

**THE FLUCTUATION OF AGENCY IN TEENAGERS
AND YOUNG ADULTS WITH CANCER**

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degree of Doctor of Philosophy.**

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SUMMARY

This thesis is the result of an in-depth study, which explored the experience of choice and control in decision making when five young people developed and were subsequently treated for cancer. The study was underpinned by the sociological theories of agency and structure against the backdrop of the developmental nature of adolescence and emerging adulthood. The experience of the disease was situated at a time when these young people were in the process of developing their early adult life plans and were at a fundamental crossroad in the life cycle. The diagnosis and subsequent treatment for cancer at this juncture impacted significantly on the lives of these five young people and those close to them.

Exploratory case studies were utilised in an attempt to examine more specifically each young person's choice, intentionality, control and freedom in deciding all aspects of decision making, beginning with the onset of symptoms followed by diagnosis and treatment. Interviews, observations and documentary analysis were instigated to generate data. Multiple sources were selected to generate further insights and these included family, partners, friends and healthcare professionals who were close to the young people during their experience.

Three overarching themes were identified during analysis of the data: 'life then', 'life interrupted' and 'life reclaimed'. Key elements of these themes included a number of complex and interrelating factors which were interwoven within the everyday lives of the young people. In the 'life then' phase, 'holding on' to agency prior to diagnosis and the importance of close and intimate relationships was illuminated. In 'life interrupted', agentic power during treatment, in terms of the range of decision making and the complexity of the parental role, were prominent. In 'life reclaimed' the 'different but determined' nature of young people's behaviour and re-aligned agency was transparent as they made their way towards the end of treatment.

The findings culminated in the illumination of individual trajectories relating to the fluctuating nature of agency during the cancer experience. These incorporated the three overarching themes as three sequential phases. Commonalities in this regard were also identified across the five cases. Several discussions with practice colleagues resulted in the formulation of potential ways in which ultimately these trajectories might be applied to practice in the future.

DECLARATION

This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

Signed (candidate) Date

STATEMENT 1

This thesis is being submitted in partial fulfillment of the requirements for the degree of PhD.

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STATEMENT 2

This thesis is the result of my own independent work/investigation, except where otherwise stated. Other sources are acknowledged by explicit references. The views expressed are my own.

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ABBREVIATIONS AND GLOSSARY

DH Department of Health

GMC General Medical Council

NHS National Health Service

NCB National Children's Bureau

NICE National Institute for Clinical Excellence (now The National Institute for Health and Care Excellence).

TYA Teenagers and Young Adults

TYAC Teenagers and Young Adults with Cancer

UNCRC United Nations Convention of the Rights of the Child

NB: Throughout this thesis young people are simultaneously referred to largely as either teenagers and young adults or young people. However because of the complex historical terminology and lack of consensus on definition, they may also variously be referred to as adolescents or occasionally as youth.

NB: In the data extracts, all names have been changed to protect confidentiality and anonymity. Ellipses have been used (...) to denote sections removed from the interview transcripts.

ACKNOWLEDGEMENTS

Most importantly many thanks go to all those who participated in this study. I was a little anxious about people wanting to accept the invitation to take part but this was unfounded as the study unfolded. The interviews and observations that followed were full of in-depth and meaningful descriptions, which are at the heart of this study. These have formed the basis for what I believe will provide further valuable insights into the experience of teenage and young adult cancer.

For the wise words, constant encouragement and unconditional support, I want to say thank you to my supervisors, Professor Daniel Kelly and Dr Ben Hannigan, who have kept faith in my ability to navigate my way through this process. Their advice has been invaluable and I have learned a great deal from them in the last three years. My dear friend Dr Dave Clarke has also been central to my progress.

My family, Al, Ellie, George and mum, extended family and not forgetting my dog, have all played a part in helping me along especially in challenging moments, of which there were quite a few. They would consistently tell me that I could complete the study and often reminded me of the many other interesting and rewarding areas of my life, which helped to keep an appropriate perspective on my experience.

My network of longstanding colleagues and friends often provided a platform for discussion relating to many aspects of my progress and were always happy to talk especially when I needed to clarify aspects of the work or just to have a chat. A special mention must be given to Jenny who was vital in helping me by inviting young people to take part in the study, as well as always being there to talk and share her expert knowledge.

Finally thank you to the Brocher Foundation in Geneva and the other scholars who I met there, where I was awarded a visiting residency for a month close to the end of my study.¹ This gave me the space to think, read write and reflect on what has been a unique and transformative experience.

¹ *The Brocher Foundation is a non-profit foundation and was created under Swiss private law by Mr and Mrs Jacques and Lucette Brocher. Its purpose, is to host scientists and experts in the ethical, legal and social implications of the development of medical research and biotechnologies* <http://www.brocher.ch/en/brocher-foundation-in-brief/> accessed 1 August 2015.

DEDICATION

For my brother Simon

1963-2011

PROLOGUE

A career in nursing was not something that I planned to do from a young age, as is the case with some of my colleagues and friends. Indeed, I remember being drawn to other possible careers which were quite different to nursing. A popular thought centred on piano teaching, which my father quickly dissuaded me from pursuing by telling me that once my hobby became a job it would likely not be as enjoyable. I then had dalliances with PE teaching and the police force before I finally settled on nursing. Thirty-five years on I still feel privileged to have had such rewarding experiences both in practice and education and to have met some truly fantastic and inspirational people along the way.

At the outset of my career, I was first prepared to certificate level as a Registered General Nurse but had already recognised in the second year of the programme that I wanted to pursue a path working with children and young people. I duly embarked on this route in 1985 and have literally, to state the proverbial term 'not looked back'. I came to higher education relatively late, having spent fifteen years in practice most of which was in the field of children and young people's nursing. I had a variety of experiences in the field including working in a children's cardio-thoracic unit, a neonatal unit, an oncology unit and an acute medical and surgical unit in a medium sized district general hospital. My favoured area was oncology but I was keen to 'climb the ladder' so to speak and there was no opportunity for promotion in the oncology unit as senior staff there tended to stay for many years in their respective posts.

My first foray into higher education at 28 was with the Open University, where I completed my undergraduate degree whilst still working clinically. My desire for formal teaching, held in childhood, returned and I began my career in education in 1995. The Open University kick started my thirst for knowledge and as our young family began to

grow I felt I had more time and successfully completed an LLM in medical law. I had a long held interest in law and in the challenges associated with the ethics of caring for young people and this led me to undertake a dissertation exploring the consent and refusal of medical treatment in minors. This was a complex task and it gave me insights and knowledge into the intricate interplay of the legal framework around consent and refusal of treatment set against the ethical challenges presented by young people in healthcare settings and those close to them.

Whilst I had always wanted to undertake study at doctoral level, my excuse as I see it now was that the time had never been 'right'. I nevertheless began to develop my scholarship through generic publications and presentations, both locally, nationally and internationally and was promoted to Senior Lecturer in 2011. By this time I was also the professional head for children and young people's nursing, a post which I held from 2008 until the commencement of doctoral study.

A significant personal experience which resulted in the untimely death of my brother was followed soon after by a 'carpe diem' moment and I decided that I would waste no more time and do something that I had long thought about but not acted upon. What better group to focus on than where I had most enjoyed my time in practice.

1. INTRODUCTION

1.1 SETTING THE SCENE

The painting below was completed in the spring of 2014 by Ellen, one of the five young people who took part in the study. She was keen for it to be shared to explain her feelings during treatment (Figure.1.1).



Figure 1. 1. Painting by Ellen

The following narrative is from an email that she sent me when I thanked her for giving me permission to use it in my work:

This painting was finished on the 13/4/14, it took me a month to complete. It's named Worm's Head, after the beach in Swansea . When I was a child I loved being at the beach, it is one of the happiest memories I have. The sky represents my confusion, frustration, and anger towards cancer. The Viking ship wreck represents my worries of death and becoming an empty shell of a

person. The waves represent hope, the sea brings calmness to the painting that keeps me grounded (email sent by Ellen, July 2014).

These words typify this study and act as a fitting backdrop where each young person experienced fluctuating levels of choice and control as they made decisions in their lives at this difficult time. Subsequently, with Ellen's permission I entered the painting into a postgraduate competition, 'Images of research' at the institution where I undertook the study. The image was awarded first prize from amongst nearly 50 other entries. Following discussion with Ellen, the £200 prize money is to be donated to the unit where she was treated and the research completed.

The context of this study is situated within the realm of teenage and young adult cancer experience. More specifically the study sets out to answer a number of questions focusing on the agency which includes, intentionality, motivation, choice, freedom and control that young people have when making all types of decisions throughout their cancer trajectory. Young people were firmly at the centre of this investigation. Nevertheless, it was recognised and acknowledged that those closest to them at this time including family, friends, and partners, played a significant part in helping and supporting them through this period in their lives. Equally, the health and social care professionals involved in their care undertook a fundamental role both in the structure and management of their care relating to their treatment and their everyday lives. The study specifically set out the following questions:

- What are the experiences of choice and control in decision making for a group of teenagers and young adults during their cancer journey?
- What are the experiences of parents or carers, health or social care professionals, partners and friends relating to young people's choice and control in decision making during the cancer experience?

- What is the nature of interaction in decision making taking place in oncology outpatient settings where the teenagers and young adults are receiving care?
- What evidence is there in the written medical notes from each of the teenagers and young adults, which records, and thus contributes to, insights into choice and control in the decision making process?

In this opening chapter, the backdrop to the study will be introduced. Cancer is uncommon in this age group, however, for those affected the disease has a significant impact on their lives as they make the transition to adulthood. The incidence of cancer specifically in the UK and worldwide, provides an overarching picture of the most common types of cancer in the 16 to 24 year age group, some of which formed part of this study. The transient nature of the shift between later teenage development and the emergent stage of young adulthood reflects some overlapping and important junctures. These require consideration in helping to specify this group and their distinct needs. These developmental transitions provide the basis of the underpinning philosophy for the formulation of service provision in the UK. This is complimented by the development of expert knowledge, policy and guidance acting as catalysts for the evolution of care in this age group. The structure of the thesis is such that it will provide a largely sequential, logical and in depth examination of the questions arising from gaps in the literature to complement and enhance existing knowledge. Further and most notably however, the thesis will make a contribution to knowledge which has not been previously presented.

1.2 INCIDENCE OF TEENAGE AND YOUNG ADULT CANCER

Cancer in teenagers and young adults (TYA) is relatively rare, which means that large scale data on cancer incidence and survival takes more time to become available than when cancer is common, such as in older adults. These cancers accounted for 11% of deaths in this age group, making cancer the second most frequent cause of death in young people aged 15-24 years after accidental causes (Whelan and Fern, 2008).

Recent figures based on data from the Information Services Division Scotland, the Office for National Statistics, the Welsh Cancer Intelligence and Surveillance Unit and the Northern Ireland Cancer Registry and provided for Cancer Research UK, state that less than one per cent of cancers are identified between the age of 15 and 24 years. This accounts for an average of 2,234 TYA per year in the UK. This can be divided into 1,153 (52%) males and 1,081 (48%) females. For every million males and females respectively aged 15-24 there are 277 and 267 cancers diagnosed each year (crude rate) (ISD Scotland, 2013; Office for National Statistics, 2013; the Welsh Cancer Intelligence and Surveillance Unit, 2013; Northern Ireland Cancer Registry, 2013). Estimated figures documented by Cancer Research UK (2013), which are sourced from the International Agency for Research on Cancer, suggest that there were around 173,000 cases of cancer in TYA diagnosed in 2008.

The most commonly diagnosed group of cancers in the 15 to 24 age group overall are lymphomas and these make up 21% of the total cancers. The incidence is slightly higher in males than females. carcinomas (such as of the thyroid, cervix, bowel and ovary) are the next most common group of cancers diagnosed, accounting for 20% overall. Germ cell tumours are the third highest, which make up 15% of the overall total. However, 90% of these are due to germ cell testicular cancers. Other common cancers occurring in this age group overall include, brain, central nervous system and intracranial tumours (14%), malignant melanomas (11%), leukaemias (9%), bone tumours (5%) and soft tissue sarcomas (4%) (Cancer Research UK 2013). Although cancer is uncommon in teenagers and young adults, incidence data is now presented specifically for this age group. It could be argued therefore that teenagers and young adults warrant specific attention in terms of targeted research. The development of policy and guidance would support this argument with a number of recent national policy developments. These policy developments have influenced the formulation of guidance most notably by

organisations such as the Teenage Cancer Trust and Teenagers and Young Adults with Cancer (TYAC).

1.3 INFLUENTIAL POLICY AND GUIDANCE

Recent policy and guidance outlines the requirement to understand the needs of this particular age group in relation to cancer treatment and care. The emphasis here has been primarily on recognising that this is a unique age group who therefore require care, which is tailored to their specific needs (Kelly and Gibson 2008). A key cited document in the literature was published by The National Institute for Health and Clinical Excellence (NICE), now The National Institute for Health and Care Excellence who recognised that the needs of children and young people with cancer were different from those of older adults with the disease (NICE, 2005). The guidance covers all types of cancer from birth to the age of 24 years. NICE comment for example, that during childhood and adolescence there are a number of physical changes which occur that will have an impact on the type of cancer present, how it needs to be treated and how well the treatment works. Children and young people's emotional response to cancer might also be affected due to the psychological changes they experience (NICE, 2005). This observation is important as part of the argument for conducting this research. Policy reflects very clearly some of the differences in cancer experience due to age. As a result, it is advocated that distinct approaches to care, which include awareness of the role of decision making, need to be applied to this group. Equally there are a number of other relevant guidance documents and reports which advocate similar strategies in providing care for this group throughout their cancer journey and beyond treatment (Department of Health, 2007; Department of Health, 2008; Gibson and Levitt, 2010; Rajani *et al.*, 2011; National Cancer Intelligence Network, 2012; Department of Health, 2014). Evaluation of regional services have also been completed to ascertain both performance and the future needs of young people (Wright, 2012).

Following the NICE guidelines and in response to the argument for a tailored approach, Wales has recently produced National Standards for Children and Young People with Cancer (Welsh Government, 2012). These standards cover a wide range of aspects of care including diagnosis, referral, treatment options and the environment in which care takes place. These standards have relevance to this discussion as the study being described here was undertaken in Wales. The Welsh publication attempts to strengthen the argument for working in a way that is focused on the unique needs of this age group. There are also a number of specialist organisations and charities in the UK who have acted on policy recommendations by publishing guidance. This is aimed at providing targeted information for anyone involved in the field of teenage and young adult cancer. One such organisation is Teenage Cancer Trust.

This organisation in consultation with a number of experts in the field of TYA cancer, including TYAC the organisation for professionals in this field, have published a guidance document, A Blueprint of Care for Teenagers and Young Adults with Cancer outlining the needs of those aged between 16 and 24 years with the disease. This document provides extensive advice for those who work with this age group. The development of this guidance drew directly on recommendations from teenagers and young adults who were either receiving or had completed cancer treatment. In the document there are numerous examples of issues encountered in decision making during treatment (Smith and Case, 2012). Policy and guidance can act as a catalyst and has the potential to drive forward focused change. This can be the case in a number of contexts and the development of service provision in the area of teenage and young adult cancer is one such example.

1.4 SERVICE PROVISION IN TEENAGE AND YOUNG ADULT CANCER

Despite developments in the treatments and settings where 16 to 24 year olds are cared for, limited specialist service provision is still a feature of practice for young people. These limitations involve the choice of treatment protocol, the institute to which they are

referred and the healthcare professionals involved (Palmer *et al.*, 2007; Smith *et al.*, 2011). Entry into clinical trials is also comparatively low in this age group (Fern *et al.*, 2008). Depending on the medical personnel managing the care, and also the choices which currently exist, some young people may still be treated on paediatric protocols and in paediatric units. Conversely, others may be treated on adult protocols in adult wards, hence there is a diversity of treatment and management of care available for this specific age group.

Despite this variation there is growing evidence demonstrating that adolescents treated on paediatric protocols have better outcomes in the long term for some tumour types (Fern *et al.*, 2008). Although there is no definitive reason as to why this should be, multiple and interrelating factors have been acknowledged and include patient, doctor, protocol and management of the individuals' care requirements. In addition, biology, drug doses, compliance and supportive care from a multi-disciplinary approach are also key influences (Albritton, and Bleyer, 2003; Fern *et al.*, 2013). Furthermore attention is drawn to the expertise of practitioners in the field and the characteristics and competencies which might be preferable for those working with young people who have cancer (Thomas *et al.*, 2006; Gibson *et al.*, 2012; Smith *et al.*, 2014).

Although organisations such as the Teenage Cancer Trust and TYAC, promote and enhance the needs of this specific age group, evidence still demonstrates that not all young people are receiving state of the art physical and psychosocial care. Consequently, they sometimes fail to receive the benefits of multi-disciplinary involvement in their treatment regime, this can have long-term effects on their quality of life in future years (Smith and Case, 2012). During the period this study was being undertaken, national multi-centre research was generating data considering the 'added value' for young people being cared for in specialist environments. The so called 'Brightlight Study' has not yet reported its findings. The results however are eagerly awaited as this is the first large scale study of its kind to examine this question and it is

anticipated that it will provide further insights into the experiences of young people with reference to the use of specialist services. There have been a number of outputs linked to this study with the most recent publications reporting the validation and development of an experience measure reported by patients (Taylor *et al.*, 2012; Gibson *et al.*, 2012; Taylor *et al.*, 2013; Fern *et al.*, 2013; Gibson *et al.*, 2014; Taylor *et al.*, 2015a; Taylor *et al.*, 2015b). The study however, is only being undertaken in England, nevertheless there will still be much to learn from this work for those from other countries in the UK and beyond.

1.5 DEVELOPMENTAL CONSIDERATIONS

The backdrop to the experience of young people who developed cancer in this study came at a time when they were either at a particularly important crossroads in their life or in the early stages of building their lives through either a career or education. Generally the potential challenges that are faced by this age group should not be underestimated as they make the transition to adulthood where they are faced with a number of changes in their lives.

These challenges for example, may be associated with risk, peer group issues, family difficulties, intimate relationships, education and work (Kelly, 2003; Kelly and Emery, 2003; Sanders and Mumford, 2008; Davis, 2012; Kenny *et al.*, 2013; Scoles-Balog *et al.*, 2013;). The young people in this study were in the midst of a web of activity, albeit at different stages and with different family sizes and backgrounds, they nevertheless all had to continue to negotiate their path to adulthood. The freedom with which they either wanted or were able to do this was governed by a number of individual variables. The social theories of agency and structure were utilised to provide a theoretical framework in which an attempt was made to understand the nature of this element of their experiences.

1.6 THE NATURE OF AGENCY AND STRUCTURE

In attempting to define the nature of agency and structure there are a number of competing ideas and theoretical debates which have been documented in the literature, spanning both before and during the 20th century up to the present day. Armstrong (2014) asserts that the nature of agency has constituted a myriad of meanings and explanatory theories over time. He describes the use of the term agency, for example, when referring to types of organisations which provide services on behalf of others and therefore are constituted in a different context than applied within this study. The way in which agency is differently situated within the parameters of this study is tailored primarily to the young people as they develop and are treated for cancer, those close to them and others involved in their care and therefore not the model of agency described above. Agency and structure in this study focus on well documented sociological definitions but have been adapted to achieve more resonance with the subject matter, whilst acknowledging key principles of each theory. Independence, autonomy and choice, which are also important in decision making, are implicit in representations of agency and have featured much more prominently in health settings, particularly during the last decade. Moreover there is evidence supporting this from the general literature focusing on healthcare issues and young people (Hutton, 2005; Schaeuble *et al.*, 2010; Young, 2012; Adams *et al.*, 2014). Consequently, there are particular aspects of the nature of agency and the ways in which it is relevant and illuminated in the experience of these participants which requires further exploration.

1.6.1 THEORETICAL EXPLANATIONS OF AGENCY AND STRUCTURE

Arguably the most prominent debate concerning agency and structure in essence sets out the capacity for individual human agency in having the freedom to choose one's own action at a micro level, situated against the structural control of action at a macro level. Sociological theorists have over several decades, examined the differences and unease with the two concepts (Giddens, 1984; Bryant and Jary, 1991). Giddens, possibly the most prominent proponent of this debate, is commonly recognised for his work

concerning the 'duality of structure'. In his appraisal of agency and structure, his view asserts that the two theoretical perspectives are co-dependent. He proposes that agency not only produces structure but maintains it over time. Equally however, he also maintains that agency would not be possible without structure. Running parallel to this Taylor *et al.*, (1997) explain the view of Giddens who asserts that a significant amount of agency is banal and routinized. This results in what could often be construed as unconscious agency. They comment further that Giddens accepts that sometimes structure will be changed rather than reproduced as a result of agency. People, Giddens poses, do not always just react to structural forces but reflect on their own actions and as a result they have the capacity to change their choices in the future.

Bourdieu (1990) whilst trying to move beyond this duality of agency and structure provides some comparison to Giddens' view of the everyday unconscious nature of agency. His work in this respect culminated in the so called 'logic of practice' which fundamentally included the concept of 'habitus' and links to the idea of the unconscious actions in everyday life. As Williams (2003) put this as paraphrased by an early German philosopher:

'people make their own history, through their social practices but that the conditions under which these practices are formed are neither known nor chosen by them' (pg. 143).

In later collaborative work Bourdieu and colleagues further illuminate the power of structure in terms of its capacity to override both personal and cumulative agency (Bourdieu *et al.*, 1999). The context of this study is primarily concerned with the notion of conscious rather than unconscious action, however, it is not unreasonable to recognise that awareness of everyday agency will shape structure sometimes without intention. Emirbayer and Mische (1998) suggest that despite all the detailed theoretical discussion, the concept of agency has received little attention as a theory which stands alone. They remark that regardless of the important ideas linked with the concept of for example, freedom and choice linked to agency, it has only occasionally been subjected

to systematic analysis. They further suggest that it is because agency is so closely linked to structure that the ability of the concept to demonstrate its power of 'social action' is often ignored or lost altogether. Emirbayer and Mische (1998) provide an extremely detailed proposition of the position of agency and its relationship to structure, presenting a number of ideas which describe the concept as 'differently situated' than previous discussions.

One of their arguments is to demonstrate 'the ways in which agency interpenetrates with the diverse forms of structure' (Emirbayer and Mische 1998, pg. 963). The other aspect of this proposition is that they argue the need for agency to be understood as a temporal phenomenon, which incorporates the past, present and future. They refer specifically to this as 'the temporally embedded process of social engagement' (pg. 963). They further argue that the intricacy of the different agentic positions at different points in time cannot otherwise be captured. They propose that as agents move through this temporal space from the past, through the present and into future action, they are in turn able to change their relationship to structure (Emirbayer and Mische 1998). Interestingly Mayall (2002) places a strong emphasis on children as 'agents' who take part in their present and future, whilst working with and against structures. In addition to trying to establish the nature of agency and structure, the other important consideration within this study was to try and differentiate between types of agency. Often the complex interplay of actions in decision making were not solely due to the agency exerted by the young person alone. It was therefore important to identify and explore not just personal agency but to think about how this was defined when others were involved in decision making.

1.6.2 TYPES OF AGENCY

Decision making which explicitly illuminates types of agency in the context of teenagers and young adults with cancer was difficult to locate within the literature. Nevertheless there is evidence of the use of the term in some healthcare research. In a paper which considered agency and structure with respect to sex workers, the authors examined

women's individual agency in their everyday work comparing this to the structural forces which controlled their work. The research highlighted very clearly their personal/individual agency as they worked alone often in situations where there was risk to them as individuals not just in terms of their clients but where they chose to work (Bungay *et al.*, 2011). Proxy agency is outlined as someone acting on behalf of another, for example in decision making. In Bjerke's, study (2011) although not about healthcare but about home and school life, young people valued the way in which parents made decisions about some aspects of their lives and did not seem unduly frustrated by the need for constant individual agency. A third example of agency comes in the form of collective agency where there is a sharing of actions between a number of individuals. Kippax *et al.*, (2013) demonstrated the use of this type in a study which considered the capacity for communities to engage in strategies for HIV prevention, thus drawing on a group approach to agency rather than an individual one.

1.6.3 AGENCY, STRUCTURE AND YOUNG PEOPLE

Coffey and Farrugia (2014) emphasize the importance of the central position of agency in explaining young people's lives from a sociological perspective. Agency as already noted however, cannot be utilised as a 'stand-alone' concept in defining the position of young people with cancer. Structure also provides a relevant theoretical position in the context of this study. Sercombe (2010) raises the idea of empowered agency as a concept in which there is the notion of facing and resisting structures, enabling young people to become active participants in the social worlds which surround them. Sercombe further proposes that the opportunity for action changes with reference to scope of different types of options that are available to them. This, it transpired, was the case in this study as different contexts provided a fluctuating level of opportunity for the young people as they attempted to articulate their need for choice and control. It was very clear though that for much of the time they displayed motivation and intentionality in desiring the freedom and choice to control a variety of events in their lives.

1.6.4 THE ADOPTED STANCE IN THIS STUDY

In this research, the case study design enabled the research to be undertaken in real time as events unfolded within the bounded context of the development of teenage and young adult cancer. Inevitably there were structural factors which limited the choice and mobility of young people in making decisions. However, these were constantly changing in relation to the past, present and future depending on their stage in the cancer trajectory. Therefore utilising elements of the concepts proposed by Emirbayer and Mische (1998) the afore mentioned ‘temporally embedded process of social engagement’ and its temporal nature including the past present and future is, I believe, an appropriate and useful stance. Their arguments in this regard, presented a wider analytical lens through which agency and structure could be applied in this study. Emirbayer and Mische (1998) asserted that important aspects of the ways of defining agency had not been attended to. Arguments, in their view, had often paid attention to the habitual and routine practices referred to earlier, for example by Bourdieu (1990). They therefore proposed that whilst habitual and routine practice formed a part of the picture of agency, other explanations failed to demonstrate the full complexity of the theory. In going further, by paying attention to the temporal and changing nature of agency and the importance of the socially embedded nature of agentic power, Emirbayer and Mische argued that wider perspectives of agency could be understood and applied. In terms of this study, my interest lay firmly in the context of ‘conscious agency’, which was situated at the heart of many of the decisions made by young people. Thus the discussion provided by Emirbayer and Mische (1998) offered practical and realistic ways in which agency could be considered both consciously, socially and over time.

The acknowledgement of the impact of structure is also accepted in this study and as such, demonstrates the complex interplay between fluctuating levels of agency over time as part of the experience of the cancer trajectory in this age group. I have concluded that it would perhaps be naïve to ignore the structural elements of young people’s experience based upon the available sociological evidence and the challenges in terms of structure

which are present in their worlds and accept that this is part of their experience. Nevertheless the 'structures' are not in this case ones which might be immediately associated with a traditional idea of structure in society such as class. Instead I would hold with the idea of the interrelationships and diverse range of structures alluded to earlier in the concepts described by Emirbayer and Mische (1998). The structures in this case relate more relevantly to family, the medical team and healthcare system and the treatment protocol itself.

Thus taking into account the types of agency, the interrelationship of diverse structures, the temporal aspects and the social embeddedness of the experience, I have adapted a framework for conscious agency which will be adopted throughout this study. The diagram below denotes the types of agency coupled with adapted structures which were relevant to the study in presenting how these two theories will be utilised. This is accompanied by the use of arrows denoting the continuum of the temporal nature of past, present and future and the temporally embedded social engagement which was present throughout the experience (Figure.1.2).

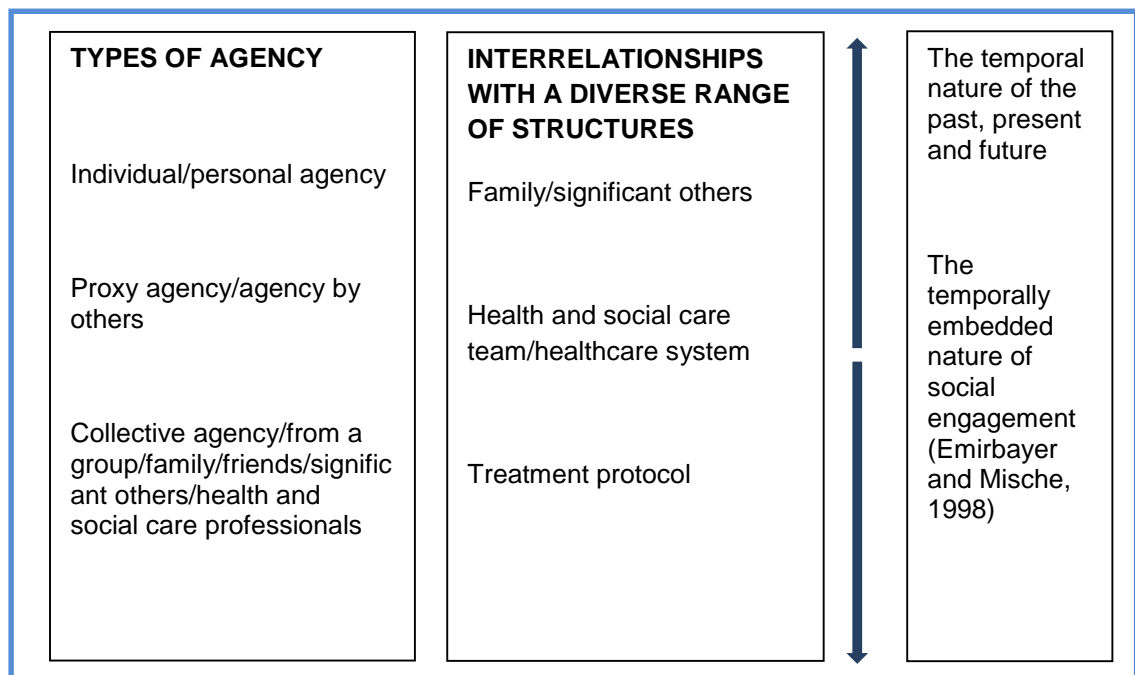


Figure 1.2. An adapted framework for conscious agency when teenagers and young adults develop cancer.

Using the temporal nature of agency in encountering the past, present and future as the young people made their way through the experience of cancer, resulted in the subsequent production of ideas concerning specific trajectories relating to their agentic power, as highlighted in the abstract of the thesis.

1.7 HEALTHCARE TRAJECTORIES

The concept of illness trajectories is not new. The work of Corbin and Strauss (1985; 1988) in examining the lives of people at home with chronic illness was instrumental in the development of this concept. The illness trajectory in their study exemplified the nature of a myriad of changes both routine and out of the ordinary, which governed the trajectories of those with long term health problems and those involved in their care including family, friends and healthcare professionals. Corbin and Strauss described the concept of three types of work which take place within this trajectory, everyday life work, biographical work and illness-related work. These are further explained in the context of chronic illness. Everyday life work is linked to the activities that take place despite the presence of illness and refer to routine actions which are part of daily experience, for example providing meals. Biographical work is concerned with the changes individuals' experience, which might for example affect their identity or limit their former lives when restricted by treatment. Illness work is associated with treatment related issues such as symptoms and treatment management (Corbin and Strauss 1988). Originally this model was applied to living with chronic illness in the home. However, it has been adapted for use in a number of contexts including cancer care in adults where the trajectory has been used to take account of particular facets of the specific area (Klimmek and Wenzel 2012). Similarly there have been other healthcare contexts where the trajectory has also been applied (Miller, 1993; Nokes, 1998; Halcomb and Davidson, 2005). Corbin and Strauss (1991) went further in providing conceptual ideas for the development of a nursing model using the framework of the trajectory for chronic illness.

The trajectories of agency in this study and their fluctuation in relation to decision making was evident with respect to both the timeline of experience and the three perspectives outlined in the Corbin and Strauss model above. The way in which the proposed trajectories are utilised in this study links strongly to both the ongoing time line of experience and the concept of illness. The so called 'three types of work' identified by Corbin and Strauss also resonate in this context. There are clearly examples of everyday, biographical and illness-related activity in the context of choice and control in decision making. It could also be argued that there is some similarity in terms of how long term illness is situated, however, attention to definition in this respect is worth considering. The term chronic illness has in recent years been replaced with 'long term' illness and more recently 'long term conditions'. Kirk *et al.*, (2012) refer to these in discussing children and young people as 'conditions where life-long support will be required'. Equally Viner and Booy (2005) make reference to common long term conditions in young people, such as asthma and diabetes. Whilst many young people with cancer will recover from their illness there is some argument for suggesting that it is a long term condition, particularly in situations where treatment is very lengthy and where the young person experiences either single or multiple relapses. Additionally some of the late effects of the disease which may result in a long term condition mean that young people can continue to have complex health needs (Vassal *et al.*, 2014).

1.8 AN OUTLINE OF THE THESIS

The thesis will include nine chapters, of which this introduction has been the first. In this opening chapter cancer incidence statistics provide a picture of the numbers and types of cancers diagnosed in the UK. This provides the impetus for useful policy and guidance and the development of service provision which was briefly outlined in this chapter.

Chapter Two presents a detailed outline of the landscape relating to the study, highlighting the complex discussion which centres on the history, nature and context of 'growing up' from teenager towards adulthood. The context and processes of healthcare

decision making are briefly presented. Existing evidence in the context of decision making is illuminated and discussed in the form of results from literature searching, focusing on young people who develop cancer. Emergent areas are illuminated and categorised into treatment and non-treatment decision making providing a number of themes and thus identifying gaps in the existing evidence base.

Chapter Three is concerned with the design, planning and operationalisation of the study. The early planning work is detailed, particularly with reference to how I engaged with service users, young people and experts in the field to help inform the study. The subsequent phases of development are outlined with reference to underlying philosophical approaches, methodology and research design. Within the design an outline is provided of the methods which were utilised along with details of setting, sampling, recruitment and data collection. Data analysis is detailed with reference to specific steps that were taken to achieve the identification of themes. Trustworthiness is accounted for in outlining the dependability, credibility, transferability and confirmability of the study. The logistical elements of the study which were important in safeguarding participants, are documented and their importance is recognised. Ethical discussion and the gaining of the said approvals are given some prominence and the challenges of this part of the study are provided. Reflexivity was an important facet of the work both in learning about others and understanding 'self' and this is briefly outlined and supported by a number of footnotes in the subsequent findings chapters.

There are four findings chapters in total. The first of these, Chapter Four, introduces the five young people who participated in the study and what follows is a within case analysis of each of their experiences, as is the tradition in case study design. With each case comes a short history of events using a sequential longitudinal approach of their lives prior to diagnosis, in the early part of treatment and as they approach completion.

The next three chapters (Five, Six and Seven) provide cross case analyses identifying three overarching cross-case themes. These comprise 'life then' (the pre-diagnostic period), 'life interrupted' (the phase concerning the point of diagnosis and the early part of their experience) and 'life reclaimed' (where the young people were beginning to move nearer to the end of their treatment). These three chapters are also presented in a sequential format. The emphasis in all the chapters is on the availability of motivation, choice, intentionality, control and freedom that each of the young people had in their decision making at any point in time. The other participants' views are also recounted in these four chapters, they were gathered from three methods including, interviews, non-participant observations and documentary analysis.

The discussion chapter which follows illuminates a summary of the findings, followed by an in depth examination of individual trajectories followed by across case discussion of the three themes, demonstrating comparison to the existing literature and what has been added to the evidence base. This discussion results in the contribution to knowledge through the proposal of trajectories of choice and control during the development and subsequent treatment of cancer using the identified theoretical framework of agency. In the concluding remarks in the final chapter, the thesis is summarised with attention given to future work with emphasis on the contribution to knowledge as a result of this study.

2. OUTLINING THE LANDSCAPE

2.1 INTRODUCTION

Providing the evidence for the justification of this study was fundamental in determining what was either minimal in or absent from the existing literature. It is also the case that to study something that could make a genuine contribution to this important and unique area of practice was highly desired. Arguably the field of teenage and young adult cancer care is still an emerging discipline and whilst there are clear streams of work and some key researchers in the field, there is still much to learn about aspects of cancer care in these age groups.

This chapter has two overarching objectives. The first is to outline the landscape of young people's development and associated issues, including the importance of decision making in young people. This provides a backdrop for understanding this complex period of development. The second objective by means of a literature review focuses on the existing evidence relevant to decision making in teenage and young adult cancer. The subsequent discussion of the literature identifies gaps in knowledge which led to the development of the study.

Historical accounts of this time of growth are complicated by both the lack of existence of the differences between childhood and adulthood in earlier periods of history and by the different dimensions of development. These include the biological, social and emotional stages of this part of the life course. This is further complicated by the use of terms, with reference to early explanations of adolescence following a biological model, in contrast with issues of youth development being concerned with social experience. The development of theories which focus on emerging and young adulthood add a further dimension to what is already a complex picture of this age group. The importance of 21st century society must also be recognised as being a time of rapid change for young people, particularly in relation to new technologies and in particular the significant rise of social media as an important platform for young people in their everyday lives. This is

accompanied more recently by a difficult financial and economic climate which adds further challenges in successfully navigating the path to adulthood. The back drop to this complexity is set against what could be described as a slowly emerging legal rights agenda which has important implications for recognising freedom and choice relating to young people (Fortin, 2006).

The concept and process of decision making requires clarification, however, it needs to be clear that the emphasis of this study was not concerned with the commonly identified processes, rather the purpose of investigation was specifically focused on the choice and control in decision making with reference to agentic power. Therefore whilst an outline of these processes was necessary, the subsequent execution of work was narrowed to the aforementioned area.

Searches of literature were undertaken prior to the planning of the study to ascertain the evidence relating to decision making in teenage and young adult cancer (Hart, 1998; Aveyard, 2010). These were executed through the use of a number of databases in order to retrieve relevant literature. Further manual searching was also completed and new evidence was collected in the final year of the study. The emergent themes are documented and the chapter concludes with a summary of the findings prior to the detailed explanation concerning the subsequent planning and execution of the study in the research design and methods chapter.

2.2 HISTORICAL AND CONTRADICTIONARY PERSPECTIVES OF ADOLESCENCE

The concept of adolescence is one which has been interpreted widely throughout history, locally, nationally and globally, and thus the way in which this group have experienced life as they grow towards adulthood has varied widely and changed significantly over time. The lived experience of the adolescent in twenty first century Britain bears little comparison to the lives of this group in recent history. This so called 'time of transition' is influenced by many factors, and although not exclusive, they include, culture, religion, family, peer groups, politics, organisation and structure (Raja *et al.*, 1992; Sinha *et al.*,

2007; Oliva *et al.*, 2009). As will become clear these influencing factors have resulted in a great deal of change in the way society views this period of life. Over time the lives of this age group, in some countries of the world, have undergone a number of transitions.

2.2.1 EARLY HISTORY

The social historian Ariès (1996) comments that the nature of organisation in terms of age groups is reliant on institutions and in the period of the Ancien regime adolescence was not clearly identifiable. As an example, Ariès asserts further that this persisted within educational settings for some time. Differentiating between age groups in school for example was not considered necessary and thus all ages including youths, adults and children alike were in the same educational classes.

The term adolescence derives from the Latin '*adolescere*, to grow up'. However, over time, adolescence has not been identified as a 'stage' in life (Chudacoff, 1989). It could be argued therefore, that whilst it was Aristotle who first recorded the physiological changes in terms of the development of secondary sexual characteristics in both sexes, (which is only part of adolescent development), adolescence remains in essence a modern phenomenon. Rogers (2005) poses the question concerning what is meant by modern times in UK society? He confirms that in the context of his discussion on modern youth in Britain, this began around 1770. Rogers cites that at this time there were two key developments which had a significant impact upon the lives of adolescents today. The first of these he suggests, was the introduction of 'humanistic forms of governance', where there was more consideration given to the interests and welfare of individuals. The second was the development of industrialisation in some parts of the UK which was the catalyst for regulation and some degree of social control.

Although there was modernisation at this time due to industrialisation, it could not be said that the lives of young people were given any prominence in terms of their status. Indeed those in the lower classes of both sexes were often uneducated and working in mines and mills. This gave rise to growing concerns amongst social reformers at the time, which

led to the development of a number of welfare and educational agencies designed to help young people (Griffin, 1993).

2.2.2 TWENTIETH CENTURY DEVELOPMENTS

It is generally agreed that the study of adolescence (in particular adolescent psychology) and its development as a discipline stems from the publication of a double volume of work entitled *Adolescence: Its Psychology and Its Relations to Physiology, Anthropology, Sociology, Sex, Crime, Religion and Education*, published by Hall in 1904. Although these volumes are no longer commonly read, his work is cited in a number of contemporary texts (Stainton Rogers and Stainton Rogers, 1992; Griffin, 1993; Ream and Savin-Williams, 2003; Kehily, 2007). There are numerous interpretations of Hall's work. His identification of adolescence is the now commonly contested period of 'storm and stress' which is driven by the biological changes which take place in puberty (Kehily, 2007). Griffin (1993) however, suggests that Hall's work was a mixture of his own understanding of genetic psychology and Christian theology. Griffin therefore asserts that Hall's writing was rich in contradiction, particularly between the roles of instinct and environment in adolescent development. Griffin also comments that it was because of the broad range of his work that the ideology of adolescence moved from a religious to a medical and scientific sphere.

In the 1900s young people fared better than in previous periods of history. The Children Act (1908) meant medical attention for minors became a right. The setting up of a number of organisations such as charitable child welfare clinics and juvenile courts saw the distinction more clearly drawn between childhood and adulthood. This was around the time when there was a significant shift from protection by the voluntary sector such as Barnardo's to the development of statutory mechanisms (Stainton Rogers and Stainton Rogers, 1992). Examples here include Prevention of Cruelty to and Protection of Children Act (1889) and The Custody of Children Act (1891).

2.2.3 GLOBAL DIFFERENCES

The afore mentioned was not of course a global picture and in some countries this situation has not changed. Some cultures do not recognise adolescence in the same way as in many Western cultures. Boyden (1990) for example asserts that in capitalist countries in Europe and the United States there is a connection between interests and priorities and how these connect to what she calls the 'ideals' of childhood being a happy and safe period. As an example of exploding the 'ideal' she refers to children in Thailand who are trafficked and sexually exploited. Furthermore it is commonly recognised that children still work in the same way as adults do in some countries. In 2006, media reports exposed Indian children as young as five working alongside their mothers for up to sixteen hours a day in matchstick making factories. Campaigners at the time stated that there were over 11 million children forced into work in India at the time. Thus one could argue the absence in recognising the demarcation between adult and child and therefore most certainly between adolescent and adult (Dhariwal, 2006). It is also the case that for children born and living in the UK, whose preceding generations are from countries such as those mentioned above, everyday life and health experiences can vary widely according to culture (Kelly, 2008).

2.2.4 DILEMMAS OF DEFINITION, INFLUENCE AND TERMINOLOGY

Subsequently defining contemporary adolescence is a complex task. It is certainly clear from a number of definitions that it has been described through chronology, with authors commonly citing the period of adolescence as being between 10 and 20 years (Smith *et al.*, 2011; Bee and Boyd, 2009). It is also documented that it is strongly influenced by biological change. The commencement of puberty is associated with the onset of adolescence, where the development of secondary sex characteristics denotes the physical journey to adulthood. The changes in both boys and girls are clearly apparent, particularly the physical changes such as the growth of body hair, the development of breasts and in boys the deepening of their voice. Montgomery (2007) however, argues that the role of biology should not be 'overdone' as there is a danger in ignoring the other

sometimes complex changes that are taking place. Montgomery asserts that the social changes experienced by the young person are what gives 'meaning' to their experience.

Hall's 1904 work referred to the adolescent period as one of storm or stress which he claimed was characterised by biological changes which ensued during this period. This view was contested by anthropologists at the time. It was the early work of Mead, (1943) who in the early 1920's conducted fieldwork which explored the notion that it was puberty which was the cause of storm and stress. Mead travelled to Western Samoa to work amongst young people and examine how adolescence was experienced and understood. Mead explored the differences between the young people in Samoa and those in her own country, North America. As a result of this Mead rejected the idea that biological change was responsible for some of the problems in adolescence. She asserted instead, that in part it was the way in which society managed young people which created problems. Her work has been discussed widely and in some cases contested since.

To complicate the debate further the literature is split between two discourses, the study of adolescence and the study of youth. Adolescence has thus been the established term for the biological and psychological influences which happen following puberty. The perspectives associated with Mead's and others work is often described as the study of youth. These two terms 'adolescence and youth' are therefore in contrast. Subsequently Hall's work is described as being linked to adolescent development. Whilst the study of youth is concerned with social groups and the way in which they are defined in society. These social components are centred on culture and practice. The way in which youth is experienced in different parts of the world therefore will stem from individual lived experience encompassed by particular cultures and practices. In early life, for example, children will develop behaviours, ideas, attitudes and beliefs which are established essentially from primary socialisation in the form of their family. However, as they grow they begin to be exposed to secondary socialisation which means that these components

will potentially change. The key elements of secondary socialisation include, school, interest groups, the church, the media and importantly peer groups (Bee and Boyd, 2009).

2.2.5 EMERGING ADULthood

To add further complexity to the already confounding debates, more contemporary writings on young adulthood add further scope to how this period of life can be conceptualised. This is important for the study as the young people's lives that are described here fall outside the debate commonly held relating to adolescence, with some of them being over the age of 21 years. Arnett (2000) suggests this is an evolving area of development which spans further than 21 years up to and including those aged between 18 and 25 years. It is specifically described here as neither adolescence nor young adulthood but as a period in between the two identified concepts and thus referred to as emerging adulthood. Arnett notes in his original discussion, that the baseline of 18 as a starting point for emerging adulthood is based primarily on the common age of leaving school coupled with the acquisition of legal rights. He also comments that there has been a marked shift in terms of demography and that the age at which young people begin to establish their lives in terms of work and relationships is later than in previous generations. Arnett ultimately proposes a theory of development spanning from the late teens to the middle twenties based on three premises which he argues are distinct. These include demography, subjectivity and identity exploration. Interestingly in the context of his discussion Arnett refers to the use of the term 'volitional' as being very common at this stage of life which is defined as involving the power to make a choice and the act of making and determining a decision. More recently, however, Arnett (2014) identifies further development in this constantly emerging area, including the relevance of social media in the lives of this group and some of the specific problems they might face. He refers to the ability of the age group to assert confidence and express optimism in what can sometimes be an unstable environment.

Konstam (2015) complements this and notes that in a rapidly evolving world, where work practices are changing, pressure on young people is increasing. Importantly, the development of technology impacts upon the lives of those in emerging adulthood. Consequently, confusion, stress and a degree of vulnerability in terms of emotion can render this stage a confusing and overwhelming time. Both Arnett and Konstam's recognition of this changing landscape has implications for those who alongside all these potential challenges also face a cancer diagnosis. It is perhaps this discourse, centred around the conceptual ideas of emerging adulthood which resonates most with this study. Only one of the participants in this study was under 18, although she was close to the age at which many of the choices referred to already needed serious consideration. The other participants were all firmly in the midst of navigating their way through this exciting but challenging and sometimes uncertain time.

The breadth of debate about adolescence and the emergence of young adulthood with its emphasis on biology and psychology and the study of youth outlining many of the social issues facing young people are clearly distinct. However, common to all areas of life are the rights of young people. The issue of rights lies at the heart of this study, affording not just the choice but acknowledging the right of this age group to make decisions and the right to be able to control these decisions if they so desire.

2.3. A QUESTION OF RIGHTS?

Historically children and young people were afforded little acknowledgement in terms of their rights. Well known anecdotes such as 'children should be seen and not heard' have been repeatedly played out in all areas of life which include education, healthcare and position in society. However, these facets of children and young people's everyday lives have all begun to be supported more recently by statutory frameworks including The Children Act (1989), Children (leaving care) Act (2000) and The Children and Young Person's Act (2008).

