of social media platforms was also raised as ways to engage TYA in general health monitoring and the emergence of worrying symptoms. It was felt that through specialist psychological support, it could be considered how modes of independence could prior to diagnosis be reinstated at an early point during treatment when TYA are at their most vulnerable. At local levels, it was articulated that models of care need to be developed which will provide more of an ambulatory status to those receiving treatment, with greater emphasis on self-management and potentially less disruption to everyday life. The notion of trying to achieve 'normality' has been identified as important to TYA during the cancer experience (Taylor et al., 2013). Finally, it was proposed that systematic early planning about what the young person intends to do following treatment was paramount. Support it was argued, is important but the offer of the young person leading and progressing with future plans after cancer should be firmly in place at an early stage.

6. Conclusion

This study provided a temporal picture of the changing nature of agency as TYA developed symptoms, were treated for cancer and began to recover and complete their treatment. The fluctuation of personal, proxy and collective agency was apparent both within individual cases and across cases, providing a rich and detailed account of the challenges that these TYA face both in treatment and everyday decision making. Future work needs to be undertaken to further explore the enablement of agency, perhaps more specifically in everyday life decisions during this time, which will benefit the position of the young person in managing their experience with perhaps more balance towards their everyday lives. Further work needs to be undertaken to test the notion of the fluctuation of agency which was apparent in this study to ascertain ways in which interventions in practice might help TYA to cope with the complex and constantly changing circumstances during their cancer experience.

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References

- Adams, J., Evangeli, M., Lunnon-Wood, T., Burch., M. 2014. Restriction and dependence to autonomy and freedom: Transformation in adolescent heart transplant recipients, *Pediatric Transplantation*, 18, 637-650.
- Ayres, L., Kavanaugh, K., Knafelz, K. A., 2003. Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research*. 13, 871-883.
- Barakat, L.P., Schwartz, L.A., Reilly, A., Deatrck, J.A., Balis, F., 2014. A qualitative study of phase III cancer clinical trial enrollment decision-making: Perspectives from adolescents, young adults, caregivers, and providers. *Journal of Adolescent and Young Adult Oncology*. 3, 3-11.
- Barnett, M.E., Shuk, E.M., Conway, F.P., Ford, J.S., 2014. Cancer-related disclosure among adolescent and young adult cancer survivors: A qualitative study. *Journal of Adolescent and Young Adult Oncology*. 3, 123-129.
- Bednar, D.E., Fisher, T.D., 2003. Peer referencing in adolescent decision making as a function of perceived parenting style. *Adolescence*. 38, 607-21.
- Bjerke, H., 2011. 'It's the way they do it': Expressions of agency in child-adult relations at home and school. *Children and Society*. 25, 93-103.
- Bowen, G., 2009. Document analysis as a qualitative research method. *Qualitative Research Journal*. 9, 27-40.
- Boyatzis, R.E., 1998. *Transforming qualitative analysis: Thematic analysis and code development*, Sage Publications, Thousand Oaks CA.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3, 77-101.
- Bryant, G.A., Jary, D., (Eds). 1991. *Giddens' theory of structuration: A critical appreciation*, Routledge, London.

- Bryman, A., 2012. *Social research methods*, fourth ed. Oxford University Press, Oxford.
- Bungay, V., Halpin, M., Atchison, C., Johnston, C., 2011. Structure and agency: Reflections from an exploratory study of Vancouver indoor sex workers. *Culture, Health and Sexuality*. 13, 15-29.
- Cancer research UK. 2016. Teenage and young adult cancer statistics. <http://www.cancerresearchuk.org/cancer-info/cancerstats/teenage-and-young-adult-cancer/incidence/> [Accessed: 8th March 2017].
- Casey, D., Murphy, K., 2009. Issues in using methodological triangulation in research. *Nurse Researcher*. 16, 40-55.
- Corbin, J.M., Strauss, A.L., 1985. Managing chronic illness at home: Three lines of work. *Qualitative Sociology*. 8, 224–247.
- Coyne, I., O'Mathúna, D.P., Gibson, F., Shields, L., Sheaf, G., 2013. Interventions for promoting participation in shared decision-making for children with cancer, *Cochrane Database of Systematic Reviews*, DOI: 10.1002/14651858.CD008970.pub2
- Coyne, I., Amory, A., Kiernan, G., Gibson, F., 2014. Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing*. 18, 273-280.
- Davis, K., 2012. Friendship 2.0: Adolescents' experiences of belonging and self-disclosure online. *Journal of Adolescence*. 35, 1527-1536.
- Downs, J. S., Fischhoff, B., 2009. Theories and models of adolescent decision making, In: DiClemente, R.J., Santelli, J.S., Crosby R.A., (Eds), *Adolescent health: Understanding and preventing risk behaviors*. Jossey-Bass, San Francisco, pp. 77-90.
- Dunsmore, J., Quine, S., 1995. Information support and decision making needs and preferences of adolescents with cancer: implications for health professionals. *Journal of Psychosocial Psychology*. 13, 39-56.
- Emirbayer, M., Mische, A., 1998. What is agency? *American Journal of Sociology*. 103, 962-1023.
- Fereday, J., Muir- Cochrane, E., 2006. Demonstrating rigour using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*. 5, 1-11.
- Fern, L.A., Taylor, R.M., Whelan, J., Pearce, S., Grew, T., Brooman, K., Starkey, C., Millington, H., Ashton, J., Gibson, F., 2013. The art of age-appropriate care: Reflecting on a conceptual model of the cancer experience for teenagers and young adults. *Cancer Nursing*. 36, E27-E38.
- Geiger, A.M., Castellino, S.M., 2011. Delineating the Age Ranges Used to Define Adolescents and Young Adults. *Journal of Clinical Oncology*. 29, E492–E493.
- Gibson, F., Pearce, S., Eden, T., Glaser, A., Hooker, L., Whelan, J., Kelly, D., 2013. Young people describe their pre-diagnosis cancer experience. *Psycho-Oncology*. 22, 2585-2592.
- Giddens, A., 1984. *The constitution of society*. University of California Press, Berkeley.
- Gill, P., Stewart, K., Treasure, E., Chadwick, B., 2008. Methods of data collection in qualitative research: Interviews and focus groups. *British Dental Journal*. 204, 291-295.