Notably in healthcare, the important precedent set out in *Gillick v West Norfolk and Wisbech Area Health Authority* (1986) was to radically change the landscape with reference to the narrow terms of The Family Law Reform Act, (1969). This had previously only outlined provision for those of 16 and 17 years to provide consent for medical treatment. The Fraser guidelines established in the Gillick case afforded more rights for young people under 16 years of age. Equally in healthcare a number of policy, reports and guidance publications have documented the need for recognition of children and young people's rights (NHS Plan, 2000; National Service Framework, 2003; Kennedy, 2010; Department of Health, 2012). This is in contrast to earlier accounts of healthcare for children and young people. As few as fifty years ago children who required a period of hospitalisation would be presented for admission with their mother who would, once all of the paperwork was taken care of, leave the ward and only return when it was time for the child to be discharged. The seminal work of Bowlby (1988) was to reveal the importance of attachment for children rendering the aforementioned account today as unrecognisable in many countries.

In spite of some of these early approaches, children's and young people's rights have begun to emerge in a number of countries around the world and to be recognised as having the same importance as the rights of any individual regardless of age. In terms of legislation in England and Wales the most influential statutory development of the 20th century came in the form of the Children Act (1989). At this time the United Nations Convention on the Rights of the Child (UNCRC) also published what was hailed as a landmark document containing a number of rights statements, most notably in the context of this study. Article 12 determines that:

'States parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child being given due weight in accordance with the age and maturity of the child'
(United Nations Convention, 1989).

There are those, perhaps most notably Freeman (2014) an internationally known legal academic, who create the impression that there is a strong case for revisiting the convention rights with a view to establishing a 21st century treaty which will reflect children's and young people's needs today. Similar views could also be espoused in relation to the Human Rights Act (1998). Although only enacted in 1998 in England and Wales, the convention rights were first published in 1950. Fortin (1999; 2006) comments on the legal impact in respect of children following the implementation of the Human Rights Act. Fortin argues that the Convention Rights were not designed to meet the specific requirements of children and proposed that application to children had to somehow be fitted into the Articles. This again reflects how many societies viewed the needs of children in the first half of the 20th century. In further commentary Fortin asserts that from an adult perspective it appeared that both parents and the courts forgot that children, who are at the centre of a case, have rights and interests too and that these deserve to be given attention and consideration. This is viewed by Fortin as the problem of competing rights against welfare.

Whilst there has been a significant increase in the number of policy and guidance documents relating to children's and young people's needs, the children's rights agenda has not yielded any further rights legislation in England at the time of writing. In Wales however, the Welsh Government recently introduced the Rights of Children and Young Person's Measure (2011), the first measure of its kind in the UK. In doing this the Welsh Government have enacted the UNCRC into domestic law. They have therefore set out to strengthen the rights of children and young people aged from 0 to 25 through government policy. The measure has been warmly welcomed by those working with children and young people in all sectors, including health (Welsh Government, 2011). At the heart of the rights movement has been the notion of the involvement of children and young people in making choices about their lives. Central to this is choice in decision making and with reference to this study, specifically in the experience of cancer.

2.4 THE PRINCIPLES OF DECISION MAKING AND YOUNG PEOPLE

In the process of increasing independence and autonomy, generally young people will begin to engage in decision making, which is governed primarily by them rather than by others. They may of course be guided by others such as peers, parents or important and valued people in their lives (Bednar and Fisher, 2003). Nevertheless they begin to be able to navigate their paths through life decisions 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 making relationship decisions. Downs and Fischhoff (2009) argue that adolescent development is centrally dependent on being able to make such choices. Developing autonomy is generally experienced as young people mature. Leffert and Petersen (1999) comment on the increasing capability of young people in decision making as they grow towards adulthood and how this increasing autonomy shifts responsibility from the parent to the young person. However, young people will still look to others to help them in decision making and sometimes they may return to a state of being dependent when they have a serious illness and this may continue for some time once treatment is complete (Grinyer, 2004, Ressler *et al.*, 2003). Models of decision making are therefore bound up with the concepts of autonomy and dependence during adolescence and beyond (Davies *et al.*, 2015).

Decision making models during adolescence involve a complex set of actions which in the literature have been divided into several steps (Byrnes *et al.*, 1999). In using these steps which include *'identifying the possible options, identifying the possible consequences which might follow these options, evaluating the desirability of these consequences, assessing the likelihood of those consequences and combining the aforementioned according to some decision rule'*. Furby and Beyth-Marom (1992, pg. 4) describe two types of decision making models applied in adolescence, normative and behavioural. They identify the same steps outlined above for each, as advocated in the decision making literature. However, the former (normative) is concerned with how

decisions should be made and the latter (behavioural) with the reality of decision making and how it actually takes place. Central to decision making is the ability to reason and the capacity and competence to decide.

Weithorn and Campbell (1982) argue in their research that adolescents are comparable in the attainment of their reasoning abilities with adults by the time they reach the approximate age of 14. In an earlier study Grisso and Vierling (1978) found that fifteen year olds were able to make decisions in the same way as adults. It was noted however, that in these studies they were asked to make decisions relating to hypothetical situations rather than real life events. Therefore decision making in reality and in the context of healthcare in particular, might take on a different guise with reference to behavioural decision making. Downs and Fischhoff (2009) refer to this as the 'normative ideal' and the 'descriptive reality'. This observation has important implications for young people's decision making during the cancer experience. In essence, a normative model would constitute how all types of decisions could be made by considering all of the options available. However, in reality the way in which a decision is likely to be made could potentially be different. It could be confounded by a number of factors, which may include the added emotion, confusion and shock which would be likely to have an effect on the young person, particularly in the early stages of treatment. This has implications for the application of proxy and collective agency in assisting in decision making when young people experience fluctuation in their choice and control, either by their own design or sometimes against their wishes.

Recent scientific studies have focused on the adolescent brain and decision making (Blakemore and Robbins, 2012). The authors comment that there is evidence that structures in the brain, particularly in the prefrontal cortex, play a role in decision making in adults. Blakemore and Robbins suggest that these processes are different in the adolescent brain and that there is evidence that social and emotional factors

physiologically may influence decision making. They acknowledge that this is a relatively new field where many questions still need to be answered.

In the context of this study, the emphasis on decision making is situated in young people's cognitive ability, capacity and competence to take control of their lives. This is the most prominent measure utilised in healthcare practice (Fundudis, 2003; Alderson, 2007). This factor was evident both in reviews of the literature and resultant findings in the data set.

In outlining the landscape of young people's lives we now turn to focusing on the experience of decision making when they develop cancer. The discussion thus far has provided a back drop of developmental issues, issues of definition, terminology and rights alongside an outline of decision making in this age group. These issues have relevance to the specific literature explored as part of the study.

2.5 LITERATURE REVIEW: BACKGROUND

This second part of the chapter, as outlined in the introduction, involved undertaking an in depth search of the literature to ascertain the range of evidence relating to decision making in teenage and young adult cancer. In determining the scope of the literature review, there were a number of initial questions regarding the proposed area of research, which required some exploration. Early ideas focused on the refusal of cancer treatment in teenagers based on the legal framework in England and Wales. This framework whilst providing a precedent for consent to medical treatment in teenagers, does not include the rights of the teenager under the age of 18 years to refuse medical treatment (Brazier, 1996). There is currently no legal precedent, which has supported a refusal of medical treatment in an individual under the age of 18. It became clear from the legal evidence, that this was an extremely sensitive area potentially fraught with tension between parents, teenagers, healthcare professionals and legal personnel (*Re E (Minor) 1990*); *Re S (a minor) (consent to medical treatment) (1994)*; (*Re M (child refusal of medical treatment) (1999)*).

Added to this, it is rare for these matters to reach the courts and so there would be very little scope for accessing research participants, as well as what I believe to be insurmountable ethical challenges. The interest in examining these types of decisions was fuelled by the notion that when young people are making the transition to adulthood, they normally become increasingly independent in their decision making (Smith *et al.*, 2011). They often desire more control in this aspect of their life in relation to a number of areas. These may include, their future career, work, education or relationships. Questions were subsequently raised in relation to young people making decisions during the development and treatment of cancer, not just focused on treatment but in all aspects of their lives.

The proposed focus of the research was further refined following consultation with experts in the field of teenage cancer. This was accompanied by discussion with non-professionals, a cancer survivor and a family who had been affected by cancer. In terms of service provision, teenagers from 16 years are normally grouped with young adults in this field of care. Thus the search for evidence of decision making looked for research that focused on the 16 to 24 year age group. Subsequently a discussion paper was published which raised some issues illuminated in the literature. Excerpts from this paper, including the initial search, have been reproduced in this and the last chapter (Davies *et al.*, 2015) (see Appendix 1).

A literature search was undertaken to retrieve articles published between 1990 and 2013 using the following databases: Cumulative Index for Nursing and Allied Health Literature (CINAHL), SCOPUS, Medline, Databases and Abstract of Reviews of Effectiveness (DARE), Applied Social Sciences Index and Abstracts (ASSIA), (Psych Info) and The Cochrane Library. Only papers written in the English language were retrieved but these were not limited to those published in the UK. Keywords were used in combinations and included: adolescent; teenagers; young adults; cancer; autonomy; dependence and decision making. The aim was to identify evidence in the literature outlining teenage and

young adult experience of the different types of decision making during cancer treatment. Initially 817 articles were retrieved. The articles included reports of original research using a variety of methods (primarily interviews, focus groups and observation), commentaries and opinion papers. Some articles focused on children, adolescents/teenagers and young adults with cancer and whilst an attempt was made to exclude all materials that referred to those under 16 this was not possible in sources of this type. These materials also covered a wide range of issues other than decision making and some were concerned with chronic illness, generally in young people. These were then filtered for relevance in order to focus only on those who had experienced cancer treatment. This resulted in identifying 124 articles. Again there were several issues relating to elements of care and management other than decision making, for example health promotion, education and treatment issues. The articles were further reduced by focusing on those where either decision making and autonomy and dependence were in the title or the abstract and/or there were themes in the publications which related to these concepts. This resulted in 29 articles being considered for discussion (Figure.2.1).

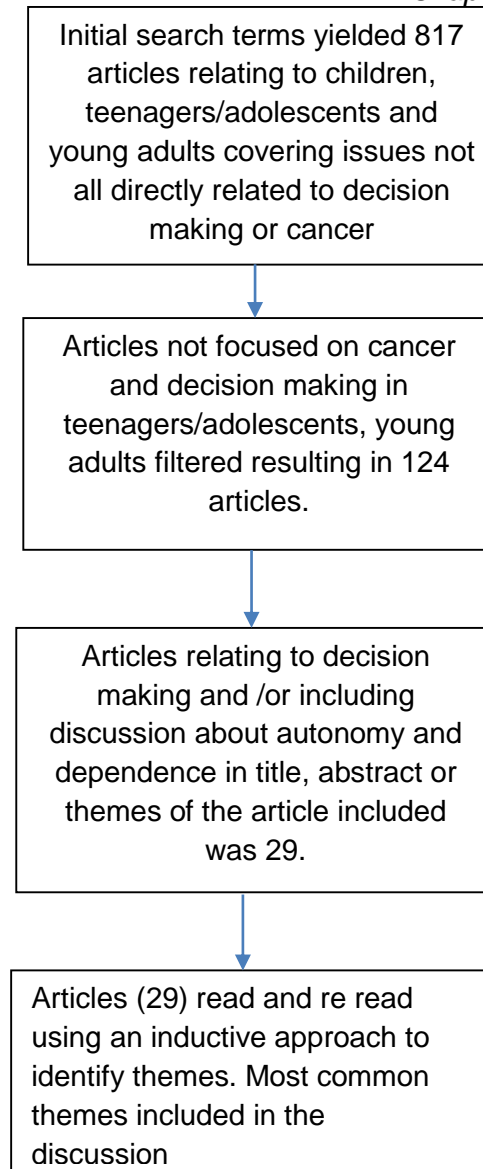


Figure 2.1. Selection strategy following initial literature search in 2012.

This provided a number of themes which related to treatment decision making in cancer. The perspective of the teenager and young adult was considered in some of the literature but not all and a number of studies were undertaken using samples across a much wider age range, which included those under the age of 16 years. Despite glimpses of the differences in everyday life in terms of a loss of dependence and control, specific studies in the literature on everyday decision making during cancer treatment were not evident. It was therefore felt that this research would provide evidence to begin to populate the gap. This action could prove potentially important in determining how everyday decision making during cancer treatment is facilitated in practice settings.

In the first literature search there were only two studies which resonated strongly with the experience of decision making being explored in this study, although these both had a different focus to the plan for this study. A study undertaken by Hokkanen *et al.*, (2004) investigated the views of adolescents using focus groups to highlight their experiences of cancer. The study did not include those over the age of 18 years, but it identified 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).

This had important relevance for this study. The data reflected several months of their journey and there were many different examples of how the decision making process was played out in the ongoing treatment and everyday life situations experienced by the young people in this study. Some of the categories identified by Hokkanen *et al.* (2004) would support this through the illumination of different types of decision making which perhaps reflected the fluctuation in control amongst participants over time.

In the second study Wicks and Mitchell, (2010) specifically documented a loss of control in decision making during treatment and detailed some of the frustration that this resulted in for young people. This related almost exclusively to treatment decisions. However, in the other part of the study results 'benefit finding', reflected their positive experiences which enabled them to make decisions about their future lives. The sample in terms of age was close to the sample being examined in this study and the data gathered were directly from the young people as in the Hokkanen *et al.*, study. The sample, however, were further away from diagnosis than in this study and data were not collected in real time as they made their way through treatment. Nevertheless this was a useful account of the presence of independent decision making prior to cancer diagnosis, compared with a lack of control whilst having treatment. Despite this, positive effects were

illuminated which appeared to reflect a renewed independence as a result of the occurrence of cancer.

2.6 OTHER PERSPECTIVES ON TREATMENT DECISION MAKING

Limited work exists in the sphere of decision making in the field of teenage and young adult cancer treatment. Early work by Dunsmore and Quine (1995), which explored decision making by young people during cancer treatment did not seem to lead to a proliferation of further evidence in the same context. In a recent Cochrane review Coyne *et al.*, (2013) were unable to find any results in a systematic review of the literature pertaining to interventions for shared decision making in children aged up to 18 with cancer, albeit that they were limiting this to clinical trials. However, their results reflect the lack of evidence which is focused on tools to assist in young people's decision making. The authors concluded that more research was required. Although this work was limited to quantitative evidence, it reflects the general position with reference to empirical research in the context of decision making and young people with cancer.

The search of the literature identified a number of papers relating to treatment decision making. However, these were not generally across the cancer journey, rather they focused on specific elements of treatment, for example, involvement in clinical trials (Chappuy *et al.*, 2008; Read *et al.*, 2009). These studies examined decision making about participation in clinical trials (although the Chappuy *et al.*, study also considered HIV patients). The authors identified issues in terms of both capacity and competence on the part of the young people, including their decisions about whether or not they would take part. Competence was raised in a number of discussions in relation to decision making, interestingly Duncan and Sawyer (2010) suggests that competence can be accepted if the young person makes the 'right' choice but is perhaps questioned if the 'wrong' choice is made. The difficulty here, as with a good deal of the evidence relating to treatment and indeed cancer experience, was the age range included in the sample. In both of these studies children younger than 16 were recruited into the sample. This

presented issues of sampling in terms of age which undoubtedly had an impact upon the analysis of the process of decision making in these studies.

Another aspect of treatment decision making relating to the cancer experience gathered from the literature was in the area of palliative care (Hinds *et al.*, 2001; Hinds *et al.*, 2005; Tomlinson *et al.*, 2011). Again this work focused on one aspect of the cancer journey. In 2001 Hinds *et al.* undertook a study to develop guidelines that would assist in end of life decisions. These guidelines did not just consider the perspective of the parent and healthcare professional but also included the adolescent perspective. Adolescent patients who took part in the study reflected on the significance of being well-informed but commented that they valued the opinions and suggestions given to them by both their parents and healthcare providers. Equally parents and healthcare professionals, reported positively when the child or adolescent patient was able to highlight preferences and take part in decision making. All three sets of participants in this study commented that it was crucial everyone was informed about treatment decisions which were made.

A later study by Hinds *et al.*, (2005) considered end of life care preferences of children and young people with cancer but again although the mean average of the sample was 17 years and 4 months, children as young as 10 were interviewed. The total sample was twenty patients. All the patients were involved in end of life decisions which included, enrolment onto a phase one trial, adoption of a do not resuscitate order or initiation of terminal care. Almost all the patients (18 out of 20) could remember their treatment options. They were able to identify the outcome of their decision as leading to their death and understood the consequences of their decision in terms of the complications, for example of entering a phase one clinical trial. The authors claimed that their findings demonstrated that children between the ages of 10 and 20 who were in the final stages of their cancer trajectory were able to take part in the decision making process. The nuances expressed in these types of decisions are important and as such contribute to

the evidence on decision making and are informative for this study. Rather than focusing on one particular aspect of the journey though, the questions proposed in this work attempted to examine a much broader picture of the cancer trajectory. In doing so this picture was able to inform how young people could be helped at a number of junctures during their experience.

2.6.1 PARENTS AS TREATMENT DECISION MAKERS

An issue which added a further dimension to the retrieval of literature and which had relevance to this study was the evidence relating to parental roles in decision making. This highlighted the inextricable link between parents and young people and the parental role as proxy or shared decision makers (Stegenga and Ward Smith, 2008; Zwaanswijk *et al.*, 2011). Most generally in developed societies where traditional family forms exist, parents are those who are closest to their children. Traditional stereotypical nuclear family forms are most commonly explained as those where there are parents with children. However, in recent years there are a range of variations in terms of these arrangements with the emergence of alternative family forms (Bengtson, 2001). For example, single parent and reconstituted families have become more common as well as children being brought up by those in lesbian and gay relationships. Families though do not sit in isolation, rather they are influenced by the societies in which they live (Hemphill and Dearmun, 2011). These authors argue that the family can be whoever it chooses itself to be due to the many diverse forms that it may take. Nevertheless, parents or indeed carers, in whatever family form, are those most likely the people who know their children best and have helped and guided them at particular points in their lives.

During socialisation, particularly primary socialisation in the first five years of life, parents are normally the central contributors to their child's development. Guiding and supporting them at each juncture, influencing their values, thoughts and beliefs are all well recognised aspects of the parental role. At this time they are undoubtedly

dependent on their parents for significant parts of their everyday lives (Bee and Boyd, 2009). Everyday life decisions will, in these early years, be most often made by parents with little independence on the part of the child in terms of their individual autonomy.

As children begin to experience secondary socialisation they grow and develop intellectually, emotionally and socially and will begin to make more and more decisions for themselves. However, parents are still often involved in the lives of the young person and will still seek to influence their decision making. Sometimes at this stage parents find it difficult to give increasing freedom to their now 'adolescent' and there is still an element of control in decision making situations. Lashlie (2011) provides the analogy of the young person crossing a bridge. The journey across the bridge is to adulthood. The parent can go a little way along the bridge but then must allow the adolescent to complete the journey. Lashlie comments on one mother who was not only unable to leave the bridge but who was 'camped out' on it. Her work does focus only on adolescent boys and largely mothers, nevertheless it serves as an example of the problematic nature of 'letting go' in order for the young person to develop increasing autonomy which will include independent decision making.

It is therefore not surprising that when this age group develops cancer, parents will almost invariably be involved in decisions which concern their child or adolescent. Following a diagnosis of cancer, parents experience high levels of emotion, stress, fear and anxiety. Added to this, parents may have to navigate a range of complex family relationships and there is also the requirement to develop relationships with those providing healthcare (Stewart *et al.*, 2005; 2012). Thus, one must acknowledge the specific context in which these experiences take place. Stewart *et al.*, (2012) attempted to explore the process of treatment decision making in this context and interviewed 15 parents of 13 children who were facing cancer treatment.

Overarchingly, parents described that their key objective was making the right decision, through an obligation of best interests in relation to their child. In the Stewart *et al.*, (2012) study, interview questions consisted of how parents thought and felt when preparing for, during and after treatment decisions. The study also considered the participation of others and the impact the decision making had on the parents themselves. The study again was not focused on late teenagers and young adults, the age range of patients, was from three to seventeen. This was a common feature in much of the evidence relating to parental decision making, thus making it unclear as to what specific issues there might be relating to these processes in the 16-24 year age group. Stewart *et al.* identified the sense of responsibility that parents felt in doing the right thing for their child. Responsibility is a key word in this context, it has structural and indeed legal overtones. Parental responsibility in law is such that parents have a legal duty for their children until they reach the age of 18 years in England and Wales and therefore can override their decision making in a number of areas, one of which is medical treatment (British Medical Association, 2008). Further Grinyer (2004) asserts that young people can still be vulnerable at this time in their lives.

In supportive terms parents in Stewart *et al.*'s study also emphasized the need to act as advocates for their child and to protect them. In doing so they suggested that they were acting as their child's surrogate. Their main goal in making these decisions was to act in such a way as to ensure their child had the best chance of a cure whilst remembering their quality of life. In proceeding in this way, they sometimes limited their child's involvement in decision making. Even in the case of older children (teenagers) they did not want them to have the 'burden' of decision making. Out of all those interviewed in the Stewart *et al.* study only two parents indicated that their child had made treatment decisions.

Similar findings were identified in an earlier study undertaken by Holm *et al.*, (2003) which explored a broader range of issues which constituted parental involvement in their

child's cancer care and treatment. Here 45 parents were interviewed at least a year after their child's cancer treatment had been completed. Advocacy emerged as the key overarching theme in care. Parents spoke of the need to act on behalf of their children. They stated that they (the parents) made 'critical' decisions. One mother described it as 'needing to stay on top', this she argued was because no one really knew how her child felt or what they were going through.

As already pointed out, at the time of diagnosis parents are thrown into a situation of high emotion which can potentially create difficulties in decision making. In an illuminating study by Noyes (1999) mothers' responses to a child becoming acutely ill were what could only be described as distressing and significant. Noyes discussed some of the rather startling effects that this type of situation had on mothers. Her study was only a small sample of 10 women and referred to situations in intensive care, nevertheless arguably these responses could translate to other acute situations. Noyes highlights accounts which included mothers forgetting the telephone numbers of their close relatives. It is therefore understandable that parents are placed in a position where they too are vulnerable, one in which their usual approach to negotiating decisions with their children might change because of their emotional state and their instinctive need to protect them at a distressing time.

2.6.2 DECISIONS CONCERNING FERTILITY PRESERVATION

This literature is difficult to place in the overall picture of decision making 'types' in the experience of cancer. Whilst it is a treatment decision it is not a cancer treatment decision, rather a treatment which results from the effects of the prescribed protocol. It also forms a part of future life decision making. The impairment of fertility for both males and females can occur as a result of cancer treatment. Long term issues relating to survivorship include the possibility of infertility as a late effect of some cancer treatments. This can have significant implications for teenagers and young adults who are undergoing treatment, some of whom are unlikely to have started or even contemplated

having a family of their own. Nevertheless it is probable that at some point these teenagers and young adults will want to have a family. If they are unable to realise the desire for a family their future quality of life can be affected. Zebrack *et al.*, (2004) commented that revealing suspected or actual infertility raises concerns for some adolescents who thus choose not to disclose such matters when embarking on a relationship. In this study the authors carried out semi structured interviews exploring the quality of life in a convenience sample consisting of 32 individuals who had been treated for cancer in childhood aged between 19 and 37 years. Surprisingly, 59% of participants disclosed that their fertility status was unclear to them, whilst only half of these remembered a healthcare professional or their parents ever discussing the potential fertility issues that might have arisen from their cancer treatment.

There have been well documented arguments that accurate fertility information should be given to those with cancer at the point of diagnosis and that this information should include the potential reproductive problems encountered following cancer treatment (Quinn *et al.*, 2011; Peddie *et al.*, 2012). These papers raised issues about the level of involvement that young people have relating to matters concerning their possible impaired fertility. It is not in dispute however, that at the point of diagnosis the overriding concern is to treat the patient effectively and as soon as is possible. Therefore there might perhaps be some argument for why fertility issues are not raised immediately.

Quinn *et al.*, (2011) support the work undertaken by Zebrack also highlighting that discussions about the impact on fertility and fertility preservation with adolescents has often not been given full attention. In the Quinn *et al.*, paper an analysis of decision making in teenage cancer patients and the utilisation of fertility preservation was undertaken through a search of peer reviewed studies between 1999 and 2009. A key question posed by these authors asked whether adolescents with cancer could make decisions about fertility preservation. The results were interesting not least because there was some variation in patient experience with discussions about fertility

preservation being more common in some studies than others. However, central to much of the work carried out in this field was the need for information. Other issues, which in essence formed a barrier to decision making, included gender, females were perceived to be more open to discussion than males even though they were more distressed at the prospect of being infertile. Some patients were embarrassed or anxious at the thought of discussing fertility preservation and in some cases this was because the discussion would be with the oncologist.

The findings in this paper also presented evidence that joint decision making between parents and the young people themselves was a strong feature of the decision making process. Quinn in conclusion argued that more research was required which would examine participation in the decision making process in this topic and suggested that the use of an assessment tool that was able to measure specific understanding of fertility preservation, decision making, competence and the desire for decision making to be shared needed to be developed. Another study (Crawshaw *et al.*, 2009) had some interesting findings in terms of the nuances of decision making amongst young people about fertility preservation during cancer treatment, which included their suggested ability to cope with fertility information on diagnosis, particularly when there was good professional and personal support in place which was proportionate to their needs. However, the age group sampled was up to 30 years old. There are some suggestions of young adulthood spanning to this age and beyond (Zebrack *et al.*, 2010). Both the Crawshaw *et al.*, (2009) and the previous paper from Zebrack *et al.*, (2004) were of this type, however, whilst interesting they fell outside of the age group being scrutinised in this study.

2.6.3 SUMMARY OF TREATMENT AND ASSOCIATED DECISION MAKING

There are a wide range of issues raised in what appears to be a generally limited area of research identified in the context of cancer treatment decision making and there is some complexity within the resultant findings. It would appear that there is no standard

set of responses to the experience of decision making in such matters, rather this is very much connected with individual circumstances. Decision making tends to focus on particular aspects of care, for example decision making in clinical trials and palliative care. The relationships that young people have particularly with their parents are fundamental. These relationships can determine the level of control in decision making and the extent to which young people are involved in these processes. Decision making relating to fertility matters is important for future life and sits in between treatment and everyday issues. It is clear that an issue as fundamental as possibly not being able to have a family of one's own, has the potential to impact significantly on an individual's future quality of life. Whilst the immediate priority is to effectively treat the cancer with the aim of curing the disease, it needs to be acknowledged that decision making whether shared or made autonomously by the teenager or young adult needs to arguably be a consistent feature of the management of this patient group.

2.7 FURTHER EVIDENCE

A further search of the literature during the latter part of the study was undertaken which looked for evidence of specific decision making during teenagers' and young adults' experience of cancer. The same approach was utilised in the search as described earlier in this chapter.

The findings in this study illuminated the young person's experience prior to the cancer diagnosis which was not originally an intended element of the initial research aims. However, it provided fascinating insights into the choice and control that young people exercised during this part of their trajectory, therefore the second search targeted evidence of literature relating to this. As before, multiple database searches were undertaken looking for evidence between March 2013 and July 2015. In this search using the original selection strategy a further 273 papers were retrieved. Of these, 12 papers were considered for inclusion in this discussion. However, three had the most resonance in the context of decision making and this study.

Once again papers were retrieved which related to specific decision making issues during the treatment period from the other perspectives mentioned earlier in this chapter (clinical trials and decision making, parental decision making, survivorship and decision making and fertility and decision making) (Hollen *et al.*, 2013; Scherer *et al.*, 2013; Kilicarslan-Toruner and Akgun-Citak, 2013; Baraket *et al.*, 2014; Barnett *et al.*, 2014; Stein *et al.*, 2014). The literature which was retrieved and concentrated on decision making prior to diagnosis was sparse, with only three recent papers which had relevance to this study. One of these described the complex pre diagnostic experience of young people in terms of the reasons for their delay in diagnosis. This provided some useful evidence of how young people made decisions to control their situations prior to diagnosis and was one of three papers identified above (Gibson *et al.*, 2013). An earlier paper by Fern *et al.*, (2011) considered the number of times young people visited their GP with symptoms of cancer and, although useful, this paper only provided some evidence of the whole pre diagnostic picture.

There was also a small number of recent papers which concentrated on raising key issues during the experience of teenage and young adult cancer (Taylor *et al.*, 2013; Stegenga and Macpherson, 2014; Olsson *et al.*, 2015). The second most relevant paper constituted a meta synthesis of young people's cancer journeys. This detailed the range of issues during the cancer trajectory, producing a conceptual model based on a number of papers which considered cancer experience. There were useful themes identified in this paper which had relevance to decision making and these included, the young person's experience of healthcare, the impact diagnosis had on them and their need to be 'normal' (Taylor *et al.*, 2013).

The third study of note was a recent exploration of shared decision making from the perspectives of children, adolescents, parents and healthcare professionals (Coyne *et al.*, 2014) which resonated with the aims and approach of this study quite strongly. There were some useful findings in relation to the older children who took part and were

frustrated at the limitations on decision making as they saw it, leading to a loss of control. The study findings were dominated by the overarching theme of 'it has to be done' portraying very strongly the participants' views on the requirement of treatment irrespective of choice. The study focused on what were termed major and minor treatment decisions. Those decisions other than treatment were not evident. The multiple sources used for data generation were similar to this study, apart from the nominated friend or partners who were included here. Once again it must be mentioned that the upper age limit for the work was 16 years old, therefore the young adult population was not included.

2.8 EVERYDAY DECISION MAKING

Whilst this study was not concerned with the experience of decision making in the longer term following completion of treatment, there is an emerging body of literature which explores this and in doing so focuses on everyday life decisions (Stern *et al.*, 2010; Wakefield *et al.*, 2011). Making the transition from active therapy to follow up care is an important emotional step in the experience of cancer and young people will be faced with a number of decisions which relate to life 'outside' treatment. Despite this the evidence relating to the young person's experience of decision making here is generally limited but growing (Zebrack and Isaacson, 2012). When being treated for cancer, it is understandable that decisions about future life plans may be put on hold. Added to this young people will worry about how they might make take part again in some of the activities they undertook prior to their illness (Albritton and Bleyer, 2003; Kelly *et al.*, 2004; Gibson *et al.*, 2005).

Some of the work which does exist focuses on psychosocial functioning following the completion of treatment which does involve the experience of decision making at this time (Stern *et al.*, 2010; Wakefield *et al.*, 2010). Whilst other work focuses on risk taking and decision making (Hollen *et al.*, 2007). Stern *et al.*, (2010) produced a study which explored psychosocial functioning but also focused on career decision making. The study was undertaken in Israel and attempted to find out how surviving childhood cancer

related to several key areas of adjustment in life, paying particular attention to career decision making. Quality of life tools were used to measure optimism in young adult survivors. Those who had higher quality of life scores were not only able to explore career choices more easily but reported overall that they had higher career decision making abilities. This was a complex piece of work and it was difficult to ascertain what created the higher levels of optimism. It is possible that as patients, those with higher optimism had a different experience and were able to make choices during treatment. If this was the case and decision making was not suspended, perhaps these survivors were more able to undertake these activities because they had been less constrained around choice during treatment. This however, was an assumption based on what was a complex study.

In part, the purpose of the search in this study was to try and find evidence of research which examined everyday decision making throughout the cancer experience. This proved much more difficult than finding evidence of decision making relating to treatment. However, as already pointed out the treatment decision making was issue specific, relating to a wide number of age groups and did not consider the entire cancer trajectory.

Despite glimpses of the differences in everyday life in terms of a loss of independence and control, (Smith *et al.*, 2007; Hollen *et al.*, 2007; Palmer *et al.*, 2007, Treadgold and Kuperberg, 2010; Morgan *et al.*, 2010; Wicks and Mitchell 2010, Marris *et al.*, 2011; Wakefield *et al.*, 2011; Fern *et al.*, 2013), specific studies in the literature on decisions other than those concerning treatment were not evident. Interestingly, The Health Foundation recently published a review of the usefulness of shared decision making in health settings and commented that few studies have been undertaken considering the views of children and young people (Health Foundation, 2012). More particularly studies about this issue, which consider the views of young people and significant others over a period of time during treatment were limited.

It was reported that some young people on treatment may miss many social events, for example, due to fatigue following treatment. In terms of decision making in this area the suspension of social events is often made jointly with parents. However, sometimes parents can take over this responsibility, when normally these decisions would be made by the young person themselves (Wakefield *et al.*, 2010).

In terms of psychosexual maturation, Morgan *et al.*, (2010) comment that at this time young people will experiment in the form of developing relationships. These could include sexual exploration and whilst they may experience a change in priorities when having cancer treatment, it is important to understand these matters even though this can be a difficult issue to raise. Morgan *et al.*, (2010) comment for example, that it is important to outline the differences here between fertility, which is talked about in the context of treatment and sexuality, which is completely separate from treatment issues and therefore requires a different discussion. These two papers provide useful examples of decision making which does not relate to treatment.

In terms of more minor life decisions Kilicarslan-Toruner and Akgun-Citak (2013), particularly those concerned with routine which could be termed everyday decisions, it has been reported that the degree of flexibility in hospital environments can sometimes be limited (Palmer *et al.*, 2007). Not everyone is treated in a designated treatment centre in the UK. This results in the experience of having to conform to particular ward routines in adult wards rather than being afforded the consideration of individual needs which are cognisant with age.

2.9 CONCLUSION

Apart from the Coyne *et al.*, (2014) study outlined above, which proved to be a very useful example following the collection of data in this study a small number of studies were helpful in further determining the course that this work would take. The studies which resonated most closely with the material which I was attempting to locate prior to the study were those undertaken by Hokkanen *et al.*, (2004) and Wicks and Mitchell

(2010). The later work following the original literature search authored by Gibson *et al.*, (2013), Taylor *et al.*, (2013) and Coyne *et al.*, (2014) were all influential in assisting in terms of the discussion of findings.

In summary, this was complex and sometimes confusing literature to examine (Coyne *et al.*, 2014). Whilst there is certainly a growing body of evidence which relates to the field of teenage and young adult cancer care, there are a number of continuing caveats which render the work difficult to specifically locate. The early part of this chapter reflected on this by providing a long history of the changing nature of adolescence, youth and emerging and young adulthood. This is coupled with the rights agenda and the emergence of policy which should strengthen the position of this group in articulating and achieving choice in their lives. The variety of stances relating to the decision making process further serve to 'muddy' and sometimes conflict with the already complex scene. This is with reference to the legal framework, competency, paternalistic protection, the ethical position of the best interests of young people being treated for cancer and the unpredictable nature of the disease itself.

Nevertheless there is a gap in the literature which provides a detailed examination of not just the challenges in decision making but a number of other aspects associated with this during the cancer experience. The age group as a distinct group, that is those aged 16 to 24 years with cancer, have not been the focus of study in terms of decision making throughout their cancer trajectory. Added to this there has been very little attention given to the period prior to diagnosis (Gibson *et al.*, 2013). The decision making literature tends to focus on particular aspects of care such as clinical trials, palliative care and survivorship. Most importantly, detailed examination of decisions which are not about treatment are absent. It was therefore envisaged that by focusing on young people at this crucial time of transition and considering their choice and control of decision making throughout their experience of cancer, we could begin to learn more about this. By working with the young people directly through several interviews over many months as

well as collecting the perspectives of others and by using multiple methods, it was envisaged that this would provide a rich multi layered landscape of choice and control in cancer experience.

3. RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

This chapter will outline the planning, development and subsequent operationalisation of the study. The chapter will begin by discussing how the research is philosophically framed. Following this, the epistemological and ontological perspective will be briefly outlined. The fundamental beliefs of the philosophical stance underpinning the subsequent development and interpretivist paradigm will also be explained. This will be followed by outlining the chosen methodology. The second part of the chapter will discuss the development of the work through engagement with service users and experts in the field of teenage and young adult cancer, leading to the formulation of the research questions. The final part of the chapter will address the research process and will look sequentially at the research design, ethical issues, methods, data collection and analysis. The logistical elements of the study will be examined along with the issues relating to consent, anonymity and confidentiality.

3.2 PHILOSOPHICAL STANDPOINTS AND RESEARCH PARADIGMS

Two of the commonly cited philosophical concepts in health and social care research comprise ontology and epistemology. The latter refers to the nature and development of knowledge. Ontology however, is concerned with the perception of reality. The dominant dimension historically in research, particularly in healthcare, has been concerned with what are referred to as epistemological positivist paradigms, which determines that it is only that which can be observed which can provide facts which are plausible. This paradigm focuses on causality through experiments which confirm observation and subsequent generalisations that can be compared to 'law like' outcomes. In this context phenomena are reduced to the simplest elements (Guba and Lincoln, 2005; Hallebone and Priest, 2009). The application of the positivist paradigm has been instrumental in the significant growth of scientific knowledge in healthcare, producing extremely high numbers of replicated facts about health and illness. This can result in the advancement of treatment for many patients (Polgar and Thomas, 2013). However, there has been a

shift, particularly in social research, which has moved from this restricted positivist stance to a post positivist position also known as critical realism (Hammersley, 1992). This is not to suggest that those who reject notions of positivism would identify themselves as critical realists, rather there are a number of philosophical ideas which are positioned in between the two. This approach provides a number of ways in which one can think about scientific research. Ontologically within the two paradigms, positivist thinking holds that the view is shared in that social reality is external, objective and independent of social actors. Post positivist thinking is objective but this exists independently of human thought, and belief or knowledge of their existence, however, this is interpreted through social conditioning (Guba and Lincoln, 2005; Hallebone and Priest, 2009).

At the opposite end of the spectrum is the naturalistic approach to research often using the interpretivist position. This position argues ontologically that reality is socially constructed by social actors and that people's perception of reality is part of this process. It is acknowledged that people from a variety of backgrounds, with different experiences and views will formulate the construction of reality in an ongoing way through social interaction. In epistemological terms the focus is on the situation, its detail and the reality behind this. There is a view here that meanings are subjective and that there are motivating actions for this (Wahyuni, 2012).

Those who oppose positivism are agreed that they would argue against the idea that behaviour in humans is such that it is governed by general universal laws. Furthermore they would suggest that it is the individuals who are being studied that will provide insights and understanding into the social world. They would also propose that this understanding of behaviour comes from having knowledge of how individuals interpret the world and that this needs to come from within and not from external sources (Cohen *et al.*, 2001).

This is a common approach in social science where research is sometimes subjective rather than objective in nature, where the intention is to unravel and explore the experiences of individuals. These experiences are normally in specifically chosen contexts. This was the case in this study, where individual experience was explored through engaging with individuals who have been directly in receipt of healthcare. Young people were regularly engaged in interaction with others in the context of decision making. This was their reality and ontologically the understanding and exploration of interpreting meaning was important in recognising and meeting their needs. In epistemological terms the study focused on the interpretation of the detail in these interactions, attempting to build a detailed knowledge of their decision making.

3.3 METHODOLOGIES

The methodologies which are identified with the positivist and naturalistic approaches to research are qualitative and quantitative, about which there is considerable debate in the literature (Bryman, 1984; Guba and Lincoln, 1994; Bryman, 2006; Preissle, 2006; Denzin, 2009; Sandelowski, 2010). The positivist approach is more usually associated with quantitative research, whilst the naturalistic approach is associated with qualitative traditions. Quantitative research is commonly paired with a natural scientific approach and this is governed by a particular set of methods which set out to provide measurements, normally in the form of numerical values. This type of research typically has larger numbers of participants providing data sets which can be statistically analysed. Polit and Hungler (1999) refer to the objective nature of this type of research and they note that the aim of quantitative research is commonly to gather data of which the findings can be generalized to a broader audience rather than just the participants. They further point out that in this type of work a control can be put in place thus minimising possible biases and increasing the validity of the research.

In contrast qualitative methodology is often concerned with a range of complex human issues, where the experience of participants is explored by the researcher. Data are collected which produces a narrative, commonly by undertaking interviews with participants. These narratives are then analysed and through interpretation, themes are identified which subsequently illuminate experience. The narratives often provide rich in depth accounts which enable the researcher to extract detailed sections of data. These findings are often judged to be less generalizable to populations because of the smaller numbers involved and the emphasis on individual experience (Silverman, 2001).

This study focused on the individual experience of teenagers and young adults when they developed cancer and subsequently underwent treatment. Further it sought to identify their choice and control in terms of level and types of agency they experienced. To elicit such information about these experiences, rich textual data were required, which lent the study to a qualitative approach. It was judged most likely that information gathered using qualitative methods would provide some in depth insights into how young people felt about their choice and control in agentic terms. This was in the knowledge that they had to navigate many events during the cancer trajectory. Before the study began, a decision was made to engage with a range of professionals, families and young people. This was to determine what types of issues were important to teenagers and young people throughout their cancer treatment, which related to all types of decision making. The specific intention was to try and acquire knowledge on the intentionality, motivation, freedom, choice and control that featured in the lives of young people at this time. The accounts below helped to shape the study in terms of approaches, research design and methods, particularly interview schedules and questions contained therein.

3.4 ENGAGEMENT WITH OTHERS IN PLANNING THE STUDY

During the development of this project, there were a number of exploratory meetings with a range of individuals and groups to ascertain the potential usefulness and relevance of carrying out the proposed study. Between September 2012 and June 2013

meetings took place with:

- Heads of Quality at Teenage Cancer Trust (Nursing)
- Policy Professional at the Teenage Cancer Trust in London
- Senior staff including a nurse and psychologist at a local specialist cancer unit
- Consultant Haematologist at the local specialist unit (gatekeeper)
- Specialist funded nurses, Teenage Cancer Trust from around the UK
- Mother and son aged 15 years (son had undergone treatment for a brain tumour and was receiving palliative care)
- Healthy sibling aged 16 years who has a brother with cancer
- A young person who had completed cancer treatment.

Overwhelmingly these were all positive meetings and they provided me with some valuable early insights into how the study might usefully develop. Individuals, families and professional groups welcomed me into their homes and meeting places and were keen to help. The research questions were subsequently informed through both the evidence and the meetings outlined above. As examples, discussions helped to formulate ideas about the following, disease focused cases, clarifying the age range being studied and the time span within the cancer trajectory being explored. The meetings also informed the possible nature of questions to be included in the interview schedules.

3.4.1 SENIOR LEAD NURSES

The first meeting was with senior lead nurses working for the Teenage Cancer Trust who had significant experience of cancer care relating to children, teenagers and young adults. The meeting focused on my initial ideas around treatment decision making with a view to exploring how this was undertaken and what some of the possible challenges might be, for example if a young person refused treatment. At this point, I had no idea of the sample I might access only that they would be under eighteen. This would bring them within the legal framework of parental responsibility. Both nurses were very receptive to

my ideas and offered a number of suggestions, including observing interactions between specialist nurses and the young people in their care where examples of decision making might arise. They also suggested that I might want to be part of a discussion with a group of specialist nurses where I could raise some of my ideas to try and further develop the project. At this meeting it was difficult to seek more advice as my ideas were not sufficiently developed but it was still useful in terms of networking and familiarising myself with the specific field of teenagers and young adults with cancer.

3.4.2 DISCUSSION WITH POLICY PROFESSIONAL

This discussion provided important underpinning material as guidance and policy helps to develop frameworks and structures for the way in which care is delivered. This can subsequently provide drivers both for the maintenance and advancement of care for those young people who experience cancer.

We discussed the importance of statutory age limits for decision making in care, taking into account the requirement to provide independent consent for those who were Gillick competent but were still at the age when their parents had responsibility for them. We then discussed the notion of refusal as an opposing position to consent as outlined in the legal literature. The policy professional raised the Teenage Cancer Trust's recently published Blueprint of Care in February 2012 which amongst its key messages called for an understanding of the 'wider lives' of individuals taking into account their interests, past experiences, relationships, future aspirations and coping strategies. It also, she informed me, highlighted the loss of control which can emerge during the cancer trajectory, both in life choices and the freedom to make decisions. This document provided some thinking around not just treatment decisions but every day decisions and life choices both in the present and the future. We also discussed the high degree of reference to dependence and autonomy in the treatment phase and how this might be challenging in the care of this age group. We discussed the National Cancer Standards in England and Wales and what their impact might be. We also touched on other resources that may be useful and

in policy terms might act as a comparator for the work I was developing. The Council for Disabled Children was mentioned as was the Marie Curie Report on transitional care.

3.4.3 LOCAL UNIT DISCUSSION WITH SENIOR NURSE AND PSYCHOLOGIST

At this meeting I had developed my thinking in terms of the topic area and had written a short overview of the project followed by a number of questions relating to my ideas. After reading the literature, the notion of treatment decision was showing a rather narrow focus and I therefore began to consider other decisions not necessarily linked to treatment. The psychologist alluded to a number of issues taking place in the lives of young people which they may wish to have autonomy over during their cancer experience. This supported my more recent thinking which related to the fact that everyday decisions and choices still needed to be made and thus what is the young person's experience of this? I pondered at what points did they feel or want the autonomy to do this and in contrast at what points were they dependent on others to help them make choices? The senior nurse commented that potentially she could think of a number of young people who might want to participate and would welcome a discussion about this area of their lives. We discussed the age range of young people who might take part in the study. They suggested that older teenagers and young adults may provide interesting perspectives and insights in terms of the breadth of decision making at this time in their lives. This complemented the literature I was reading at the time and the fact that early signs indicated there was not much evidence in this particular context. The staff at this meeting noted that approaching a wider age group, including younger teenagers may prove not as useful because of differing priorities that they had witnessed in their practice between younger and older individuals

3.4.4 MEETING WITH MEDICAL PROFESSIONAL

A consultant who played a key role in the specialist unit agreed to meet with me. She was keen and enthusiastic to collaborate. One of her recent students had done some work exploring what influenced young adults in their decision to take part in clinical trials. We discussed the ideas for the project and she made a number of suggestions. Firstly

to consider the age range and think about 16-24 year olds. This made sense as all of the most recent policy concerning the care of teenagers and young adults reflected this age group as outlined earlier in Chapter One as did the most prominent cancer charities. We also discussed the participants and how these might be selected. She agreed with my suggestion that the richness of data could possibly be enhanced by choosing a range of diagnoses. She also suggested that a lot of decision making might take place when treatment completion was approaching, this was certainly true and I later took this into account when planning the interview schedules aimed at the young people. The consultant agreed to act as gatekeeper in terms of access to cases and so it was really important that I established a good working relationship with her. There was also the possibility of collaborative work in the future.

I met with the consultant and my supervisors for a second time to inform them of my progress. The meeting was very positive and we discussed a number of issues. We outlined the case study design, which she felt was a small sample and was concerned that not enough data would be generated. I tried to reassure her by outlining the different methods of data collection and sources, which would result in up to 45 primary sources of data. A suggestion was made that it might be worth interviewing someone with a rare cancer in the age group as their experience of decision making may differ from those with a more predictable outcome. We also discussed access to patients and what types of treatment each would undergo. Finally we discussed interviewing healthcare staff and how this could be undertaken and where it would take place.

3.4.5 MEETINGS WITH YOUNG PEOPLE AND THEIR FAMILIES

Tom was a fifteen year old boy who had been having treatment for a brain tumour for five years. He was receiving palliative care when I met him. I knew his father and therefore had discussed my work with him. Working in the healthcare field he thought it would be helpful to talk to a family prior to undertaking my research and thus offered his help. I sought permission from my supervisors for this as I was a little concerned that it

might not be appropriate. I was reassured that this was not part of the research and that the offer to talk was something the family were happy to do and might indeed be mutually beneficial. I explained my ideas to Tom and his mother and loosely framed a number of questions which related to these. This was an illuminating discussion which lasted for over an hour.

It was challenging though as Tom had a degree of cognitive impairment as a result of his illness and for much of the time we talked he was supported by his mother. This was an important part of the learning process for me as it was clear that she had played a major role in supporting him throughout his treatment. She would explain each part of our discussion to him with patience and wait for his responses. They both commented that when he was diagnosed at ten years old he did not really feel that he understood what was happening to him. His mother talked about the importance of information throughout the process. She also stressed that choice was important and that this ranged from the everyday matters such as what he wanted to eat, to fundamental decisions about treatment. Interestingly he commented that he no longer wanted to attend clinic for appointments and so did not do so. Instead he went to visit family and friends and still attended school occasionally.

The outreach nurse visited whilst I was there, with medications for Tom, and we spoke briefly about my research. This was such a rich source of information for me. I asked questions which I felt were relevant to what I was doing and this produced some interesting answers which often involved Tom's mother encouraging him to talk. The key issues for me concerned advocacy, information giving, hierarchy, coping with the severity of treatment, not bombarding too much and support groups.

Tom died peacefully at home six months after our meeting, I was grateful for his family's contribution as they raised some fundamental issues which were not discussed in any of my other meetings.

Meg was the 16 year old sibling of Tom. She was about to start her GCSE examinations and kindly agreed to talk to me about her experience of family life when a sibling has cancer. We went for a walk as she said that she would find it easier to talk and so left her mother at the house and took the dog out. We talked generally about how cancer had made a difference to her life and how over the four years that Tom had been ill, the family had no choice but to continue with their everyday lives, although things were different to before he was ill. An example she gave was, sometimes they had to change plans at the last moment and sometimes if Tom wanted something as simple as a particular meal, mum would go out and get what was needed. We talked more specifically about decision making and Meg commented that their family had a strong religious faith. As the children of the family, it was important that they respected what their parents' views were and trusted that decisions were always made in their best interests. For this reason the children were happy for decisions to be made for them. It was interesting that she said that some of her friends 'did not listen to their parents' and made their own decisions regardless of their parents' advice. She did not believe that this was a good thing. When we talked about Tom and his decision making, Meg said that when he was first diagnosed, her parents made the decisions about his care. She felt that this was the right thing as he was ten when he was diagnosed and needed his parents to help and support him at this time. In recent months when his treatment had been palliative, he had not wanted to do so many things. One example was that he did not want to go to clinic appointments any more as he did not see the point. His parents had respected this and did not try and persuade him otherwise. This meeting underlined for me the disruption to family life when someone is diagnosed with cancer and also importantly how individual families will have their own approaches to decision making, something that I would learn much more about during data collection. Since my meeting, Meg has had outstanding results in her GCSEs and is hoping to study medicine.

3.4.6 VIDEO CONFERENCE WITH RESEARCHER AND SPECIALIST TYA CANCER NURSES

Prior to this meeting I had sent a short overview of my work with accompanying questions, this proved very useful. The group comprised a number of very experienced cancer nurses from around the UK. They had several suggestions the first of which was to title the work teenage and young adult cancers, as adolescence denotes a developmental process and was not really adequate in terms of what I was trying to describe. This was useful and was borne out in a number of papers I had read. They were also keen, as others were, that I study the 16- 24 year age group. They felt that I must talk to young people on their own and then interview parents separately to try and gather the most useful information. They were very interested to know about everyday life decisions and thought that there was definitely a gap in the literature relating to this. They were concerned about the suggested sample size but agreed with the idea of choosing a range of cancers. They talked about collusion as a key issue for them, where patients may collude with staff leaving out parents or parents may collude with staff leaving out the young person. This was again something I learned more about as the study was undertaken. They said they would be happy to act as a reference group and invited me to further meetings to discuss my progress, they were happy to be used as a sounding board for ideas.

3.4.7 A YOUNG PERSON WHO HAD COMPLETED CANCER TREATMENT

I met this young man through a friend, he was keen to discuss his experience and my ideas. We met for a lunchtime discussion and he began by telling me about his diagnosis. The summer immediately preceding his enrolment at university he was troubled by pain in his lower leg. This was particularly so when he was playing sport. He was a keen sportsman and so decided to visit his GP. As with many young people who are in the main very healthy, the GP said he did not think it was anything to worry about and prescribed pain killers and physiotherapy. He did not have the physiotherapy due to the waiting list but put it out of his mind and travelled North in September to start his

university programme. He went to a trial for the football team and was thrilled when he got into the squad. A few weeks later he was out at a social event when a young woman, who as he said had clearly had a few drinks, tumbled into him and he fell over. The pain he said was very severe in his leg as he landed on the floor. Following a visit to the emergency department, where they said there was something on the X-ray but it was probably nothing, he returned home. It was only when the X-ray was reported on by a radiologist that a mass was confirmed, which later was diagnosed with a solid tumour in his leg.

He told me that his parents were divorced and he contacted his father in the first instance, who said he would drive the five hours to pick him up immediately and that he was to return home with him. His own view was that he wanted to continue with his degree in some way and indeed he looked at cancer centres near the university but both his father and the university said he could not continue with the programme. He said he disagreed with this but felt it was out of his control. He underwent 28 weeks of chemotherapy in his local hospital initially and then in a specialist TYA unit, in the middle of which he had limb sparing surgery and a large plate placed in his leg where the bone was removed. He told me that he discussed things regularly with his father but not his mother as she lived many hundreds of miles away. This did seem to trouble him as he said his mother was not as involved as she might have been had his parents been together.

He commented that there were a number of decisions that he made himself even though he referred to them as not really important to anyone else. The example he gave me was that during treatment, however bad he felt, he would wash himself in the morning and get dressed and that this was really important to him. He said that sometimes he wanted to do other things such as go out from the hospital but the staff and his father would not let him do this even though he said he felt perfectly well enough to do so.

Since he had finished treatment he had made a number of decisions one of which was against the wishes of his family and the medical team. He raised £14,000 for charity by cycling from John O'Groats to Lands' End. He was also just completing a degree in a university nearer to home and was planning to marry in 2014. He has been disease free since 2010.

It was an absolute pleasure to meet him and he gave me many examples of decision making that had taken place during his cancer treatment and since completion. He thought that the research idea was in his words 'fantastic'. Since this meeting he has obtained a first class honours degree and has married.

Following the meetings with all the people identified above and further examination of the literature, the aims, objectives and purpose of the study were developed. These were refined a number of times throughout the development period. The theoretical ideas of agency and structure, control and choice in decision making remained central to exploring the young persons' experience and that of those close to them.

In summarising these consultations, there were a number of useful findings which helped me significantly to further develop the study ideas. From a professional perspective, there were key issues to consider which related to service provision and meeting the needs of young people. Choosing the age range from which to select a sample was an example of this. The professional meetings also helped me to think about the range of different types of cancer that might be included in the study. In particular, the suggestion from the consultant about choosing a cancer which was rare in the age group ultimately provided a rich source of data. This subsequently provided a useful comparison with other cancers in relation to decision making.

In terms of talking to others in the preparatory phase, in particular those who had been affected by cancer, there was much to be learned. Some of this related to practical issues involved in living with cancer as a young person including the management of the

disease process and the impact that cancer had on the family. Importantly there were also glimpses of how control of decisions had been important, even where these had been not related to treatment or seen as relatively small or everyday matters.

Perhaps most helpfully, meeting people from a number of perspectives provided a valuable insight into the cancer experience. It helped me to develop confidence in talking to people in this context and to develop further awareness of the need to develop specific skills in working with this group of young people. This included, listening, using silence, probing, clarifying and developing reflexivity. The development of these skills was to prove enormously helpful when I was in the field working with participants.

3.5 THE STUDY DESIGN AND PROCESS

3.5.1 AIMS, OBJECTIVES AND PURPOSE OF THE STUDY

Specifically the study sets out the following:

Aim:

- To provide a detailed understanding of how different types of choice and control in decision making are experienced in teenagers and young adults (n=5), (aged between 16 and 24 years) during the cancer experience alongside an exploration of the views of parents or carers (n= up to 10), health or social care professionals (n=5) and friends (n=5) (see Appendix 2).

Objectives:

- Using a qualitative exploratory case study design and methods to generate new knowledge of the experiences of choice and control in decision making as teenagers and young adults experience cancer.
- To explore the views and experiences of parents or carers, health or social care professionals and friends about their views of choice and control in decision making during the cancer experience with

young people

- To examine interactions involving decision making, taking place in oncology outpatient settings where the case study subjects (n=5), are receiving care
- To investigate the written medical notes from each of the five cases, which records, and thus contributes to, insights into the decision making process.

Purpose:

- To influence thinking and action in research, policy and practice relating to the way in which decisions are made during the cancer trajectory for young people. This will be achieved through the publication of papers during and following the study, attendance and presentation at relevant conferences and networking through interest groups, which are linked to the practice setting.
- To disseminate the views of teenagers and young adults with cancer across the wider professional community in order to highlight the key issues related to decision making during the cancer trajectory. I am currently a member of the national Teenager and Young Adult with Cancer group who produce weekly bulletins and hold regular education days, which I intend to contribute to once the study has gained approval and subsequently when I have collected and analysed all data
- To identify ways to influence legal commentary and thinking in this area of practice.

3.5.2 CASE STUDIES

Case studies have application across a wide range of disciplines. Social scientists in particular have used case studies to examine contemporary real-life situations in a specific context (Feagin *et al.*, 1991). Yin (2009) who has written extensively about this

method, defines the case study as:

'An empirical study that investigates a contemporary phenomenon in depth and within its real life context, especially when the boundaries between phenomenon and context are not always clearly evident' (pg.18).

In this study, there was commonly a 'blurring of boundaries' as young people, for example legally, had the right to make independent decisions about refusing treatment if over the age of 18. However, the development of cancer contextually imprinted itself on this situation and thus produced what could sometimes be a difficult, confusing and challenging landscape.

Yin further explains that case study approaches use multiple sources of evidence from a variety of participants and multiple methods which can include the use of interviewing, non-participant observation, documentary analysis and the use of artefacts. These sources and methods can be utilised to either explain or explore particular cases. Exploratory case studies are concerned with as Yin puts it the 'what' question. The so called what question was central to this study as it effectively yielded the experience of choice and control in the young people's cancer journey.

Commonly, case study research involves investigation of a small number of cases in considerable depth over what can be a considerable period of time although occasionally, one single case may be studied. Case studies can also be used to study organisations and groups and political or social phenomenon. Single or multiple real life cases are selected where there are multiple, cross cutting, themes that can be identified as a part of the analytical framework (Gomm *et al.*, 2000).

In espousing his explanation of case study Stake, (1995) determines that there are a number of different ways in which case studies can be undertaken. His reference is to intrinsic, instrumental and collective case studies. The intrinsic refers to studying a case uniquely to further learn about just that case. When more than the case needs to be

understood (i.e. the individual) he uses the term the instrumental case study. Moreover in studying more than one individual he further refers to collective case studies, enabling researchers to define important similarities between individuals.

Case studies however, have faced criticism. Yin (2009) reported that there was opposition to the case study as a type of empirical inquiry. One particular argument he highlights concerns the rigour of the approach, where the researcher has not followed procedures systematically and has allowed personal views to influence the results and subsequent conclusions.

However, one of the key criticisms of the case study approach is that findings are not generalizable to populations as can be the case for example in positivist scientific enquiry (Flyvbjerg, 2006). This is true of other qualitative approaches to research and is often defended by focusing on the type of results which the data produces. Hammersley, (1992) argues that the objective of this type of research approach sets out to achieve depth and a richness of data rather than the breadth that one would see in other types of study, particularly that stemming from a quantitative tradition. Stake, (1995) however, refers to 'naturalistic generalisation' where he argues that general things can be learned from one case and those reading the case will often know something of the subject and will therefore add new findings to existing cases, thus broadening generalisation.

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 contemporary cases to be studied in depth using a range of data collection methods. This provided the opportunity to begin with the young person and acknowledge them as central to the study. Following the exploration of this initial groups experience led to illuminating the perspectives from others who were known to the cases and were related to them, were either partners or friends or who had cared for them during their cancer trajectory. The variety of evidence gathering which resulted from the interviews of the cases and those

close to them, produced a number of dimensions which served to illuminate the research aims from a number of perspectives. Each case, referred to by Yin (2009) as units of analysis, was bounded by those who participated in each individual data set. The boundaries of each case are highlighted as being significant (Dopson, 2003). This boundedness was also secured in the selection of four out of the five participants who had a more common cancer in the 16 to 24 year age group.

The application of multiple methods also enabled the experiences of young people and those close to them to be examined from a number of perspectives. The application of such approaches enables 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). Added to this where different methods of data collection are applied which provide consistently comparable results, the credibility of findings can be strengthened (Knafl and Breitmayer, 1991).

3.5.3 INTERVIEWS

Interviews are a commonly used component of the data collection tool kit (Gill *et al.*, 2008). The involvement of the participant and the interviewer is central to the exchange of information. During interviews those taking part will be provided with the opportunity to discuss issues, experiences and interpretations of their lives and express these from their own perspective. Kvale (1996) illuminates the conversational nature of the interview as having structure. Cohen *et al.*, (2001) argues that in this sense the interview is part of life and not just a way of collecting data. They further comment that regardless of the purpose of the interview the objective remains, the seeking and giving of information. Walker (2011) adds to this notion by highlighting the close connection between interviewing and hermeneutic enquiry, which attempts to consider everyday lived experiences through description and interpretation.

There are a range of interview types and techniques which can be used to suit the purpose of the project being undertaken. Most commonly in healthcare the unstructured,

semi structured and structured interview types are utilised. These are variously expressed by a number of authors (Patten, 1980; Lincoln and Guba, 1985; Le Compte and Preissle, 1993; Kvale, 2015). Cohen *et al.*, (2001) argues that this presents the researcher with real challenges in choosing which type of interview to utilise. Nevertheless one that is commonly cited and used in healthcare research is the semi structured interview (Holloway and Wheeler, 2010). It is usually the research design which will determine the type of interview adopted as researchers will be attempting to elicit particular accounts from participants. In case study design, the researcher needs to collect in depth, 'rich' data for the purpose of analysis. Since sample sizes can often be small, the depth of the interview gives the opportunity to provide a rich narrative which can be explored for each individual case. This can also contribute to across case analysis. Interview schedules for this study were derived from the literature, the research aims and objectives and as a result of discussions with professionals and young people and their families as illuminated earlier in this chapter (see Appendix 3).

The semi structured interview consists usually of a small number of questions which whilst guiding the interviewer and participants, are a loose framework which can act as a starting point for data collection. The use of prompts or probes can help to assist the participant in illuminating further on answers that they provide. Doody and Noonan (2013) argue however, that this can present challenges for those who are new to research as they may either find it difficult to prompt a participant or they may not know when there is a need to probe more deeply. This they comment can result in important data being missed. Questions in this type of interview are open ended which is a way of allowing the participant to provide depth in their answers. In more structured interviewing, answers might be relatively restricted leading to less information being imparted.

When considering the experience of decision making in cancer treatment, there may be some very complex scenarios, where there has been much discussion in reaching a decision. Equally there may have been disagreement in the decision making process. It

is in these types of situations that open ended questioning, which allows for an in depth explanation, was helpful. Explaining such events, took time and the answering of questions was not always concisely conveyed. The use of probes assisted here in acquiring more in depth accounts. The participants alluded to a particular aspect of a decision making situation and then swiftly moved on. It was at this point probing proved a useful tool in attempting to extract more information (Britten, 1995). The use of probes when working with young people it could be argued, has the potential to be very beneficial. Their limited life experience and exposure to in depth discussion may mean that they are not used to explaining issues in detail. This may also happen particularly in younger teenagers, as their communication mechanisms whilst usually very strong with their peers, may not be as well developed with the adult who is interviewing them and who they will not know.

In terms of collecting data in this way there are also implicit differences in interviewing this age group. Dashiff (2001) articulates a range of considerations which need to be acknowledged when engaging in this type of activity. These include developmental considerations, being aware of research settings which might inhibit conversation, gender differences in this age group and cognitive understanding. Coad *et al.*, (2014) provide an interesting account of the interview setting and make explicit recommendations for stages involved in conducting interviews specifically in home settings. These include, the preparatory stage, the interview itself and how to appropriately both end the interview and leave the young person's home. Being aware of the influence of others in the interview setting is particularly important in terms of not just the privacy of the young person but of them being comfortable to speak when others might be in the house albeit not in the same room (Duncan *et al.*, 2009).

3.5.4 OBSERVATION

Observational methods comprise another common tool which can be used to gather data. This provides a different data perspective and provides insights into the

experiences of participants which would not otherwise be captured. In case study research, the use of multiple methods is part of the process of data collection and as such observation is commonly used. Gillham (2000) describes observation in its simplest form. He asserts it concerns listening, watching and sometimes asking questions about what people say and do. The author goes on to describe different types of observational techniques as those which involve participation and those where the observer is not involved. He is keen to point out though that these two approaches are not mutually exclusive and can indeed be used together as a mixture of methods. These have been variously described as participant and non- participant observation (Spradley, 1980; Mays and Pope, 1995; Punch, 2005; Hammersley and Atkinson, 2007; Holloway and Wheeler, 2010).

Observational methods are not without their challenges. Polit and Beck, (2004) make reference to two key issues, the relationship between the observed and the observer and observer bias. They comment on those who are being observed and how they may have varying degrees of awareness of the activity taking place and how they might also change their behaviour because the researcher is present. The second issue that they raise is observer bias. They note that as human beings observers may make errors, misunderstand certain activities or perceive matters observed in a different way to which they are intended. They argue that objectivity in these contexts is difficult and that it is possible that it cannot be achieved fully in any observation activity.

In this study, observation was one of the methods used to gather data. This was carried out in a range of adult outpatient clinics with only one taking place in a young person's outpatient setting. The venue was dependent on where each particular consultant held their adult or children and young people's clinics. Interviews had provided an opportunity for young people and their families and friends to discuss their experiences in a safe and private setting with just the researcher. In this context however, the interaction was staged to some extent. Young people knew loosely that the interview would cover certain

aspects of care in their lives and so in some sense they could prepare themselves for what might happen.

In the observational setting whilst they might have an idea what their appointment would be about, the appointments were always with either one or both parents present and this applied to all young people in this study apart from one. The interactions were either with the consultant in charge of their care or one of the medical team. They were conducted in very different environments to the specialist unit and this also brought a different perspective to the observations. Added to this as the researcher, I had permission to observe the consultation but I did not take any part in the conversation whilst the appointment was in progress. Thus I followed the tradition of non-participant observation utilised in case studies. I did however have a pen and paper on which to make notes and always sought permission to do this when I attended a clinic. As an aide to the observations I used an adapted checklist (Le Compte and Preissle, (1993) which fitted most closely with what I was trying to achieve relating primarily to how decision making played out in a live albeit observed setting. Cohen *et al*, (2001) refer to the myriad of different checklists available and how this creates difficulty and confusion in knowing which one might be most appropriate.

3.5.5 DOCUMENTARY ANALYSIS

The third method utilised in this study involved examining and analysing documentary evidence relating to each young person in the form of their medical notes. Documentary analysis can provide the researcher with significant information and as with all methods there are advantages and disadvantages in using any particular one (Appleton and Cowley, 1997).

In the pursuance of empirical knowledge Corbin and Strauss (2008) assert that documentary evidence needs to be analysed and interpreted in the same way as other data sets. Bowen (2009) describes the various purposes of documentary analysis and proposes five categories. These include:

- *Documents can provide data on the context within which research participants operate*
- *Information contained in documents can suggest some questions that need to be asked and situations that need to be observed as part of the research*
- *Documents provide supplementary research data.*
- *Documents provide a means of tracking change and development*
- *Documents can be analysed as a way to verify findings or corroborate evidence from other sources (pg.29-30).*

The specific purpose of documentary analysis in this study was to further add supplementary materials to interviews and non-participant observation as is one of the purposes of utilising documentary evidence (Connell *et al.*, 2001). This involved reading the whole medical record. Not all records were held in the specialist unit and so were compiled in different ways. In some medical notes there were contributions from other professionals allied to medicine which included the unit psychologist, dietician and physiotherapist. There were also entries from the nursing notes by either senior nurses or advanced practitioners in the form of unit specialists or research nurses. Other nursing notes were kept separately and unfortunately it was not feasible to examine and analyse these within the time frame of the study. I made this decision based on the premise that the most common group interviewed in the healthcare professional category were nurses and so there was an opportunity to discuss decision making with them.

The aim of this examination was to try and look for evidence of decisions that had been made during the course of treatment which either related to the treatment protocol itself or other aspects of the young person's life. Bowen, (2009) warns that whilst there are advantages in this method including, its unobtrusive nature, and the cost effectiveness of the method, one needs to guard against there being insufficient detail in the record and the fact that it might be difficult to retrieve. Atkinson and Coffey (2004) also advise

that researchers need to be cognisant of the reasons for using documentary analysis and its purpose in any chosen research strategy.

3.5.6 RESEARCH SETTINGS

Choosing and accessing a research setting can be fraught with challenges. Gelling (2015) clearly outlines the need for regulation in research ethics when undertaking studies which take place in the NHS. At the heart of this, the setting in which the research takes place and most importantly where patients receive treatment is the subject of lengthy but required procedures before the setting can be entered to undertake any project. The Health Research Authority is the organisation which oversees this process. However, each health board also has in place mechanisms for approving access to sites for research through each separate research and development department. Building professional relationships with gate keepers is central to negotiating support for access to these sites. Whilst the process of gaining access was lengthy in this project (to which I will refer later in this chapter) the choice of setting was less fraught with complexity.

The site from which young people were invited to take part in the research was the only specialist unit in the country. This made it the clear choice for selection. Added to this no other research investigating choice and control in decision making had been undertaken in this unit nor indeed anywhere in the country of study. The age range of those cared for in the unit was between 13 and 24 years which was compatible with the sample selection in terms of age. The unit included eight inpatient beds and facilities for day patient treatment. It was different from traditional hospital wards for adults or a typical children's ward. It had a number of facilities which were felt to be conducive to making the aforementioned age group feel at home. It provided a 'chill-out' zone, a private kitchen and access to media facilities such as the internet, TV and music. All patients who participated in the study undertook part or all of their cancer treatment in this unit. Patients did not always receive all their treatment in the unit and therefore some of the study pertaining to the observation of outpatient appointments took place in a local

specialist adult cancer centre where some consultants held their clinics or in the main adult hospital outpatients where the specialist unit was situated.

3.5.7 SAMPLING STRATEGY

The way in which participants come to be involved in research is both wide ranging and sometimes complex. Choosing an appropriate sample is vital in helping to establish the rigour of the study and as such poor or inadequate sampling can result in research that is not robust (Higginbottom, 2004; Hammersley and Mairs, 2004; Tuckett, 2004). Examples of how a misinformed approach to sampling can have significant implications for research, is demonstrated by Coyne (1997) who provides an interesting discussion by examining the differences between purposeful and theoretical sampling. She argues the importance of understanding the differences between the two approaches and suggests that where there is a degree of misunderstanding, results can be compromised. She makes a very clear distinction between theoretical sampling, which she argues is driven by analysis and has purposeful elements as opposed to purposeful sampling, which has a clear set of defined criteria by which participants are selected at the outset of a study.

Silverman (2001) makes clear that purposive sampling is not a simple procedure. The researcher needs to spend time deciding on a number of factors which determine the group requiring study. It is only after carrying out careful planning of these factors that the sample criteria should be identified and participants recruited. This can be a lengthy process, which can involve a number of important steps before the commencement of the study. Silverman goes on to say that theoretical sampling is often seen to be part of the same spectrum as a purposeful approach.

Qualitative sampling utilises a number of purposive sampling methods which would illuminate a specific set of issues. Maximum variation is an example of such a type. This involves purposively selecting a wide range of particular elements which are connected to the chosen area of study. The purpose of using maximum variation is that it is possible

to outline patterns which cut across the whole sample (Polgar and Thomas, 2013). In the case of this study, a decision was made at an early stage and during discussion with experts in the field, to adopt an approach using maximum variation. As wide a range of cancers as possible were selected within the sample using some of the commonly occurring types in the 16 to 24 year age group, which were reported in recent national cancer statistics (Cancer Research UK, 2013). One participant however, was invited to participate who had a rare cancer in the identified age group, to provide further variation within the sample. This was to try and establish if patterns of agency in decision making for different diseases had themes of commonality.

During the timeline available for recruitment and data collection between February and August 2014, in total 33 new cases were diagnosed at the identified site. A further 39 cases were already receiving treatment in the chosen site. Of the 33 young people diagnosed during the above timeline, 13 were not treated at the chosen site. This left a possible 20 new patients of whom a further eight did not meet the inclusion/exclusion criteria developed for the study (see Appendix 4). Subsequently from a sample of 33 recently diagnosed young people, there were 12 potential participants.

Maintaining the focus for maximum variation, three out of the five participants were invited to take part from the 12 young potential participants diagnosed between February and August 2014, who had received two months or more of treatment, (one participant with a solid tumour, one with a haematological cancer and one with a rare cancer in the age group). The remaining two young people who were invited to take part were at a later stage in the treatment process and thus from the existing 39 young people receiving treatment. Both were having treatment for different but common disease types in the age group being studied (one participant with a haematological cancer and one with a solid tumour).

In view of the timeline available as already outlined, potential participants were invited to take part as they visited the unit for treatment, providing they met the identified inclusion/exclusion criteria. Each participant was approached during the period identified for recruitment to provide the opportunity to collect data in a timely manner. In total eight young people were approached and five of these agreed to take part. Consideration was also given to other factors during selection, which included the school/work/education status of each young person, their family backgrounds and their gender.

Being clear about the range of participants I was looking to recruit based on my research design was part of my discussion with the key contact at the site. This enabled her to approach those who would be appropriate for entry into the study. Once the key contact had spoken to a potential participant, each young person was asked to consider the information that they had received and to respond within an identified timeline if they were interested in taking part.

A networking approach was then used to recruit further participants with the young person at the heart of this activity. They, for example, nominated a friend or partner and also provided information on the professionals who had been involved in their care. They also gave permission for me to approach their parents to invite them to participate. This provided a snowballing technique in gathering the data (Handcock and Gile, 2011).

3.5.8 RECRUITMENT

Huntington and Robinson (2007) describe the numerous skills which are required in the process of recruiting participants for research. This involves interaction and negotiation in a partnership to achieve the appropriate outcomes. Equally important are the challenges in recruitment, particularly when participants are vulnerable (Gemmill *et al.*, 2012). I was acutely aware of this when the senior nurse agreed to act as the first contact for recruitment of the participants in this study and recognised the crucial role which she played. We discussed the inclusion, exclusion criteria for the study (see Appendix 4) and

also worked through the information sheets which I had prepared and gained approval for through the ethics committee and research and development departments.

All participants were recruited from the single specialist clinical site described previously. In collaboration with the lead consultant, who was involved with the study development, the senior nurse made the initial contact with potential participants (teenagers and young adults) to assess their interest in taking part. Those who were interested received an introductory letter and information sheet from the researcher via the senior nurse. They were provided with a contact number to ask any questions they may have prior to agreeing to take part in the study. If they agreed to take part, then I met with them and went through the information again before gaining their consent to participate in the study. Subsequent participants were recruited using a networked approach as outlined in the previous section. They were also provided with information sheets which I discussed with them, responding to any questions or queries before obtaining their consent (see Appendix 5).

3.5.9 DATA COLLECTION

The five young people and those close to them who agreed to participate in the study undertook the following:

- Three in-depth audio-taped interviews (each lasting up to 90 minutes) conducted during their treatment at a mutually agreed time but not over a period of longer than 12 months. These interviews were broadly organised with an initial introductory session to establish the case context, the middle interview explored decision making across all spectrums of life during cancer treatment and the final interview attempted to clarify and bring together the series of discussions .
- Non-participant observations of two healthcare oncology appointments involving the young person were conducted over a six month period.
- Documentary review of medical records was undertaken for each young person relating to their cancer care and treatment.

- The network sampling approach, using the snowball technique, resulted in further data collection, which comprised audio-taped interviews exploring different perspectives of decision making relating to each case as follows:
- One in depth audio-taped interview with parents/carers, which lasted between 45 and 90 minutes.
- One in depth audio-taped interview with the identified health or social care professional which lasted between 30 and 45 minutes.
- One in depth audio-taped interview with the nominated person identified participant, which lasted between 30 and 45 minutes. A summary of the primary data sources can be seen below (Table.1).

Interviews with 5 young people	15 (3 X5)
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 1.3 Primary data sources resulting from data generation

3.5.10 DATA ANALYSIS

Data analysis is central to the research process. Rigorous approaches to data analysis, which result in a systematic examination of the materials collected have the potential to produce work which will contribute new understandings of phenomena (Miles and Huberman, 1994., Pope *et al.*, 2000). These new understandings once disseminated then provide the opportunity to question, develop, change and ultimately improve

existing frameworks of care. Yin, (2009) identifies a number of analytical strategies in case study research one of which is within case and cross case analysis.

In case study design it is important to be able to recognise the relevant themes both within individual cases and across cases. Ayres *et al.*, (2003) argue that this is central to data analysis in case studies. 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 each individual case. Ayres *et al.*, (2003) justifies this by saying although these individual experiences have a limited value, there are aspects of the experience which are unique to them and thus help us to understand one particular person's story.

In this study the age range varied between 16 and 24 years. All the young people had experienced different cancers, some had experienced surgery, which included amputation, one had relapsed and was being treated for a second time and had undergone a bone marrow transplant. Another needed treatment in intensive care whilst the youngest participant had a very rare cancer in this age group. Equally all the participants' families had a diverse range of backgrounds. Consequently a within case analysis provides a detailed and unique picture of each young person, their experience and the perspectives of those close to them.

There are however, some themes which may apply across the cases. Whilst not providing generalisability to populations, these themes have the capacity to contribute to further understanding the experience of this age group through the development of a number of common statements. As common statements are extracted from the data, some contribute significantly to the identification of themes (Burnard, 1991; Kavanaugh, 2007).

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 (see Appendix 6).

In this study these steps were followed. I immediately immersed myself in the data by listening to each of the audio- taped interviews as soon as was practical, I then read and re read transcripts once they were available. The transcripts amounted to 24 hours of interviewing. This comprised 31 interviews in total (I interviewed one set of parents separately as they requested). I applied the same principles to field notes which were made following observations and the written documentation which was taken from the medical records. The observations amounted to 3 hours. The total number of words from the data set was approximately 315,000 and this included all the reflexive accounts which I completed following each data interaction. This ran concurrently with the verbatim typed transcriptions of data as soon as was practicable. The identification of codes was achieved by initially working 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). The coding was largely data driven, however, the development of the case study design involved the emergence of a theoretical proposition (in this study this comprised the theories of agency and structure) as suggested by Yin (2009). Subsequently there were a small number of theory driven codes which were mapped against the premise of agency and structure. Ultimately six codes were used to map relevant extracts. The six codes were, full control, no control (theory driven) and negotiation, helping, disagreement and advice (data driven).

As this was undertaken, points of relevance relating to the research questions and theoretical propositions were highlighted and either words or phrases were given to each chosen extract. Once all the data sets had been worked through, it was considered for a second time to group similar sets of words or statements together which were identified

on the first occasion. Mind maps were then utilised to decide final code names and descriptions. Two of the codes were proposed deductively taking into account the theoretical propositions (theory driven), the remaining four codes were produced through inductive techniques (data driven). Early mapping of phrases against each data item yielded a high number of similar phrases and words. These were all considered and then reduced to a more manageable number. In doing this similar words and statements were categorised into, everyday life issues, treatment issues, cognitive considerations and decision making contexts, before arriving at the final codes for use in NVIVO 10 the chosen software package utilised in the study. An example of two of the later inductive and deductive mind maps for two of the codes are presented overleaf (Figure. 3.2 and Figure. 3.3).

Key: (Green) everyday life issues, (Blue) cognitive considerations, (Yellow) decision making (Lilac) treatment issues.

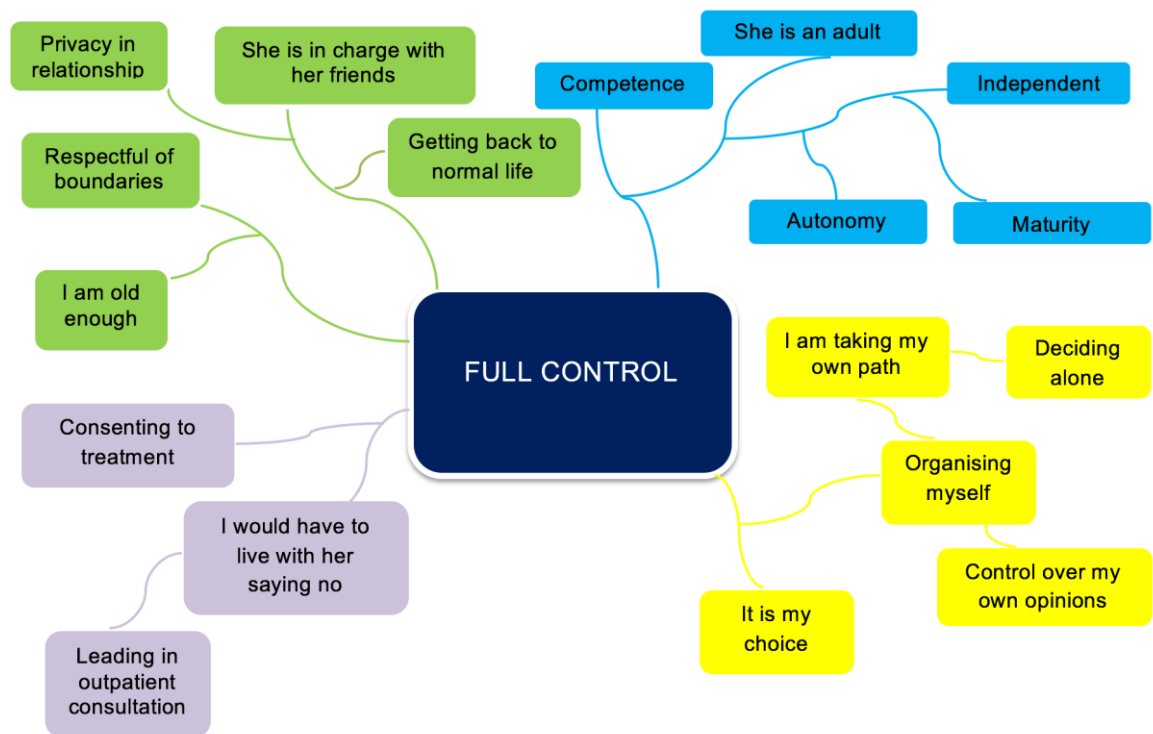


Figure 3.2. Mind map of deductive code (full control) and associated earlier codes.



Figure 3.3. Mind map of inductive code (disagreement) and earlier associated codes.

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 materials (see Appendix 7). Some extracts were lengthy but this was in order not to lose the context of the conversation (Bryman, 2012). Comparisons were continually 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 each individual case. Each case was then fully written up separately and discussed during supervision, 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 but this time across cases. The temporal nature of the data collected over time provided the basis for the three overarching themes as choice and control in decision making naturally fitted with the course of time. The types of decisions being made also could be reasonably 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'.

Within each of these overarching themes, I was more easily able to categorise across case themes for discussion. I also utilised my reflective writing which included memoing to help me to recall some of the interactions that I experienced with participants. This further assisted in the identification of themes as it recreated the important emphasis that some participants placed on particular aspects of choice and control in decision making. This was often illuminated by a number of things including, body language, tone of voice and sometimes silence. Ayres *et al.*, (2003) highlight the importance of 'intuiting' which links to critical reflection and the use of 'free writing' which can assist in the identification of themes. The use of computer software as an aid to data analysis has been available to researchers for a number of decades bringing the development of a number of

software packages which assist with categorisation and coding of data collected by the researcher (Polit and Hungler, 1999). Although Yin (2009) makes clear that these tools are to assist in analysis, they do not do the analysis for you. Yin further argues that unlike statistical analysis these software programmes do not provide an outcome measure. Instead it is the job of the researcher to look for patterns in the data and from this identify themes. Silverman (2010) however clearly identifies some of the advantages of using software as an analytic strategy. He argues that the speed at which the researcher can categorise and code data can save time when the researcher is faced with large amounts of data to analyse. The saving of time he argues, allows the researcher more time to be creative with the findings. He goes on to highlight the rigour that the use of software as an analytic approach can provide. In this study there was a significant amount of data produced as a result of the methods employed and the lengthy and useful contributions made by participants. Using software to manage the data to produce relevant sets of extracts through the developed codes was extremely helpful during the analytic stage of the study. This was because both within case and across case extracts could be grouped together and considered with relative ease. This enabled me to more easily identify potential themes for consideration.

Subsequently for each of the five cases a numerical representation of the number of times a code was referenced and the number of sources referred to was displayed for each of these. These numerical summaries were not further explored in this study but rather used as a point of reference and to demonstrate the variation in the number of times a code was mapped to an extract in the data set (Figure.3.4) represents the interview data set for case one (Ellen).

Name	Sources	References	Created On	Modified On	Created By	Modified By
no control	6	93	19/08/2014 10:27	28/08/2014 14:18	JPD	JPD
negotiation	4	17	19/08/2014 10:22	28/08/2014 14:02	JPD	JPD
helping	6	31	19/08/2014 10:18	28/08/2014 14:17	JPD	JPD
full control	6	77	19/08/2014 10:20	28/08/2014 14:20	JPD	JPD
disagreement	6	21	19/08/2014 10:16	28/08/2014 14:24	JPD	JPD
advice	6	21	19/08/2014 10:19	27/08/2014 12:04	JPD	JPD

Figure 3.4. Screen shot of NVIVO 10 (Case 1 interview data set).

This analysis formed the basis for the presentation and reporting of results and subsequent discussion (see forthcoming chapters).

3.6 ISSUES OF QUALITY IN RESEARCH

Reliability, validity and objectivity have historically been utilised in both qualitative and quantitative paradigms. Sandelowski (1986) made reference to the lack of discussion relating to rigour in nursing research suggesting the development of specific strategies to manage this contention. More generally, Morse (2002) suggested that to contend reliability and validity were not relevant to qualitative studies was to render them not valid or reliable. As part of this discussion, other terms for reliability and validity have been most notably described as transferability, dependability, confirmability and credibility (Lincoln and Guba 1985) and trustworthiness (Eisner 1991) however, disagreement remains about the use of such terms. To add confusion to the debate Hammersley (1992) suggests that neither of these approaches are useful in determining qualitative work.

The debate continues with a recent paper (Sandelowski, 2015). In this discussion Sandelowski highlights the notion of taste in evaluating the quality of research in aesthetic terms and asserts the following:

‘The evaluation of the quality of qualitative research is to a significant extent a matter of taste whether we researchers like it or not’ (pg.91).

These ongoing commentaries are not particularly helpful to novice researchers such as myself. However, in the event, a decision had to be made about how to consider the quality of the research presented here. The context of this study in terms of its design, in my view, resonates with the notion of trustworthiness within the bounds of credibility,

transferability, dependability and confirmability as identified by Lincoln and Guba (1985). This view is espoused because of the long held approach to validity and reliability being traditionally framed within quantitative paradigms.

3.6.1 CREDIBILITY

The period of the study consisted of prolonged engagement with participants, in particular, the young people. This provided the opportunity for repeated conversations, whilst recognising that these were in a formal context and were planned. Triangulation of data offered the potential for experiences to be analysed from a number of perspectives, thus increasing the likelihood of their trustworthiness as similar threads were identified. The use of peer debriefing whilst not ultimately confirming credibility should be taken seriously. The opportunity to consult with experts before, during and upon completion of the study allowed the developing work and subsequent findings to be exposed to scrutiny and comment. The various presentations of the work provided examination by wider audiences (see Appendix 8). This resulted in many experts voicing concordance anecdotally from practice, that the findings strongly reflected their experience of practice. Member checking by participants is sometimes utilised as a criteria for credibility (Sandelowski, 1993; Creswell and Miller, 2000; Carlson, 2010). This option was not taken in this study, not for any other reason than I felt ethically uncomfortable with it. I felt that those involved, especially the young people who were interviewed three times and observed, were in danger of being asked to contribute more than was reasonable given their heavy schedules of treatment.

3.6.2 TRANSFERABILITY

Due to the nature of the design and methods, thick descriptions were able to be generated. This resulted in a range of in-depth data extracts. These extracts therefore provided a wealth of information which would possibly have transferability across other cohorts. This was due to a number of nuanced examples which were common amongst participants and which further added to the possibility of transferability. The rich data extracts which were documented in the findings chapters gave the opportunity for

transferability to take place, which would perhaps not be an option if extracts were less dense in information.

3.6.3 DEPENDABILITY

As with validity, triangulation can go some way towards providing a pattern of replicated data which is comparable. The way in which analysis was conducted in the study involved coding all the material in the same categories and as a result of this it was possible to see the replication of different types of data within a set of results for each code, for each young person and then across participants as reports were compared. Unfortunately inter-rater reliability could not be used in this study as there was only one researcher. However, when all cases were written up individually, which included many data extracts in the form of NVIVO 10 reports for each unit of analysis, each one was shared with the supervisory team for discussion.

3.6.4 CONFIRMABILITY

In attempting to confirm the objectivity of findings, it was important to carefully plan and execute the study. An audit trail provided the basis for recognising the formal and planned nature of this process (see Appendix 9). As with other criteria triangulation whilst not claiming any truth did help to confirm that different types of data extracts mirrored each other. Importantly, objectivity was likely to be disrupted by researcher bias either relating to previously held values or to pre-conceived ideas about what people might say or how they might behave. In ensuring that this was minimised it was important to put mechanisms in place to assist in enabling reflexivity.

3.7 REFLEXIVITY

As part of my identification of themes I used memoing and free writing as a way of reflecting on each piece of data generated. However, this also served as a way of thinking about the impact that each experience had on me and alerted me to any issues I personally might need to pay attention to. Kleinsasser (2000) believes that in the pursuit of good research outcomes, researchers should participate in reflexivity. My reflexive

writing throughout the study relating to each data generating interaction, resulted in an excess of 40,000 words of thoughts, responses and feelings (see Appendix 10).

During the preparatory phase of the study, I had some fairly serious concerns about whether young people would want to become involved as participants. The reasons for this were multi-faceted. Primarily I worried about the wellbeing of the young people as I was aware that the context of the study might be problematic. Noting that they were in the midst of their treatment might mean that they would not be keen to take part. This could be because they were physically unwell and/or experiencing some psychological difficulties in terms of their diagnosis and treatment. This was despite the rigorous process of ethical approval and the agreement of health boards to grant me access to this group. These fears were very much of a personal nature and of not wanting to 'harm' any participants. As experienced as I was I felt like a 'fish out of water'. This fear proved to be for the most part unfounded.

I placed complete trust in my contact at the chosen study site who, adhering to the requirements set out in the ethical approval process, was the practitioner who made the first approach to potential participants. This particular practitioner assured me that her professional view was that young people would be keen to take part. She asserted that the reason for this might be that they had not been given an opportunity to discuss their experiences with someone outside the clinical team in a safe and confidential environment. I was also concerned that once they had committed to taking part, it may be difficult for them to continue if their symptoms or side effects were exacerbated significantly during the study period. Indeed this was the case in three out of the five participants who all experienced serious complications and/or severe side effects during their treatment. Throughout the data generation, I was always mindful of the need to ensure that each young person and those close to them who were affected by their situation were happy and able to take part. It transpired that there were a small number of occasions when I made a professional judgement not to proceed with data generation

based on conversations with some participants, instead we negotiated and rearranged another suitable time to meet.

The other concern centred on my own fear of harm and my experience of being a mother and how I might feel about what parents said and then think about how that would play out in my own life. In essence this was related to some of the challenges that I might face in hearing the stories of young people. These included being able to ensure that they felt able to express themselves freely, providing a safe environment and being receptive to cues that they may need in order to discuss their experience of being interviewed with someone else. In particular if the interview raised further questions for them which they wished to explore. These concerns were not just limited to the young people but to all the participants who were interviewed.

Throughout the study, I relied on both the support of my supervisors and a mentor who was not involved in the project but had research experience in palliative care and was working in the same university department as myself. I maintained the confidentiality and anonymity of the study participants when speaking with colleagues.

3.8 ETHICS, CONSENT AND CONFIDENTIALITY

Effective measures in terms of rigorous ethical mechanisms are essential to ensure that the public are safe when participating in research (Orb *et al.*, 2001). It is fundamental that research is both of a high quality and has the potential to make a difference to those in receipt of the health care which the research targets. Arguably much progress has been made from the time when research participants were exposed to blatant and serious harm for example in the Syphilis Tuskegee study which only ended in 1972 (Caplan, 1992). More recently there is a clear commitment to protection through transparent governance. The Welsh Government Research Governance Framework for Health and Social Care in Wales (2009) is an example of this commitment through public policy. More specifically, the Royal College of Nursing guidance (2009) for nurse researchers provides guidance and more locally there is the Cardiff University Research

Governance Framework (2010). In addition, procedures for safeguarding children and vulnerable adults set out by Cardiff University (2010) adds further protection to those who are young and vulnerable. In this document there is guidance for researchers whose work is concerned with children and vulnerable adults. Young people with cancer in this study were over 16 years old. However, one could argue that because they were still in transition from childhood to early adulthood they demonstrated vulnerability. Added to this they were undergoing cancer treatment and therefore this also impacted on them significantly.

Prior to the commencement of the study I had to meet with the requirements of the Health Research Authority, my proposed research had to be reviewed and approved by the university ethics committee within the School of Healthcare Sciences and through the national IRAS system. I also had to meet with the requirements of the Health Boards where the research was undertaken (see Appendix 11). As a single novice researcher this was at times a confusing and frustrating process which as is generally the case took a considerable amount of time (Tod, *et al.*, 2002; Howarth and Kneafsey, 2005; Fontenla and Rycroft-Malone, 2006). However, I understood that these safeguards were important in protecting those with whom I would be working.

The National Children's Bureau (2003) (NCB) published guidance on involving children and young people in research which refers to monitoring impact when undertaking research. It was important to ensure that recommendations contained in this guidance were considered throughout the research process. The NCB noted that one of the issues which may cause concern was distress when discussing sensitive issues, which may provoke a negative emotional response. This was something that I was acutely aware of when working with all participants in this study, not just the young people but their parents, friends and those involved in their care. On a number of occasions there was some distress when collecting the data and it was important in these situations to try and minimise harm by offering support to the participants concerned (Beauchamp and

Childress, 2013). Good advice on this is provided in a recent paper published by Coad *et al.*, (2014). The publication was issued during the completion of my data collection, I nevertheless considered the advice and reflected that I had made attempts to minimise distress appropriately. Moreover at the forefront of my thinking was the voluntary nature of the participation, the nature of how the disease and treatment affected people physically and emotionally and the utilisation of the interpersonal skills I had developed in my many years of practice.

3.8.1 CONSENT

Guidelines for conducting research with children and young people published recently make clear the important considerations required in gaining consent amongst vulnerable groups (Shaw *et al.*, 2011). They identify a number of issues, which apply in the same way in all aspects of consent for research. For example: the requirement for informed consent and the need to ensure that the participant fully understands what is involved in the study before agreeing to take part. It is important to be fully aware of a number of other matters raised relating to this group. The need to ensure that safeguarding procedures are applied when necessary, in particular for those under 18 years. The requirement to seek parental consent when young people are over 16 years but have a learning disability or where the nature of the study requires exceptionally sensitive information to be shared. Where observation took place I needed to be particularly sensitive in anticipating that the young person might be uncomfortable being observed despite giving consent. This could have resulted in needing to leave the setting. In conducting this study it was fundamentally important to be aware of these specific considerations. Other relevant associated guidance was also reviewed to clarify and support understanding of the process of consent (Department of Health, 2001; Department of Health, 2009; General Medical Council, 2007; Gibson and Twycross ,2007).