- Gillham, B., 2000. Case study research methods. Continuum, London.
- Halcomb, E., Andrew, S., 2005. Triangulation as a method for contemporary nursing research. *Nurse Researcher*. 13, 71-82.
- Hammersley, M., Atkinson, P., 2007. *Ethnography: Principles in practice*. Routledge, London.
- Hannigan, B., Allen, D., 2013. Complex caring trajectories in community mental health: Contingencies, divisions of labor and care coordination. *Community Mental Health Journal*. 49, 380-388.
- Hokkanen, H., Eriksson, E., Ahonen, O., Salanterä, S., 2004. Adolescents with cancer: experience of life and how it could be made easier. *Cancer Nursing*. 27, 325-335.
- Hollen, P.J., Tyc, V.L., Shannon, S.V., Donnangelo, S.F., Hobbie, W.L., Hudson, M.M., O'Laughlen, M.C., Smolkin, M.E., Petroni, G.R., 2013. Factors related to decision making and substance use in adolescent survivors of childhood cancer: a presenting clinical profile. *Journal of Cancer Survivorship*. 7, 500-510.
- Husson, O., Zebrack, B., Block, R., Embry, L., Aguilar, C., Hayes-Latin, B., Cole, S. 2017. Cancer in adolescents and young adults: who remains at risk for poor social functioning over time? *Cancer* 123, 2743-2751
- Hutton, A., 2005. Consumer perspectives in adolescent ward design. *Journal of Clinical Nursing*. 14, 537-545.
- Kelly, P., 2003. Growing up as a risky business? Risks, surveillance and the institutionalised mistrust of youth. *Journal of Youth Studies*. 6, 165-180.
- Kelly, J.B., Emery, R.E., 2003. Children's Adjustment Following Divorce: Risk and Resilience Perspectives. *Family Relations*. 52, 352-362.
- Kippax, S., Stephenson, N., Parker, R.G., Aggleton, P., 2013. Between individual agency and structure in HIV prevention: Understanding the middle ground of social practice. *American Journal of Public Health*. 103, 1367-1375.
- Kilicarslan-Toruner, E., Akgun-Citak, E., 2013. Information-seeking behaviours and decision-making process of parents of children with cancer. *European Journal of Oncology Nursing*. 17, 176-183.
- Kvale, S., 2015. *Learning the craft of qualitative research interviewing*. third ed. Sage Publications, London.
- Olsson, M., Jarfelt, M., Pergert, P., Enskär, K. 2015. Experiences of teenagers and young adults treated for cancer in Sweden, *European Journal of Oncology Nursing*. 19, 575-581.
- Schaeuble, K., Haglund, K., Vukovich, M., 2010. Adolescents' preferences for primary care provider interactions. *Journal for Specialists in Pediatric Nursing*. 15, 202-210.
- Scherer, D.G., Brody, J.L., Annett, R.D., Turner, C., Dalen, J., Yoon, Y., 2013. Empirically derived knowledge on adolescent assent to pediatric biomedical research, *AJOB Primary Research*. 4, 15-26.

Scholes-Balog, K.E., Hemphill, S.A., Patton, G.C., Toumbourou, J.W., 2013. Cannabis use and related harms in the transition to young adulthood: A longitudinal study of Australian secondary school students. *Journal of Adolescence*. 36, 519-527.

Smith, S., Mooney, S., Cable, M., Taylor, R.M. (Eds). 2016. *A blueprint of care for teenagers and young adults with cancer*. (2nd ed) London: Teenage Cancer Trust.

Stake, R.E., 1995. *The art of case study research*. Sage Publications, London.

Stein, D M., Victorson, D.E., Choy, J.T., Waimey, K .E., Pearman, T.P., Smith, K., Dreyfuss, J., Kinahan, K.E., Sadhwani, D., Woodruff, T.K., Brannigan, R.E., 2014. Fertility preservation preferences and perspectives among adult male survivors of pediatric cancer and their parents. *Journal of Adolescent and Young Adult Oncology*. 3, 75-82.

Taylor, R.M., Pearce, S., Gibson, F., Fern, L. Whelan, J. 2013. Developing a conceptual model of teenage and young adult experiences of cancer through meta-synthesis, *International Journal of Nursing Studies*, 50, 6, 832-846.

Wakefield, C.E., McLoone, J.K., Fleming, C.A.K., Peate, M., Thomas, E.J., Sansom-Daly, U., Butow, P., Cohn, R.J., 2011. Adolescent cancer and health-related decision making: An Australian multi-perspective family analysis of appointment attendance and involvement in medical and lifestyle choices. *Journal of Adolescent and Young Adult Oncology*. 1, 173-180.

Wicks, L., Mitchell, A., 2010. The adolescent cancer experience: loss of control and benefit finding. *European Journal of Cancer Care*. 19, 778-785.

Yin R, K., 2009. *Case study research design and methods*, fourth ed. Sage Publications, London.

Young, G., 2012. From boy to man: recommendations for the transition process in haemophilia. *Haemophilia*. 18, s27-s32.