Using a template of Health Research Authority Guidance which had been approved by all the relevant bodies I requested the consent of all participants who took part in the study. Prior to consent, all potential participants were provided with detailed but easy to understand information about the aims, objectives and purpose of the study. The information sheets were developed with the help of a small group of young people. It was essential that participants had all the information that they needed to understand the study so that they could make an informed decision about participation.

I made clear the way in which the interviews would be conducted and clarified my role as a professional in the context of the research, ensuring that boundaries were understood. Understanding the need for professional boundaries is important in this field of practice and steps should be taken to ensure that the young person's best interests are protected (Davies and Wilsher, 2012). Participants were informed of the potential risks and benefits of participating in the research. They were also made aware that their participation was voluntary and that they could withdraw from the study at any time for any reason, which they did not need to disclose. Subsequently consent was sought on each separate occasion that I interviewed each young person.

I provided a point of contact for any questions participants had prior to completing the consent form. All participants completed their own consent forms. Potential participants were also given the opportunity to discuss the study with whom they wished, including parents and healthcare professionals, before they gave consent. A five day period was identified in the information sheet during which time they could make a decision about participation.

3.8.2 CONFIDENTIALITY AND ANONYMITY

Information provided by participants did not reveal their identity. This included the interpretation of all types of data received. Prior to consent to take part in the study all participants were unknown to me until they expressed an interest in taking part, at which

point I met them. All participants were given pseudonyms and these were used throughout the writing process.

Confidentiality was maintained throughout the study period and all records were safely stored in accordance with university procedures for management and data storage of research records (Cardiff University 2011). The maintenance of confidentiality is a cornerstone of all healthcare practice and as such forms part of the knowledge base of practitioners prior to entry onto professional programmes (Nursing and Midwifery Council, 2015). During the development of the study, information had to be provided to clarify what would happen if a disclosure needed to be made relating to a participant. Disclosing confidential matters with the consent of an individual always reflects best practice. However, if on any occasion it was judged that there was a risk of significant harm to the participant or wider public, in this instance the researcher could disclose information to a relevant authority without the participants' consent within the current legal frameworks in England and Wales. Participants were interviewed separately to protect their confidentiality and the requirement for confidentiality was fully respected. Participants chose the location of the in depth interviews, which they felt would be the most comfortable for them whilst taking into account the need for privacy and confidentiality (Griffiths and Tengenah, 2013). This arrangement was also applied to all other participants who were interviewed. Confidentiality was fully explained both in the information sheet and consent form and prior to each interview. The offer to answer questions confidentially was made following any interviews as a way of reassuring participants.

3.9 CONCLUSION

The purpose of this chapter has been to identify the ways in which the study was developed and subsequently undertaken. It began by considering the philosophical approach to the study by outlining the epistemological and ontological stance. This 'set the scene' for the subsequent development of the methodological approach which was

utilised and the design which was employed to collect and subsequently analyse data. Case studies traditionally use multiple types of evidence in gathering data and this was the case here. The development of the study used a number of engagement strategies and this proved to be very fruitful in determining the research objectives, the participants, including their age and the sphere of matters discussed throughout the study. The public engagement undoubtedly had a significant impact on the approach to the study and many of the people who contributed to this had either expert, family or indeed personal knowledge and/or experience in the field of teenage and young adult cancer care.

The analysis was developed using a number of tools and approaches. The interviews were subjected to qualitative coding using NVIVO 10 to enable data extracts to be placed in broad categories before being themed and discussed. This was carried out both within cases and across cases using participants from each case. The interpretive discussion which followed led to recommendations for future practice.

4. CASE STUDY PRESENTATIONS AND WITHIN CASE THEMES

4.1 INTRODUCTION

The aims of this chapter are two fold, primarily each of the five young people who participated and thus formed the basis of each case study will be introduced. This will provide the opportunity to contextualise each young person's background. An observational lens will be presented, which will provide a primary view of the young people and some of the significant others in their lives who also participated in the study. These included family, partners, healthcare professionals and friends. Staying true to the tradition of case study research, the chapter will also illuminate insights into the journey and trajectory of each young person's experience of cancer. This will be framed within the development of symptoms and subsequent treatment for their cancer, providing within case themes. Each experience was unique to each individual young person as was the experience of those others who took part in their case studies. However, there were elements of each of their accounts which yielded similarities.

In the subsequent thematic Chapters Five, Six and Seven, which immediately follow and again in keeping with the case study tradition, these similarities will be brought together to provide themes which cut across either some or all of the cases. These themes will offer important examples of cross case analysis, which will provide a catalyst for in depth theoretical discussion, following the presentation of all the results generated from the study. Extracts from the entire data set will be drawn upon and will include verbatim elements of conversation during interviews with not just the young person but with the others already mentioned who took part. Other extracts from field notes following observations of consultations with young people will be utilised as will written records from each young person's medical notes.

The stories which follow are just brief glimpses of the trajectory of each young person's experience of cancer. Illustrative examples are provided which represent key aspects of each journey.

4.2 ELLEN: CASE STUDY PARTICIPANT 1

Soon after gaining ethical approval and permission to access participants in the chosen health boards, I was informed by my contact that Ellen might be a suitable young person for invitation to participate in the study. This was in late January 2014. Ellen had been spoken to privately and confirmed that she would take the information sheet away with her and would make contact within a week. She agreed to take part and through my contact we arranged a suitable time to meet. I began the data generation in February 2014 and this was completed in July 2014.

4.2.1 BACKGROUND

Ellen was a 21 year old young woman who had been brought up in a suburb of a city in a small bungalow by her parents. She was educated in a local comprehensive school through the medium of Welsh. She was an only child with a small extended family. Her parents Phillip and Christine were experienced teachers and both were working in the local comprehensive school where they had been employed for many years, this was a different school to the one that Ellen attended. Ellen had enjoyed school and had a small number of close friends. She excelled academically and had chosen her A-level subjects independently of her parents with a view to studying architecture at university.

Ellen had chosen to leave home to attend university and moved many hundreds of miles away as a result of this decision. She achieved her predicted grades and began her degree programme in September 2011. Ellen had a quiet, unassuming character and she showed me photographs of herself before she was unwell. These were at social events where she looked happy. She had shoulder length brown wavy hair, and an impish face. Ellen was a talented artist and enjoyed painting, to which I will return later. This was partly the reason for her choice of architecture as a degree. However, when she went to university, she very soon realised that this was not the right programme for her and so transferred to civil engineering during her first term. Again she did this independently and did not inform her parents until after she had swapped programmes.

Whilst at university she had embarked upon her first serious relationship with Nigel and this was ongoing throughout the duration of the data generation period.

4.2.2 DEVELOPMENT OF SYMPTOMS

During her second year at university, at the beginning of the second term, Ellen began to experience pain in her left shoulder. Her previous medical history was unremarkable. She developed many symptoms during the months that followed and although she visited her GP several times a diagnosis was not established. Despite this her symptoms worsened and she was diagnosed with a haematological cancer after returning home in the summer of 2014 and following the intervention of her father. Unfortunately Ellen did not have an uneventful experience and suffered a reaction to one of the medications in her treatment programme. This resulted in a 'stroke like' event which rendered her at one stage completely dependent on others for all of her functioning. When I first met her she was unable to walk more than a few steps, her speech was altered and she had generalised muscular weakness. As a result of her protracted and complex trajectory eight themes were identified, these formed the basis of the within case in terms of Ellen's experience (Figure.4.1).

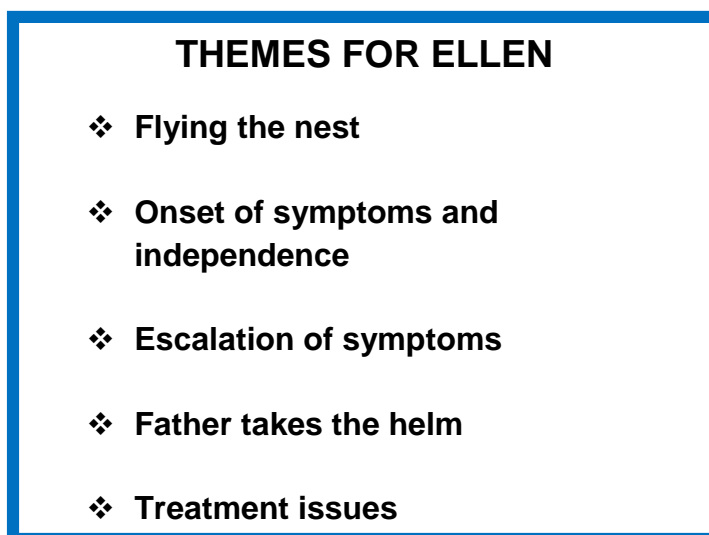


Figure 4.1. Identified themes for case study subject 1 (Ellen).

4.2.3 FLYING THE NEST

Ellen, like many other young people was eager to pursue her plans to attend university and was keen to leave home. She discussed this during the early part of her first

interview and it was clear that it had been important for her to leave home and to start to become more independent. Ellen's father also talked about this in his interview:

Well several universities offered her places but she ended up choosing (university). Umm she wants to experience other parts of the country and this that and the other and independence so fine she chose architecture in (university) (interview with Ellen's father Phillip pg.2).

Ellen's father displayed pride for his daughter throughout our discussion and was keen to support her in her desire to leave home. He recognised her growing need for independence and that she wanted to make her own decisions about what she wanted to do. Whilst she had been very close to her parents, spending a lot of time with them, her father was excited at the prospect of her undertaking her university education and being an autonomous adult. This was also an exciting time for Ellen as she planned independent living and the prospect of working towards a career in architecture.

4.2.4 ONSET OF SYMPTOMS AND INDEPENDENCE

When Ellen's symptoms began to progress she was not keen to lose control of her situation and even though she was beginning to feel very unwell, she retained her personal agency and choice and stayed at university. She was determined to keep going and complete her second year culminating in her end of term examinations, despite her state of health:

and then it (the pain) just kind of spread all throughout my body and this hand started to get painful. I couldn't dress myself. It would take me an hour to get dressed. I would have to get up an hour earlier, an hour earlier than usual (interview one with Ellen pg.12).

Although Ellen was struggling to complete her daily activities, she made adjustments so that that she could remain independent. This continued throughout the spring and for the most part of the summer in 2013. During his interview, Ellen's boyfriend Nigel expressed his despair at the continuing deterioration in her health and was very explicit about how much he tried to help and advise her and in doing so take some control of events. Nigel although at university with Ellen had decided to live at home with his parents. He became

so concerned about Ellen that he confided in his mother who herself suffered from a long term condition. However, Ellen did not accept the help of either party.

4.2.5 ESCALATION OF SYMPTOMS

From March until the time that Ellen was diagnosed, her symptoms continued to worsen. This marked a time of change in terms of the personal agency that Ellen had relating to her health and her everyday life. As her condition worsened she began to lose more control of the unfolding situation. Most of this was related to the fact that she was unable to physically cope with the demands of everyday life. However, there remained a number of examples of her 'holding 'on to her free will to make decisions. Her boyfriend Nigel played a key part in this phase as she remained at university during this time:

Yeah, yeah, well, I was on the phone to her because after the exams, I can remember, I got a phone call from Ellen and I couldn't really make out what she was saying because she was in absolute agony. She was like screaming and I said Ellen, Ellen 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 Nigel, I am going to go and get her and I was like ok mum just wait you know, so Ellen, really stubborn didn't want to impose (interview with Ellen's boyfriend Nigel pg.12).

This data extract reflects one of a number that were related to the time prior to diagnosis. Ellen had several phone calls with her father in particular, where he encouraged her to keep going to her doctor's appointments. Her priority however, was to attend her lectures and to complete her second year exams. She managed to achieve this and was successful in all her second year examinations. However, when she returned home in the summer of 2013, her father began to take control of the situation.

4.2.6 FATHER TAKES THE HELM

Ellen's father taking control was pivotal in reaching a diagnosis in Ellen's case

She was getting ripples in her muscles all the way down her back...so they gave her, I call them tranquillizers but I can't remember the actual name of it...again it's a morphine base type of tranquillizer but of course they weren't having any effect, it wasn't, it was the wrong meds for the actual diagnosis so after a couple of weeks it was, ok we have done three out of hours surgeries and we have done three lots of that so I got a consultant's name (interview with Ellen's father Phillip pg.6).

Despite her father's interventions, a number of appointments were required before Ellen's diagnosis was confirmed. This was of course a very worrying and anxious time for Ellen and her family. Once Phillip and Christine were aware of the diagnosis, Phillip said that he decided to obtain some information from the medical team before discussing matters with Ellen. He openly shared with me that there had been no negotiation about this, he had made a judgement that this was the best way forward and that what he was doing in gaining information first, was in Ellen's best interests. During discussion with Ellen she too mentioned this and agreed that this strategy had been the best course of action at this time. The doctor, she said, had also told her father that she only had weeks to live. If he had told her this Ellen commented that she would have 'freaked out'. Consequently although matters were outside of Ellen's control and there had been no negotiation with her about aspects of what was happening, she appeared happy to relinquish this in favour of accepting her father's help and guidance. This provided an example of the structural power in the notion of family and Ellen's father acting as a proxy agent, although not with her knowledge.

Her father in particular was central in sometimes taking the lead on matters in terms of treatment and this was also evident during outpatient consultations when a discussion about some of Ellen's medications took place:

Phillip again spoke and said that he realised the importance of this (drug) long term and would prefer if they just continued to work on the blood count. He then immediately asked whether Dexamethasone pushed the neutrophils up. The consultant replied a little bit. Phillip said that this happened the last time after 'dex' after which he laughed rather nervously... Ellen did not speak at all during this period and as in other consultations I found it hard to grasp the meaning of this conversation and wondered if Ellen felt the same. It was impossible to tell as she did not take part in any of the conversation. Dad looked across at me for a moment and then back to the consultant (observation one field notes Ellen pg.3).

4.2.7 TREATMENT ISSUES

The early part of treatment was demonstrated in Ellen's vividly illuminated excursion below showing the lack of choice and control that she possessed at this time. In her first interview Ellen outlined some of the things that happened:

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 and umm I have lots of err with my veins. I have problems with my veins like they can't find a good vein so umm err my skin was bruised, my feet were bruised because they couldn't find a suitable vein and so I couldn't have a PIC because I was on steroids at the time...and that apparently affects something to do with the heart...so I couldn't have a PIC line...even though I really wanted one...I hate needles, so I had all the treatment and the induction and umm that leads to consolidation and I was beginning to lose sensation in my leg and my arm like a tingling feeling... and umm I thought oh well everyone gets it and everyone does it' (interview one with Ellen pg. 17).

She however, understood that this was necessary if her treatment was to be successful. Nevertheless, the lack of personal agency in this extract provides a stark picture of the limitations that one must accept during treatment. Undoubtedly it is the case that treatment is intensive and there are many challenges in the administration of treatment. The situated context of treatment though provides such a significant contrast to the 'life' that was before diagnosis and seems very far removed in Ellen's case from flying the nest to an independent life.

4.2.8 CAN I HAVE A CHILD?

There were a number of other issues over which Ellen had no control and therefore no personal agency during treatment and some of these concerned her life outside of treatment. Amongst these was the fact that her fertility was likely to be affected as a result of her treatment. Her father also commented on this as a decision over which she had no choice. This was something that she found very difficult to accept. She talked about how it felt when she received this news:

I always wanted children umm and when I was younger I would always say I will never have any children, never have any children but when that's taken away from you, you have no control over it you know it's not your decision it devastates you (interview three with Ellen pg.9).

Unfortunately this concern was soon not a priority as Ellen had a severe reaction to one of her medications. As a result she went to her local emergency unit where her condition deteriorated dramatically. This culminated in admission to the intensive care unit in the hospital where she was receiving treatment for her disease.

4.2.9 THE SLIPPERY SLOPE

In this instance her ability to exert any choice or control over decision making was absent as she was entirely dependent on her family and those who were professionally involved in her care. Ellen very dramatically shared her thoughts at this time. This really illuminated how compromised her personal agency was during this period:

I couldn't move so I ended up peeing my pants and at that point I didn't have any control of my bladder and I couldn't control my bowels so I also pooped but that was in the ambulance on the way to (the unit), all my organs were slowly shutting down and I was screaming in agony and I didn't realise that my brain got inflamed and basically my brain, the back of my brain was shutting down block by block. So I couldn't talk (interview three with Ellen pg.3).

The physical effects of treatment rendered Ellen completely dependent on others for her survival at this point. The nurse who was immediately involved in her care at this time though was keen to point out that she did not act alone in making decisions about how to effectively manage the situation. Instead she utilised the support of those closest to her. This manifested itself as an example of collective agency between nurses and her parents, assisted by helpful judgement of the nurse involved:

umm when Ellen came into us she was very unwell, I was the person on that day and I was involved in... basically she couldn't make any decisions so it was mum, dad and myself and the doctors decided what we should do and how we should do it because she could just not communicate with us at all (interview with Ellen's nurse pg.2).

As a consequence of this very serious event, Ellen's treatment was suspended. Her recovery was very gradual and protracted and Ellen faced many challenges both physical and psychological during this time. Her dependence on others was significant for several months and when I met her in February 2014 she still had limited mobility and required considerable assistance. As time passed she made some progress and at our final interview in July 2014, it was very encouraging to note that Ellen was beginning to regain control of her personal agency again.

4.2.10 PICKING UP THE PIECES

Her progress in terms of control in decision making was particularly with reference to her future life outside of treatment. It was clearly something that was important to her and she was very clear about her intentions:

so at the end of next year by august next year I will have to make the decision whether or not I want to continue with civil engineering or basically drop out of university those are my two options they only gave me two years as an interval and if that is their policy then fair enough then I have got to follow their rules umm, so I decided after the end of the two years I would go back to university I have decided that, that's definite (interview three with Ellen pg.4).²

It was clear in this interview, not just in terms of returning to university but in other aspects of her life, that Ellen was determined to achieve some personal agency in her forthcoming trajectory. This was however an aspect of her life which not unreasonably worried her parents. We concluded our discussion together with Ellen sharing with me a painting which she had managed to complete as she recovered from what was a very difficult period of her journey. The painting at the beginning of this thesis exemplifies the myriad of feelings that she had at this time and it illuminates in some ways the fluctuating level of control which she had at this point in her life.

4.3 SAM: CASE STUDY PARTICIPANT 2

At an early stage of data generation I was made aware of Sam by my contact at the study site. His circumstances were different to Ellen as he was undergoing a second round of treatment for his cancer following a relapse after the first course. However, he was still undergoing curative treatment and so therefore could be considered for entry into the study. My contact said that she was not sure if Sam would want to take part as he was a young man who very much 'kept his own council' and did not talk much to anyone. However, having discussed and read the information sheet, he agreed that he would take part. I began to work with him in March 2014 and his data set was completed

² During the final interview I was aware of how many times Ellen repeated her intentions to return to university and this came across as a real need to assert her personal agency, she really demonstrated a desire to have control of this aspect of her life (reflection, interview three with Ellen pg.4).

in September 2014. He was still receiving treatment relating to his bone marrow transplant at this time.

4.3.1 BACKGROUND

Sam was a 20 year old young man who had been brought up in an affluent area of a different city than Ellen and had been privately educated. He was the middle child of three and had an older sibling, a sister who was a teacher, who he was close to in age and a younger brother who was 8 years his junior. He had quite a large extended family with several aunts and uncles and a number of cousins. His mother, Linda worked as a GP in a local practice and his father was a partner in a firm of solicitors. In his extended family there were others who worked in various healthcare fields which included medicine.

Sam had done very well at school academically and had planned to go to university to study ancient medieval history. He was fond of reading, gaming and playing bass guitar. He had formed a group with some friends and this was something that he was very enthusiastic about. His mother had encouraged him to undertake a range of outdoor activities as he was growing up and this included, kayaking which he had enjoyed. Sam had a reserved nature, he was gentle and modest. His interest in all things musical reflected his dress sense which was almost always T shirt, jeans and trainers sometimes with a motif on the T shirt which bore a reference to music in some way. As a younger teenager Sam had been diagnosed as having a hearing difficulty and this might have contributed to his quiet nature. He informed me in his interviews that sometimes he would try to lip read to some extent so that he could understand and participate in conversations. Although at Sam's school he told me there was an expectation that he would go on to become a doctor or a legal professional, he pointed out that this was not what he wanted. He was really interested in ancient medieval history and as a result focused his A levels accordingly. Whilst he was at school he met and got to know a girl, Harriet, who he began having a relationship with when he entered the sixth form at

school. He had subsequently continued this relationship and it was ongoing throughout the period of data generation.

During the spring of 2012 Sam was preparing to undertake his A level examinations prior to going to university in the September of the same year. He had spent some time thinking about where he might go to university and his first thoughts were that he would move away from his home city. Unfortunately once he was diagnosed a bit later in the same year he was unable to enrol at university due to him requiring treatment for six months. During this time his girlfriend Harriet decided that she would change her plans and attend the local university. She commented that this was partly to do with Sam and his illness and partly because she felt that the local university was of better quality than the one she initially intended to go to. Consequently Sam had changed his mind and had decided that he would also stay closer to home once he had finished his treatment and attend university at the same place as Harriet.

Sam was subsequently diagnosed in the summer of 2012 with a solid tumour. Sam successfully completed his treatment after six months, finishing in December 2012. Unfortunately he relapsed within a year following this and was undertaking treatment to try and alleviate his disease prior to undergoing a donor bone marrow transplant during the period of data generation. During this process five themes were identified (Figure.4.2).



Figure 4.2. Identified themes for case study subject 2 (Sam).

For the most part, the data generation relating to Sam was concerned with his relapse and subsequent preparation for bone marrow transplant as this was what he was experiencing at the time of his participation in the study.

4.3.2 MUM KNOWS BEST

One aspect of his journey that he talked about was the development of his symptoms on the first occurrence of his disease and subsequent diagnosis. Sam first began to feel unwell as he was undertaking his Queens Scout award. He had to complete a lengthy walk and felt really fatigued when he returned home, he paid little attention to this and this indifference continued even when he developed further symptoms:

umm well I don't think, I think I must have mentioned it to my mum but I didn't make that much of a thing about it and I was uhh I think I complained more about the itching because I was really, really itchy and I think I looked up and diagnosed myself (interview one with Sam pg.11).

Sam explained how the self- diagnosis had given him three options of what his symptoms might mean. He concluded that it might be anaemia. The other two options one of which was cancer did not worry him as he believed that what was happening would not be serious. What happened next was a form of proxy agency on the part of Linda, Sam's mother. Sam began to worry that whatever was happening to him was not 'going away'. At this point he was in the middle of his A level examinations and asked Linda, his mum,

to take some bloods from him which she agreed to. As a consequence of the blood results, Linda realised that all was not well and that he possibly might have some type of malignancy. This was sadly confirmed soon afterwards. However, Sam's mother chose not to disclose this news to him until he had finished his examinations. It was as though she was attempting to maintain his personal agency for what she thought were the best reasons. She did comment in her interview that to have the burden of dealing with cancer and having to take his examinations at a later date would be a double blow for Sam and that this was something she felt would have caused further distress for him. The teachers at Sam's school however had a different view but Linda was adamant about her decision which she felt would enable him to continue:

Linda: it's quite interesting because what happened was school thought the best thing was to not do his exams because they felt that if he did the exams, the universities could say he'd had a go

JD: yes

Mum: and then umm he was ill by now

JD: yes

Linda: they'd seen him in the exam room and he was hardly typing anything because he was so ill

JD: aww

Linda: and so they thought best not to do the exams and it will be perceived that he had one attempt and they might want him to get even higher grades the next year round

JD: okay

Linda: and I came over quite clear which was unusual for me, I just sat there and said I'm awfully sorry he's doing them because of this business about resitting which I couldn't face (interview with Sam's mother Linda pg. 15).

Subsequently Sam did sit all but one of his examinations before his mum disclosed his illness to him. He communicated to me that he was glad that she had done this as he managed to get 2 A grades in the ones he sat before he knew and a C grade in the last one when he was aware of his illness. When Sam experienced symptoms again (in the form of lymph nodes in his neck) as his disease returned he did confide in Linda and again asked her to take bloods, which she did. However, these were normal and his

recurrence was only confirmed when he attended his outpatient appointment on his own whilst his parents were away on holiday. His mum though had put support in place by phoning Harriet's mother to tell her that he had an appointment. Linda did not disclose that Sam was aware of this:

I did ring Harriet's mum before we went to (name of country) and I said Sam is going into the clinic tomorrow. I'm sure everything is going to be fine it's a bit like an insurance policy but just to let you know just so you are aware (interview with Sam's mother Linda pg.28).

Throughout Sam's journey Linda seemed to be central to organising, protecting him and acting as a proxy agent in decisions. However, there was some complexity in this picture.

4.3.3 SENSORY IMPAIRMENT A HELP OR A HINDRANCE?

Sam's hearing difficulty meant that it was problematic to know whether he was not exerting choice and personal agency because he did not have the desire to do so or that he was not sufficiently able to participate fully in conversations. In contrast this could have been that he made a conscious choice to not engage in conversation as a way of closing down and taking control in order to cope with his situation. This was illuminated at an outpatient appointment I attended with him and Linda prior to his transplant:

He began to play a computer game immediately and did not have any conversation with us until we went into the consultation. There are two points of interest here. Sam is partially deaf and so sometimes finds it difficult to engage in conversations. However, I wondered whether sometimes he chose to close down conversations because he wanted to focus on his treatment and this was a way of coping. The game provided him with an appropriate way of doing this without appearing to be not keen to talk (observation one field notes Sam pg.1)

Similarly there were other extracts which supported this during data generation, one in particular from his girlfriend Harriet spans both his hearing difficulty and the central role Linda played in his situation:

umm he leaves a lot of decisions up to his mum. I think, I think also the hearing thing, I think maybe he doesn't want to hear it that much, he doesn't listen to their meetings and stuff like I ask him like what did they talk about and he says I don't really know but umm maybe he doesn't want to talk about it with me I'm not sure (interview with Sam's girlfriend Harriet pg.2).

Another response from the nurse who was involved in Sam's care could also be interpreted in the context of his hearing difficulty and whether or not he wanted to have a conversation.³ In this extract he also had another tool which he potentially, it could be argued, used to exert his choice:

Just small talk, I will ask him how are your family, what have you been up to how is the girlfriend and...but otherwise I think he likes to focus on his reading (interview with Sam's nurse pg. 9).

Despite these instances he was able to exert some control and personal agency in terms of his everyday functioning both during and following his transplant procedure.

4.3.4 TREATMENT CHALLENGES THE SECOND TIME AROUND

When he was admitted for the transplant, he had to spend a lengthy period of time in isolation due to the nature of the treatment, which compromised his immunity. This constraint appeared to be enforced more following the transplant. However, before he underwent the procedure he was not keen to follow instructions, instead he took matters into his own hands in personal agentic terms:

I tried to go to the toilet in the, because you are meant to just go in the bottle umm and I didn't really like that idea anyway so I did try to use the normal toilet which was umm it was, I was given my own room and umm it was out in the corridor outside the room so I tried to use that as often as possible (interview three with Sam pg.3).

This level of personal agency continued to be a feature of Sam's behaviour as he recovered from his transplant and he was able to look forward to piecing his life back together.

4.3.5 THREE FALSE STARTS

In all Sam had attempted to go to university on two occasions and he had not managed this. He had also been told that following his transplant he would need to wait another year before embarking upon his degree. This amounted to three false starts technically.

³ *I thought about having a sensory impairment, and how difficult this might make communication during illness. I also thought about how much could be missed by a young person in terms of information if they did not disclose their hearing impairment. It was of course impossible to know whether Sam purposely 'chose not to hear' (reflection, interview with Harriet pg.1).*

He was therefore thrilled when the medical team changed their minds and said that because he had recovered so well he would not have to wait. He spared no time in making choices and taking control of this. He talked avidly about the arrangements that he was making in order to ensure that he had covered all of the practical aspects involved in getting back on track:

umm I had to email my old personal tutor to ask him what should happen and because it worked out quite nicely in that the university system still had me to come back in September or well late September so in late, so I didn't have to do anything there, I, the main thing really was student finance umm yeah student finance was the big one umm I had to, I had to remember all these details about student finance (interview three with Sam pg.9).

As well as this aspect of his life he also made a decision to move out of his parents' home. He had been living with them throughout his illness and following his bone marrow transplant.

4.3.6 HOME SWEET HOME

Sam was determined to have his own place sharing with a good friend. Whilst Linda had her concerns about this she recognised that he needed to exert some choice and personal agency in his life. Harriet outlined perfectly his desire to exert choice coupled with him taking responsibility for his health:

I think he actually wanted to move out more than he was letting on and then they (he and a friend) were looking for flats and he kind of like had hygiene, like he had to think about hygiene because a lot of the flats were like grimey flats and yeah we're like giving him advice like don't get the ones on uni road because...and umm eventually he went for quite a posh expensive one which has apparently got no mould problems or anything (interview with Sam's girlfriend Harriet pg.4).

Sam was really focused on building his life beyond his cancer and whilst he was aware of the limitations, particularly with reference to his early recovery, he was keen to have his life back and to move forward.

4.4 WILLIAM: CASE STUDY PARTICIPANT 3

During spring of 2014 my contact at the study site once again got in touch to say that there was another young person who might be interested in taking part. The young man

in question had a different trajectory to the first two participants but his cancer was still one of the more commonly occurring, according to the previously cited UK cancer statistics for the 15-24 year age group. He was the first of the participants who had undergone surgery as part of his treatment. He was approached as was the usual procedure by the identified contact. Following discussion a couple of days later he confirmed that he was keen to take part. I commenced data generation with him in April 2014 and this was completed in August 2014 following his completion of treatment in May.

4.4.1 BACKGROUND

William was a 20 year old young man who had been brought up in a small city on a large estate of private contemporary houses. He was an only child and had attended a local comprehensive school until he was 16. He then attended another school which incorporated a national cricket academy, where he continued to undertake his education and received a coaching programme to enhance his development as a cricketer. His mum, Julie, had worked for more than 20 years as a nurse in an outpatient department at the local university health board and his father, Martin had worked for many years as an upholsterer in a small company. More recently he had begun to work for a large furniture manufacturer. Although William had a relatively large extended family, he did not see many of these relatives very often.

William had performed well in his GCSEs and had chosen to undertake a BTEC diploma in sport, a vocational qualification which has comparable points to A level qualifications enabling young people to progress to university if that is their intention. William had not been sure about his own path and had therefore finished his time at school and was in the midst of deciding what he would do when he became unwell. William was extremely tall with very dark thick hair, although I only saw this later on in the study as he had lost his hair as a result of treatment when I first met him. His love of sport and cricket in particular was obvious. He also enjoyed playing the guitar and listening to his girlfriend,

Lucy, singing. They had met during his last two years of school and their relationship was ongoing throughout the data generation. He had a really casual style in terms of his dress which usually involved wearing shorts most of the time, including at his outpatient appointments. The relevance of this and his determination to continue making this choice to dress as he wished will shortly become clear.

4.4.2 DEVELOPMENT OF SYMPTOMS

William began to feel unwell just after Christmas in 2013. He was attending winter cricket training and was experiencing pain in his left knee. At first he thought that this was due to a muscular injury. He did mention it at home to his parents but did not worry about it. The symptoms did not subside and so he was referred for physiotherapy as an outpatient. Unfortunately following treatment he was still not making progress at which point William's father became involved. As a result of this William was diagnosed with a solid tumour of his knee. William underwent two cycles of chemotherapy prior to an above knee amputation followed by a further four cycles of chemotherapy. I met him when he was undergoing the post-operative chemotherapy. Five themes were identified for William during data generation (Figure.4.3).

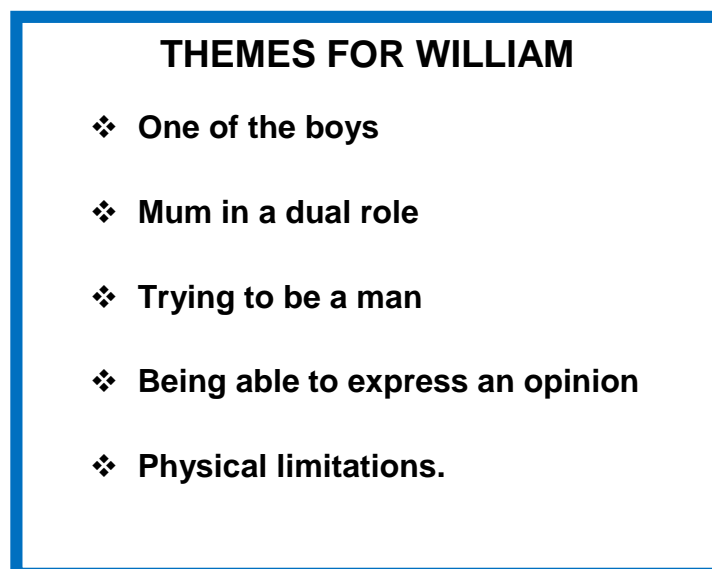


Figure 4.3. Identified themes for case study subject 3 (William).

As with the first two cases thus far described, the development and progression of symptoms marked a turning point in the lives of the young people in this study. The continuous trend of their growing independence was evident in their life course and William was no exception. He was an independent young man and this had been a feature of his life throughout his earlier teenage years. Both of his parents worked full time and he had adjusted to his situation accordingly.

4.4.3 ONE OF THE BOYS

As William matured and his cricket began to take centre stage his independence and personal agency continued to grow and he chose to leave school. This was evident in the interview with his parents:

I just knew he would be happy doing that whereas if we made him, well we couldn't have made him but you know, if we said no you're not going and he had to stay at school he would have probably might have rebelled and not have got anything from him so umm yeah and I think the cricket and obviously was the big factor for William (interview with parents (Julie mother) pg. 5).

This was referring to his choice of the cricket academy, which his parents were not particularly happy about. However, when he developed symptoms and following his own attempts to sort things out (he always visited the physiotherapist alone), Martin, his father intervened acting as proxy agent. He made a decision that the best course of action would be to take William privately to see a friend of his who was a physiotherapist. It then transpired that Martin's friend was very concerned and said they should request a scan, which William's parents then paid for. This led to his subsequent diagnosis. Although similarly as with the other cases, William was happy for his dad to take the lead in the situation:

William: yeah basically so he decided then to send me to a (name of physiotherapist) which is a sports physio that he knows from when he played rugby

JD: oh really

William: yeah

JD: ok so he had a mate basically?

William: yeah private physio

JD: so your dad made that decision?

William: yeah basically yeah I had never heard of this (name of physiotherapist) before

JD: but you were, you were more than happy to go along with that

William: yeah I wanted to start playing (cricket) again (interview one with William pg.21).

What appears to be key in the pre-diagnostic stage in terms of William's experience comprises a strong element of independence which developed at an early age. This continued when he first became unwell. His parents continued to work and he was able to manage his treatment as he was able to drive and so attended his physiotherapist appointments in an attempt to sort matters out. However, he arrived at a point where he had neither the knowledge nor the means to decide the next course of action, which is where his father became prominent in the decision making. Once William was diagnosed, this lack of choice and control was significantly exacerbated particularly because of his physical limitations.

He was unable to mobilise and used a wheelchair prior to his amputation and following this surgery in October 2013. He then underwent a lengthy period of recovery and rehabilitation, when he was treated with further cycles of chemotherapy. He was however still keen to make choices and assert his personal agency, particularly in relation to his love of cricket. This was illuminated by his friend who he nominated for interview:

and another thing that I have just remembered that he came in his wheelchair he went to a 20, 20 umm our midweek cricket team we got a load of tickets and he came in his wheelchair which was...(interview with William's friend Nathan pg.18).

Nevertheless dependence and lack of choice was inevitable given the situation.

4.4.4 MUM IN A DUAL ROLE

William's mother immediately took time off from her job as a nurse for the duration of his treatment. She was very involved in his care and whilst William clearly appreciated her help, the nurse who was interviewed in relation to William's case noticed that this was sometimes a source of frustration for him in which his personal agency was restricted:

William's Nurse: It was it was very intensive, umm (mum) kept a very good eye on William...you would see him roll his eyes sometimes and she knew it was a rolling joke

JD: so what do you think that means that she kept a good eye on him?

William's Nurse: I think she, she was very cautious of him, she knew what she was observing for in terms of whether he was ill or not. She would monitor his weight quite closely and things like that, she would monitor his eating and drinking, she was very good at that (interview with William's nurse pg.5).

Despite the severe limitations on his life William gave the very strong impression that he was determined to take back control of his personal agency and move forward.

4.4.5 TRYING TO BE A MAN

Commonly those who were involved in data generation in his case commented on

William's 'forward looking' attitude and his desire to return to his everyday life:

William was very much a go getter, he didn't let that stop him prior to amputation he was already looking up ahead of how he could get back into his cricket and things without it phasing him (interview with William's nurse pg.3).

This extract typifies William's attitude to his illness and his determination to 'get back in the driving seat' literally. Receiving his new, adjusted car would provide the stepping stone to creating his future destiny and the capacity for future personal agency. William very much viewed himself as a man and was mature in his approach to life. He had been independent from an early age and the evidence provided in terms of trying to stay on top of things and take charge of his life after cancer demonstrated this. He said that he was very keen to not ask for help and to do things for himself, particularly with reference to his mobility.

4.4.6 BEING ABLE TO EXPRESS AN OPINION

This was an important consideration for William and for the most part he commented that his opinion was valued in terms of his care and treatment. However, as with all the other young people in the study his treatment protocol rendered him with a degree of vulnerability as his personal agency was limited. This was further complicated by his lack of mobility in the early stages following his amputation. Subsequently at the end of his treatment protocol he was provided with an opportunity for strong personal agency, which was something he appreciated. As part of his treatment protocol he was offered the opportunity to not have the last dose of part of his chemotherapy and he was keen to take advantage of this. The consultant talked about this with him in a subsequent outpatient appointment:

The first discussion was triggered by mum before any questions were asked. She thanked the consultant for the fact that he had reduced William's dose of Methotrexate in his protocol and so he had not had to have the last one. Methotrexate was one of the drugs he liked least so this was welcome news. The consultant said that

*"there was no evidence that the extra dose would make a difference."
(observation one field notes William pg.2).*

Whilst it was William's mother who commented on this directly, I observed a strong non-verbal message that he had felt respected by the consultant and equally the consultant nodded to him that he was happy for him to make this decision.

4.4.7 PHYSICAL LIMITATIONS

Undergoing an amputation clearly had a significant effect on William's life. Before his cancer he had been a keen sportsman and had been fully independent in terms of mobility. He was enjoying driving and this added to his ability to not rely on anyone as he experienced everyday life. Once again his determination to return to his independent status and be viewed as a man was evident in the data set. This applied very clearly to his relationship with his girlfriend. Soon after his treatment finished he took a holiday. Although his parents were slightly ill at ease with this he used his personal agency to make a decision about the holiday. He said that his parents would have preferred that

he went with them on his first holiday after being ill. Nevertheless undoubtedly there were difficulties which he had to navigate whilst on holiday, thus demonstrating that his independence and choice was limited:

We went to a four bedroom villa with a swimming pool so during the day we didn't need to move anywhere just stayed in the garden...we got taxied everywhere because it was quite a long walk to the beach and to the nearest town but in town I would just use one crutch like a walking stick kind of thing. It was quite difficult because all the paths were all cobbled roads so that was quite difficult to walk on (interview three with William pg.1).

Despite these limitations William was able to begin to negotiate his way through adjusting to his new situation. As I stated in the opening part of his story, he was back in his shorts as most sportsmen are when I met him at his outpatients appointment.

4.5 LEAH: CASE STUDY PARTICIPANT 4

Leah was the youngest participant, at 16 years of age, who agreed to take part in the study. As part of the sampling strategy and following discussion with experts in the field, I had decided to include a young person who was being treated for a rare cancer in the 16- 24 year age group. As discussed earlier in this chapter it was likely that the experience of a young person whose trajectory was arguably less predictable would add further variation to the sample and provide an opportunity for generation of rich data that might not be illuminated in other participants. Leah had to undergo a particularly challenging treatment programme and I was concerned that taking part in the study might be an extra burden for her. Subsequently a lengthy discussion took place between my contact and I in the study site. In all of the other cases, the consultant who was looking after each individual had been made aware of their participation and had been happy for me to proceed. In this case however, I was keen to have further discussion with the consultant looking after Leah to consider her potential participation. The consultant felt that it was appropriate to approach Leah, with the reassurance that any consent could be withdrawn without reason if she decided not to complete the data generation. Leah was approached and subsequently decided to take part. The data generation began in July 2014 and was completed in February 2015, at which time she was still receiving

treatment. This was a more protracted period of data generation because of the challenging nature of her treatment. There were occasions when I planned to generate data and this was not possible, resulting in a need to re-arrange suitable times.

4.5.1 BACKGROUND

Leah was the eldest of two children, she had a younger brother who was in high school. Her parents Janice and Kevin had divorced 12 months prior to her diagnosis and this had been a very difficult time for all the family. During the study they would not visit at the same time. Instead they would stay with Leah for two days each and would not exchange any conversation, one parent would leave the unit and the other would arrive separately. Leah was in the middle of studying for her GCSES and was doing well at school. She had a small circle of friends and enjoyed rollerblading and going out with her friendship group. Her real love however was reading. She had a slight build and a quiet nature but she was fun loving and enjoyed a joke. She had a steely determination about her and did not give the impression that she could be easily swayed if she did not want to agree to something. She laughed nervously and said 'no' when I asked her if she had a boyfriend.

4.5.2 DEVELOPMENT OF SYMPTOMS

Leah as with the other cases had been unwell for several months before her diagnosis with a range of what could be described as vague and sometimes minor symptoms. Her mother Janice thought that it could have been as long as a year. She continued to attend school and demonstrated strong personal agency during this time although this diminished dramatically as time progressed because she felt so unwell. She was eventually referred to the specialist treatment centre where she was diagnosed with a stage four solid tumour in May 2014. During the data generation six themes were identified (Figure. 4.4).



Figure 4.4. Identified themes for case study subject 4 (Leah).

4.5.3 FINDING MY FEET

Leah was at the stage in her development towards adulthood where she was just ‘finding her feet’. She was beginning to socialise independently with friends and coming towards the end of her high school education. Although her parents had divorced recently and she had not had much involvement in the decision making about where she would live, she seemed satisfied with the arrangements and saw both parents regularly. She had chosen her subjects for GCSE without any resistance from her parents, they had not pressured her into doing anything that she did not want to do, which arguably demonstrated their trust in her ability to choose her options:

umm well I got given a booklet, things with columns and I could choose the subjects in the columns and I think we were told whatever subject we liked but then I had trouble because I didn't know whether to take art or catering and then who was it, yeah I think and then decided to take catering and it wasn't much, my parents didn't really have much input because they like let me choose my own things, like I told my dad what I wanted to do and he was like yeah and my mum was fine as well (interview one with Leah pg. 4).

It was during this time however that she began to feel unwell and found it increasingly difficult to attend school. Despite the fact that she had an excellent attendance at school, there were occasions when the school were unsure as to her motives and there were

times when they believed her absence to be deliberate. However, this could not be further from the truth as she struggled to attend.

4.5.4 I WANT TO GO TO SCHOOL

Ultimately she maintained some choice and personal agency in this by negotiating with Janice that she would go to school for a short period each day and then return home.⁴ This enabled Leah to continue with her daily life and to progress with her studies:

Yeh she's 16 she's old enough to know if she feels able you know she really wanted to go you know I did say obviously don't push yourself, if alright you can't go if you are ill but I feel fine now I want to go so emm I would drop her off it was a half day at some point drop her off and I would like pick her up so it was just getting to the lessons but obviously if she wasn't able to go she couldn't go emm so we just done what we could really. She is motivated, she was still bad but she wanted to go to school (interview with Leah's mother Janice pg.4)

Once Leah was diagnosed she continued to negotiate what was happening, exerting her personal agency despite the seriousness of her illness.

4.5.5 CLIMBING A MOUNTAIN

Although she did not always ask direct questions she was very attentive in terms of her involvement in discussions about her care:

so umm I am not entirely sure if I remember her asking many questions but she was listening very intently and it was, she who first indicated her consent to umm to go for the trial, dad asked me a few sceptical questions as you know as people do and you know it is their right so he asked me about what could go wrong if the drug and you know I remember that she was listening very intently and I think took an active decision in going on the trial (interview with Leah's consultant pg.3).

The consultant caring for Leah was conscious of the need to provide involvement and choice for her and this was evident throughout his interview. He valued the importance of the place that young people took 'at the table' and viewed this as an important

⁴ In my interview with Leah's father I sensed some anger when he spoke about the continued attendance at school. Whilst he helped to pick her up when she attended only for half a day, he was very unhappy with the way the school handled the situation. They thought that she was 'pulling the wool' as he put it. This really brought into focus the frustration that parents and others must feel when they are unsure of what is wrong with their child (reflection, interview with Leah's father Kevin pg.1).

responsibility. Whilst I had envisaged that Leah's choices and how she controlled these would be limited, it transpired that this was not the case. The seriousness of her disease and prognosis meant that there were many limitations on her life, however, this did not automatically lead to a lack of agency in her care. This ability to exert some control also extended to her everyday life.

4.5.6 I WILL GO TO THE BALL

She had been very unwell around the time that her school prom was due to be held. Nevertheless Leah was very keen to attend. She had seldom been able to be discharged from the specialist site but insisted that she would go home and attend the school prom. This demonstrated many elements of collective agency, it was however led by Leah. Her mum accompanied her but kept a distance, whilst Leah enjoyed the party with her friends:

well first she was in the carpark because she only thought she would be there for an hour yeah and then she said I think it was about two hours, three hours she parked round the corner and she came in and said she was going to the pub because I just wasn't leaving so they stayed there then till about 12 when it finished and then after that then we went home got changed and then went to the after party (interview two with Leah pg. 13)

Unfortunately this level of choice was sadly to diminish as Leah's condition only improved temporarily. Following her surgery and pre and postoperative chemotherapy, she was referred to a large specialist centre to undergo a treatment which had not been available to her in the study site. This was another attempt to try and control her disease, regrettably it did not work.

4.5.7 I AM NOT TAKING THEM

This theme related to a number of aspects in the context of treatment. These included matters relating to medication and nutrition. With reference to nutrition Leah required significant help with maintaining an adequate nutritional state and this proved to be challenging during her treatment. Her parents were both concerned about her stance on nutrition with regard to feeding which had to be carried out artificially:

It's unpleasant when they first done it they done it with a line under anaesthetic and she was adamant I'm not having any more feeds done mam emm, she said one of the nurses had rushed it up and emm she said I'm not having it done again so I had to coax and tell her you know she had to have an NG feed because she wasn't eating she was adamant so I had to get to her (interview with Leah's mother Janice pg.8).

This was of course difficult for all those involved in caring for Leah. Nutritional support is very important for these patients as their weight can be severely compromised during treatment. Nevertheless Leah was clear that she wanted to assert her view on the matter. Her mother, Janice, whilst understanding this acted it could be argued as a proxy agent in decision making and had to use persuasion to achieve an outcome which ultimately would be helpful to Leah.

4.5.8 THE BEGINNING OF THE END

At a subsequent outpatients appointment three weeks after she returned, during which time I observed the interaction between the consultant and Leah, her experience began to take a different course. However, even at this stage, she had exerted control and personal agency over her disclosure of the pain she was experiencing:

Leah's Consultant: You say pain in the back of your ribs?

Leah: I don't know I have had it for a couple of days

Mum: (to JD) She only told me yesterday (observation two, field notes Leah pg.1)

Mum repeated this again to me further on in the appointment and her body language demonstrated that she wished Leah had said something about what was happening with her symptoms, however, she had chosen not to disclose this information. Following this consultation Leah was once again, as many times previously, readmitted to the specialist unit.

4.6 SOPHIE: CASE STUDY PARTICIPANT 5

Sophie was the last of the participants to be invited into the study. She was also the eldest participant at 24 years old. Again it was during her treatment that she was

approached by my contact and asked if she wanted to take part. As with all of the previous cases she was quick to respond and wanted to be included. Her treatment was given to her as an outpatient and it was the shortest regime of the five cases lasting for a period of five months. I began the data generation in August 2014 when she was two months into her treatment and this was completed in January 2015 following her completion of treatment in October 2014.

4.6.1 BACKGROUND

As with Ellen and William, Sophie was also an only child. She had been brought up in a rural area in the South of the UK and had been privately educated. She had decided to stay at school and following successful grades in her A levels, she opted to attend university and to move away from home to undertake a degree in design. She was subsequently awarded a first class honours degree and quickly was offered employment in a large city at a successful design company. She had been involved in one serious relationship and had lived with her boyfriend for a short time. This relationship had ended before she became unwell, although she remained friends with her ex-boyfriend. Her parents had divorced when she was 18 and their subsequent relationship was not amicable. Her father had a new partner whilst her mother, Brenda remained single. Sophie had a wide circle of friends and was enjoying a full, exciting and independent life. She was taller than average for a female and had a striking look about her. She was confident and ambitious and enjoyed outdoor pursuits. She gave the impression of someone who would enjoy the rush of adrenaline that a stressful or challenging situation might bring.

4.6.2 DEVELOPMENT OF SYMPTOMS

Sophie began to feel unwell in January of 2014. She had a busy life, sometimes working long hours. This was accompanied by an equally hectic social life. It was perhaps therefore no surprise that Sophie ignored her symptoms of tiredness at first. Instead she concluded that it was a result of her lifestyle. However, her symptom of tiredness became steadily worse and added to this she developed breathlessness and found that she was

unable to walk very far. She continued to ignore her symptoms and went to work as usual. This was despite advice from those who were close to her. She then developed difficulty with her sight and eventually she went home to see her mother. She was subsequently diagnosed in May 2014 with a haematological cancer. During data generation five themes were identified (Figure.4.5).



Figure 4.5. Identified themes for case study subject 5 (Sophie).

4.6.3 THE FEROCITY OF INDEPENDENCE

Arguably in terms of adulthood Sophie had all of the expected characteristics of having achieved an independent life. She had graduated three years before she became unwell and she had lived independently since she was 18. Her mum, Brenda had actually moved to where she was studying and had remained there when Sophie left university to begin her first job. It appeared that this was not a request from Sophie particularly, rather Brenda liked the city where her daughter was studying, had no other commitments and so decided to set down roots there. They also lived in the same part of the city during this time, although Brenda made it clear that she did not intervene in Sophie's life at this time. Although Sophie would visit her mum their lives were quite separate. Sophie also saw her father but again this was not that often, he had a new life with another partner and there were younger children from his partner's previous relationship. As a result of

her family life, her private education and her moving away from home at 18, I would describe her as fiercely independent and possessing a high degree of personal agency. This was very usefully summed up by Brenda in her interview:

I will go back to sort of early teens she, umm very resourceful, I am, you know sort of admire that quality in her umm she umm, you know there is quite a high income in the family her father worked, earned quite a substantial amount of money and umm, she didn't need to work but he liked to keep hold of the money really so and I would sort of do things on the sly to you know, to provide things and what have you and I think at 14 we talked about it and her working and I said well if that's what you want to do so, we lived in the middle of the countryside and the nearest town was a sort of seaside town in (town) and umm she said well can you give me a lift down to the next village so I said fine yeah and then picked her up later and she had gone round sort of restaurants and looked for work and got herself a job as a waitress (interview with Sophie's mother Brenda pg.2).

This early control and choice in her life continued as Sophie matured. Unfortunately when she became unwell, she continued to make her own choices and stay in control despite the advice she was given. She made these choices despite her increasingly deteriorating state of health.

4.6.4 ALL TALK BUT NO ACTION

As Sophie grew nearer to diagnosis she was physically restricted in her everyday life. Increasingly she found that walking just a few hundred yards from her train stop to her office building was very difficult, however, she did not take any time off sick, instead she forced herself to continue as she normally would. At work her close friend Pip, became increasingly concerned about her wellbeing and began to articulate her fears to Sophie. However, Pip became very frustrated by Sophie's response to her advice. Sophie nominated Pip to participate in the study and she was able to share her frustration at her interview:

I thought she was attention seeking because every day she would come in and say I'm a bit dizzy and I can't see out of my eyes and I thought yeah well if it's that bad surely you would go to the doctor and I kept thinking well go to the doctor, go to the doctor and then she would say no I'm fine and was coming out

and drinking in the evenings and she would be fine and I thought surely it is not that bad (interview with Sophie's friend Pip pg.3).

This trend continued until Sophie was not physically able to continue at work. She informed her boss that she would be taking some time off and drove the 150 miles by car to stay with Brenda. Brenda's account of this time was quite harrowing as she struggled to help Sophie as she continued to deteriorate, whilst still maintaining agentic power.

4.6.5 I NEED TO GO HOME TO MUM NOW

Diagnosis followed relatively quickly following her arrival home and Sophie commenced her treatment. At this time there is evidence that Sophie became restricted in her choices and her personal agency was compromised significantly but she was very keen to control the elements of her life that she was able to as this was a factor which was important to the way that she coped with her treatment:

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 would 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 Sophie pg.4).

Other aspects of Sophie's care were more difficult for her to keep control of and she was frustrated by this.

4.6.6 NEGOTIATING TREATMENT

At an early stage during the process of treatment Sophie made her intentions clear in terms of negotiating her treatment. She was keen to gain information on her condition and receive this in a way that was preferable to her. She was not keen for there to be too many people 'looking on' so to speak and she definitely wanted to avoid the 'gold fish bowl' effect. To this end she decided to take control of the first discussion that she had with the medical team following diagnosis:

we were still getting information (name of doctor) and ward rounds they can be up to about 10 people and I said to her this is a teaching hospital this is how it works, this is how they learn, there will be lots of people and she said ok but I don't want them to just stand around my bed so that's when she organised for us to go into the boys' bay, there were no boys in there and she set the situation up where (the doctor) sat in the chair... she arranged it so that he would sit there and Sophie and myself would sit in front of him (interview with Sophie's mother Brenda pg. 11).

Despite how unwell Sophie was feeling she instigated this approach. She must have felt very strongly that she wanted to receive the information in a particular environment with the space set out in a particular way, perhaps this helped her to process the information more effectively with the consultant sitting in front of her. Possibly also she felt that negotiating what would happen was more achievable if she and the consultant assumed similar seating positions. Although Sophie said that staff were surprised by her request they were happy to help.

4.6.7 I AM GOING BACK TO MY OWN HOME NOW

As she came to end of her treatment she made decisions that were not congruent with the advice of the medical team and this was detailed in the correspondence of her medical notes:

October 2014: She has already booked a holiday to Cyprus on 18th to 28th (October) although we have advised her that it would be better to delay this until she is settled with yourself particularly as she remains neutropenic (clinical record from medical notes Sophie, in correspondence).

Sophie was not in favour of letting her disease get in the way of her plans as she transferred her care to another health board and made arrangements to take a holiday when she finished treatment.

4.7 CONCLUSION

Each of the five case studies presented, provide what can only be described as a glimpse into the lives of this group of young people during their cancer journey. Nevertheless rich and individual sources of information provide a useful lens in which we can view their experience. This in essence illuminates the myriad of complexity which resides in the

trajectory of each participant. Each journey is recorded using a linear longitudinal approach, which distinctly exemplifies their levels of personal agency. In particular however, the restriction in their lives set against their freedom to make choices at certain times in their encounter with cancer is something which is prominent in all five cases through the structure of family and treatment in restricting choice, albeit in the young people's best interests and with their agreement.

Each of the young people faced serious challenges, both leading up to their diagnosis and during their subsequent treatment and recovery. Ellen unfortunately had a severe reaction to part of her treatment, which resulted in admission to intensive care. This rendered her completely dependent on the choices which others made for her during this time. Sam was looking forward to his recovery and a return to university when he had a recurrence of his disease, resulting in the need for a bone marrow transplantation. His agency was severely restricted particularly during this time and in his subsequent recovery. William required radical surgery, an amputation of a lower limb, the consequences of which were dramatic both in terms of physical restrictions, notably in his everyday life and in his love of sport. Leah the youngest of the sample who was at the time of her diagnosis just beginning the transition to adulthood, was faced with the prospect of arduous treatments which meant that she was faced with some very complex decisions. Her significant hospitalisation during this period also culminated in serious restrictions to her life and subsequent choices. Sophie the eldest participant was the most independent of the group in terms of her everyday life. She was self-reliant financially, enjoying a successful early career and leading a busy and exciting social life in a large city. When her symptoms began to develop a marked transition occurred in her life as she struggled to maintain control of everyday activities. Ultimately however, Sophie would also experience the restriction and lack of choice associated with the diagnosis of her cancer.

The accompanying participants in the study all contributed to this notion of restricted lives both relating to treatment and in everyday life. Some of their contributions to easing the situation in which the young people found themselves included the provision of help and advice. This almost exclusively was valued by the young people as being helpful. Nevertheless examples of negotiation were evident as young people asserted their opinion and articulated their needs and desires. This evidence demonstrating how care and life was navigated during the cancer journey was revealed in all the data generation methods. Interviewing and observation of outpatient appointments yielded most of the findings. The exploration of participant medical notes was less fruitful. There was relatively little evidence of detailed discussion which usefully exposed how much choice the young people had during their care.

Reflexivity was central in terms of selecting some of the key data extracts in each case and detailed accounts relating to each data item were recorded in a reflective narrative. Each case when it was originally analysed and themed amounted to an average of 11,000 words. Included in this word count were selected extracts illuminating each theme from the data comprising multiple sources, accompanied by a supporting narrative. It was therefore important during data reduction to demonstrate in depth reflexivity in order to try and capture some of the central elements in each case.

Despite the type of disease and treatment, gender, background, family size and the age span between 16 and 24 years, there is evidence in each case study of themes which cut across all five data sets. This again presents itself as a linear perspective of the undulating choice and control relating to personal, proxy and collective agency, set against the range of structural constraint, which exemplifies each experience. The temporal nature of the journey provides an interesting picture in terms of fluctuating agency. The socially embedded nature of choice and control in decision making is clear as the interactions between young people, partners, parents, friends and professionals takes place. In determining the thematic chapters which follow, this linear approach was

subsequently used to try and accentuate the key points in the trajectory of where agency changed, why this happened and what impact this had on the ability of young people to be agentic in their care.

5. LIFE THEN: MAINTAINING AN AGENTIC POSITION

5.1 INTRODUCTION

This is the first of three chapters that will detail themes which were evident from the data in either the majority or all of the five cases in the study. The aim here is to explain and illuminate the experience of the young people and those close to them through a specific perspective. This perspective relates to their need for control over their situation prior to their diagnosis, which was commonly identified during initial and subsequent coding, leading to the identification of these themes. The events as they unfolded during data collection provided a sequential series of events which reflected an analogy of three acts in a play. These three elements of their experience highlighted a logical picture of their journey and whilst there were some instances of them taking steps backwards, particularly as a result of the effects of their treatment, their trajectory was essentially linear. This was in terms of their levels of different types of agency relating to their control and choice during their development of symptoms and subsequent treatment and care.

As explained in the earlier research design and methods chapter, cross case analysis is situated firmly in the tradition of the case study approach. Within this particular cross case analysis there was an opportunity to explore the key elements of the experience relating to the development and subsequent treatment for cancer in young people. At the outset of the study period, during the preparatory phase, my intention was to concentrate on exploring the experience of just the curative element of treatment. However, it soon became clear that the ability of the young person to act as a personal agent, exerting choice and control during their pre-diagnostic period was important to them and this time provided pivotal examples of how their agency altered as their health deteriorated. The development of their symptoms became very much entangled with their 'life then' and this ultimately impacted significantly on their emerging independence as young adults. All of the five young people in the study were journeying along the developmental path that would generally be expected of the 16-24 year age group. Commonly, accounts of this period of development are concerned with the move from dependence to

independence in the broadest sense as young people make the transition to adulthood. Whilst each of the young people's aspirations was understandably different and they all came from different social backgrounds, there was a sense of common aims amongst the group. These aims were concerned in essence with the development of life plans. Although it is accepted that young people do not always have a clear path which they have chosen to follow in terms of their long term life and career, they are generally in the process of engaging in what might be termed 'stepping stones' as a means to achieving their future goals. In order to appreciate the impact that the development of their cancer had on their lives and most importantly their choice and control in decision making, it was both relevant and important to consider their level of agency during the period immediately prior to the development of their symptoms.

5.2 THE NEED TO PURSUE LIFE PLANS

All five young people were interviewed three times over an average period of six months. This proved to be very useful as the first interview was an opportunity to briefly talk with them about their life before the development of their symptoms. This helped to highlight the contrast in their everyday lives as their health worsened and they inevitably began to struggle with controlling their life course. Both Ellen and Sam had made decisions to pursue a university education and this had been something that they had maintained full control of in terms of what and where they would study. Indeed when interviewing both of their parents, they attested to this by giving accounts of how their children had both chosen their subjects not just at A level but also at university. Sam's mother talked about his choice of where he wanted to go and study:

and he went up and it was a nice campus university and easy accessible, modern and he didn't want to stay in (local area). He was quite emphatic about that (interview with Sam's mother Linda pg.7).

Unfortunately these plans had to change when he underwent treatment following the recurrence of his cancer and he ultimately attended university close to his home.

Nevertheless his initial decision was one he made independently and with personal agency and this would have remained so had his circumstances not changed.

In both of these families there had been evidence amongst their parents of traditional professions, arguably professions that follow an inter-generational trend in terms of following parental careers, namely teaching, the law and medicine. Nevertheless neither Ellen nor Sam were following in the footsteps of their parents. Both had chosen to pursue degree paths which reflected their own interests. This highlighted their emerging independence and the need for both young people to be autonomous in their decision making, despite the added pressure on Sam's part in particular that in his school there was an expectation that he would study law or medicine as revealed in the last chapter. These two young people had also chosen to leave their family homes to pursue their education and although Sam attended a university that was very close to home he nevertheless still moved out of his parents' home to gain more independence. Making the decision to move away from home had also formed an important part of Sophie's development as she too chose to leave home once she decided to go to university. All three young people wanted to live separately from their immediate families not because their relationships were problematic in any way but that they saw it as an opportunity for independence and as part of their life experience. Ellen expressed this in her first interview:

Ellen: And um, so I just decided to go to a university with a reputation

JD: Yeh, of course.

Ellen: Because I thought that might help me.

JD: Definitely.

Ellen: and um, so that was the decision behind that. Well I thought I might grow up a bit more

JD: Yes

Ellen: and be a bit more independent

JD: Yes

Ellen: In myself, sometimes it's the best thing (interview one with Ellen pg.4).

The desire to leave home is not unusual in this age group and is an accepted part of the transition towards an independent life. Each year many thousands of young people make

the journey to their university accommodation to begin a new chapter in their lives. Subsequently a number of young people will continue with this trend as they transition into work following the completion of their education, thus building their agentic power in this regard.

Whilst the other two participants, William and Leah, did not leave home to attend university, they too were making independent decisions about their education. William's parents had not been keen on his choice to attend a cricket academy instead of continuing with his sixth form education following his GCSEs. However, he exerted his personal agency and made the decision to leave school and pursue his plans to develop his skills in cricket. Although this highlighted a disagreement between William and his parents they acknowledged that this was a decision that they should respect as it was what he wanted to do in his life. In contrast, Leah had chosen her GCSEs without opposition from her parents. She commented that they had not been involved particularly and that she had felt fully in control of this decision:

my parents didn't really have much input because they like let me choose my own things, like I told my dad what I wanted to do and he was like yeah and my mum was fine as well (interview one with Leah pg. 4).

Two observations emerged from studying the data set in this part of the study. The first concerned the idea that despite the family backgrounds of each young person, there was a clear sense of their emergent independent decision making and increasing personal agency which related to their development into young adulthood. Whilst Ellen and Sam's families had backgrounds which were situated in traditional professions, Sophie and Leah's parents largely worked in semi-skilled jobs. William had one parent who worked in a service industry, whilst his mother was a nurse. Thus arguably the autonomy of the young person in this sample did not appear to be dependent on the occupations of parents, rather the young people had ownership of their life plans and made decisions accordingly.

Secondly the age range of the sample spanned eight years in total with the youngest participant having just had her 16th birthday while the eldest was 24 years old. Inevitably the decisions which were being made varied widely. However, the freedom which each young person had in terms of taking control of their destiny was similar in that they were able to take charge of their future life plans.

5.2.1 THE DEVELOPMENT OF INTIMATE/SERIOUS RELATIONSHIPS

In establishing a picture of each young person as they made their developmental journey prior to their cancer diagnosis, it became evident that they placed an important emphasis on the development of their relationships. Four out of the five young people in the study were either in or had been in what they termed a serious relationship. Only Leah who was the youngest participant said that she did not have a partner and when asked about other people in her life had become embarrassed and laughed nervously. Perhaps in this context, she had not had experiences of this kind and therefore had not made the transition to these types of decisions. This was in contrast to the previous section and it could be argued was possibly related to her age. Whilst there may be a number of young people who are in serious relationships at this age, equally there will be those who do not have a partner and this would not be unusual. The four other young people were aged from 20 years upwards and it would perhaps be more likely that they may be involved in a serious relationship.

Ellen, Sam and William had all been in relationships for more than a year and their relationships were reported as being independent of their own family lives. All three of the young people discussed examples of decisions they had made with their partners that had not involved anyone else. William in particular was keen to keep his relationship private from his parents in the first instance and the friend whom he nominated, Nathan, highlighted this in his interview:

right first time his mum or dad found out about it was his dad's 50th, I had been out in (name of town) umm I went to watch the rugby, went back to (name) rugby club where the party was being held and his mum asked me what the film

was like and I said oh it was good thanks, and I was like why is she asking this? William had told her that he had gone with me to the film (interview with William's friend Nathan pg.5).

This provides an example of the private nature of his relationship when it was in the early stages. It marks out the boundaries of what he was prepared to share with them at this time and reflects his control of the situation, even though his strategy did not go to plan! In the event his parents learnt of his relationship and were pleased that he had a girlfriend. Sophie the eldest of the participants had made considerably more commitment in her relationship, which ended before she became unwell. For a short time she had lived with her boyfriend but it did not work out. She had been the one to finish the relationship and her mother remarked that she only became aware of what had happened when Sophie arrived home with her belongings.

This part of the chapter gives what is only a brief glimpse into the everyday life decisions and events that formed part of the lives of the five young people before they became unwell. It is apparent that in a range of ways they all had good levels of choice, control and personal agency in their lives. They exercised their free will in mapping out their future plans. They would attempt to hold on to this control as their symptoms manifested themselves.

5.3 HOLDING ON TO CONTROL

Despite the onset of some significantly distressing symptoms, the five young people in the study remained to a large extent in control of their everyday decision making. Their desire to continue with their lives in the same way as before they felt unwell presents a complex picture. In the first part of this chapter it appeared that their situational context was not central to their ability or desire to make choices freely as they were all at different stages of their development and all pursuing different goals. Nevertheless this demonstrated no real evidence of difference between individuals. Similarly the range of family backgrounds that they were from did not appear to restrict their emerging independence in terms of choosing their life course in early adulthood. In contrast once

they began to develop symptoms, whilst all five young people held on to their control, this did however differ in terms of their situational context.

5.3.1 LIVING AWAY FROM HOME

One of the interesting findings was the amount of time that some of the young people delayed their return home despite their deteriorating health. Two of the young people, Ellen and Sophie aged 20 and 24 years of age respectively, had left home. Ellen to go to university and Sophie to take up employment following completion of her degree programme. At the time both young women returned home they had been experiencing symptoms for a period of six months and both were acutely unwell.

Ellen had visited her GP on several occasions and had been told that her symptoms were not serious and that 'she did not have cancer'. Whilst she was reassured by this, her symptoms worsened and she gradually became more restricted in the choices she made in her everyday life. Rather than make a choice to return home and act on what was happening she made adjustments to her everyday activity, exerted her agentic power and tried to carry on with her usual routine:

I couldn't, because I had a heavy rucksack with me I couldn't really carry the rucksack because it was digging into me. I couldn't walk far without having to have a breather you know...so my stamina was affected... it was a struggle (going to university), yes the pain that I experienced was err I can't even remember it I think I've blocked it out of my mind (interview one with Ellen pg.12/13).

Ellen continued to attend university throughout the development of her symptoms. She was in her second year of study for a demanding degree in engineering and was determined that she would finish this part of her programme, which culminated in a set of examinations in the summer of 2013.⁵ There are a number of pressures for young people during their higher education period, not least the financial constraint which they

⁵ *On reflection I began to think about the significant pressure that young people find themselves under and to what extent this might prevent them from taking a break when they are unwell. I felt sad that a young person should feel so pressured especially when considering that Ellen was developing a life threatening illness (reflection, interview one with Ellen pg.3).*

are under and the debt which they are accumulating. There is also the uncertainty of finding employment once students have finished their education. Peer pressure is also very much a part of this period of development as with the rest of this stage of adolescence and young adulthood, this group are keen to stay aligned to their peer group. This was the case for Ellen as her close friends had all gone away to university, therefore it would not be unusual for her to want to complete her studies in the same way as her peer group. In families such as Ellen's where parents have been educated at university there will often be an expectation that their offspring will follow in their footsteps and obtain a degree level qualification. Ellen had also been in her first serious relationship for more than a year. This multitude of reasoning provides a myriad of explanations as to why she would want to stay in control of her life and continue with her plans. Of course the notion of fear is also a real possibility in the development of any symptoms which alter health. I acknowledge that this is a more generalised feature of ill health which occurs across the lifespan and is not just confined to teenagers and young adults. However, it is possible that they may be more fearful because of a lack of experience of ill health. It is also unlikely that many young people will have visited a doctor for advice on more than a handful of occasions.

Similarly Sophie continued with her everyday life choices, despite the development of what were to become significantly debilitating symptoms. Her level of control and choice in decision making was more marked in terms of seeking medical advice. During her interview she commented that she believed that whatever was wrong it was not going to be anything serious. She did not seek any advice until immediately before she was diagnosed and seriously ill. Sophie was a very successful young woman, who worked in quite a high pressure environment for a global design firm. She had a very strong work ethic and was very rarely absent from work. Despite difficulties with fatigue and subsequent breathlessness she continued going to work:

it got to the point now where I was walking to the station in the mornings and I feel out of breath and getting to the point where the small hill up to work, and if I ended up having to walk from the station it was really embarrassing because I couldn't really walk and talk (interview one with Sophie pg.14).

Sophie's job also brought with it a very busy social life. Living in a major city and working hard there were opportunities to socialise regularly. It is not unusual for young people of this age to enjoy active and full social lives and again this is an important part of peer cohesion and alignment to a particular group. It was clear that in Sophie's circle there was an expectation of 'work hard, play hard'. In Ellen's situation it had been her examinations that had caused her to make the decision not to return home. Sophie was also in the position of having left her family home but she was a little further along in terms of her career development and was not only living independently but was self-financing and had the responsibility of meeting the demands of a challenging job. Despite a deterioration in her health and a visit to her dentist to diagnose a dental infection she felt compelled to exert personal agency and maintain her involvement in work :

they asked me to go over to do a pitch project on the Monday and I did say I don't know if I can because we have a really early start so I held back from that one so was off the Monday and Tuesday and then I finished the antibiotics and thought I'll go in on Wednesday I wasn't really feeling much better but you know you've got to get back to normal life by this point I'm taking lots of vitamins and drinking my green smoothies and stuff thinking that it will just give me a bit of...(interview one with Sophie pg.11).

Whilst Sophie acknowledged that she was not able to meet her commitments fully, she still made a decision to return to work and was focused on the idea of 'normal life' which included attending her job. She had also made choices to try and instigate the use of her own therapies, including supplements and healthy drinks to try and combat her symptoms in an attempt to stay in control.

In terms of Ellen and Sophie's situations they both decided to stay away from home whilst they pursued their life plans. They both had priorities and were insistent that they would meet their commitments rather than interrupt their lives to return home to their respective families.

5.3.2 LIVING WITH THE FAMILY

The remaining three young people in the study were all living at home when they developed symptoms prior to diagnosis and so the notion of returning home and how this impacted on their choices was not a feature of their trajectory. Nevertheless there was evidence of their capacity to hold on to control and personal agency in their situations as they unfolded. Although their commitments and life plans were different to Ellen and Sophie, Sam, William and Leah all had aspirations which they were in the process of pursuing when they became unwell. Leah, the youngest participant, was only just 16 years old 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 felt she could not stay in school. Rather than stay away from school completely she exerted her personal agency by negotiating her attendance with both her parents. She persuaded her mother, Janice, to contact the school (demonstrating elements of proxy agency) and make arrangements on her behalf so that she could maintain some control over her situation:

I said look she can't come to school if she's ill like I probably, they thought that she didn't want to go to school was there problems, 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, yes that's ok (interview with Leah's mother Janice pg.4).

Sam was also in the middle of an important set of examinations but for him it was A levels. He began to feel that his fatigue prior to his diagnosis was beginning to compromise him and wanted to find out what the problem was. His situation was different from Leah in that his mother Linda was a GP. Whilst she had not felt the need to take any action, he had a different view and insisted that she investigate the matter for him exerting strong personal agentic power. He requested that she take his bloods herself and he was persistent in his desire that this action should be taken:

No he was nagging me really because he was tired...he wasn't sure if there was a problem...he'd never said that before...and I said, come we will do some blood tests and umm hopefully they'll be alright and that will prove to you that you're okay' (interview with Sam's mother Linda pg.6).

His mum did as she was asked, she said because it was what he wanted, although this must have been a difficult request for her. Not least that as a GP there could arguably be a conflict between her professional and personal role in this situation. It was noted that she did perform the task of blood taking in the surgery and therefore in a public setting but she did not delegate the task to one of her colleagues. Interestingly when she received the results and realised that there was something wrong, she asked one of her partners to see Sam and examine him, rather than be involved in the task herself.

For William who like Leah and Sam was living at home, there was also a need to hold onto control of his life. However, this was in a different context and related distinctly to his social life and most importantly to his peer group and sporting colleagues at his cricket club. He had been in considerable pain for several months and had been receiving physiotherapy. This had not led to any improvement and subsequently he attended the local hospital following a scan of his knee. He was not diagnosed at this stage but was waiting to go to a specialist centre for assessment. Being 'one of the boys' was central to William's lifestyle and his participation in sport very much reflected this context. The desire to remain in contact with his group was very strong, so much so that even when he was advised that it was possible that his leg might fracture due to the mass that had been detected on his scan and X ray, he was still determined to drive to the cricket club and support his team.⁶ The consequence of this decision and desire to make his own choice in asserting personal agency was to result in very serious implications for him:

⁶ *I knew that William had a strong need to be amongst his peers but I was shocked that he still ventured out driving to the cricket club to watch. Although he hadn't been diagnosed he knew that there was something seriously wrong and had been warned that his leg might fracture. Perhaps he did not realise the seriousness of his condition, perhaps he needed to distract himself (reflection, interview one with William pg.3).*

and it could fracture yes that was on the Wednesday, (the hospital appointment) on the Saturday I went up the cricket club to watch the cricket... it fractured at the cricket club (interview one with William p.26).

For Sam, William and Leah, whilst they had not left their family homes when they developed their symptoms, they still maintained their level of independence by pursuing their individual life plans. Their parents and those close to them, whilst available to help, made little difference to their desire to 'get on with life' despite all of them experiencing distressing symptoms. However, all three were medically assessed and both Sam and William were diagnosed relatively quickly. Leah unfortunately was not and this was probably due to the rarity of her disease. One element that was different in terms of the situational context of those who lived at home with family and those who had moved away was that Ellen and Sophie had less daily face to face support from their immediate families than those who lived at home. Arguably this may have had consequences for the two young women who lived independently as their families were not able to physically see them, although in Ellen's case she used skype as a method of communication. Therefore it must have been difficult for parents in particular to note how they looked. This is important as both the families of Ellen and Sophie commented on how seriously ill they looked and how shocked they were by their appearances when they finally arrived home. Had they ventured home earlier, then parents in particular commented that they would have taken more of a lead in the situation at an earlier stage. In both cases when the two young women did arrive home their parents immediately took charge of their respective situations and ensured that they were both medically assessed within a very short period of time.

This notion of holding on to control then is fraught with complexity, however, it does appear that in each context and to some extent for each young person there was a need to exert their personal agency in some way, even as in Leah's case where this was particularly restricted due to the limitations placed on her by her symptoms.

5.4 HELP AND ADVICE FROM OTHERS

Although these young people continued to progress with their lives during the development of their symptoms, during this period they were not without help and advice from those closest to them. This however did not deter them from exerting personal agency. In essence these examples of help reinforce their desire to make their own independent choices. Understandably those who were involved in the lives of the five young people were concerned about what was happening to them and they tried to offer assistance with the aim of acting in their best interests. This was strongly evidenced in Sophie's case during the interview with the friend whom she had nominated. Sophie relied on and was close to Pip as they had started their jobs at the same time. They were a similar age and came from the same part of the country and had become great friends both professionally and socially. Sophie had told me that she trusted Pip and respected her judgement, however, she repeatedly refused to take her advice in relation to what she should do about her symptoms:

she really started to lose colour, every day she would come in and she was very out of breath and she was saying I can't breathe and I'm getting out of breath and I was like Sophie then go to the doctor but she wouldn't go to the doctor and she just kind of had this anti- doctor thing going on and anti- doing anything about it that then made me kind of lose interest' (interview with Sophie's friend Pip pg.3).

Pip was really worried about her friend but because she did not take her advice, she began to doubt Sophie and even resorted to thinking that she was attention seeking. She commented in her interview that she had lost patience with her and felt that Sophie was attention seeking. Pip's view was also reinforced by Sophie's behaviour outside work relating to the social lives of their peer group. The importance of peer alignment has already been highlighted and in Sophie's case the ethos of working hard and equally playing hard had been a feature that was central to her life in terms of maintaining her position in her group. On one occasion she had sustained an injury on a night out, which had resulted in a significant bruise, which following a degree of alarm from her friends still did not lead to her taking any action:

Yeah and umm and she sent me a picture of it the next morning and I said oh my god and then we went to the pub that day all the girls went to the bathroom and she got it out again and we were going oh my god Sophie, oh my god do you bruise this easily normally and she was going oh you know do you remember falling that hard because it was severe (interview with Sophie's friend Pip pg.5).

The need to 'keep pace' with peers is not to be underestimated, particularly in young adults. Following the completion of education, it is a time when this group will begin to build on their emerging identity and lifestyle choices are an important part of this process. Socialising forms part of this picture and young people would be expected to play their part in participating. Sometimes alcohol consumption can be part of this and this is of course when minor incidents can happen as was the case for Sophie. Rather than the bruise being viewed as something that she was going to worry about, it could possibly be contended that it was more of a 'trophy', something to be proud of and show off to her friends. She certainly played down any thought that it was unusual or could be related to something more serious. It could of course be that it was something that worried her that was not revealed but this was certainly not the impression during data generation.

Ellen was also in a position where those who cared for her were worried about what was happening as her symptoms developed. She made adjustments to her daily routine as her initial symptom of shoulder pain began to compromise her everyday activities but still continued to go to university. Young people who are committed to high achievement in their education are unlikely to be absent from lectures for fear of missing content and falling behind. They would also commonly undertake extra hours of study to enhance their understanding and thus produce higher quality work and Ellen certainly fell within this student type. Ellen continued to live in halls whilst her parents lived many hundreds of miles away and they were keen for her to return home. However, whilst she recognised that there was something wrong, her priority was to continue with her work at university and thus maintain her personal agency:

and going through it in a fair amount of detail she was obviously in discomfort and pain and this was of concern to us as parents and we were encouraging

then because it was oh, okay the doctor thinks it's this and yes you have to turn up for these appointments and then you get questions like, well there is a lecture then because she is very conscientious' (interview with Ellen's father Phillip pg. 5).

Ellen's parents were essentially attempting to help her with decision making in this situation and felt that the priority for her was to make sure that she kept her appointments so that her health problem could be managed effectively. However, she was constantly thinking about her lecture commitments and it was clear that her decisions centred around the importance of this. As with Sophie whilst this phase of her illness may well have been frightening for her, the preference for remaining with her group of friends who were high achievers and in particular her boyfriend Nigel who was intent on doing well, was something that dominated her decision making. Ellen's father Phillip further described the importance of this period in her life and disclosed that she did eventually return home but this was only once she had completed her examinations. She was in considerable pain at this point and had been experiencing symptoms for six months. The difficulty in functioning whilst enduring chronic and worsening pain has the potential to severely disrupt the lives of all who have such symptoms. However, in a young person this might arguably be a different experience. It is unlikely given the good health of this group that they will have had these types of symptoms. Would it perhaps be more likely that they would seek help quickly because the symptom of pain provides a significant deviation from their everyday pattern? If this is the case then the tenacity which Ellen showed in forging ahead with her studies is quite remarkable. Her father illuminated this very usefully:

Ellen's father Phillip: She came home but what it was she went through a month of university exams which she was determined to do

JD: Yes

Ellen's father Phillip: and although she passed her first year relatively straight forwardly she was struggling much more the second year because she was in more pain than anything else. But she still passed those exams (interview with Ellen's father Phillip pg.6).

Educational examinations and the completion of them were a phenomena which formed an important element of the data generation. Equally this context also demonstrated

important examples of the need to maintain and protect an agentic position during this time. Leah experienced some very distressing symptoms which included frequent episodes of vomiting. She continued to go to school during this period and made a decision to continue preparing for her GCSEs despite these episodes. When interviewing her father Kevin, he was clearly distressed by this but he still colluded with Leah as a proxy agent in terms of accepting that she needed to continue having control in her situation:

in the end I was having a phone calls, in the end they wouldn't let her use the school phone to phone me she would have to use her mobile because I would have to make sure she had money on her mobile to phone me so she phoned me one morning and said dad I have been sick all over the classroom come and get me so I go get her (interview with Leah's father Kevin pg.2).

As with Sophie and her friend Pip who thought she was attention seeking, the school which Leah attended also appeared to lose some patience with her situation. They too wondered whether she was attention seeking and as the above extract suggests were not particularly helpful towards her. The underlying issue here though is not one of seeking attention but rather to continue with everyday life as an attempt to maintain personal agency.

The importance of achieving qualifications to provide impetus for future life in adulthood is a central factor in the data generated by the study. It is a crucial phase for young people as they make decisions about how they build their future lives.

5.5 COPING WITH SYMPTOMS

Throughout the data generation there were some interesting accounts of the nature of the symptoms experienced by the five young people in the study. Some of these were distressing and serious. As time progressed they also escalated, however, there appear to be examples of each young person coping with what was happening to them in order to keep progressing with their lives. In Sophie's case it was in her last interview that she reflected on how she had coped with her symptoms before diagnosis. The severity of her situation was alarming, however, she still found a way to manage everyday activities:

you know living in a house where I remember feelings how I felt before I went away, you know I could I remember even silly things like I had a shower there and I remember thinking oh my god the last time I was in this shower I couldn't stand up I was sat on the floor because I was so ill and I noticed things like that, that play on your mind and you can't you know I don't think I could have lived there again actually (interview three with Sophie pg.2).

It was only when she returned to her old flat following treatment that she realised the gravity of what had happened there and that the memory of this was not something she wanted to be reminded of, despite the fact that she had somehow coped with the situation. Sam's mother, Linda, provided a different example of coping with symptoms in an attempt to continue with immediate commitments. These were social commitments but no less important. Just as he was at the point of diagnosis, he had come to the end of his A level examinations, he remarked that at this time he felt very unwell. He attended his first consultation with the haematologist and was prescribed steroids:

we went down to pharmacy and got the prescription and he wolfed them down the car because he wanted to go out that night. It was the last night of his exams, last day of his friend's exams (interview with Sam's mother Linda pg.16).

Sam was desperate to alleviate the effects that his symptoms were having on him and was determined to go out and celebrate following his exams. His way of trying to achieve this was to take his first prescription as quickly as possible, even before he arrived home. This demonstrates Sam's desperate need to try and cope with what was happening, whilst taking action to enable him to go out with his friends, in the same way that Sophie was prepared to go to great lengths in caring for herself so that she could go to work despite her symptoms.

Pain was a common symptom within the group and in William and Ellen's case, they used pain relief medication as a way of coping with their increasing distress. This enabled them to continue with their daily routines. However, in Ellen's case even though her pain became particularly severe but she was still intent on completing her second year at university. Her boyfriend Nigel was on the same programme as her and she enlisted his help as a way of coping and preparing for her examinations. She was beginning to lose

some control as the situation worsened but as with the others in the study, she was steadfast in her resolve to hold on to personal agency in decision making and succeed despite her situation:

I think as the pain grew she started, it started to get worse she started to ehh, I'm not so sure that she lost control, but like other aspects. It started affecting other aspects of her life really hard. Like she was really, really worried how her exams were going to be because either the pain was going to affect them or the drowsiness from the strong painkillers were going to affect them but we got it so we revised together...we revised a lot together, I helped her a lot, if there was any problem with anything, I have a really good memory so I can remember what seven lectures and I could sort of try and work together (interview with Ellen's boyfriend Nigel pg.11).

The support of Nigel was crucial here in enabling Ellen to continue with her studies and he was certainly a catalyst and I believe at this time a proxy agent for ensuring that she could continue to cope despite her symptoms.

Leah had made a decision to continue attending school and her parents had helped her to maintain this choice. However, her symptoms were such that she was not always able to do so. She nevertheless coped by sometimes adjusting her decision making and maintaining personal agency so that she still had some control in terms of her attendance:

JD: did you stop going to school altogether?

Leah: no

JD: you always went?

Leah: yeah at least an hour a day, not if I felt really bad but if I was feeling a little bad because by the end there was points where I would be randomly sick. I would be fine in the day and then I would have to go the toilet and the sickness would come on so

JD: so you would be sick in school?

Leah: yeah sick in school sometimes yeah (interview one with Leah pg.8).

The symptoms that Leah described must have been certainly very distressing and were compromising her ability to have her usual full time at school. In spite of her continued vomiting she coped with this in a way that she had determined. Her ability to cope was not something that was however applauded by the school. During data collection the school raised some concerns that her behaviour might be possibly that she was seeking

help or attention and at one stage they asked if she was being bullied. Regardless of this she was undeterred, it was clearly very important for her to be at school rather than at home.

It is of course acceptable to suggest that in adulthood there would generally be an attempt to cope with symptoms as they develop. The key question in the context of this research however is concerned with the particular stage of development within the life cycle. Adults move through a number of transitions in their lives and these may include for example, establishing long term partnerships and undertaking marriage, having children, promotion during work life, becoming a grandparent and retirement. These are it could be argued, all different to the experiences of this age group. In adult situations individuals have a base line or a platform that they have likely built over time.

In the teenagers and young adults, this platform needs to be established. Young people find themselves at a number of cross roads in their lives where they are required to concentrate their energies in order to place themselves in the most beneficial position to achieve success in their future lives. Of course this does not happen in all situations. There are examples of this type of activity happening at a later stage in the life of an individual and they still no doubt achieve success as a result. However, it is most likely that the majority of young people will in a number of ways be building these early adult life platforms. It is arguably one of the most crucial phases in the life span and because of the lack of life experience young people have, it can be a challenging stage to negotiate despite support from others who are close such as parents.

5.6 SURRENDERING AGENCY

Inevitably all the young people in the study arrived at a point where it was no longer possible for them to navigate their own course, asserting their full independence and their personal agency in the context of their situations. Their symptoms were so serious that without intervention, the consequences would have been irretrievable. The evidence supporting the seriousness of their symptoms and their actions during this time was both

stark and worrying in terms of their wellbeing. This was most demonstrable in Ellen and Sophie's cases when they had already left home. Sophie was at a crossroads in terms of her symptoms, she was at a stage where she could no longer work. She made the decision to leave work without warning and whilst she was very unwell, would still not surrender her choice to control the situation and told her friend Pip that she was going to drive home to see her mother. This was not an inconsiderable distance, her mother lived approximately 150 miles away by car. Pip was very concerned but was powerless to stop her from proceeding with the journey. Sophie's mother only really became fully aware of how her health had deteriorated when she arrived home:

So she got in the car and drove to (city) and yes given her counts, I, you know try not to think of that but I still think of horror, so she got down here Wednesday afternoon and when she arrived, I just thought jeeze you look dreadful, she was as white as anything (interview with Sophie's mother Brenda pg.6).

This extract relates to the earlier narrative which made reference to the circumstances of those young people who lived away from home. It was more difficult for families to be fully aware of what was happening to their children's health and not seeing them visually meant that they were not in a position to make a decision to intervene because they did not have the evidence to do so. A very similar thing happened in Ellen's case. She completed her second year examinations and then returned home, again alone, arriving in a poor state of health and much to the distress of her father, Phillip. He commented on how pale she looked and that he immediately felt the need to take action to help. For Sam, William and Leah there was also assistance from their families. In Sam's case we have witnessed that this was something he asked for when he wanted his mother to take his blood. With William and Leah, parents made suggestions about decision making to them. In William's case his father, Martin, was concerned about the lack of progress with his physiotherapy and the persistence of his pain and therefore made a decision to take William to see a friend of his who was a physiotherapist privately. This led to a private scan to try and determine what was happening and establish a diagnosis. In Leah's case

there were many visits to the GP to try and establish what was happening to her and whilst she was maintaining some personal agency in terms of attending school, both her mother and father were beginning to take the lead in trying to make progress in ensuring that she received the treatment that she required. Indeed both were becoming frustrated with the lack of a diagnosis and her father Kevin was particularly concerned in speaking for his daughter:

so I went in one afternoon I said look I said hold on (mumbles) I want her to be seen now and they said oh alright then if you want to and I said don't you think Leah should be referred now she is in here more than she is in school, oh let's get her referred so he got her referred then down to (local hospital) and they started doing tests then, well not tests it was just he thought, they thought what did they think, that it was to do with Crohn's disease, they thought she had Crohn's disease (interview with Leah's father Kevin pg.2).

However, even in these circumstances there was an emphasis from the professionals involved in the situation to focus their consultation on Leah rather than on her father. This appeared to frustrate him further. However, it would be expected that a young person of 16 would be approached in this way during a consultation. This would be based on an array of evidence stemming partly from the legal framework focusing on competence in this age group. The need to respect the competence of young people has increasingly become a central feature of care and is framed very clearly within the young people's rights agenda. Nevertheless Kevin still found this difficult:

one thing at (name) age you want to say, because you are the parent and she is only 16 and she is my baby, I want to do all the talking to say to the doctor what is going on, everything but a doctor won't even look at me because she is talking to (name) so I am trying to say something and the doctor is saying woh let me talk to the patient here so that is a bit, that done my nut in (interview with Leah's father Kevin pg.6).

It is not unusual during the transitional phase between childhood and adulthood that families and most usually parents will do all that they are able to help their developing offspring. It is inevitable for most families that as the young person's independence grows they will take more control over the decisions that they make and parents begin to move into the background and are there but usually only when help is needed.

What was of interest in this phase of each of the young people's trajectories, whilst previously there had been a strong sense of needing to control their situations, all five young people were in many ways overtaken by the seriousness of their symptoms. Their ability to choose what would happen to them next was not something that they could control. The most usual course of action in this situation led then to the intervention of parents in trying to help with establishing a diagnosis. Parents became involved in visits to healthcare professionals and were instrumental in making ground with the management of each situation. Some of the group were more dependent than others purely in terms of their symptoms. Sophie was severely affected by her fatigue for example and when she arrived home her mother, Brenda, had to completely take control of the situation and made an appointment with her own GP. An extract from her interview demonstrates the gravity of the situation:

I think it was agreed that Thursday afternoon I could ring to see what the results were meanwhile a nurse and a phlebotomist had well they had got Sophie to walk out of the clinic room and umm I was at reception and I just turned round and I just saw her go like and she just went and that was a whole different story then because we had everyone on her and umm they were doing various things, blood pressure and what have you, one thing they were doing was the pin prick thing and after I think you shouldn't have done anything like that and then I had to wait to see the GP again so we were put on chairs away from everyone you know she couldn't walk I had to, when we went down to the GP it is just around the corner here, she was just like a little invalid she could not walk, she had to have my support for 10,15 yards all the time I was thinking how are we going to get here umm so got her in, so we had to wait about half an hour to see a GP again (interview with Sophie's mother Brenda pg.8).⁷

It is therefore no surprise that Sophie was not really in a position to exert choice and control in decision making any longer, although she had refused to go to the local emergency department between the time of the appointment and her subsequent blood results as Brenda was becoming exasperated by her condition. During data generation

⁷ In this extract Sophie health had deteriorated to such an extent that she was seriously putting herself in danger. I found it difficult to imagine how her mother must have felt at this time as she tried to sort out what was happening (reflection, interview with mother Brenda pg.2).

when each young person talked about their parents becoming heavily involved retrospectively they were clear about their opinions.

This was a time when they were happy to hand over their 'free will' to others. It has been acknowledged that they had no choice because of their medical conditions, all five were acutely unwell. However, they could technically have still resisted and made their own decisions, this just did not happen. Would this be the case with older adults, who had more life experience, would they have resisted doing anything about their symptoms? Would they have delayed until they were at a 'point of no return'? In contrast would there be some argument that they would have sought help at a very early stage and in some cases have been diagnosed more quickly? In that sense they would be using their control and personal agency in an informed way, perhaps thinking that something was wrong which needed attention immediately. The question at the heart of this is, would older adults have behaved in the same way as teenagers and young adults in holding on to their control? This might well be the case. The key difference is the context in which these decisions take place, one group are as I have said creating that early life platform and just beginning to emerge as adults and so their loss of independence in the face of this feels somehow more acute or abrupt having only just become accustomed to their situation. An older adult might be more adaptable and willing to accept this change in their circumstances because their life platforms are more established.

5.7 CONCLUSION

This chapter has presented a complex series of events which were all concerned with the experiences that occurred as the five young people in the study were making the transition to independence. It was relevant to set the scene in terms of how their lives were developing, intellectually, professionally, socially and emotionally as this provided the backdrop to each of their situations. These were varied by reason of their own individual life plans and each of their stages of development. Leah was at the beginning of her adult educational journey and preparing for her GCSEs, she was still to decide on

what path she would like to take in the future. William had completed his school education and attended a specialist sports academy and was in the process of deciding how he would like to develop his future career. Both Ellen and Sam had already begun degree programmes in higher education and had both independently chosen their degree programmes and were progressing successfully. Sophie was also experiencing a productive and exciting time working for a design firm after obtaining excellent degree results. Their paths were in many senses unremarkable in that they were all engaging in the type of activities that one would expect to see in teenagers and young adults.

All but one of the group were either in or had been in a long term serious relationship and as with the development of their life and career plans, this is a common feature of this stage of development. For the four young people these partnerships were the first serious relationships that they had encountered and as such they were a central part of their everyday lives. As with young people of this age, this was a time when they were moving away from their immediate family being the centre of their attention to partners beginning to take this role. Sam, for example spent a lot of time at his girlfriend's flat sleeping over several nights a week, even though technically he was living at home. These relationships involved high levels of personal agency, choice and control as did their pursuance of their chosen life courses.

As each young person began to develop symptoms, there were a number of cross case examples resulting in several sub themes. The first of these was identified as holding on to control. All of the five young people in various ways maintained their agentic position. This was explained in the context of two environments, living away from home and living with family. Ellen and Sophie who were living away, had a longer period of time in terms of action being taken to try and ascertain their problems. Both had important priorities and were determined to meet their commitments. It was apparent that in both cases although help was sought by Ellen from her GP, the two young women both made decisions to continue with their choices and importantly not to return home. Those who

were living at home however, still maintained agentic positions as they continued with their daily lives. They controlled decisions, for example Leah was determined to try and go to school even if this was for a short time. Sam took control of his symptoms in a different way. His mother's role as a GP played a part in this as he instructed or 'nagged her' as she put it to undertake some blood tests to establish what was happening to him.

These agentic positions continued to be a feature of each young person's context as their symptoms progressed. Despite their level of independence and their need to continue to exert their personal agency, those who were closest to them wanted desperately to help them. This help was not dismissed and in Leah's case for example her mother and father's offer of assistance to enable her to continue going to school was gladly accepted. However, Leah was still maintaining her choice by continuing with school on her terms. Sophie in contrast was offered help repeatedly by her good friend Pip but chose not to take it and made her own decisions. In both cases choice was maintained by the young person. For those who were not living at home, fear could possibly have been influential in their decisions to not seek more help but equally neither Ellen nor Sophie thought that their symptoms represented cancer.

Coping with symptoms was a feature of the data set and in some cases these were alarmingly serious. Nevertheless by making adjustments the young people were able to manage and continue to function albeit in a compromised way. Ellen's pain in her shoulder was severe and started to restrict her mobility. She therefore got up earlier so that she still had time to dress before she attended lectures. As Williams' symptoms progressed he was unable to weight bear but still made the decision to attend a cricket game, even though the consequences of this decision were to result in serious implications for him, namely the fracture of his leg. Leah decided to cope with the distressing symptoms of vomiting and despite her school suggesting that she might be seeking attention or help, she continued to attend when she was able. All five young people unfortunately reached a point where they were no longer able to maintain a

position of choice in their view, instead they acknowledged that some choices would be made for them and that in the lead up to their diagnosis they would lose a significant amount of control.

This loss of personal agency close to diagnosis was however something that they did not resent or feel the need to contest. On the contrary they were at a stage when they needed assistance from those closest to them and they recognised that this help was in their best interests and borne out of the love of their family and friends. Some of them were so ill that when reflecting on the situation during data generation they commented that they felt they had no choice.

This chapter has focused on 'life then' and the maintenance of choice, control and largely the use of personal agency, coupled with the eventual surrender of that choice immediately prior to diagnosis. The following chapter will raise a second cross cutting theme which follows sequentially from 'life then', and has been entitled 'life interrupted' This will detail the further changes in agency as the young people are diagnosed and progress with their treatment.

6. LIFE INTERRUPTED: DISRUPTED AGENCY

6.1 INTRODUCTION

The last chapter provided evidence focusing on the experience of emerging independence in teenagers and young adults. Some of the early generated data was firmly situated in their everyday lives and aspirations for the future. This provided an observational lens which demonstrated what is largely a positive and exciting time in the life trajectory. Commonly young people are healthy and largely without any demanding commitments and can focus on building what was referred to in Chapter Five as an early adult life platform. Unfortunately the development of symptoms which lead to a diagnosis of a life threatening illness can undoubtedly have a significant impact upon this period of what could be viewed as a time of high optimism. Nevertheless as the data suggest, the young people in this study held on to this concept of control and personal agency which accompanied their independence, despite their worsening and in some cases dangerous health status.

This is the second of the three cross case chapters, which will provide an explanatory account of the experience of the five young people from the point of diagnosis, followed by their subsequent treatment. The first act of the play, recalling the analogy adopted for the three cross case chapters, essentially sets the context of the participants worsening health and introduces their presenting symptoms and their subsequent deterioration. This 'second act' develops the analogy of the play as it presents what could be argued is the 'heart' of the story, with all the challenges that this presents for young people in this situation. The concept of the three act structure has often been debated as inhibited because not all the content of a story can fit easily into the three component parts, some therefore contest the restrictive nature of this model. In this study there is an element of the nature of this restriction in all three cross case chapters as the young people manage their lives during the onset and subsequent treatment of their disease. In the second chapter this is most acutely witnessed as their health status during treatment is unpredictable. In the evidence which follows, whilst the journey is largely sequential in

terms of their treatment plan, there are many of what could be described as 'peaks and troughs' in their journey, which provide 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 as the title of this chapter suggests, 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. As this chapter develops and following the findings of the last chapter, a pattern of choice and control begins to emerge which is further evidenced in the third cross case chapter which follows this and explains the latter part of their journey. The development of this pattern of choice and control will form a central part in the forthcoming theoretical discussion and subsequent recommendations for practice resulting from the study.

6.2 DIAGNOSIS: THE TURNING POINT

In the period leading up to diagnosis, there were many accounts from the young people and those close to them of the general decline in their ability to manage their situation. In terms of their personal agency in the context of their situation, when they came to the point of diagnosis their control over events was very limited. It was apparent and perhaps expected that it would be those who were closest to each young person and had the most enduring relationships with them who stepped in to help.

6.2.1 PARENTS TAKE CONTROL

The data clearly revealed that it was the parents of the young people who were central to the experience of helping their grown up children in reaching a diagnosis. Whilst the control that parents took was for a number of different reasons, in essence the goal for all of them was the same, to ascertain what was happening to each young person. As discussed in the last chapter the two young women who lived away from their parents delayed their return home for a relatively long period of time. Subsequently their symptoms were the most debilitating when they finally went home. In Ellen's case it was

her father who made decisions about what should happen once she returned home. This did not prove to be particularly straightforward and he had to utilise his assertiveness and experience to try and ensure that he had control of what would happen next:

I started taking her to the doctors but the doctors would not see her because she is not registered with them... You have to get (city) to send medical records down to (home town) health centre. Before they become registered you are seen there by an out of hours doctor so we did a couple of times as out of hours but they carried on giving, now then, again check the meds. I have forgotten the name of them but I will remember it soon (interview with Ellen's father Phillip pg.6).

This difficulty in being able to make progress in this case is interesting. One contemplates how the situation would have been played out had Ellen exerted more decision making control in her situation. Therefore rather than a matter of her losing her agency, this situation is perhaps an example of her father trying to protect her agency. Her father did not manage to make much progress and subsequently had to resort to further measures in finding out what was wrong with Ellen. It is highly doubtful that Ellen would have been in a position to exert the level of choice and control that her father did in the situation because his next action involved financial costs:

and we went to ... umm privately...a consulting hospital...they don't do operations there and then in fairness we had to wait a week to get a slot because he's a rheumatologist... and to be honest with you if you want to find out what's wrong with you get a consultation with a rheumatologist because they can point you in the right direction... they are brilliant, absolutely brilliant...so waited a week umm because he comes in on a Monday basically and in that time I had persuaded (city) health centre to send copies of the records down...because and that was a lot of red tape there to be honest because you phone up and it's no and I don't know how (country) is, how (country) I but we can't do this, we can't do that and after about seven or eight phone calls of determined dad...going it's needed...umm basically by getting through to the practice and explaining the situation then the lady who was head of the practice was very, very understanding but you have got to go through three lots of barriers to get there' (interview with Ellen's father Phillip pg.8).

This extract demonstrates the difficulty of being able to make progress in Ellen's situation. During all her interviews she did not make reference to what happened in terms of the consultations close to her diagnosis in a negative way. Indeed she did not seem to crave control of the situation. She was clearly at a stage where she was very unwell

and welcomed the help of her parents. She was nevertheless becoming more anxious about her situation and also wanted confirmation of the nature of her symptoms. This feature of her trajectory was sustained past early diagnosis and her father Phillip continued to play a prominent role in her care in acting as a proxy agent. Following observation of an outpatient appointment however, I wondered if despite his desire to help and protect Ellen he wondered if he had intervened too frequently in conversation:

The consultant then asked if the family had arranged a holiday in the summer and Dad said yes in the UK. He started to speak again but then stopped. After this the consultation ended. We went outside and along the corridor and dad said to me “was I speaking too much”? (observation one field notes Ellen pg.3).⁸

Despite his worries these examples demonstrate very clearly this idea of the protection of agency as a proxy. Thinking about the notion of ‘proxy’ agency persisted with respect to this aspect of data generation in other cases within the study. I pondered whether the young people, not personally agentic themselves, were no longer with the free will and choice to make decisions. Instead they had someone who, acting in their best interests, was able to advocate on their behalf in helping them to make the choices that they desired and achieve a satisfactory outcome. In Sophie’s case as we learned in the last chapter, her health had deteriorated to such an extent that she was barely able to mobilise. In a similar way to Ellen’s dad Phillip, Brenda, Sophie’s mother took charge of the situation in terms of securing an appointment when Sophie returned home:

on Friday, Friday morning I was leaving for work and I just said I can’t leave her you know and started the GP route and phoned up my GP and said any appointments, no not for ages and I said oh well she does need to be seen you know what do we do here and she said well we have an emergency clinic tomorrow, Friday afternoon so I said fine okay so took her along to the emergency clinic, she saw the GP (interview with Sophie’s mother Brenda pg.7).

⁸ I returned to the field notes for this observation and counted the number of times that Phillip had intervened in the conversation and in essence here he had spoken ‘for’ Ellen and this amounted to several occasions and as the consultation progressed it happened more frequently (observation one field notes Ellen pg.2-3).

Once again this example of Brenda leading was something that there was no evidence of objection to in the data generation. Brenda said that she regarded her actions as 'what mum's would do' but in the same sentence in contrast, said that she was being a 'pushy mum' perhaps indicating that this is not something that all parents might do? Perhaps if other parents were not 'pushy' as Brenda put it, would they have possibly left the choice with the young person and not intervened even though they were very unwell? This is doubtful as it is probably the case that almost without exception parents would intervene and assist at this time. The idea of 'proxy' agency pervades here and the need to advocate is again clear.

6.2.2 PARENTS WITHHOLDING INFORMATION

At the point when the diagnoses were confirmed, for some of the young people the disruption to personal agency became more marked. Parents made conscious decisions to withhold information for a variety of reasons. They therefore did not provide any choice to their grown up children and all those involved in this felt that this restriction was a good decision given the circumstances. In Sam's case he was in the middle of his A level examinations, this was a crucial time for him in terms of his education and his mother Linda was convinced that she had made the right decision not to tell him straightaway about his diagnosis:

Sam's mother Linda: and you know the way 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 of 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

JD: and was this maybe because in the back of your mind there may be something wrong?

Sam's mother Linda: well yeah I thought that there may be something

JD: the blood picture was umm...?

Sam's mother Linda: yeah, so what I did was I didn't tell him at all the diagnosis for about three weeks

JD: okay, can you talk me through that

Sam's mother Linda: yeah, Thursday we did the blood and got results back and I think oh my god... rang my brother in law

JD: who's an oncologist?

Sam's mother Linda: yeah, umm he's a paediatrician (interview with Sam's mother Linda pg.11).

Like Linda there were others in Sam's family who worked in the field of medicine and more specifically with children and young people. Linda felt it was important to obtain their view before taking any further action. This was all carried out without Sam's knowledge. She was also keen for Sam to be fully examined by one of her partners before he was referred to a specialist. Again when he went to the surgery she did not disclose her concerns to him. When interviewing Sam, it was interesting to note his response to these occurrences at diagnosis. He was aware that his mother had withheld information of his diagnosis and said that he was pleased that she had done this. This was because had she told him immediately, he felt that this news would definitely have had a negative impact on his subsequent A level grades which he revealed he was very happy about. So whilst he had no choice in whether or not he knew, this did not seem problematic to him. However, he had become increasingly suspicious, so whilst Linda had kept it from him she was not quite able to make this last until the end of his exams:

Umm she was like oh yeah umm but I didn't mind that, like I did pretty well in my A levels I think I got like two A's and a C and the one I got a C in the day before I got told that I had cancer because I actually asked my mum like is there something wrong? (interview one with Sam pg.13).

Subsequently Sam did manage to exert some choice even in what could be viewed as a restrictive phase in terms of information giving. This was not the case for Ellen as her father was not happy to reveal any information to either her or her mother until he felt ready to do so. He again had made a conscious decision once they were in the specialist unit, that he would disclose the diagnosis at the time that he thought was best. He gave the very strong impression that he was giving both Ellen and her mother the most protection that he could in an attempt to safeguard their best interests. He explained that his first task was to make sure he understood the information before he disclosed it to Ellen and her mother. Incidentally the referring doctor had said to Phillip and his wife that he was glad that he had referred her promptly as he feared that she only had weeks to

live. When speaking with Ellen, she too was grateful for the concealment of this information:

Ellen: well within a week, by the end of the week I was here in this unit... and the doctor (consultant) told my GP that I only had a few weeks to live. My parents didn't tell me that. They only told me after I got through the first few obstacles in treatment'.

JD: how do you feel about that?'

Ellen: I think err I understand why they did tell me because I would have freaked out...and I would have just cried and that would have made me worse because I'm panicky, I'm susceptible to panic attacks...so they didn't want me to get worse...so I'm grateful for that really but it did actually help me...my parents basically took over and just being parents you know (interview one with Ellen pg. 16/17).

Once again this provides an example of choice and control being restricted in terms of receiving information, however, the caveat is the same in that it was acceptable to Ellen, as in that moment of time it was helpful to her that not everything was disclosed as soon as it became known. In Leah's case the opposite occurred as the news of her diagnosis was disclosed to her in the first instance along with both her parents. Throughout the interview the consultant who was taking care of Leah, was keen to point out his view of the involvement of the young people that he treated. He was not only focused on the young person in isolation but valued also the importance of, as he put it, 'taking the family along'. This had resonance for the long held practice of child and family centred care. This model holds that whilst the child is at the centre of the care process, the family are integral to the experience and need, in varying degrees, to be involved in the care of their child. In adulthood families are clearly still important to the patient, however, the involvement in their care is arguably different. In early childhood the involvement would be for example often negotiated on the premise of cognitive ability. Purely on this basis the assistance and involvement of the family would be required and in most cases preferable to the child. Unless there is a cognitive impairment, it is likely that in adulthood the level of involvement on a daily basis would not be so profound. This is borne out for example in the visiting arrangements in most acute inpatient settings where younger children are cared for. Without exception in the UK following findings relating to

theoretical models of separation in children's wards, visiting by families is open, with many parents being resident in these areas. In adult areas this is not the case with restricted arrangements in place. Interestingly in the teenage and young adult unit where this research took place the arrangements for parents families and friends fell between the two above mentioned criteria. There were no overnight stays for parents and they were not allowed to visit before 10.00hrs or after 22.00hrs, although there was some flexibility in the evenings. This observation of being involved in the care of young people in terms of the time families spend in ward areas is a useful analogy. The TYA unit occupying this 'in the middle position' in terms of visiting times fits well with their transitional position as emerging adults. Returning to the consultant interview in Leah's case, he commented 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 Leah I felt that at all times, I am trying to think if there ever has been a discussion where Leah 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, Leah on the bed and then either one or both parents on the other side and then we have this discussion (interview with Leah's consultant pg.2).

This extract it could be suggested describes as informal arrangement as is possible for such matters. Whilst it is held at the bedside it does not demonstrate the formality of a consulting room along with the usual office chairs separated by a desk. The environment in which discussions about the lives of young people took place certainly impacted on my own response to the dialogue between healthcare professionals and young people, I will return to this in a theme towards the end of this chapter. Despite this openness on the consultant's part to discuss matters openly and together, Leah's mother Janice was uncomfortable about the sharing of information at this stage in Leah's journey. She was taken aback by the interaction at the point of Leah's diagnosis:

emm yeh I was surprised that they done us all together because in my eyes Leah is a child I know that she is 16, but 16 they are involved that is the rules (mumbles) I think if I was told beforehand maybe I'd been a bit calmer, I didn't like the fact she see me upset in front of her I I I, cos I want to be the strong one so what was I going to say I know it's the rules and regulations but if they told me beforehand maybe I could have been a bit more composed, maybe I could have handled my emotions a bit better cos I don't want Leah ever seeing me upset because I got to be the strong one for her so yeh she took it ok but she was upset (interview with Leah's mother Janice pg.5).

This extract provides another but different example of the way in which parents might want to protect their children in the context of information giving. In this situation Janice did not indicate that she wanted information to be withheld as such, however, it would appear that she would have preferred that Leah was not there when the news about her diagnosis was given. Janice wanted to be in a position where she could provide strength to Leah at this time and because she was crying she very much implied that she had let her daughter down by showing her emotions. There is perhaps the notion that had the news been broken to the parents without Leah, then they perhaps would have chosen a time that they felt appropriate in which to disclose the information to her and that of course would have given them control over this particular aspect of her care. This theme whilst presenting different and sometimes conflicting views about information giving and also varied reasons for withholding information, essentially demonstrates the same phenomenon. This is illuminated in the lack of choice and control the young people had in terms of information disclosure even though they were happy with the way that matters were managed, apart from Leah whose mother wished that the information had been withheld so she could provide what she felt was more robust support.

6.3 MANAGING TREATMENT

Following their diagnosis each young person entered into a new phase of their lives as they grappled with the demands of their treatment protocols. Each of them had a different cancer and therefore implicitly their treatment paths varied widely. The severity of their disease was also an important factor in recognising the different challenges that they faced as individuals. Leah for example faced a particularly intensive course of therapy

as the healthcare team attempted to treat her stage four disease, Sam had to face further treatment, which included a bone marrow transplant following his relapse and William had to cope with the loss of his leg as part of his treatment. As was outlined in Chapter Four, the within case chapter, the young people were also at different stages of their lives in terms of their aspirations. Their level of independence was variable as was their family formation, size and occupational background. Despite this variability, there were a number of examples in the data set which demonstrated that in terms of their personal agentic position, which was governed by their choice and control, there was marked disruption to their agency. In contrast there were also cross cutting examples of the ability of young people to exert some control during decision making. Before treatment commenced the young people in the study were faced with where their treatment would take place.

6.3.1 THE CARE ENVIRONMENT

The opening chapter outlining the background to the study briefly describes current models of service provision for this age group. Significant progress has taken place during the last decade to promote the care of teenagers and young adults with cancer in appropriate environments, consistent with their age and stage of development. As is apparent the point of diagnosis is fraught with dilemmas around information giving and who controls events during this process, however, there was some evidence in the data to suggest that the young people themselves were offered the choice of where they would be cared for during their treatment. William provided an account of this during discussion:

ok umm one of the first decisions I had to make was where to have my treatment to because when I was referred to (adult cancer centre) I should have had my treatment at (adult cancer centre) but when I saw my oncologist (dr...) said to try out a (TYA) unit in the (hospital) which is sort of young adults so I fitted into that age group so I went to (unit) to see the nurses and because of (the adult cancer centre) had been full of the older patients it wouldn't have been the nicest environment for me to have my chemo so I went to (unit) and saw that it was people my sort of age and umm I just thought that that's a much nicer environment and that was my choice which I discussed with my parents and they said do what you want to do and I just felt it was the best option for me

to have my chemo which wasn't exactly the nicest thing but make the most of it I guess (interview three with William pg.2).

In William's case his consultant was an oncologist who specialised in his type of cancer but was based in the adult cancer centre a few miles from the TYA unit. However, arrangements were in place for young people to have their treatment in the unit. It was something that William was particularly positive about and recognised that his personal agency control and choice in this respect had resulted in a good outcome for him. This became apparent when he had to be admitted to the adult unit on one occasion because there were no beds in the TYA unit and he commented that this did not hold good memories for him. In Sophie's case she was initially admitted to an adult haematology ward for investigation. Being the eldest in the sample at 24 it was not immediately made apparent that she could possibly receive treatment in the TYA unit. There are many examples of the help given to young people during this time of their lives and for Sophie's mum Brenda finding out about the TYA unit was no exception. She was keen to find out where the best place would be for her daughter to be treated. There was no evidence that Sophie was involved in the act of finding information on the TYA unit, this was driven completely by her mother who quizzed staff in the haematology unit, namely one of the specialist nurses:

Sophie's mother Brenda: what's (the unit) (the nurse) has talked about this it sounds, is there a chance we can have a look you know and that's when the (unit) decision came in and (the nurse) spoke to Sophie about what it was like so she was transferred there

JD: did Sophie make that decision?

Sophie's mother Brenda: yes, god yes she made the decision

JD: she wanted to go to (the unit)

Sophie's mother Brenda: She was making the decision yes the thought for her of being in, I am sure lovely on (haematology ward) in a room on her own for initially however long it was going and initially we thought it was AML so much longer I think she was yes, no I didn't make that decision, she was the one with that and (the nurse) obviously painted a good picture of (the unit) as opposed to the ward (interview with Sophie's mother Brenda pg.10).

The style of language used by Brenda 'god yes' indicated to me that it was a choice which without question belonged to Sophie. However, one could not help wondering whether this choice would have been given to a patient of this age as a matter of routine.

6.3.2 IMMEDIATE TREATMENT DECISIONS

Following diagnosis, and for Sam a relapse of his disease he was treated for, treatment began very quickly for all the young people in the study. In terms of the conceptual ideas focusing on choice, control and their free will in deciding, negotiating and agreeing to treatment, this was a window which stood out quite dramatically in the data set. The magnitude of what was happening to each of them and those close to them was significant and was bound up often in examples of high emotion, sadness confusion and shock. These types of situations witnessed in my own practice experience were often compared to those of grief reaction. Long held theories of this type of phenomenon, outline a number of 'phases' which individual's experience and include shock, denial, anger, thoughts of 'why me' and sadness. The thoughts, feelings and emotions of the young people in this study were no exception. It was a difficult and challenging time in terms of decisions which needed to be made. The first of these concerned the protocols of treatment that each young person would undergo to treat their particular cancer. Apart from Leah, all the young people were over the age of 18 years of age and therefore in terms of the legal framework, providing they had capacity, had the power to decide whether or not to accept treatment. However, understandably, this is not something that any of them mentioned at the outset of their treatment. It may be the case that an older adult, based on the information they are in receipt of, might make a decision not to proceed with treatment and there are certainly examples of this in healthcare practice. Further there are examples which have been tested in the courts resulting in decisions which support adult choice to refuse treatment. This point highlights I accept, dramatically perhaps, the difference between teenagers and young adults and the position of older adults in treatment decision making.

The young people were only at the start of their emerging adult life journey and therefore their context it could be argued was different. Of course their families and those close to them also played an important role in this aspect of their treatment course. In discussion with colleagues, they accepted that technically there was a choice but referred to the situation as a 'Hobson's choice' again reinforcing that to decline treatment was not realistically a choice which any of them would make. Ellen was quite clear about this in one of her interviews:

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 Ellen pg.17).

She explains here that there was no choice but at the same time highlights that in essence there is a choice and that is, either to have treatment or to die (the Hobson's choice referred to in discussion with colleagues). This view was one that resonated with others in the study. William interestingly used very similar words in his interview as he was diagnosed and again expressed his perspective about the inevitability of his situation in his conversation:

basically yeah... that's the way I thought about it you know ...it's either that or my life you know a leg or life (interview one with William pg. 34).

In the early stages of the work William was succinct to say the least in the discussions that took place in data generation. This was particularly marked during the first and second interviews when he was in the middle of treatment. There could of course have been a number of reasons for this. In analysing his full case, there was a theme which related to the importance of him being 'one of the boys' and this was briefly alluded to in the within case chapter. Added to this the title of 'man and boy' was chosen for his particular story as he moved between the two positions on the journey through his treatment. This pragmatic approach with his short and clear responses with regard to treatment was indicative of not only where he was in his developmental process, but also

how he wanted to portray himself as still parallel with his peers. The need to be identified as a man rather than a boy was important to him.

The previous methods chapter also made reference to the difficulties of interviewing this age group, particularly in terms of in depth discussion on the part of the young person and this was evident when William was taking part. Leah's view at the onset of her treatment was also clearly stated by her when she was asked about choice in the treatment process. Again her response was succinct but emanated from a different position. As the youngest participant, her developmental position was markedly different. The tone of her conversation about this very much reflected that you did what you were told. Her response whilst still acknowledging that there was no control was very much about not questioning what was happening, rather it was important to listen to the doctors. She extended this position to her parents as well:

Leah: umm first of all chemo, then scans then bone marrow and biopsy and CT scans and stuff like that and then operation and yeah

JD: right ok and then more chemo?

Leah: more chemo yeah

JD: ok so can you tell me if you can remember how you felt at that time about the choice that you had?

Leah: no choice

JD: ok exactly so you, so you didn't feel that there was a choice?

Leah: no

JD: no ok umm well umm the choice of you know when you would start the treatment, how long it would be

Leah: no listen to the doctors

JD: really no choice?

Leah: no choice

JD: no choice did you sort of think about that at all?

Leah: no just listened

JD: just listened to the doctor?

Leah: yeah

JD: ok what about your mum and dad what did they say can you remember?

Leah: listened to the doctors

JD: ok, ok so in terms of the treatment the actual protocol like the chemo and the surgery that just went ahead no choice?

*Leah: no*⁹ (interview three with Leah pg. 1/2).

⁹ On reflection I remembered that Leah was almost laughing as this conversation took place probably out of frustration or the fact that she thought I was perhaps trying to push the point too

Leah made it perfectly clear here that she did not have control over the nature of the treatment. However, in all these conversations was it that the young people did make a choice? Although they had no control about the type of treatment to be implemented, did they make a choice to accept the treatment? This idea of control and choice extended to Sophie, the oldest young person in the sample she too had no control over the type or duration of treatment utilised in her cancer but again did she make a choice to agree? The restricting structure of treatment was really evident in these conversations. However, rather than the interaction with other structures such as families where structure might change, the structure here was maintained. Sophie's mother Brenda again did not see that there was a choice and indicated the need for Sophie to proceed with her treatment:

she felt in her treatment, she wasn't in control of any of it, I mean you're not it is protocol you don't have a choice, there isn't a choice and she was aware of that and she, she didn't enjoy everything about when what how, this needs to be done, that needs to be done, no you can't do that, this needs to be done, no she was aware that she wasn't making any decisions but she was also aware that she was in a situation where you can't (interview with Sophie's mother Brenda pg.11).

Again in this extract, the idea of choice and control are treated through the same lens. If there is no control then there is no choice. In terms of treatment, in this extract there was again a very clear account of the need to do what was asked, however, this is framed understandably in a more mature response as it comes from an older adult.

Despite the complexity of the interplay between choice and control in this discussion, it is clear that personal agency was disrupted. The agentic position of the young people was compromised by the nature of the treatment they had to undergo in that it involved specific protocols. Technically there still was choice but this concept was not adopted, rather choice was not considered an option, the overriding priority was to begin treatment. However, once treatment began, there were many examples of choice and

much. I wondered afterwards whether or not I had overdone the questioning (reflection, interview three Leah pg.1).

control which did not provide a picture of 'accepting' all aspects of treatment that the young people faced.

6.4 OTHER TREATMENT ISSUES

Many aspects of treatment for cancer include a repeating set of procedures and activities. Issues such as routine investigations for monitoring the progress of treatment are undertaken on a regular basis. Equally there are aspects of care which are concerned with medication management, these included medication management, the maintenance of adequate nutrition, infection control, monitoring as an outpatient and for some young people formal psychological support from specialist practitioners. These treatments are a fundamental part of the overall management of the young person and it is therefore important that these treatments form part of their overall plan. In all five young people there were aspects of their care that they were not given a choice about, times when they were advised that certain actions would be helpful to them and equally time when they desired some control over these events. This discussion is in contrast with the previous section where we saw the marked compromise and disruption to agency at the onset of treatment. The disruption to agency continued, however, there were challenges to these situations and evidence of times when young people made choices that were not congruent with treatment plans.

6.4.1 MEDICATION MANAGEMENT

This aspect of care revealed that there were a number of issues concerned with the freedom to choose relating to medication required in treatment. There were examples of the actions of young people essentially demonstrating their desire to be agentic. This provides some of the small peaks in the otherwise deep troughs where they believed they had no choice. The choices that they made relating to their medications of course were not always wise. However, in terms of capacity, statute in the form of the Mental Capacity Act, provides in its general principles that decisions should be respected even if these are unwise. Since the Act applies to all those over the age of 16 years, making unwise decisions should be accepted. However, this is not borne out by the evidence in

terms of treatment refusals by those under 18 as judged by the court as we have already learned.

Sam was in the process of recovering from his bone marrow transplant when I attended one of his outpatient visits as an observer. His mother Linda, the GP, was present as was a student nurse who was also observing. The consultant who managed his transplant led the consultation:

The consultant then asked what medication Sam 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. After writing some notes and another couple of questions about blood tests and attending the dentist, the consultant then said that the only 'naughtiness' was that Sam was not taking antibiotics. It is a 'mute point' the consultant remarked, you started and then stopped early. He then said that if your CD4 count was low then you should continue with these drugs (observation two, field notes Sam pg.2).

It is difficult to know the reason that Sam stopped taking the medication but it was a choice he made alone and one that his mother was aware of it seemed.¹⁰ When he was informed that he would possibly need to continue the medication, he did not respond verbally. Given that he was in the early stages of recovery and there may have been complications for his health in terms of his immunity, this perhaps was not a particularly wise choice, however, he had clearly not been deterred by this and exercised his personal agency in challenging the structure of treatment. Before and after the transplant his personal agency had been severely restricted as he had to spend time in an isolated environment, where he had almost exclusively no choice or control over most events in his life at that time. His new found freedom may have influenced the choices he subsequently made.

¹⁰ *When I remembered the consultation, at the point when it was revealed that Sam had stopped taking medication his body language changed and he was very reticent to engage in conversation. The scenario put me in mind of a school child who had misbehaved. (reflection, observation two field notes Sam pg.2).*

William also struggled with some of his medication, there were particular medicines which he sometimes refused to take, despite the fact that these were the ones used to help with nausea during chemotherapy. William's nausea and vomiting was significant in the early stages of his treatment and this along with surgery for the amputation of his leg, severely disrupted his personal agency. Nevertheless his choice was to not take them and then cope with the consequences of his actions. The nurse who I interviewed in William's case highlighted this issue:

The biggest battle I had personally with William was with his medication...umm his compliance wasn't always great...when he was at home my understanding was that he was very good with his medications (interview with William's nurse pg.7).

The use of the word battle here was interesting as it perhaps gives the impression that there may be a winner and a loser in this situation. Equally it conjures up thoughts around power and someone trying to exert this power. William's parents (his mother Julie in particular) also raised this issue, however, their stance was one of accepting that he had a right to make a choice in forming a decision and there was little that they could do about it. William's mother illuminated this:

He has made the decision, well he's decided that the anti-sickness tablets with him don't work so he is not taking them...there is not a lot I can do if he doesn't want to take them I can't force him can I? (interview with William's parents, mother, Julie pg.25).¹¹

In this extract the idea of force is an interesting use of the word. It resonates for me in a similar way to the idea of the battle and the notion of having power over someone. I have no doubt whatsoever that all those involved were acting in the best interests of William as they believed that his symptoms would be alleviated if he were to take his anti- emetic medication. Nevertheless in reality he had the right to exert his choice and did so a number of times in this context.

¹¹ *When Julie articulated this view, her body language became more guarded as she said that she could not force William to take his medication. I felt that his actions were something that she did not agree with but had to accept. (reflection, interview with William's parents pg.3).*

Leah too had difficulties with taking her medications. Her mother and her father were both very keen to follow the guidance that they had been given and wanted Leah to agree with their view. Again they were trying to help but Leah did not agree and went to some lengths to try and exert her personal agency and control over the situation. Her main worry was about one particular type of medication and the side effects of withdrawing from it. It transpired that there was a misunderstanding about this, the side effects were not as worrying as first thought. Nevertheless at the time she was adamant about her choice not to take the medication:

if she didn't take the tablet she would have to tell the nurse because if she didn't take all the tablets these particular tablets she could get emm severe withdrawal symptoms giving her convulsions so as the nurse went she said to me I'm not having the tablet mam am not having it I said well if it does you good you're gonna have to have it and they told me that if she didn't take half her tablets she was so sick, if that tablets not in my body and I have been having it for a while I will I will get convulsions and I do not want convulsions hide it. And she hid the tablets and I said to her you have got to tell the nurse you can't do that because they have a record for what tablets you are taking they need to know what you're taking you cannot hide your tablets. If you don't want your tablets you have got to tell them you don't want the tablet but I am not taking it mam I don't want convulsions I'm not taking the tablet I'll put up with the pain (interview with mother Leah's mother Janice pg.7).

Janice was clear that if Leah wanted to make the choice and not take the medication then she should at least inform the nurse. She commented to me afterwards that if Leah had elected not to do this, then she would have overridden Leah's control and told the nurse that the tablets were hidden (the place of hiding was underneath Leah's leg). It would appear however, that the lead nurse for the unit accepted the fact that young people may make a choice not to comply with some of their treatment as a note in Leah's medical records reveals:

September 2014: Ongoing issues of not taking medication contravenes ward policy. Staff to remind 2-3 times then remove 15 minutes later if not taken (clinical record in medical notes, Leah).

This entry is confusing, the contravention of policy I understand, is that medicines were left unattended when not taken. Rather than this occurring they should be removed when

the young person decided that they would not take them within that time. Persuasion was employed however by reminding the young person up to three times before the staff accepted that they would not be taken. These issues provided evidence of young people attempting again to challenge the structure of treatment by exerting personal agency. Management of medication was certainly an area of care where young people were not always in agreement and wanted to assert their agency in decision making. It would seem that those on the receiving end of this, including staff and parents were not immediately accepting of this, however, their actions were always veiled in protection of the young persons' well-being. Another important example which paralleled the management of medication was focused on the issue of nutrition

6.4.2 MAINTAINING ADEQUATE NUTRITION

The importance of maintaining adequate nutrition formed a fundamentally important part of the care within this group. As with all patients undergoing treatment which is likely to affect hydration and is toxic, there are a number of side effects which subsequently lead to a lack of appetite resulting sometimes in significant weight loss. Carers and staff on the unit were involved in a continuous cycle of trying to help, advise, encourage and negotiate. This was fraught with challenges as the young people found it difficult to have any control over their desire to eat and drink despite their best efforts. Added to this, on some occasions some of the young people had to be artificially fed in order to protect their nutritional status. This raises the question that striving for personal agency was not pitched against the wishes of others as in the last sub theme, the disruption and restriction here was directly related to the type of treatment that the young people received. This was so debilitating that despite their attempts to re-ignite an agentic position, they were unable to do so purely because of the physical effects of their treatment.

Ellen had unfortunately experienced a serious complication in her treatment which resulted in a stroke like syndrome (more of which I will come to in the next sub theme).

Due to her condition in the early stages of this she was unable to have any choice or control about her nutrition because she was unable to communicate. Whilst care was negotiated between the staff and Ellen's parents, she was unable to play any part in this.

The medical notes at this time give a clear indication of Ellen's health status:

October 2013: Further impression not sure she can see or hear curious jaw clenching ? Impression infection, (no record of discussion with parents)

MRI abandoned patient too agitated so discussion with mum about tetanus

October13 Transferred to critical care, worsening neurological functioning, impending respiratory compromise (clinical record in medical notes, Ellen).

It is clear from this entry that the lack of control for Ellen was significant. There is no record of any discussion here, that is not of course to say that this did not take place.

Thus her nutritional status was managed by the team:

It was very very gradual you're saying things like obviously she has a food pipe so the amount of liquid she can take is all monitored (Interview with Ellen's father Phillip pg.16).

Similarly for Sam whilst he was pre-warned so to speak, he was informed prior to his bone marrow transplant that he would have a naso- gastric tube inserted as part of the lead up to this procedure and once again the effects of the treatment would leave him with no choice. He was very concerned about it and had some negative thoughts about the way in which these types of tube were used based on some historical knowledge:

I wasn't very keen on the idea but I thought if it was necessary I would do it umm because the first I heard about it was when I spoke with the head nurse of the ward a couple of months before I went in and they said there is probably going to a tube put up your nose and I was a bit like uhh and I was put off because mainly you hear about suffro, the suffragettes and they were force fed umm with up the nose and umm yeah so I didn't think it would be like that but they showed me it wasn't quite as bad and it was a small tube but still present and not nice like you could always feel it in the back of your throat and in your nose yeah (interview three with Sam pg.3).

This requirement for adequate nutrition was a compulsory component of care and one where if refused would have ultimately meant that a good recovery was highly unlikely.

6.4.3 CRITICAL SITUATIONS: A DIFFERENT CONTEXT

Sadly, there are occasionally times when young people may become critically ill as a result of treatment complications. Added to this there are also some treatments which require what could be argued is not critical care but is certainly high dependency management. Ellen, Sam and Leah all fell within these two categories. The importance of this sub theme demonstrates their highly restrictive position at points in their treatment which rendered them with neither control nor choice of their situations.

Ellen's position was perhaps the most marked as she experienced serious complications following treatment with Methotrexate. This was, for her and her parents, a time of what could be argued was a complete absence of any personal agency, choice or control as she rapidly deteriorated and ultimately was in a semi- conscious state:

By this time she is lying down on a trolley but her jaws locked out, her legs were in spasm uhh she was not coherent but she was making noises... and grunting sounds obviously it was through her teeth because everything was locked out now, I think cognitively she knew it had all gone wrong...so you start to think this has gone seriously wrong (interview with Ellen's father Phillip pg.13).

As outlined in the within case chapter this was the very lowest point for Ellen and she was in a position where she was unable to make any decisions. Her parents also felt completely helpless in the situation and indeed were unable to influence her transfer to the specialist unit, instead she remained in the local emergency department for several hours despite her father's clear frustration.¹²

At perhaps a less critical level, but nevertheless an intensive period of treatment, both Leah and Sam had exclusively no control over the environments in which they were cared for as they both received treatments which had strict parameters in terms of conditions of isolation. The idea of the choice to go ahead with their treatment here was questionably something they did not consider challenging. Both were at a critical stage

¹² *The distress of Ellen's father was palpable in this interview, he was close to tears as he described first of all his feelings of frustration and ultimately of anger. I struggled to think about how frightening a time this must have been for the family (reflection, interview with Ellen's father Phillip pg.3).*

in their disease management, Sam had relapsed and Leah's disease was not being controlled by chemotherapy. They both required isolation, Sam because of his bone marrow transplant and Leah because her treatment involved the use of radioactive materials. Interestingly though both young people stated that they would not want to go through these treatments again and indicated this in their final interviews:

umm very intense chemotherapy, umm it wasn't enjoyable at all and umm it is not something I would want to do again, I can't think of any circumstances under which I would want to do it again (interview three with Sam pg.1)

umm well it doesn't seem to be working so I don't think I want chemo again (interview three with Leah pg.3).

It is difficult to predict what would happen in reality as these are prospective decision making thoughts. If further restrictive treatment were required would Sam and Leah want to make a choice to disagree and ultimately refuse what was proposed?

This discussion has been primarily concerned with treatment issues beginning at the point of diagnosis and then considering the many challenges as treatment progresses. This of course remains against the already identified backdrop of their ongoing development and their life as a teenager or young adult. This context of their life was extremely important to them and their subsequent desire for choice and control of their lives was evident across the whole data set.

6.5 STRIVING FOR AGENCY IN EVERYDAY LIFE

Undoubtedly there were clear indications during the young people's experience of cancer relating to their desire for independent choice. Maintaining this option in their everyday lives was manifest in a number of examples. However, this was not always straightforward and again there were 'peaks and troughs' in the level of choice and control that was exhibited in each case. An aspect of their future lives as adults which was raised on a number of occasions related to their future fertility. Before they became unwell, it is unlikely that this would have been a subject which was at the forefront of their thinking. However, following diagnosis, for some of them at least, it was brought

sharply into focus as they began to come to terms with the possibility that their treatment might result in future infertility.

6.5.1 THE CHOICE TO HAVE A FAMILY

William, Sam and Ellen had all taken part in discussions with the medical team about their future fertility. As far as I am aware it was not a discussion that Leah had participated in.¹³ Sophie on the other hand disclosed that this was something she could not remember talking about. In her final interview, I raised this and she did say that there were other priorities for her, it was as though she had made her own decision not to think about it, how conscious this was I am not sure:

umm I don't really remember I mean I don't think I ever really had, I didn't dwell on it that much umm and you know if it would have been something that would have affected me in later life but at the time it wasn't the most important thing to me there were more important things that I would lose my hair and all these other things that would happen to me and that was kind of a last thing (interview three with Sophie pg. 11).

The nurse who was interviewed about Sophie's care attested to this and also reinforced the notion that it was something that she had not discussed with Sophie. The reason for this though she argued, was more to do with the speed that was required in progressing immediately to treatment, giving the impression that there would be difficult choices to be made should a young woman have a strong desire to harvest her eggs prior to treatment:

I can't umm, I am sure she would have mentioned because it is a really big thing but I can't think of a specific conversation umm and I think that is the hard thing about these diagnoses it is such a quick fast awful presentation so you don't have time to do things like egg harvesting, umm and that's really hard but I guess umm (interview with Sophie's nurse pg. 11).

The prospect of future infertility therefore in Sophie's case whilst a possibility and the constraints of the urgency in the situation paint a complex picture. On the one hand there

¹³ *I wonder whether on my part this was something that I found difficult to ask about? Did this reveal my inexperience of interviewing? Perhaps it had stayed in my mind that her parents had talked about her being 'young' for her age and I had therefore thought it might not be appropriate. However on reflection this I think was ill judged, why would someone discuss fertility with her she was a maturing adult? (reflection, interview with Leah's father Kevin pg. 1).*

is the opportunity to be personally agentic and make choices about what is important to the individual but on the other the reality of the lack of control over the situation is again governed by the disease itself. This returns us to the opinion of the young people earlier, the 'you have the treatment or you die' view of the situation. For Ellen it was important and it was something that she asked about immediately after she was diagnosed. She desperately wanted the choice and to have the personal agency to make a decision to harvest her eggs. However, this did not result in the outcome she expected:

umm at the beginning I was having quite a lot of treatment and I was asking them quite a lot of questions like can I have my ovary samples taken now? And they said no you haven't got time to do it so I didn't have that decision to make (interview one with Ellen pg. 17).

This had a significant impact on Ellen and she was worried about how it would not only affect her future but her relationship with Nigel. He however did not raise the issue at all. However, it was not something as with Leah that was asked about directly.

6.5.2 PROVIDING A SAMPLE

For William and Sam the issues were different. Both young men had been given the opportunity to store their sperm samples for possible use in the future. This was recorded in both of their medical notes, however, there was no documentation of detailed discussion, rather just that it had been discussed and advice given. There was no evidence that either of them had any objection to this or that they agreed or disagreed. It seemed to be more of a matter of 'going along' with things. Their issues appeared a little more complex than Ellen's and Sophie's and related to matters of embarrassment and in Sam's case having to provide a second sample as the first was not sufficient. It was not revealed whether his mum Linda had accompanied Sam on the first occasion, although she did say that on the second occasion 'she sent his father with him' so it is a possibility that she went with him the first time. Added to this there was marked sorrow on his mother's part at the fact that matters could be completely out of his control and how definite this was:

Oh yes definitely yeh its definitely and you it's just that suddenly you just I just spend my time feeling sorry actually but that particular afternoon when I just felt do you know what I mean, it's defining in terms of your life there is an increase risk without doubt if and what can we do you know I mean what can we do we just got to (interview with Sam's mother Linda pg.32).

Sam did not raise this as part of our discussions and his mother remarked that he never discussed it with her. Did he make a conscious choice not to do this, was he embarrassed by having to provide two specimens and also by the whole discussion or as with Sophie was it not a priority? In William's case it was raised in one of his interviews and he accepted that this was something that provided a sensible option for the future, what he did not talk about was his embarrassment at his mother going with him when he had to provide a sperm sample:

William's biggest embarrassment he said he had ever felt that his mum had taken him to the sperm banking which perhaps could have been prevented further if you had just sent a member of staff and he said that was one of his most embarrassing moments...a sample yeah and then mum is outside the door (interview with William's nurse pg.14).

It is unclear whether he had any choice in this matter. Regardless of whether he did or not, there are issues to consider here. The nurse mentioned a member of staff accompanying William, it seems unlikely given the information that there was a standard way of approaching matters such as this. There is also the added dimension that Julie was a nurse and there could possibly have been some unconscious cross over with her role in this instance. In a similar vein fertility was mentioned at one of William's outpatients appointments, this again was in the presence of William's parents and girlfriend:

He said "have we sperm banked you"? He then said that William's fertility should return after a year so to be careful. When he wanted to have a child the consultant said he should try for a year and if nothing happened he should contact him (observation two field notes William pg.3).

I wondered at this point, having interviewed the nurse involved in Williams' care how he felt at this time. Had he been given a choice for a private conversation would he have taken it?¹⁴

There were a number of examples in the data set for William where it was highlighted that his mother did 'cross' roles and indeed one of the themes in his case was that of 'mum in a dual role'. Aspects of his care such as monitoring weight and vital signs were examples of this role. This might not generally have been a problem for William and indeed he said that he was glad of his mother's assistance in the early stages of treatment, however, perhaps with reference to sperm sampling he may have made a different choice had there been the option for her not to accompany him. Other matters which were very much more 'live' for the young people were concerned with social and personal matters and relating to their desire to continue their lives outside of treatment. There was evidence here of negotiation, helping, advice and sometimes disagreement as the young people exerted their personal agency.

6.5.3 I HAVE A LIFE YOU KNOW!

The title of this sub theme evolved after witnessing the strong desire of the participants to try and (what I would refer to as) salvage activities and social engagements that they enjoyed in their everyday lives. This without exception was important to all of them. It gave them a sense that they were continuing in some way on their journey of emerging adulthood and having some control over this provided a sense of optimism for them. They of course, all had their own particular context in terms of the things that they liked to do and what they wanted to achieve. Whilst in the data extracts provided there are examples of personal agentic behaviour and the propensity for independence these choices were not always totally 'free'. There were compromises to be made in ensuring

¹⁴ *This was a difficult moment knowing how he felt about the sperm banking issue and the fact that his mother was present and I admit to feeling awkward when this conversation was taking place, moreover I was wondering if there was some embarrassment for him.(reflection, observation two field notes William pg.3).*

that as much as possible the young people were able to have an enjoyable time in their chosen endeavour.

Leah, the youngest in the group as we have learnt, was undergoing a particularly intensive regime due to the nature and stage of the cancer she had been diagnosed with and spent most of her time in the unit. From the outset of her treatment she had only spent a handful of days at home. She was, as we are aware studying for her GCSEs and 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. Staff in the unit were familiar with this type of occurrence and always tried to accommodate the wishes of the young people in enabling them to fulfil their requests. However, Janice, Leah's mother found it incredibly difficult to relinquish control and although Leah did go to her prom there was a caveat in order for her mother to feel confident that she would be ok:

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 by ere she did (nose) because her haemoglobin was a little bit low emm so she had a bit of tissue and we were going back and for and in the morning we were back in the hospital so no, no was it that day or (mumbles) have to think now, no they checked in the hospital to see if everything was alright but she had a bit a blood and so I was worrying now that (mumbles) so that was a bit of an issue (mumbles) 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 Leah 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 Leah's mother Janice pg. 16).

Janice was unable to give full control to Leah as her anxiety for her daughter's well-being understandably overrode everything else. This extract provides more of an example of collective agency, however, Leah's presence in this situation was strong in terms of her agentic power. William was also keen to get on with some socialising once his surgery was completed and he was coming towards the end of his treatment. He had a girlfriend

who he had been seeing for some time, Lucy. She had her birthday and William wanted to go away for the night with her. Whilst he was able to do this it involved some compromises. Albeit his amputation had only recently been carried out and so his confidence was not high, there were a number of things that he had to change for the trip. He had been driving before his surgery and unfortunately he did not feel he could travel by train and so the couple stayed somewhere relatively locally and his father dropped them at their destination and picked them up. William also had to change the hotel that they were previously booked into because the first one was too far from the centre of the city and would have proved difficult in terms of mobility. He was also planning to go to a music 'gig' but changed his mind about this as his friend alluded to:

he was not confident I said why don't you just take a chair and go to the back because it was a band he liked.. but he said no he couldn't be bothered because gigs people pushing round and stuff like that (interview with William's friend Nathan pg. 16).

Nearly all William's choices were constrained by his recent surgery and despite his desire to exert choice he found himself constrained by practical challenges. Again collective agency pervaded in this situation. In order for him to enjoy a weekend away it would seem that his view was that he had no choice but to make the changes so that he could go away with Lucy.

Ellen in a demonstration of her sheer determination to recover from the serious complications of her treatment and regain some control of her life, decided to organise a fund raising event for teenage cancer. She completely immersed herself in this activity displaying significant agentic power and providing some very lengthy extracts about how she had almost singlehandedly arranged a fete which had subsequently raised several thousand pounds. Unfortunately her choice was compromised, on the day of the event that she had been so looking forward to her blood count was low and although she made a choice not to attend of her own volition, it resulted in a marked degree of disappointment for her.

6.6 CONCLUSION

This chapter has been extremely rich in revealing data that has provided a window enabling us to view the lives of the five young people and those close to them as they began and made their way through cancer treatment. There are some clearly identified points of a lack of choice and personal agency in decision making, for example at the point of diagnosis. The not unreasonable protectionist approach of parents resulted in young people not being involved in the early stages of diagnosis. Instead their parents assimilated the information before disclosing matters to their children. Where the process was open in Leah's case, her mother whilst understanding her daughters' right to be involved would have preferred, it would seem, for her not to be there as she did not want Leah to see her upset. There was a need on the part of her mother to be strong for her daughter.

It was refreshing to see that the care environment which has been the subject of much debate in teenage and young adult cancer circles was an area of discussion that was buoyant in terms of choice, with evidence that young people were able to freely make decisions about where their care would take place. However, once treatment began there was a reminder of the restrictive regimes which had to be implemented and that these were out of the control of the young people. The argument that there was still choice at this stage is a complex and sensitive one. The idea of this being a 'Hobson's choice' is one which was highly recognisable in the data set.

The treatment issues encountered ranged from everyday treatment issues including, as examples, medication and nutrition to critical situations. Equally within these there were a range of experiences in the struggle for choice and personal agency set against the backdrop of not having control over treatment requirements. In the most extreme situations there was a complete absence of any notion of choice due to a universal lack of control.

Everyday issues make up a smaller part of the chapter, which is perhaps indicative of the smaller role that these played during treatment in terms of the opportunity to partake in daily life. It was clear however, that there was a real determination on the part of the young people to strive for some independence and exert their personal agency despite their challenges. However, once again fertility issues stood out as something that was beyond their control due to the nature of treatment. The following chapter details the concluding act of the play as it explores the rebuilding of lives and looks forward to a time when the young people reclaim their independence by once again exerting choice and moving forward to an autonomous adult life.

7. LIFE RECLAIMED: AGENCY RE-ALIGNED

7.1 INTRODUCTION

The last chapter demonstrated the acute nature of change in the personal agency that young people had as they made their way through cancer treatment. Although by its very nature treatment was in some ways a linear process, there were examples of ‘peaks and troughs’ in terms of each young person’s desire to have control over their respective situations. This was not just related to treatment but to other aspects of their lives. Matters that were important to them remained relevant as they negotiated and navigated their way to achieving their life goals. This so called ‘second act of the play’ provided what I have described as the heart of the story. Indeed in this group it was the time of most activity in terms of treatment and of course the side effects that this inevitably brings. However, the young people had busy lives and equally they had events and engagements that ‘would not wait’. The chapter essentially demonstrates that whilst there were some elements of their life that they had little control over there were occasions when they were able to make choices, albeit that these times often presented challenges for them. Even when they were able to make a choice this was still somewhat restricted by their circumstances.

What follows is the final results chapter and also the final act of the play. The final act would normally look towards the outcomes of the story and sometimes towards the future, where there may be a rediscovery of self in terms of the characters. They may emerge for example as different individuals having experienced the ‘main event’ which we witnessed in Chapter Six. This chapter in many ways presents an optimistic picture of the future for the young people involved in the study, a time when they could reclaim their lives and as the chapter title suggests, a time for the re-alignment of their agency. This was for all the young people a time of intense reflection as they considered their future, re-evaluated each of their respective positions and took action to ‘make things happen’ in their lives. Again as with the last chapter the neat three act structure does not always fit the content and this is indeed the case within this chapter. There were once

again setbacks and challenges as each young person strived to regain their lost independence in attempting to move towards a fruitful adult life.

This chapter further develops the conceptual model of choice and control, which in many ways shows an 'upward trend' particularly in terms of increasing personal agency and decision making choice. However, not all the young people were able to fully re-align their agentic position. This resulted in compromises, which commonly tended to be a feature of their lives as they came towards the end of their treatment. Unfortunately this type of research ultimately brings with it the possibility that young people will not successfully complete their treatment and sadly this was the case for one of the participants in the study.

7.2 LEAH

yeah, I wouldn't know what to do in university though I still haven't thought what courses I would like to do. I don't know yet but I want to go to University I know that (interview three with Leah pg. 15).

As was outlined in the within case chapter where each young person was introduced, it was pointed out that Leah had a cancer that was rare in her age group. She was 16 years old and approaching her GSCE examinations. She underwent a very intensive regime of treatment as her disease was not only rare in her age group, it had unfortunately progressed and was widespread. When she was approached to take part in the study however she was keen to participate. I remember that some staff were surprised as they found her to be a quiet young woman and they wondered how much she would talk to me. Despite all her challenges, Leah did not withdraw from the study. The data generation period for her was significantly more protracted than for the other young people as there were periods when she was too unwell to take part. On those occasions when we had planned to meet and did not, it was her strength of decision making coupled with clear ability to exert her personal agency which governed the response, which I of course respected. During our discussions she gave a number of examples relating to her disagreement with certain aspects of her treatment including

medication management and the maintenance of her nutrition as we have already seen in the last chapter. Both her parents strove to try and acknowledge that she was approaching adulthood and each of them respected her desire to have an opinion and choice in what was for her and them a very difficult situation.

Her trip to the school prom was undoubtedly a highlight for her and she was at her happiest when discussing this event. For her this was probably the most she achieved in terms of reclaiming her everyday life and the happiness it brought her was obvious as she talked about the night with her friends. That night though the prom was not the end of the event, she insisted on going to an 'after party' at a friend's house. After some negotiation her mother agreed to take her. This was the 'icing on the cake' for her:

Leah: it was all fantastic, it was really good.

JD: was it just being back with your friends and doing a normal thing?

Leah: yeah and I hadn't been to an after party or anything like that before, it was fun we just went to friends and had a good time (interview two with Leah pg. 14).

In retrospect it reinforced the importance of the need for flexibility, the need to continue with everyday activities, with celebratory events, with experiencing all that life had to offer in Leah's situation. Leah continued with her treatment and underwent surgery to remove her tumour. The post-operative chemotherapy unfortunately did not improve Leah's situation and following discussion her consultant decided to suspend the treatment. She then travelled hundreds of miles from her home to have treatment in a leading specialist centre where even at that stage she reclaimed aspects of enjoyment in her life by doing some sightseeing, although she was unable to mobilise independently at this time.¹⁵ At the outpatient appointment following this we had our final interview together where she talked about her future with respect to the extract at the beginning of this section. She

¹⁵ I reflected on the conversation I had with Leah and her mother immediately following her visit to the specialist centre as we were waiting in outpatients. She was keen to tell me that she had gone with her mother for a manicure and chosen the brightest turquoise to paint her nails and was really proud of the choice of colour because it stood out. She was the happiest that I had seen her during the study period (observation one, field notes Leah, pg. 1).

was in a very optimistic mood and felt better than she had for some time. She was thinking about how she would reclaim her future by going to university. This was indicative of all the young people who were treated, this notion of looking forward to a time when they would be able to make independent choices which would prepare them for what they hoped would be a successful life. Sadly I attended an outpatient appointment later the same month to observe Leah's consultation but on this occasion she was very unwell. She was admitted to the unit on that same day and was discharged home shortly afterwards with the support of the palliative care team. She died peacefully at home seven weeks later.¹⁶

The four remaining young people in the study had all faced many challenges both prior to diagnosis and during treatment. Each of them had to navigate and manage some difficult issues. Ellen in particular was negotiating and coping with a long recovery after being admitted to the intensive care unit at the regional hospital early during her treatment. Unlike Leah who had not recovered from her cancer, they were all optimistic about their future lives, this was illuminated by them in their later interviews and by those close to them and involved in their care.

7.3 THE IMPORTANCE OF LIVING INDEPENDENTLY

Sophie and Ellen were both living independently from their families when their symptoms developed and both returned to their home towns for treatment where they stayed with their families. Sam was very eager to move out of his family home following his transplant and was keen that this should happen as soon as possible. Moving to an independent living space is possibly one of the fundamental elements of the transition to adulthood. Not only do young people acquire their own private space, they have to manage many other aspects of daily life for the first time. Whilst living at home for example, utility bills

¹⁶ *I felt extremely sad about Leah's death and once I had told my supervisors, I sat quietly for a few minutes. After some tears, I thought about the tremendous contribution that she and her family had made to my work and how her story would always be 'alive' in this study, informing others of elements of her own journey.*

are organised and paid, meals are prepared and if parents care to admit it, washing is usually done! These are all important life skills and this marks a significant change in the everyday lives of the young person. Equally young people may be sharing accommodation with friends rather than family and for the first time, have to negotiate and manage a different dynamic than they would have previously experienced. Of course living independently also brings much contentment to young people as they build their early adult life platform.

7.3.1 LIVING INDEPENDENTLY SECOND TIME AROUND

In Sophie's case she was very keen to move back to the city where she lived and made no apology for this. Indeed when the nurse involved in her care at the unit where she had her treatment was keen for her to attend as an outpatient (at least initially) following completion of her treatment she had different ideas:

and I think that is fair as well because you know, that one thing, she understood the risks and she can make that decision but from my point of view, my job is really to inform her and people may not want to do things that we want them to do but it is their life at the end of the day and their body, you know I think it is difficult (interview with Sophie's nurse pg.9).

Therefore in Sophie's case her move back to her flat and to her place of work so quickly following the completion of treatment, resulted in her care also being transferred to another centre. As her nurse remarked, the job of practitioners is not to make judgements about decisions but to sufficiently inform patients about the benefits and risks that they are exposed to when considering a course of action. Enabling a patient to make an informed decision therefore is at the heart of helping individuals to exert and retain an agentic position. Sophie regardless of the involvement of anyone who was linked to her care took the same stance. Indeed the consultant who was looking after her made a note in her medical records which attested to this:

October 2014: I would normally be expecting to do a marrow imminently, however, she is determined to return to (town), in fact she has already done so (clinical record in medical notes, Sophie).

This extract was another indication that Sophie was intent on reclaiming her life and did not discriminate between members of staff in perhaps listening to the nurse, for example, but not the consultant. Sophie not only decided that she would move back to her workplace but that she would move to a new flat. She 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 Sophie's 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 and then drove that back down, loaded up all the stuff and then drove up to (suburb) umm so I did it all over the weekend moving, actually moving part of it 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 arring about stuff but there does come a point where you have to get on with it (interview three with Sophie pg.4/5).

It is quite remarkable that this was only two weeks following the completion of chemotherapy. It is almost as though Sophie was refusing to acknowledge that her disease had ever existed. When she reflected on this of course she recognised that the decisions that she had made may have possibly been a little unwise. Nevertheless at the time she exerted all of her personal agentic power in determining what would happen next in her life. Her mother Brenda recognised her strong desire to have the free will to decide her future and was very supportive of Sophie. She knew her daughter well and I recalled the conversation about Sophie going out and getting a part time job in the within case chapter when she was young and how she had been clear about her choices even when she was barely sixteen years old. Having this support clearly enabled Sophie to take the course of action that she did, had her mother Brenda been less supportive, then her personal agency may have been disrupted in her quest to reclaim her life:

coming back up again umm right ok fantastic that she is able to do this, fantastic that she is doing it because the prospect back in May that she might not ever be able to do that so you know great and great encouragement with moving flats and me saying to her yes, I think that this is a great idea (interview with Sophie's mother Brenda pg.15).

There is a sense here that Brenda was also acting out the same thought process as Sophie. It was something that she wanted to put as far out of her mind as was possible. Witnessing Sophie's independent behaviour created the image of Sophie as she remembered her before her illness.

For Ellen matters were not proceeding quite so quickly. Following her severe reaction to Methotrexate she was making a slow but steady recovery. Before her illness, she had lived independently for two years and had moved a considerable distance away from home.

It is noteworthy to comment that both Sophie and Ellen were only children and female. Established theories of development attest to the notion that the trajectory of development is different for boys than girls, with girls moving to physical, social and emotional maturity generally more quickly than boys. Therefore arguably in terms of living away from home, one might expect girls to have left the family home whilst sometimes boys might do this slightly later. In terms of their position as single children in a family, there is also evidence which points to the self-reliance of such children, which is also something which could be factored into these two particular cases, in that both demonstrated a high degree of independence. There are of course a myriad of other reasons why this might be including, their primary and secondary socialisation, their personality, their family relationships and the parallel aspirations of their peer group.

In Ellen's case she too was keen to return to independent living, however, the story here was markedly different. In light of her reaction to Methotrexate, her choice and control and personal agency in decision making had been severely compromised as we witnessed in previous chapters. The 'stroke like syndrome' that she had experienced

resulted in her having to re-learn a significant amount of the activities of daily life that she had previously taken for granted. Her ability to process information had also been affected by the event and she therefore had to undertake daily intellectual tasks which would improve her verbal and written literacy skills as well as her ability in numeracy. An indication of the gravity of these tasks was articulated by Phillip her father:

Ellen's father Phillip: we are going from someone with thirteen GCSEs at A umm baccalaureate and A levels which she got five GCEs at A umm doing ok at University even with illness to cognitively not being there anymore now when she's back home in between treatments, might sound a silly thing but it's useful umm we watch programmes like countdown

JD: yes, yes I see

Ellen's father Phillip: because dad, and Ellen because I position myself to be there as full support so we do the numbers game, we do the words game this that and the other because at one time it was like two nines hang on, dad what's two nines? This is somebody that could do partial differentiation, integration and this that and the other (interview with Ellen's father Phillip pg.21).

It is nothing short of remarkable that her vision was to return to independent living. This demonstrates the power of needing to have personal agency as an emerging adult. Prior to her treatment, Ellen had previously been in the top 10% of the population for her age in terms of academic achievement and was already enjoying a full and independent life. It was therefore perhaps no surprise that she had this aspiration in her sights. However, the fact remained that this would be a significant undertaking. She had nevertheless worked extremely hard to regain control in her life and this had not gone unnoticed. Her love of art was undeniable as expressed in the painting she kindly gave me permission to use in this thesis. She produced this eight months after her admission to the intensive care unit and her progress towards realigning her skills and agency did not go unnoticed:

June 2014: She showed me some pictures on her phone of the painting she has done and the quality of her work is completely outstanding. To think that she is doing this only six (it was eight as it happened in October 2013) months after a stroke affecting her dominant side is quite extraordinary. This level of achievement seems to be moving her forward which is really nice to see (clinical record in medical notes, Ellen).

The resultant aspiration stemming from her progress filled Ellen with a sense of optimism and this was in essence the reason that she was keen to be living in her own accommodation again. She discussed this at length in her final interview and it was evident that it was a priority for her. However, there was probably, not unreasonably, some trepidation about how she might manage her life once she returned to her university accommodation. This was perhaps to be expected particularly in Ellen's case. Whilst Sophie had been seriously ill when she was diagnosed and one must not underestimate the perilousness of her illness, her course of treatment went relatively smoothly. This is not to lessen the significance of her return to a new flat but to emphasize the severity of the complications experienced by Ellen. As she spoke about living alone again Ellen remarked on her reservations thus:

whether or not I can have accommodation near (name of campus building) because they offer accommodation for foreign students who aren't able to get accommodation elsewhere. So I am going to try and ask if I can be near (name of campus building) because that is literally a two minute walk to the lecture hall and that would be a big deal for me umm because I won't be able to do public transport because going back to my original point I won't know if I am neutropenic or not (interview three with Ellen pg.4).

Ellen was thinking in some detail about where she might be best placed so that she could get on with her life but at the same time her personal agentic position was restricted yet again by the effects of her treatment. Ellen's protocol was over a two year period and her plan was to go back to the city where she lived whilst she was still receiving treatment. However, as she asserted, there would possibly be challenges that might initially prevent her from achieving her desire to resume her life. She was nevertheless not willing to compromise her freedom by being assisted by her partner who was keen to help. Living at home with his family Nigel was in a different position, his mother had been keen to get involved in making sure that Ellen had some options, however, Ellen did not take her partners mums' offer up:

when she was first talking about coming back to (city) she was scared that she wouldn't be able to get a flat or she wouldn't be able afford a flat and I said you can come and stay with us... and my family will look after you they are like you

are always welcome there, you can sleep in my bed I can sleep in a sleeping bag...not a very comfy sleeping bag umm and but Ellen would say a very resounding no to that because she, she would again feel like she was imposing (interview with Ellen's boyfriend Nigel pg.28).

Nigel was prepared to significantly disrupt his own life so that Ellen could have a private space in his family home and this denoted the strength of his commitment to her. I will return later in this chapter to the impact of these close and intimate relationships in encouraging the realignment of agency as cancer treatment either finishes or progresses. Despite Ellen's concerns about her return to living alone she was still determined to achieve this on her own terms.

Her parents whilst keen for her to recover and continue with her life were also concerned about her desire to live independently again. Their worries were borne out of their earlier experiences of Ellen's illness:

I'm concerned that the distance between (university and home city) is a great distance, if she had been in (a local city) and she was offered places to go to (a local University) for example to do architecture. If she had been in (the local city) and said about her shoulder this that and the other she could have come home for the weekend we would have been on top of it much, much sooner but because the distance is involved with (University in distant city) it took a couple more months, several more months before if you like parents and family could actually get something done (interview with Ellen's father Phillip pg.22).

This extract reflects Phillip's desire that Ellen should perhaps think about staying close to home as she recovered and returned to pursuing her future. This is an understandable position when considering the extent of her compromised personal agency, following the complications she experienced in her treatment. It must have been incredibly difficult and no doubt extremely upsetting for Ellen's parents to think about what might happen should anything change significantly again in her health status and that if this happened she might be alone. Phillip also made clear his thinking about how he could have perhaps intervened and helped before she was diagnosed. This stance relates to the discussion in the last chapter relating to grief reaction. That however related to the young person

rather than parents, nevertheless it is understandable and indeed arguably common that these feelings may extend to all those who are closely linked in these situations.

Throughout his interview, Phillip displayed nuances of guilt, not just relating to Ellen's diagnosis but to her experience in the local emergency department when she was critically ill as explained in Chapter Six. There was also some evidence of anger and frustration at what had happened at that time.¹⁷ It appeared therefore that the idea of Ellen living independently a long way from home was something that not unreasonably troubled him. I would suggest that it was not that he wanted to intentionally compromise her agency, instead his intention was to protect her from what he thought might potentially happen and in doing so provide helpful interventions. Once again the idea of 'proxy' or shared agency is prominent.

7.3.2 LEAVING HOME FOR THE FIRST TIME

Sam whilst hoping to leave home to go to university was instead diagnosed with cancer and thus did not begin his studies as planned. This resulted in him living with his family as he received his treatment on the first occasion. After the completion of his treatment in December 2012, he commenced his programme in September 2013 whilst still living at home and attending the local university. Unfortunately following his relapse in October 2013 he needed further treatment which included a bone marrow transplant. He had been busy re-gathering the threads of his life when the disease returned and so once again his emerging adulthood and personal agency were severely disrupted. He had been seeing the same girl, Harriet, throughout this period of time and whilst his base was at home he did spend a lot of time at her flat as she was also attending university locally. This pattern represented his fluctuating independence and his ability to be agentic in terms of where he decided to stay on a daily basis. It seemed that his mother Linda was

¹⁷ When interviewing Phillip I had such a sense of overwhelming sadness at what had happened to him whilst he sat in the emergency department with Ellen. He felt completely powerless and he stopped at one point where I thought that he was going to cry. He used the quote 'as parents we were shredded' which exemplified his desperate state at this time (reflection, interview with Phillip pg.3).

happy with this arrangement as there was close proximity between the properties which he chose, which also included Harriet's family home:

Oh yes he stays here, but he goes and stays there as well (Harriet's flat). Yes but it's only down the road and we are very fortunate because Harriet's parent's only live up in (name of suburb) and sometimes they go there and sometimes they stay here and sometimes they are on their own...it works really well (interview with Sam's mother Linda pg.26).

This was Sam's choice and it was certainly congruent with what his mother felt was a good decision. Linda however, had a different view about him living further away. This was something that she worried about. The scenario in reality did not arise but one could not help thinking that there may have been some disagreement and compromise in agency had Sam made a decision to move away from the area of the family home:

I would have been very unhappy if he was away from home and I'm not actually a neurotic mum but if you think about it, that is what scares me if he's in halls of residence in (a university in a distant city) and he got ill...we weren't the type that would go up visiting...I know he would have lingered away... and so when he decided to go to (local university) and umm I was quite relieved and I just thought well...I thought that's great (interview with Sam's mother Linda pg.21).

Linda was worried that being away from home might mean that Sam would be compromised by being alone and becoming ill. This corresponded to the fear that Phillip had for Ellen in the previous sub-theme. This arrangement of moving between houses continued, however, Sam did have a desire to progress his independence a step further.

Following his relapse, Sam began to talk about moving out of the family home permanently and proffered the idea of finding a flat with a friend. It is unclear as to why this aspiration emerged. It could be argued that perhaps he felt he was falling behind the lived experience of his friends and peers. They were all at university, living independently and enjoying the freedom and personal agency that this brought them. There was also the notion of Sam perhaps feeling that the time to be independent and take control of his life was now more important to him than ever before having experienced the reoccurrence of his disease. He made no secret of his desire to find an independent living space and had discussed this at length with his girlfriend Harriet:

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 Sam's girlfriend Harriet pg.3).

There does appear to be something of a paradox here on Linda's part. She was it seems perhaps trying to balance his freedom to choose independent living and in doing so recognise his status as an emerging young adult, against her concerns in terms of him securing his own accommodation and how this might put him at risk. Despite Linda's reservations Sam was intent on navigating his way through finding, viewing and moving into a flat. He was also determined that he would govern the whole process without the help of his parents.

This was all happening against the back drop of his impending transplant. His plan was to move into the new flat following his treatment and he began by selecting somewhere to live. He was mindful of his need to find somewhere suitable and his health needs were a priority in this context. He had talked with Harriet about this and she had played an important role in helping, she was not only his girlfriend but one of his peer group and as such central to his decision making. The need to protect Sam's health was clearly something they both took seriously. Whilst some may argue that leaving home at this time might have perhaps been unwise, again as with Ellen and Sophie it demonstrated the strong desire for independence at this point in the life cycle. What was also transparent was both Sam and Harriet's maturity in understanding his health needs. Sam systematically searched for flats before making a choice although he was not always highly organised:

we organised it very, very late umm we it took a long time to do it and eventually we decided we were going to go in and look around a load of estate agents and see what we can find and it turns out it was bank holiday Monday when we did this and the only estate agents which was open was this one called (name) lettings (interview three with Sam pg.6).

Sam was able to exert his personal agency in this situation and was able to secure a flat, however, he required support in this venture both from Harriet, his parents and his friend who he eventually shared the flat with. The way in which he managed this progression in his life was in many ways not any different to that of a young person who had not been unwell. He took advice from his girlfriend, he received financial help from his parents and he had help from his friend. The help from his friend however was crucial to his independence and health and was probably more than one would normally expect to see in this type of arrangement:

he knows that my immune system is awful and so like whenever it comes to cleaning bins or washing up like he is quite like are you sure you can do this like he is quite understanding and generally I do try to do it if I can but umm like he is quite understanding of it yeah so it's nice (interview three with Sam pg.5).

The help from Sam's friend marked the difference in his situation compared to that of other young people. Whilst he had the ability to exert choice, as he did so he required what could be argued was specific help and intervention for him to safely maintain his chosen lifestyle.

William was in a different position to Ellen, Sophie and Sam as he had been living at home at the time of his diagnosis and was in the midst of deciding what career path to take. At this time he had no plans to move out of his family home. However, his views about this were to evolve and change as he made his way through treatment. When he was in the middle of his treatment he expressed his need for independence and privacy on a number of occasions. The example relating to providing a sperm sample explained in the last chapter, clearly illustrates this need. In terms of his own space at home, when I interviewed him he requested that we talk in his bedroom upstairs as this was exclusively his space. Of course he was in the early stages of reclaiming his mobility and so may not have wanted to mobilise on the stairs too much but on other occasions such as his attendance at out-patients clinic his mobility was excellent and so my interpretation was that this was perhaps not the reason. During our interviews at his home his mother

was present on two occasions, subsequently this need to occupy his own space was also perhaps linked to this and again a need to be able to talk privately.

William's friend Nathan went to see him regularly at home during his treatment and again would go to his room to chat. This need for privacy and discussion 'behind closed doors' is not at all unusual in young people, however, in William's case his parents and his father in particular found it difficult to maintain his choice for privacy. Nathan alluded to this in his interview:

umm we was up in his bedroom and his dad came up asking if we wanted a drink or he was just making sure you know...and he would say to him you know bugger off, fuck off just leave me alone (interview with William's friend Nathan pg.20).

Nathan commented that he was shocked by William's response to his father as his view was that he was just trying to help. However, this was not the way that William saw it. He was 20 years old and as far as he was concerned he wanted to assert his choice and to make a decision not to be interrupted. Had he for example been living independently at this time then this event would not have occurred, he would have had the freedom to not be interrupted. Poignantly his mother acknowledged William's desire to become more independent:

I think to be honest because of the sort of person William is once he is fully functional, when he is fully mobile with his leg...he will be doing his own thing, I mean he has told us he can't wait to move out so it's going to happen you know but umm (interview with parents, William's mother Julie pg.26).

She went on to express that she would find this 'heart breaking' but understood it was something that he strongly desired.¹⁸ As with Ellen and Sam, whilst William wanted to pursue independent living arrangements he felt also that this could not be achieved without help. If he was to take control of his life he feared that he could not do this alone:

¹⁸ William's father Martin was quiet when we discussed William moving out and did not make any comment relating to his feelings about this but his head was bowed at this point and he withdrew from the conversation. I felt that William wanting to make this choice was something he was finding very difficult to cope with.(reflection, interview with William's parents pg.3).

I've been saying that I'll leave home like next week if I could sort of thing but I would have to live with someone. I couldn't live on my own because there are some days that I don't want to put my leg on and if I want to do stuff like cook myself food then I have to have my leg on so I know I need someone there to help me around so in a few years (interview three with William pg.16).

Moving away from the family either for the first time or a subsequent time was a fundamental element of the reclamation of life for these young people. This transition was fraught with challenges, where the young people gave detailed thought to how agentic they were able to be in this regard. Alongside their need to live independently, they were all keen to plan their future careers and work and this was to prove an area of their lives where they wanted to and needed to take full control.

7.4 RETURNING TO EDUCATION AND WORK

This undertaking was fundamentally important to each of the four remaining young people in the study. The notion of returning to their previous aspirations in terms of building a future for themselves was crucial in continuing to build their early adult life platforms. At this time, young people are commonly journeying their way through an exciting period of exploration, achievement and personal growth. Their choice of education and career are part of the building blocks which are likely to play an important part in the next stage of their lives. Once established in a career they are able to create further opportunities for life experience which will include a myriad of elements including their relationships with others, lifestyle choices and aspirations for further development. Each of the young people's lives had been significantly disrupted as had their choice and control but for all of them the time had arrived to make steps towards this future.

Sophie was the only one of the group who had already graduated and was pursuing a career. As already explained in the previous sub theme of this chapter, she found herself a new flat and returned to work within a month of finishing her treatment. She was transparent in her interviews that this was an absolute priority for her and she was not going to make compromises in her choice to 'get back on track'. However, her decision to not discuss her health in any detail and certainly not in any formal sense with her

employers led to a particular approach when she returned to work. This could be described as a 'hands off' style, which on reflection, I perceived that she found rather unnerving:

Sophie: they obviously had my best interests at heart and they wanted to keep me on and they have looked after me whilst I have been away but I don't know if, no one actually sat me down and talked me through what I was going to be doing umm no one sort of, no one talked to me about whether I was going to come back full time or whether you know

JD: phased return?

Sophie: no one really mentioned whether I would be taking on less work I think possibly they didn't give me as much work as I would normally have had, you know the run up to Christmas was quite quiet for me and I think that is possibly their way of just letting me ease myself back in but there was no formality to it at all they just sort of let you get on with it (interview three with Sophie pg.4).

It may have indeed been the case here that Sophie was perhaps expecting some sort of proxy agency and shared discussion to enable her to re-engage in her workplace. However, her fiercely independent nature had determined that she had perhaps, albeit unconsciously, had such dominant control that she shared very little with her work colleagues. This as with other evidence in the study could have been for a number of reasons. These could have included her state of health before she left and the urgency with which she decided to return to her mother's home, her fear of what was happening, the lack of contact with her company during her treatment (which had been her choice) or indeed the speed with which she returned after finishing her treatment. Thus giving herself little time to adjust to what her needs might be once back at work.

For Ellen and Sam their key objective was to return to their respective university programmes and to complete their studies successfully. For Ellen as we have seen, this was to be a significant undertaking following the cognitive effects of the stroke like syndrome that she had experienced. As her father Phillip had highlighted in the previous sub theme of this chapter, she had been an extremely able student who following the complications associated with her treatment had found it challenging to perform even the simplest tasks. She had attended a university which was many hundreds of miles from home and importantly had embarked on her first serious relationship. In returning to

university this relationship was also an important factor to which I will return in the next sub theme. Ellen was making a slow but steady recovery and had been tentatively beginning to catch up with some of her programme notes. She was steadfast in her desire to return to university:

so at the end of next year by august next year I will have to make the decision whether or not I want to continue with civil engineering or basically drop out of University those are my two options they only gave me two years as an interval and if that is their policy then fair enough then I have got to follow their rules umm so I decided after the end of the two years I would go back to University I have decided that that's definite (interview three with Ellen pg.4).

This extract provides an indication of Ellen's intent and the use of the word definite is rather like a rubber stamp at the end of the narrative, making it known that this is not something that she was unsure about, rather it was something that would happen regardless of the difficulties that she experienced. As regards the idea of her living away from home, her parents were again concerned that once she re-embarked on her university programme they would not be comfortable with her decision, although their 'surface' response to this was a positive one:

ok so my parents, my dad is ok with it umm my mums ok with it too they are all like ok with it they also support me to the best of their ability as all parents can do umm because it's my decision, I am, I have been made aware to me they made it aware to me that I will be on my own therefore they can't help me, they can't say that I need to go to hospital. I will have to basically take on all the responsibility of myself and that is daunting, scary but at the end of the day that's the only way you are going to grow and move forward because at the moment I am sharing it with my parents like do you think this is ok? Do you think I should go on this? Do you think this or do you think that? I am asking their opinion but I won't have that in (University city) (interview three with Ellen pg.5).

This extract has resonance for living independently but also links automatically to the fact that Ellen would have to be away from home to continue with her programme. This conversation was also cognisant with comments from the nurse who was involved in her care. She had worked very closely with the family and no doubt had come to know something of the type of personality that Ellen possessed. Despite the fact that Ellen had been critically ill, once she began to recover she was keen to reclaim her choice and

personal agency and this was obvious to the nurse. She knew her well enough to realise that she was not a young person who wanted to depend too heavily on others close to her. She also knew that in the same way as some others in the study, Ellen was not without concerns about how she would take control of events if she became unwell:

she doesn't like to be a burden and as much as I think she would love to go back to (University in distant city) and continue her education and fit back into her social life which she absolutely adored up there I think she worried if she became unwell (interview with Ellen's nurse pg.7).

There were also the logistical and practical tasks involved in organising a return to study and Ellen was happy to embrace these matters and in so doing wanted to have personal agency in managing her educational affairs. She did require some help with this but as her father Phillip put it, she was the one who was leading the discussions. The correspondence to the university had to come from her rather than her parents. This is the case generally in matters relating to students. As an example, with reference to the student loan service in the UK, should a parent contact the service they would not be able to talk directly with someone from the finance agency without the express permission of the student. The student has full control of this aspect of their finances, just as would be the case when ringing an insurance company or any service where the young person has their own account.

These logistical matters were managed more or less singlehandedly by Sam who also wanted to make plans to return to University. He too had to make contact with the university department for his programme in order to organise matters:

I have contacted student finance to ask them whether they have gotten it and uhh it is a local address I have to send it to so it should be fine umm and I just had to send them, what I had to send them was err stuff proving that first of all I had yeah I had to send them umm I had to send them one letter saying help for my deafness and dyslexia and then I also had to send another letter saying that my illness had affected my study (interview three with Sam pg.9).

As outlined in the within case chapter, Sam had some particular needs relating to his hearing impairment. He also had dyslexia and of course he had been unwell. This

amounted to a fairly complex set of circumstances which Sam had to manage, however, he did not appear to be perturbed by this. During the examination of his medical notes, I came across a fascinating entry from the psychologist who had seen him as part of his treatment plan. This assessment of his response to treatment and his coping style brought into focus his ability to take control of serious matters and this persisted it would seem even after he relapsed. It did appear both brave and confident of him to recover so positively from his transplant, find a flat and manage his re- entry into university. The assessment may arguably also account for his high level of personal agency throughout the study period:

November 2012: Not sufficiently sick to challenge his coping style, his belief that he had a good cancer. His life was running smoothly and he was able to set the threshold for asking for help quite high. Used to being independent with little experience of being the focus of nurturing attention or asking for support, a habit he is finding difficult to break (clinical record in medical notes, Sam).

When interviewing the nurse who was involved in Sam's care, it soon became apparent that the extract from the psychologist perhaps demonstrated Sam's individual style in managing his control of the situation in which he found himself. In this interview there was very little continuous narrative on the part of the nurse and each time I tried to probe further in the pursuit of more in-depth information it was not forthcoming. Instead the nurse in question reiterated her previous comments each time a question was put to her:

I have only discussed the (drug) with him to be honest...side effects how he might feel...he listens...but he doesn't seem too worried...yeah he just says it's fine' (interview with Sam's nurse pg.10).

Seeing the excerpt from the medical notes created a clearer picture in relation to the participation of the nurse. It could of course have been that her responses were such because of other reasons, including my ability to gain information, her own style of communication or perhaps that we undertook the interview on the unit during her working day when she may have been preoccupied with other issues.

Sam's approach may also account for his early return to university following his transplant. Again rather interestingly there is another paradox at this point in the evidence. When Sam was in discussion with his consultant he informed him that he had returned to his programme but as with his other initiatives whilst he had a good degree of agency, he proceeded with caution in informing the consultant that he did not attend everything. The consultant's reply to this was at odds with what was recorded in his medical record after the consultation. During the consultation the following was observed:

During the consultation he asked Sam about his current activity. Sam said that he was slowly getting back into the lectures and seminars but wanted to be careful not to overdo things. The consultant said that he should just return fully and that he should not be half hearted about it, half there and half not there he needed to be fully back on his programme' (observation two field notes Sam pg.2).

However, in the medical notes there was an entry as follows:

November 2014: Notes from consultant, despite having been advised he was not to return until he was at low risk of GHD he informed me that he had started (University) in the autumn (clinical record in medical notes, Sam).

Possibly this was an example where whilst the consultant was not in agreement with what Sam had done, because Sam had already made the decision the consultant felt whilst it might not be wise it was Sam's right to do so. William was less clear about his future plans during treatment. This may have been because he was not sure about what he was going to do when his symptoms began. Sophie, Ellen and Sam had already made these decisions and so had clear plans to reclaim their lives as soon as they felt able. At the first observation of the outpatients' appointment at the end of his treatment, there was an attempt to encourage William to think about his options, however, it was clearly something that he did not wish to discuss at that point:

The consultant asked him about work and William's one word answer was 'unemployed'

There was a silence following the mention of cricket coaching. The consultant then remarked that there were a number of jobs that were advertised which used positive discrimination. He also asked William if he had thought about University and said that perhaps in his circumstances, perhaps he could make a direct application. There seemed to be some sense here of trying to enable William to think about how his situation was different to other young people but how he might be able to navigate this in his future.

This part of the appointment was rather 'laboured' in that a number of jobs were discussed here including teaching, non -manual work, the police force. It felt a little bit like the group involved were suggesting as many varied professions as possible giving William the impression that he would have a number of choices in the future in terms of his career (observation one field notes William pg.3)

However, when I met him for the final time, he had what I perceived to be high levels of optimism and was keen to think about the opportunities he might pursue in the future. He talked about university and possible careers relating to his love of sport. My perception of this conversation when comparing it to the outpatient appointment was that he was more relaxed, more in control and having a discussion in his own home. His parents were also out, so it was just the two of us. Work and education were important facets of the return to everyday life and undoubtedly the young people were keen to move forward and make progress in their lives. However, of almost equal significance, was the reclamation of their social lives.

7.5 I WANT TO DO STUFF AGAIN

The enjoyment of a social life during this period of transition forms a central part of life experience. As already witnessed, the young people in the study enjoyed a wide variety of pursuits which ranged from having fun with friends to indulging in a variety of hobbies from art to sport. As they recovered from their illnesses and treatment, they began to look forward to some of the things that they might do. William as we already know was very keen on sport and made it clear that 'losing' his leg, as he put it, was not going to disrupt his choice to continue with this pastime. The choices open to him were different than they had been previously in terms of the type of sports teams he might play in. However, he was, it was clear without disruption to his personal agency in making these decisions:

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 William pg.10).¹⁹

In William's within case analysis, there were many examples of the importance of his peer group and his transition to being a 'man'. This was strongly represented through sport as is the case for many young men. His rite of passage was for him strongly linked to his participation in sport and therefore it was perhaps no surprise that this remained central to his future life plans.

Ellen had been severely compromised in a different way by her disease and treatment complications. Whilst this was not a rite of passage issue specifically, she too was determined to reclaim the enjoyable aspects of her life as she recovered. In the same way as William, she had had some disability albeit temporary and this made it difficult for her to produce any art work. She however remained in control of this by adjusting her expectations and accepting that she needed more time to complete a painting than before and she was fully in control of this activity. She commented that it had taken her many months to complete her first piece after her period of critical illness. However, she did not stop there, it would appear that her personal agency was so dramatically disrupted there was what I perceived a need for her to prove that she could make decisions independently, take control of events and equally manage these successfully. Consequently she undertook the challenge to organise the fundraising event outlined in the last chapter. As was illuminated in that chapter she ultimately made a decision not to attend due to her white blood cell count being low, however, the following extract provides evidence of her increasing agency and control particularly amongst her peers:

¹⁹ *This was such a positive discussion and one where it was clear that William was determined to realign his agency and reclaim back the things that he loved in his life. Having an amputation marks a significant physical change in a person and with the added emotional issues of the change in the visual representation of the body and all the further matters that this might raise, his attitude was inspiring (reflection, interview three with William pg.2).*

I informed the group that because we are doing a fundraiser for (the charity) this Saturday umm I have I informed the group that is co organising with me that I thought it was important to have a (charity) stall and have an information centre running from it. Umm I managed to get hold of some leaflets from (the charity) itself and some fliers and some little cards, I printed information from the (charity) website about various cancers and then on the actual day we will answer any questions to the best of our ability as well to people with any queries and I also decided to do a (charity) stall game kind of thing. It is for little children in particular it's basically a game based around the common signs of cancer and what to look out for (interview three with Ellen pg.1).

It is worth noting that the extract is from page one of the interview as Ellen was very keen to share her experience. There is a really strong sense of her exerting agency in decision making here, as she put it she did not discuss this with the group she 'informed them'! Considering her plight of the recent months prior to this time there was evidence of a striking degree of independence.

Other young people were more interested in having some time away from home. Sophie as we have learnt returned to her new flat and work extremely quickly following her treatment. She had booked a holiday prior to her illness and saw no reason why she should cancel this whilst she was having treatment. Her father was not particularly happy about her taking a holiday so soon following completion of her treatment. This is perhaps not so surprising since parents would naturally worry that something might go wrong, in a similar vein to the sub theme in this chapter relating to living independently. It is I would argue, certainly the case that parents worry for a considerable time following a life threatening event such as these young people have experienced. Sophie was not in agreement and would not change her decision, exerting her agency in choosing to take the holiday as originally planned:

the thing is though, I was in, my counts had recovered well I mean I wouldn't have gone away if I was still neutropenic, I wouldn't have and the fact is I was going to a place, I wasn't going to stay in a resort I was going to my (mumbles) house out there and I don't know I guess maybe by this point I thought well all the bad stuff has happened now, what more can happen. I know you shouldn't think that but I think I had finished my treatment and my counts had recovered, that to me was enough I think and again I think enough is enough, you can carry on. I was thinking about it today I think that (the unit) was very nervous about me going away and actually said to me a few days, or maybe a week

before hand look can you postpone it and I, at the time I said well I actually can't. I have booked it now and just so you know I am going away with like family friends just as reassurance umm but then I think back now and I would have been really pissed off if I hadn't have gone on that holiday and nothing had happened to me you know and I had stayed here for absolutely no reason and that's what I kind of felt (interview three with Sophie pg.6).

Sophie was confident in her own ability to make the decision and gave the strong impression that she had used a measured approach in this respect.

7.6 THE CONTINUATION OF INTIMATE RELATIONSHIPS

Throughout the period of illness, which included the presenting symptoms and treatment, some of the young people maintained and continued their relationships with partners. This was despite the many challenges which they faced during this time. Each of them shared some of their most difficult moments with their partners and relied heavily on their opinions. Ellen, Sam and William had all been in relationships for more than a year at the time when I met them. The key issues in terms of choice and control focused on pragmatic and emotional issues.

7.6.1 EMOTIONAL CONSIDERATIONS

In terms of emotional matters, both Ellen and William had said to their partners that they would not mind if their partner decided to end the relationship. This was connected to feelings of being burdensome and of a desire not to hold their respective partners back from continuing with their lives. The views of their partners however did not demonstrate evidence of wanting to end the relationships. Indeed their perspectives were at the opposite end of the spectrum as they highlighted the need to support each young person throughout the experience. It was noteworthy that the young people who were unwell attempted to exert their control in the relationship but that this had no effect on the way in which their partners behaved. Furthermore partners did not give any indication that they listened at all to their suggestions, instead they made their own decisions about their participation in the relationships:

I have probably led those decisions more than Ellen ... I wanted to keep it going...I love her...and I knew, all this is, is she is going to be away for two years I immediately went, I made the decision I am going to see her every

couple of months if I can...so I started taking on work as a maths tutor... so I started taking on tutoring so I could pay for the flights... to get some money (interview with Nigel pg.21).

Ellen's boyfriend Nigel: yeah like she said, and she has numerous and I think that's probably a result of the sadness from it is she said, like she has told me numerous times like I'm going to have changed from this and I am going to be away for two years like if you decide to move on I won't blame you

JD: she doesn't want to hold you back

Ellen's boyfriend Nigel: she doesn't want to hold me back or anything and I said don't be stupid (interview with Nigel pg.21).

Not only did Nigel disagree with Ellen's suggestion, he made significant arrangements to try and earn extra income so that he could spend time with her. The relationships between these young people were likely to be the first serious partnerships that they had experienced and in this respect were fundamentally important to them. It was therefore more likely that they would want to maintain their relationships whatever lengths they had to go to. The young people who were sick probably felt the same but the nuances of guilt were once again present in their thinking. They were it could be argued so prominent that Ellen and William both wanted to eliminate this feeling and so tried to control the situation by offering to finish their relationships. William went further, he told his girlfriend that he would take action to end the relationship if his circumstances worsened:

William: no because I did say to her if it does come back again then I would leave her

JD: you would leave her?

William: yes because I wouldn't put her through it again (interview two with William pg.15).

In some ways the data above illuminates that rather than those who were ill reclaiming their lives in terms of their relationships, they were altruistic in wanting their partners to reclaim their lives and move on.

7.6.2 PRACTICAL MATTERS

There were of course pragmatic issues in terms of exerting choice in the intimate relationships in the cases of Ellen, William and Sam. Their illnesses required that they take control of some choices in order for them to maintain their health and wellbeing and

these related directly to some of the consequences of their treatment. Sam had originally intended to go to the same university as Harriet his girlfriend, this was many miles away from his home. However, in reclaiming his independence, he had successfully organised his enrolment at the local university. Harriet it could be argued had been central to this initiative. In her interview she made it clear that he had specifically asked her not to change her preference, however, she had gone ahead and decided to stay locally and enrolled at the same university as Sam:

Well obviously we like discussed it together and he was like oh don't change your stuff because of me and I was thinking well it's half because of you and half because (local city) is better and do I want to move away? (interview with Sam's girlfriend Harriet pg. 1).

Once again the partner of the young person had overridden the request to make choices which would affect their relationship, however, in this case it did help Sam significantly in both reclaiming his life and control and continuing his relationship. For William the practical example of personal agency in his relationship was rather different but nevertheless important in terms of the choices that he might want to make with his partner. This matter related to his sexual health, however, this did not relate to any interaction and negotiation between himself and his girlfriend. Rather it linked to advice which was not available to him and could have not only affected his choices but the way in which he would be able to reclaim his life in the future. When interviewing the nurse involved in his care she alluded to this:

Yeah I mean I did sort of approach the subject of umm obviously you have to protect your partner because the chemotherapy is kept within bodily fluids between 48 and 72 hours so you are putting your partner at risk if you don't use protection...so William didn't actually know that until quite late on in treatment so it was something that we didn't discuss with him (interview with William's nurse pg. 15).

This provides an example of the way in which William and his partner may have been consensually making choices about their sexual relationship but without the required

information, thus possibly affecting not just William's future choices but also that of his partner.

7.7 ONGOING TREATMENT AND THE REALIGNMENT OF AGENCY

In this chapter the focus has been on the progress of the everyday lives of the young people in the study, nevertheless treatment or follow up still featured strongly in their lives. In some cases however, their agency began to change in relation to decision making as they grew more confident and their health began to improve. There was also evidence I believe of their interactions with the medical teams and parents (or in one case alone, in outpatients) which demonstrated greater agency on their part. When I had first observed Ellen in her outpatients appointment, she had contributed and the consultant was very attentive to her, listening and asking for her views. However, in a later observation the interaction saw Ellen strengthen her agentic position by strongly leading a treatment decision:

Ellen spoke at this point and said that she didn't mind taking the steroids and said "let's just do it". The consultant said to remember the constipation abdominal pain and anxiety. She followed this by saying "I am not trying to talk you out of it when I should be talking you into it" and then laughed. The consultant said "Okay let's do it that is good shared decision making." (observation two field notes Ellen pg.4).

Ellen's mother was also present in this consultation and did not intervene. Whilst Ellen had been struggling with the steroid therapy in her treatment, she was keen to continue and the extract illuminates perfectly her agency in this situation. The consultant was open to her suggestion but had not given the impression that she wanted to restart the steroids, nevertheless she accepted Ellen's opinion in the matter. Sophie was more autonomous in her decision making. Her move back to the city where she was working had meant that her follow up care had been transferred. Unfortunately I was not able to observe her first outpatient follow up because I did not have permission through the research and development department at that health board and it was agreed that it would not be feasible to apply for this for two observations. However, it was agreed that when Sophie attended her outpatient appointment, she would reflect on the event and

send me an account of this. She kept her promise and sent a wonderfully demonstrative piece in terms of her ability to make choices and be fully agentic:

I went to the appointment on my way to work at 9.30, so I went alone which suited me fine as it was only a little check in. I went for blood firstly when I got in and then had to wait for the results to come back before going in for my appointment. As this was the first time meeting my consultant he asked for me to just go over a brief history of things with him. I was told my latest bone marrow results which incidentally are completely negative which is great. My bloods are also back to normal, he asked me if I was someone who wanted to know the details of them which of course I am so it was nice to be given an option to find out more, rather than just assuming I wasn't interested. Again I'm not sure they are used to someone turning up to these appointments on their own and the patient themselves wanting to know all the details as I was still being seen on the (TYA) floor. Following this he did talk to me about the chances of the cancer returning, which are slim, but again I appreciate being told these things. I was also told that if it was to return the treatments are just as effective the second time around and the reason I am having bone marrows for the next three years is so they can pick up on things a lot sooner, even before I was to start showing symptoms. The last choice I was given was whether I wanted to go to clinic after each bone marrow to get the results or whether it would be ok for them to phone me with the results. I chose just to have them phone them through. I feel this will help with getting me back to normality as I won't have to be meeting with doctors so often. In fact the next time I will be seeing him is in 6 months after I have had a few marrows done (account provided by Sophie following her outpatient appointment).²⁰

7.8 CONCLUSION

This chapter has examined the lives of each of the young people as their treatment progressed. As this was happening they strove to make sense of their disrupted and fragmented everyday worlds and began to salvage what was rightfully theirs. Unfortunately Leah's treatment was not successful and she died. She was not able to realise her aspirations relating to adult life, however, even in the final stages of her illness she still wanted to look forward to a time when she would make choices about her future. She made an insightful contribution to the study as did her family and those who cared for her professionally. It is this which gives richness to the work from the point of view of

²⁰ When I received this I wanted to put the whole account into the chapter. For me it provided such an optimistic picture of a young person who was making good progress and had successfully realigned her agency and was moving on. The extract took me back to the early thinking about the study and the excitement which is normally experienced at reaching adulthood with everything set out before you to look forward to, the options, the opportunities, the personal growth and most importantly freedom.

the younger population in teenage and young adult cancer which would otherwise be missing.²¹

Once again we were to witness elements of restricted agency as young people tried to make plans, nevertheless there were many examples of them taking control of their affairs. One must acknowledge that they still relied on help and advice from others and sometimes there were concerns, not unreasonably so, about their proposed course of action from those closest to them. Despite this they made significant progress in realigning their power to choose and act on their options.

Living independently was fraught with challenges as was returning to work and education but as we saw in Sam's and Sophie's cases they were successful in achieving their aims. Their lives were significantly restored as a result of their endeavours and they were both happy that they had chosen the most appropriate path for them. Social lives and interests were equally important and the sense of 'getting back to where they were' was prominent in this part of the data. William's sense of satisfaction at the thought of taking up his sport was something that was crucial to his recovery and his enjoyment of everyday life as was Ellen's ability to be able to paint again.

The area of intimate relationships was complex, with almost an invisible 'tug of war' taking place as young people who were unwell tried to protect their partners and they in turn tried to do the same. This created some noteworthy discussion about the nature of agency in this context. Treatment issues played a less prominent role in this chapter which is the opposite of the last chapter where treatment issues dominated the discussion. In many ways the chapter lived up to the introduction where the word 'optimism' was used as the young people successfully weaved their way through the 'twists and turns' of their continued life experience.

²¹ *I would like to express my gratitude to Leah and her family for their participation in the study.*

8. DISCUSSION

8.1 INTRODUCTION

The four preceding chapters in the thesis focused on the findings resulting from the data, which included in-depth interviews, non-participant observations and documentary analysis. In keeping with the tradition of case study design, the chapters were separated by an overarching within case account where all five participants were introduced. Their individual trajectories and experience of agency and adapted structure were analysed and discussed. This was in the context of their choice and control in decision making relating to treatment and everyday life. This was followed by three cross case chapters, situated in three major themes, 'life then', 'life interrupted' and 'life reclaimed'. The level of agency afforded to the young people in terms of the choice and control over their lives was illuminated with reference here to common themes, which cut across the whole sample. The analogy of a three act play was used as a way to illuminate the journey of the young people. In the first act, 'life then', the life course of each young person was examined and data was gathered relating to their presenting symptoms. The findings emphasized varying levels of agency both within and between individuals in the sample. This was followed by the second act, 'life interrupted', where young people continued to experience variation and in some cases, the significant loss of agency. The concluding act, 'life reclaimed' highlighted each young person's return to a re-narrated life course and considered their aspirations for the future. Within this phase, again, levels of agency fluctuated both in terms of individual trajectories, whilst providing some commonality between participants. This data revealed some contextually rich, powerful stories concerning the young people as they developed symptoms and were subsequently diagnosed and treated for various forms of cancer.

This study primarily considered the changing nature of agency over time, with particular reference to the fluctuating levels of agentic power that young people possessed during their cancer experience. Equally the study considered how relevant structures restricted agentic power. I was not only interested in exploring the experience of choice and control

relating to decision making but also the notion of how different types of agency were manifest in the everyday lives of young people. The literature provided some insights into this aspiration and provided focused examples of specific choice and control in decision making in the context of treatment (Hokkanen *et al.*, 2004; Hinds *et al.*, 2005; Chappuy *et al.*, 2008; Stern *et al.*, 2010; Quinn *et al.*, 2011). However, many of these were difficult to categorise as ‘belonging’ to the particular literature which I was seeking as the work often referred to samples far wider than those aged 16 to 24 years and few were focused on young people in the identified age group. Instead parents or healthcare professionals were the point of reference. Studies focusing on everyday choice and control in decision making were difficult to locate. A number of papers contained glimpses of discussion relating to everyday life (Smith *et al.*, 2007; Hollen *et al.*, 2007; Palmer *et al.*, 2007; Treadgold and Kuperberg, 2010; Morgan *et al.*, 2010; Wicks and Mitchell 2010; Wakefield *et al.*, 2011; Fern *et al.*, 2013). However, studies in their entirety which explored choice and control in all aspects of life throughout the cancer experience were absent. In addition, the literature review provided some overarching themes, which were generated from the specific decision making papers and a range of other opinion papers, policy and guidance. These included the notion of life being put on hold, issues concerned with the need for independence, concerns about competence and future plans.

I was also interested, through the use of multiple sources, to find out what the perspectives of others who were close to the young people thought about the levels of choice and control in decision making. Non-participant observations provided an alternative lens through which to view choice and control during interactions about the care and treatment of the young people. The observations provided a fresh insight into how relationships ‘played out’ with reference to the way in which decisions were made. This type of method is able to demonstrate live interaction as it happens and was also an opportunity to observe the social exchanges between all those involved (Caldwell and

Atwal, 2005). The exploration of medical notes, whilst yielding less data still contained written nuances of ways in which young people on some occasions maintained their agency whilst asserting choice. Whilst in other areas of the notes it was clear that the structure of the treatment and the way in which the healthcare system operated was documented, there was rarely any written reference as to the desired choice of the young person. Limitations in using documentation for analysis do however exist and one of these concerns the selection of information to be included by each individual who contributes to the record (Bowen, 2009). Consent forms were signed by the young people for various procedures and for involvement in clinical trials for example. However, this only provided 'mechanical' evidence in the form of a binding agreement that they were happy to proceed. The forms did not reveal anything other than the young person's permission for treatment. Nevertheless on all occasions except where the young person lacked capacity as in Ellen's case (temporarily) when she was admitted to intensive care, documents were signed by the young people adhering to the legal framework for consent (Palmer and Gillespie, 2014).

What transpired in the study was a series of experiences, which demonstrated the fluctuating nature of agency set against the structures as adapted for this study during the three identified phases of 'life then', 'life interrupted' and 'life reclaimed'. The examples cited from the data encompassed a broad range of topics. These examples articulately and often poignantly demonstrated the complex nature of the changing levels of choice and control in terms of agency set against the intentions of parents and sometimes staff during this time. In particular the intention, choice, motivation, control and freedom afforded to the young people fluctuated in parallel with the nature of their disease and treatment, those close to them and those involved in their care. In the three identified phases of the young people's experience of cancer, key issues were highlighted which were mapped against the elements of personal, proxy or collective agency. The structural limitations in terms of family and significant others, healthcare

and healthcare systems and the treatment were also aligned to the experiences of each young person. This approach was couched in a conscious attempt to demonstrate not just the extent to which their levels of agency fluctuated over the entirety of their experience but also to demonstrate types of agency which were adopted in particular situations. The critical focus of the remainder of this chapter will emphasize the individual and across case themes illuminated in the findings. This will then be translated into the idea of trajectories of agency during the three phases, which substantiate the contribution to knowledge.

8.2 SUMMARY OF FINDINGS

In the time before diagnosis, 'life then', there was a clear recognition on the part of the young people with respect to the development of their symptoms. This was sometimes but not always accompanied by seeking advice from a healthcare professional. However, both individually and collectively there was a 'holding on' to their everyday lives. The findings relating to the 'life then' theme demonstrated examples of personal agency in which young people kept control of their lives and made decisions without involving others who were close to them. Some had important targets or goals that they were determined to meet, which stretched beyond the everyday routine aspects of life. The assistance of others close to the young people was apparent in this phase as they tried, sometimes without success, to help them in determining a diagnosis. In some cases however, parents were not always fully in receipt of all the information particularly for those who were living independently.

A feature of independent living in young people will often involve a change in relationships with parents, which inevitably means that communication routines will change as young people seek to become members of the community in their own right, whilst developing financial stability and moving into the labour market (Jones 1995; Seiffe-Krenke, 2006; Chiuri and Del Boca, 2010). This does not of course mean that young people will cease to communicate with their parents but that their emphasis on

becoming an autonomous individual will begin to emerge more strongly. Friends and partners were equally important in this pre-diagnostic period as they consistently tried to help their friend, girlfriend or boyfriend. Despite these offers of help, the young people in some cases remained largely unresponsive to advice and continued to 'hold on' and to pursue their everyday lives and more particularly the targets and goals mentioned previously. Worryingly there did not always appear to be a tipping point in seeking help for those who lived independently. It was they alone, utilising their personal agency, who made the decision to return home but seemingly still not with a view that they were seriously ill, rather that it would be good to visit home. In one case this was returning home from university, whilst in another it was just to have relaxation time with family. However, ultimately the young people appeared to have 'no choice' as they put it but to surrender their agency.

Once diagnosed each young person's personal agency became significantly disrupted and they found themselves governed by a number of structural factors. These sometimes stemmed from what their family or the healthcare professionals might have advised them, set against their own desire for agentic power. There was evidence of parents withholding information whilst having the best intentions and also examples of them taking over the control of situations in order to protect their children from further distress. These actions were sometimes favoured by the young people as they were themselves finding it difficult to cope with news of their diagnosis and subsequent treatment. However, there were also occasions when they felt restricted by the actions of their parents. This latter context left them feeling sometimes that they were peripheral to their situation. Young *et al.*, (2003) describes this type of situation in a study of communication in life threatening and chronic illness, however, as is the case with many other studies identified in this research the age range was younger than those referred to here and only spanned as far as 17 years old. Similarly Beresford and Sloper (2003) found constraining and helpful elements of parental support but again sampled a similar

age range. These examples are useful and arguably there is some transferability but the need to account for the young adult age group in this context is still required as evidence here is limited (Grinyer, 2009).

The nature of the treatment also severely constrained the lives of each young person in a way which made it difficult for them to feel that they had any control over what was happening to them. However, they did attempt to exert their right to make choices. Sometimes they disagreed with their treatment and associated care, thus exerting their personal agency against the structural factors which they faced as they moved through their experience. Glimpses of control emerged in their everyday lives but these were limited again, often constrained by the intensity of treatment. Nevertheless they were able to exert some control in their decisions to pursue their lives outside of treatment. The final phase of the findings provided insights into the lives of the young people as they continued and in some cases finished their treatment. Unfortunately, Leah's death meant that she was not able to realise her aspirations, however, the other four young people began to make progress in terms of their ability to exert higher personal agency as time passed. However, once again, these levels of agency fluctuated for each of them as they faced the challenges of trying to realign their lives. Here there were also examples of proxy and collective agency in terms of supportive action to enable young people to try and regain their independent lives and aspirations. Matters in everyday life were more prominent in this part of the study and the data proved to be largely optimistic in terms of the progress made towards greater personal agency. The young people were all busy thinking about reclaiming the lives that they had previously and moving forward towards education, work and living independently. Relationships at this time were also central as everyone involved in their experience adjusted to their lives coming towards the completion and beyond cancer treatment. In particular intimate and peer relationships were important as the young people put together their future ideas and aspirations. The importance of these relationships running concurrently has been

identified as influential in helping successful development into adulthood (Zimmer-Gembeck, 2002; Galliher and Kerpelman, 2012).

Detailed analysis using reading, re reading, reflective memos, coding and theming of these results culminated in the study of fluctuating agency described through a detailed unfolding of each young person's trajectory during the stages of their journey in terms of 'life then', 'life interrupted' and 'life reclaimed'. These illuminated their fragmented and disrupted levels of choice and control throughout the experience. These trajectories will build upon the literature identified by providing new insights into the entirety of the cancer journey of teenagers and young adults. It is that which will form the focus of discussion for the rest of this chapter. The chapter will culminate with the proposed development of ideas for practice taking account of the findings and subsequent discussion from the journey taken by each young person. These ideas followed the results of a series of discussions with experts in the field of teenage and young adult cancer care, using the trajectories as a starting point. It is envisaged that these trajectories will contribute in helping to predict times of restricted choice and thus put in place mechanisms to help young people to decide on their preferred level of choice and control in decision making during their cancer experience. This contribution sits firmly within the timeline of experience in teenage and young adult cancer and refers specifically to the choice and control in decision making encompassed by fluctuating levels of agency during this time. The final section of the chapter will illuminate both ongoing and future dissemination of the findings of this work, whilst encompassing some of the challenges but more importantly the strengths of the study.

8.3 INDIVIDUAL EXPERIENCES

The tradition of case study analysis outlines a number of possible routes to illuminating research findings. One of these as outlined in the earlier methods chapter is to utilise within case and cross case analysis, which was the chosen approach in this work. In this study, five young people and those close to them and involved in their care

participated in describing their cancer experience. This resulted in the development of individual accounts, which provided personal evidence of unfolding fluctuating agency over the timeline of their illness.

8.3.1 ELLEN

Ellen having moved many hundreds of miles from her home had a degree of personal agency, which enabled her to use motivation, choice, intentionality and control to make decisions in her life (Holdsworth, 2009). Despite escalating symptoms, she continued to have a high level of agentic power in continuing to attend university. This decision making was challenged by those who were close to her, nevertheless, she maintained this stance until she was diagnosed. She was subsequently faced with many challenges, which significantly reduced her personal agentic power during her early treatment particularly. Furthermore, proxy agency was utilised for a period of time, as she was unable to make any decisions because her health was compromised by the side effects of her treatment. At this time her parents were central to any notion of active agency. Sometimes, the side effects in cancer treatment can significantly affect the individual's ability to maintain effective functioning and this was clearly the case for Ellen (Soussain *et al.*, 2009). It is also the case that the effects of treatment can lead to a lack of choice and control in other aspects of life. Ellen had to face this when she was unable to undertake fertility preservation procedures. This can be a particularly upsetting time for young people but evidence suggests that immediate treatment is the priority as was the case for Ellen in her discussion with her consultant (Knapp *et al.*, 2011). Despite this Ellen's personal agency was limited in this context. As Ellen began to recover from her experience of intensive care and continued with her treatment, her thoughts turned to her future life and she began to reclaim her personal agency and think about returning to university. This nevertheless was beset by a number of challenges, which Ellen had to navigate. Not least were her problems with her cognitive skills following her reaction to her treatment. This also resulted in a loss of confidence in returning to life after

treatment, although this is not an unusual feature in young people following their experience of cancer (Wakefield *et al.*, 2010; Zebrack 2011).

8.3.2 SAM

Sam was positioned differently in terms of his cancer journey than the other four cases, enabling maximum variation within the sample as outlined in Chapter three. He was receiving treatment for his disease for the second time and ultimately would have a bone marrow transplant once he had completed further chemotherapy. Whilst he had a good level of personal agency and was planning to begin university in the year that he was diagnosed, his mother played a prominent role in using her own agentic power as a proxy to protect him during his diagnosis on the first occasion. A number of Sam's family were healthcare professionals (one of whom was an oncologist) and subsequently some of them played a prominent role in his journey. His mother, who was a GP, was sometimes aware that she was reducing his choice and control during discussions with the consultant and remarked as such once some consultations were completed. Having a healthcare professional as a parent when experiencing a serious illness is likely to be different to a situation where a parent has limited knowledge of the situation. However, it proved challenging to locate any literature which outlined this particular type of experience and how it may be different.

Sam's hearing impairment was also relevant in the context of his fluctuating agency. Those involved in his care described him as quiet and 'wanting to just read and get on with his treatment'. His hearing nevertheless may have had an effect on his ability to choose and to control given situations during his treatment. People who have hearing impairment can often withdraw from conversation, feel isolated or embarrassed and hearing can often be further limited by noisy areas in hospital settings such as outpatients clinics (Middleton *et al.*, 2010).

Sam's choice and control was severely restricted during his preparation immediately prior to his transplant. Whilst he fully understood this, he found the restrictions difficult

particularly some of the everyday aspects of life including nutrition and elimination. The requirement for restriction in these circumstances is well known but this does not reduce the challenges of restricted agency, when one is usually able to make everyday decisions, indeed on some occasions using unconscious agency as referred to in Chapter one. This restriction of choice and control in these circumstances may result in more marked responses with serious consequences. The emotional effects on those undergoing transplant can be significant leading to a marked deterioration in the quality of life (El-Jawahri *et al.*, 2015). Sam nevertheless, was determined after his transplant to try once again to resume his studies. In spite of his relapse and further treatment, he appeared to have a renewed confidence and was able to look forward to finally taking up his studies. Wicks and Mitchell (2010) underline some of the perceived positive effects reported by young people treated for cancer in this age group, which include improved personal skills.

8.3.3 WILLIAM

William was living at home when he was diagnosed after completing his school education and attending a national cricket academy. Although this was the case, he had high levels of choice and control in his life and had been independent in many ways since his early teens when both his parents were working full time and he made many individual everyday decisions. His desire to maintain his personal agency continued to be a priority for him even after he was advised that his leg might fracture before his treatment began. Attending the cricket club and being with his peer group was important to him, despite his restricted mobility attesting to the emotional nature of peer alignment and acceptance and the part these matters play in young people's lives (Guyer *et al.*, 2014). William was assisted by his father's intervention prior to diagnosis who made arrangements for him to have a scan, paid for privately. William's family and his mother in particular continued to play an important role in his experience after diagnosis and there appeared to be a number of examples of collective agency in his care, this was apparent during outpatient consultations. Nevertheless, there were times when he would take control and make

choices about his treatment relating to medication and nutrition. He also would have preferred to have more agentic power when fertility preservation arrangements were being made. Embarrassment can be a factor in the context of this area and having more choice and control of privacy in William's case may have made this experience more appropriate for him (Wright *et al.*, 2014). Panagiotopoulou *et al.*, (2015) outline a number of barriers to effective fertility care and describe these as both 'intrinsic and extrinsic'. In William's case these factors were both present, that is, his own feelings about the situation and the way staff approached this matter.

As William was coming towards the end of treatment, he had begun the process of coming to terms with the effects of his surgery. The amputation of his leg had been the chosen treatment and whilst he had control over this decision, his own words were that he felt he had no choice and that it was 'his leg or his life'. Nevertheless, he began to adjust after surgery and had a strong determination to exercise his agency in continuing to play sport. His mother worried about him subsequently leaving home in the future but recognised that he would take control of these decisions and accepted that this was an important aspect of his recovery.

8.3.4 LEAH

Leah was the youngest participant in the study and was diagnosed with a rare cancer in her age group. She had to undergo long periods of treatment and her personal agency was significantly disrupted throughout the whole of her treatment journey. She, like the other participants, found ways to 'hold on' prior to her diagnosis, in an attempt to have choice and control in her life. School was important to her and so she consciously engaged her parents as proxy agents to advocate on her behalf. They helped her to continue to attend her lessons, despite this sometimes being curtailed by some disruptive symptoms. Both in the lead up to her diagnosis and in the initial discussions which followed, both of her parents sometimes struggled with the idea of her choice and control in decision making. This was understandable in their desire to protect her,

nevertheless, it was important that they recognised her status as a young adult in terms of competence (Alderson *et al.*, 2006; Griffith and Tegnah, 2012). Following her diagnosis Leah had to undergo a series of treatments including surgery, chemotherapy and a novel type of treatment, which involved radiation, which was only available in a centre many miles from home. Her capacity for control during this time was seriously restricted, nevertheless, she was very clear about her disagreement in terms of elements of her treatment and aspects of her social life. Leah exerted her personal agency in determining her choice and thus her control in the situation. She was particularly keen to attend her 'school prom' and even though she was very unwell at the time it took place, she did manage to participate in the event. However, her control was still restricted in comparison with her peer group as her mother and aunt remained outside the venue in their car for the whole evening. This approach from parents stems from the need to protect their children and be alert to any changes in their condition. Their need to stay close and to be aware of anything which might jeopardize the progress of their child is a feature of behaviour which remains with them long after treatment is completed. This applies across all age groups experiencing cancer throughout childhood and through the transition to adulthood (Casillas *et al.*, 2010).

Whilst Leah did not recover from her cancer, she maintained her desire to take back full control of her life. She had some firm plans relating to further education and was looking forward to being able to continue on her path to adulthood, where she would be able to freely make choices and decisions about her future.

8.3.5 SOPHIE

Sophie was the oldest participant in the study and in terms of her personal agency, she had more experience than any other young person taking part relating to the decisions she made in her life. Prior to her diagnosis, she was working for a successful company in a large city and had been living independently for six years. As her symptoms progressed, she continued to work until it was no longer practicably possible and she

returned home to be with her mother. Sophie outlined that she had a very busy schedule and did not want to take time off her work and did not think that she had a serious health issue. She had deadlines to meet and her work was important to her. Arnett (2014) argues that work has taken on different meanings particularly for young women in recent decades. Women are more prominent in the workplace, have career aspirations and thus these aspects of their lives are fundamental to their development into adulthood. Added to this, women are more financially secure and can therefore make choices about the ways in which their lives are organised (Gerson, 2009). Sophie had been in a relationship but was single when I met her and was enjoying the choice and control that she had in her life at that time.

Throughout her treatment, Sophie continually focused on her return to having her own personal agency restored and although she had relied on her mother during the time that she was receiving treatment, she was very keen to return to her workplace and personal life as soon as possible. Sophie insisted that the management of her care should be back in the city where she was working and that she would return there as soon as her treatment was completed. I perceived that staff in the unit where Sophie was treated, fully understood her request to receive follow up near to where she worked and acknowledged that she had made an informed decision about this. There was in essence an example of collective agency in this instance. The need to 'rebuild' and reclaim life after cancer treatment is not just important but often desired by young people. Indeed Bellizzi *et al.*, (2012) suggest that future plans and goals are positively impacted on following treatment for cancer.

8.3.6 SUMMARY

Individual experiences during the cancer journey were context specific and resonated with each individual young person's life. There were many examples of the variation in their fluctuating agency and equally in the way in which parents and those who were caring for them were always there to help and advise. There were instances of collective

agency, particularly when young people were unable to make decisions or requested help from others. Equally, there were occasions when each young person wanted to exert their own personal agency in decision making, this was most strongly represented in their life before diagnosis, and when they were recovering from their disease as their treatment progressed and in some cases was completed. Nevertheless, there were many contextual examples, which lent themselves to cross case analysis, and these are outlined in the next three sections of the chapter. Individual examples of evidence however will continue to be used in illuminating the discussion.

8.4 LIFE THEN

The majority of young people in the study exercised their personal agency before diagnosis in continuing with their daily lives by adjusting and coping with their everyday routines as their health deteriorated. In terms of their individual situations they had all been in a position where their agentic power had been high, affording them a high degree of choice and control in their developing lives. Making individual decisions as their health became worse continued, which could only reasonably be described as worrying. The young people sometimes acted in direct opposition to advice from others, including medical professionals, despite the seriousness of their symptoms.

This period prior to treatment has received some attention in the literature in the context of delayed diagnosis. Dang-Tan *et al.* (2008) measured this from the perspective of 'diagnosis delay', 'oncologist delay' and 'patient delay'. The methods in this instance did not involve speaking with those studied and so the reasons for patient delay could only be assumed. Delays were measured quantitatively with patient delay proving the longest in the older age group. It was suggested that the participants particularly in the older age group (the study age range was from 0-19) did not report their symptoms, thinking that they were not serious enough to warrant reporting.

This study however, adopted a different stance in placing the young people's views at the centre of the investigation and despite the sometimes serious nature of symptoms

there was a clear lack of reporting. Sophie was the most overt in this respect despite some very serious symptoms such as significant breathlessness and worrying eye disturbance, she utilised her personal agency in making a choice and decided not to report to her GP. This was a fully conscious choice and one which was challenged as we saw in Chapter Four and Chapter Five when her friend Pip protested regularly about her not seeking help.

Delays in seeking advice were just part of a more complex picture in the findings in this study. Where there has been consideration given to other factors of the experience prior to diagnosis, experts in the field have identified a number of potentially useful data relating to, for example, the number of times young people visit their GP with cancer symptoms (Fern *et al.* 2011). However, there is very limited evidence of providing a voice to young people on their journey towards diagnosis. Furthermore there is again limited evidence of the detailed exploration of the development of cancer symptoms from the perspective of young people at this time. The first detailed study providing an opportunity to try and understand the complex reasons for delayed diagnosis was only recently published (Gibson *et al.*, 2013). Some salient points were raised here and in particular there were themes which resonate with this study. These included 'symptoms in relation to other people' (pg.2588) and so called 'threshold points' (pg.2589), Gibson *et al.*, (2013) reported that the young people felt reassured by parents in particular, in their study, with parents saying that things were 'okay' in an attempt to normalise the situation. However, when symptoms persisted, parents recommended action which was accepted in turn by the young people. In terms of threshold points, this related to when symptoms could no longer be endured. This mirrors very closely to the surrendering of agency towards the end of Chapter Five Nevertheless this study adds further to these findings as is now explained.

8.4.1 MAKING ALTERNATIVE CHOICES DESPITE MEDICAL ADVICE

The use of personal agency juxtaposed to the structural nature of healthcare and the healthcare system in exerting choice is an interesting starting point. William for example despite being advised not to weight bear on his leg before his consultation at the specialist centre was determined to enjoy the company of his peers. His sport was central to his life and the importance of staying aligned to his peer group was paramount. As we are aware this had disastrous consequences for him when he sustained a fracture whilst at the club. However, for him what was most important at that time was that he was able to continue going to the cricket club where he had spent a great deal of time during his teenage years. The power of peer alignment should not be underestimated in sport as it can play a significant role in forming strong bonds which last often for many years and sometimes throughout life (Fitzgerald *et al.*, 2012).

In an example of proxy agency again, whilst she was seeing her GP, Leah and her mother agreed that although she was not feeling well enough to attend school on a full time basis, she wanted to have a choice about attendance on a part time basis. Unfortunately whilst she wanted to have control of this she was not able to organise it without her mother's help in the form of her ringing the school and negotiating her attendance. Throughout this time she was attending the GP's surgery for repeat visits. Leah did not seem to care about this. Her priority was to attend school, if only for a short time. This demonstrates the need for normalisation as suggested in the literature. However, the young people here were keen to continue asserting their choice and control in making decisions, despite their worsening health. In further examples of this 'holding on', there were more worrying signs of what appeared to be a compulsion to continue in order to 'get things done'.

8.4.2. I JUST REALLY NEEDED TO FINISH THIS

Again in comparison with the limited literature, the data in this study went further than the normalising of symptoms as some young people did not so much 'adjust' their everyday lives but continued in exactly the same way as before in terms of targets that

they had to meet. This reinforced the complexity and magnitude of 'holding on'. Although Ellen did make some concessions in terms of getting up earlier so that she had more time to dress, she was intent on finishing her second year examinations. This was despite her parents requests that she return home. Once again she made a conscious decision utilising her personal agency to remain away from home so that she could complete her second year at university.

Sophie was similar to this in her attempts to stay at work and contribute to the project that she was working on. Her mother was not aware of her ill health and so there was no intervention in terms of reassurance from her. Sophie's response to her symptoms and her decision to continue with her everyday life was I believe the most marked. Despite protestations from her close friend Pip, she did not visit a GP at all during the development of her symptoms. She was the eldest participant and arguably the one in the sample with the highest degree of agency. Even when what I believe to be the 'threshold point' arrived, as described earlier by Gibson *et al.*, (2103) Sophie continued with her project targets. She was for example unable to stand in the shower to wash her hair, she was so breathless that she was unable to complete the very short distance from the train station to her office and was unable to walk and talk at the same time.

It could be argued that these examples demonstrate the more 'extreme' approaches of the young people in keeping matters close to them and continuing to exert what was largely personal agency in determining their actions prior to diagnosis. In an interesting adjunct to the other four participants Sam's situation of 'holding on' was quite different. His mother Linda was a GP, so possibly the approach used in his case was due to medical professional judgement and the operation of 'dual roles' for Linda.

In my view, the use of proxy agency in this instance highly illuminated the idea of 'holding on' from a different perspective. Sam's mum had normalised his early symptoms and reassured him, as the work of Gibson *et al.*, (2013) suggested, however, once she was

aware of his diagnosis her decision was not to take immediate action but rather to wait until Sam had finished his A levels before revealing information to him about his diagnosis. She commented that she could not contend with the thought that he would have to undergo treatment and retake exams. There is evidence of withholding information in the diagnostic phase both in this study and in the literature (Palmer *et al.*, 2007; Fern *et al.*, 2013). However, in Sam's case this 'holding on' occurred before there was any consultation with specialist services. This perhaps exemplifies a difference where a parent also happens to be a health professional and therefore utilises professional clinical judgement. It is worth noting that William's mum, Julie was also a healthcare professional, however, there was no evidence of her acting as a proxy agent in trying to protect William from learning of his diagnosis. He was not however in the midst of examinations or projects which might be disrupted by bad news and so this could possibly reasonably explain the difference in the approach of the two women. It is nevertheless difficult to say with any certainty that this was the case. Interestingly Sam was retrospectively grateful for this as was Ellen when the same thing happened to her, only in her case this was at her first consultation.

8.4.3 THE CENTRALITY OF FRIENDSHIPS AND INTIMATE RELATIONSHIPS

In this study, unlike the majority of others in the field of teenage and young adult cancer, there was a clear emphasis on the views of those who were either in intimate relationships or had close friendships with those young people who experienced cancer. The young people in the sample were asked as part of the networked sampling approach to nominate someone who was close to them. All but one, (Leah) expressed the desire to nominate a partner or friend. This approach complimented the notion of supporting agency in young people as they controlled this choice personally without resorting to proxy or collective strategies. Only Leah was a little unsure as she had seen very little of her friends since her diagnosis because of her almost constant hospitalisation, neither did she have a boyfriend. Subsequently when I discussed this with her, her mother was present and the two of them discussed my request and negotiated a choice of participant

who was another family member, namely Leah's aunt on her mother's side. There is evidence of the consideration of peer support in other work focusing on young people and chronic illness in the field of diabetes. Lowes *et al.*, (2007) explored teenagers' perceptions of peer support in the management of diabetes, however, the data gathered were not from friends or partners, rather it stemmed from interviews with the young people who were diabetic and focused on early adolescents. Focusing on teenage and young adult cancer, Olsen and Harder (2009) explored networks of social support in care and did include partners (n=2 out of a sample of 19 others) but primarily the participants were parents.

In this research partners and friends were viewed as being central to the understanding of young people's experience of cancer. They were able to offer new insights into how young people coped with their treatment and everyday lives. There was evidence in this study, at all stages of the trajectory, of the value that young people placed on their relationships and the importance of maintaining partnerships during their experiences. However, the phases prior to diagnosis and during the reclaiming of life were more strongly represented in the data. This I believe was in some cases because the young people were not always geographically close to those who were friends and partners as they had moved many miles away from their base. The young people would often move back to their parents' home for the duration of their treatment for cancer. It was only when they began to make plans to return to their lives that their partners and friends became involved in their lives again.

During the treatment phase, a couple of the young people did make a fleeting reference to this saying that they had not seen their friends or partners because it was too far for them to travel regularly to the unit. William said that he did not want friends to visit as he was not keen for them to see him when he was so unwell. Whilst peers are important at this time and can be of significant help to the young person, those who are ill can

nevertheless be reticent to being seen and viewed as sick (Larouche and Chin- Peuckert, 2006; Lewis *et al.*, 2013).

In the time prior to diagnosis there was an interesting interplay between the young people and their partners or friends in what I have previously described as a 'tug of war' situation. Whilst the young people clearly valued the support of their friends and partners, they were not keen to relinquish their personal agency in the decisions that they made leading up to diagnosis. This was despite the significant concern on the part of friends and partners. This produced much frustration amongst friends and partners, which accounts for the 'tug of war' idea. However, the overarching feelings of those close to the participants was of sorrow and fear. The fear of the consequences around the actions of the young people it would appear, were not always acknowledged by the young people who were unwell as they displayed what can only be described earlier in the chapter as a compulsion to continue with their daily lives.

Ellen's partner Nigel for example was so concerned about her deteriorating health that he involved his own family, in particular his mother in trying to help. Their offer to let Ellen stay with them whilst she was unwell was turned down indicating the strength of her personal agency and her determination for independence. Similarly Sophie's friend Pip was consistently giving her advice and suggesting that she see her GP. Sophie repeatedly rejected this advice and attended work in an attempt to finish the project that she was working on. The direct nature of this evidence is something not previously discussed in the literature. The help of others prior to diagnosis, such as parents and professionals, has been evidenced (Gibson *et al.*, 2013), however, the help of partners and friends has not received detailed exploration in this stage of the cancer experience.

8.4.4 SUMMARY

The lives of young people prior to diagnosis were then largely under their control with aspects of work, education and social life being independently actioned. Once they developed symptoms they practiced what I have described as 'holding on' and in some

cases moved beyond the 'threshold points' identified Gibson *et al.*, (2013), in an attempt to keep control of their decision making and their lives. This was despite medical advice and sometimes in the absence of any professional help as in Sophie's case. 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'. The involvement of their 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 young people that they were closest to in their lives.

8.5 LIFE INTERRUPTED

This phase of the experience was dominated largely by treatment, demonstrating the highly structured nature of the medication protocols for each individual young person in terms of their disease management. The data in this findings chapter highlights examples of attempts by the young people relating to intentionality, choice, freedom and control of their decision making in the context of treatment and to a lesser extent in their everyday lives. Equally the evidence demonstrated how severely disrupted their personal agency was in terms of treatment decisions. The chapter contains a relatively small amount of discussion about everyday life decisions, which further indicates the significant limitations the young people experienced at this time. It should be acknowledged that this is the part of the thesis where most of the existing literature was located. Studies related to focused decision making during the treatment period formed part of the evidence (Peddie *et al.*, 2012; Stewart *et al.*, 2012). However, the notion of decision making more generally across the trajectory from the young person's perspective, particularly in the age group who were the focus of this study has received little attention (Dunsmore and Quine, 1995, Coyne *et al.*, 2013). Whilst there was literature which complemented the evidence in this study, including for example matters around fertility, there were a number of notable differences which further add to the

experience of young people during this crucial stage of treatment. These are outlined below.

8.5.1 THE COMPLEXITY OF THE PARENTAL ROLE

Parents were undoubtedly involved with their children in trying to support and help them during treatment, however, their role during this time was extremely complex and sometimes difficult to deconstruct. This was largely in my view due to what appeared to be a constant 'balancing act' in terms of decision making. There was an ever shifting emphasis in terms of their involvement in their respective situations. The balance was often between not wanting to be viewed as 'taking over' and limiting the choice of the young people but at the same time protecting each one of them from harm by making decisions on their behalf and sometimes without their knowledge. On one occasion Ellen's father for example asked me after an observation whether or not he had spoken too much and taken over the conversation, a similar stance was also taken by Sam's mum Linda when she looked at me during a consultation where she was talking a lot and then stopped. My interpretation of this was that perhaps she felt that she was talking too much.

These strategies were arguably most notable during the diagnostic phase. One could argue that there were elements of advocacy in the parental approach whilst understandably acting in each young person's best interests. Equally it may also be argued that perhaps there were elements of proxy agency. However, the young people in the study were not always aware of their parents' actions. This suggests that this may have been felt to be in their best interests, however, this was not proxy agency rather their agency was inhibited or to be frank absent on these occasions, thus rendering them unable to exert any personal agency in their respective situations (Coyne and Harder, 2011). In three of the cases Ellen, Sam and Sophie they were unaware that their parents knew of the diagnosis before they did with the youngest of these three young people being 18 years old and therefore in legal terms of full adult status. However, the private

intervention of their parents was something over which they had no control (Grinyer, 2004). Sophie was never made aware of this concealment of information, and both Ellen and Sam said that they had retrospectively agreed that this was the best course of action at the time and that they were happy to not have the power to be agentic on this occasion.

Once a diagnosis was fully established and parents had information, their role did change and their involvement tended to fluctuate. This fluctuation interestingly seemed to be controlled by the young person. An example of this was in the choice of the care environment. Indeed rather than a matter of personal or proxy agency, this was more a matter of collective agency where young people, their parents and staff involved in their care all participated in determining the place where each young person would be treated (Smith and Case, 2012). However, the young person took the lead on this and was supported by parents rather than overruled or information kept from them. This was with the exception of Leah where the discussion about where her care took place was between consultants rather than with her.

This lack of control however, was not always accepted by the young people as something that they were happy to hand over (Wicks and Mitchell, 2010). The work undertaken by Wicks and Mitchell has in part some close resonance with this study, where young people expressed their unhappiness with the way they lost control of decision making in the medical aspects of their care in particular. Helpfully the sample in their work was young people who were between 16 and 22 years of age. However, their work does not pay detailed attention to parental control rather it focuses on medical control and the non-compliance in treatment which resulted. Coyne *et al.*, (2014) explored participation in decision making in an Irish haematology/ oncology unit and whilst the upper limit of their sample was 16, there were examples of the need for young people to not just be involved but to have their voices heard in the context of decision making and treatment. The findings from those close to 16 years demonstrated their frustration at not having control of their situation. This view was less marked in the younger part of the sample

where children were happy for decisions to be led. This complexity of decision making is also reflected in the study conducted by Hokkanen *et al.*, (2004) as the authors identify the range of decision making practices which prevail during cancer treatment for example, exclusion from decision making and shared decision making.

As I have commented, during the early period following diagnosis some of the participants were glad that decisions were made for them. However, in terms of parental assistance, young people sometimes made intentional choices relating to treatment procedures and protocols and these choices were sometimes at odds with the intended structure of the treatment. In a legal context, four out of the five young people were able to independently make the decision to consent or to refuse treatment. Leah was also judged competent to consent as a result of the guidelines developed by Lord Fraser (*Gillick v West Norfolk and Wisbech Area Health Authority 1986*). However, parents would often try to encourage each of the young people to comply with treatment. Again, not unreasonably, they were very concerned that their children should follow the treatment protocols as instructed to achieve the best outcome. Whilst all of the young people understood the gravity of their situation as reflected in the statements made by William, Ellen and Sophie who stated similarly 'you have no choice you either have the treatment or you die' they did not always take their parents advice in relation to matters relating to treatment. Instead they made decisions which could indirectly influence their treatment protocol and outcome. Of note though, the treatments including surgery and chemotherapy were followed fully without exception within the sample.

8.5.2 EXERTING AGENTIC POWER DURING TREATMENT

Whilst as described above there is some evidence in the study of the shared nature of decision making in sick children including those with cancer, the literature would benefit from further work in the teenage and young adult age group. Studies during treatment are available, these also consider concordance with treatment but there is little which examines the underlying issues of the lack of choice and control which lead to this

position Butow *et al.*, (2010). Variables which are linked negatively to concordance issues have been discussed and include parents and healthcare professionals having too much control over treatment (Kyngas *et al.*, 1998). Other literature highlights the need to engage young people's involvement to promote concordance which in turn provides them with a heightened experience of control that the young person has in a time of restricted decision making (Sawyer and Aroni, 2005).

Notably, this type of evidence focuses again on chronic illness (as an example diabetes is considered here) and as is the case throughout this study, the evidence in the cancer context often provides what could be described as an 'unclear' picture due to the nature of overlap in age groups with little attention given to those aged between 16 and 24 years. What this means in terms of the findings in this study is that there is a need to illuminate some clear examples of young people's personal agency relating to treatment regimes, despite the structural limitations imposed by their protocols and helpful interventions from both their parents and healthcare professionals. Despite knowing the dangers of a lack of concordance, in this study it was clear that the young people still demonstrated intention and motivation in their need for choice and control during treatment.

There were a number of cross cutting examples which demonstrated the capacity of the young people for agentic power even during intensive treatment periods. Age did not appear to be an arbiter of this choice as Leah proved in her decision not to take some of her associated medication which accompanied her chemotherapy. Despite being informed that should she suffer ill effects as a result of this decision and not be able to start her next course of chemotherapy on time, she openly insisted that she would not take the prescribed medication. This led to much distress on the part of her mother who 'threatened' as she put it to tell the staff that Leah had made this decision, however, Leah was happy to do this herself. Ultimately the staff accepted her decision to not take her associated medication and this was alluded to in her medical notes. This was an example

of personal agency 'pushing' against the structural challenges of family, healthcare professionals and the rigidity of the protocol and the associated treatments.

Similarly Sam probably put himself at some risk when he decided he would stop taking some of his medication as part of his protocol in helping him to recover post transplantation so he asserted his personal agency essentially against the structure of the important post-transplant treatment procedures. His mother's body language at this point signalled her disagreement but also her lack of power in changing the situation. The doctor however, suggested that he restart his treatment, although he did not insist on this he just outlined what the requirements included. Nevertheless he did refer to Sam's so called 'naughtiness' in letting him know that the decision in his view was clearly not the appropriate one in terms of his treatment.

In much the same way, William would also exert personal choice over whether or not he took prescribed medication to assist with some of the side effects of his treatment. His nurse remarked that she was aware that she could not 'force' him to do this but referred to the situation as a 'battle' rather than a negotiation of choice. Despite expert guidance relating to decision making in terms of treatment (Smith and Case, 2012), this study demonstrated that there was a degree of resistance on the part of families and healthcare professionals to accept the decision of the young person to refuse some treatments albeit with the best intentions, thus restricting choice for them.

Although only one person in the study (Ellen) required admission to intensive care during treatment the significance of her lack of any agency and her lengthy road to recovery severely restricted her choice and control in decision making. The data very poignantly demonstrated the alteration to her cognition during her cancer experience, where she transitioned from being a successful, independent, articulate university student to someone who was unable to have control over the simplest decision making. Proxy agency was a very strong feature of her experience at this time as those close to her and

those involved in her care helped her in every aspect of her life. This could not be said to be an example of collective agency as Ellen's involvement was minimal at this time.

Despite searching the literature to locate evidence of experiences closely related to Ellen's situation, there was a distinct gap in terms of the discussion focusing on intensive care issues. Arguably whilst I would accept that it is uncommon for teenagers and young adults to be admitted to intensive care units in the course of their treatment, in terms of their sudden lack of control and the subsequent consequences of this during their recovery, further exploration of this type of experience might be of benefit for those who are unfortunate enough to become so unwell.

In terms of a loss of cognition there may also be some space in this context for thinking about those whose cancer treatment directly affects cognition as is the case for example in the treatment of some brain tumours. They too will no doubt experience a change in their ability to exert agency, however, for them this might be a long term situation as they may remain cognitively impaired once their treatment is finished. Any trajectory of agency in this group would likely be expressed differently. This is partly the reason for excluding this group in the study inclusion as expressed in the earlier methods chapter (see Appendix 4).

8.5.3 THE PROMINENCE OF AGENCY IN EVERYDAY LIFE DECISION MAKING

Inevitably decisions which were made, other than those concerning treatment, did appear to occupy less prominence than treatment decisions in the findings discussed in Chapter Six. The structure of treatment protocols were such that the young people in the study were bound by the treatment, rendering them with little choice in their everyday lives. The literature review revealed evidence of involvement in treatment decision making as discussed earlier in this chapter. However, choice and control of decisions which were linked to everyday life were commented on rather than being the focus of research studies. There were a limited number of studies and opinion papers which made reference to issues in everyday life but these were not expanded further in terms

of the control young people possessed in determining their choice. (Smith *et al.*, 2007; Hollen *et al.*, 2007; Palmer *et al.*, 2007; Morgan *et al.*, 2010; Treadgold and Kuperberg, 2010; Wicks and Mitchell, 2010; Wakefield *et al.*, 2011; Fern *et al.*, 2013). As outlined earlier, the work undertaken by Wicks and Mitchell (2010) demonstrated some useful elements in terms of control or indeed lack of control relating to medical aspects of care. However, their results reflected less concern about decisions made over young people's social or everyday lives.

Nevertheless in this study there were numerous examples of the young people's personal agency being restricted with respect to their social lives and their aspirations for their future. More importantly though as in the treatment discussion, their ability to ensure that their choices were not just heard but acted on was overwhelmingly clear. Their capability to lead action and to make decisions is something that needs to be further recognised. Despite the side effects of treatment of which fatigue was important in this context, they were determined to exert choice even in what I would judge to be significantly limiting situations. These 'peaks' however, as previously described were still limited in terms of their overarching independence.

William for example when he took his girlfriend away was dependent on his parents to drive him to and from the hotel, where previously he had been driving himself and whilst he had made the choice to attend a music 'gig' originally, his personal agency in this regard was he felt limited by the fact that the environment might be too busy and thus he felt threatened by this. He was unable to enact autonomy but was still able to undertake the trip with limitations.

Equally Leah was at odds with both of her parents initially when she wanted to attend the school prom. There was disagreement about this but ultimately collective agency was demonstrated as her mother Janice and her aunt both helped to organise her trip and then shadowed the event by sitting close to the venue in the car. Unfortunately these

experiences although still limited in terms of personal agency were not common. This was disappointing for the young people as these examples of freedom in an otherwise restricted life saw the young people at their most animated when recounting their experiences during my interviews with them. As their journey progressed they transitioned into a different phase in terms of their ability to exert their personal agency as they optimistically planned their futures.

8.5.4 SUMMARY

Despite the significant disruption to life and the lack of choice and control, young people were able to accept and indeed feel grateful that sometimes others acted on their behalf during the early stages of treatment. Whilst their agency showed only what I would interpret as small peaks in control, during this time they led decision making both in relation to treatment and everyday life actions. This provides some affirmation I believe in those who were involved in their care including family, friends and professionals accepting their need for choice and control. Although accepting at the same time the severely restrictive nature that treatment imposes. It is how best 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.

8.6 LIFE RECLAIMED

There is an emerging body of evidence which focuses on the issues concerned with survivorship with some of this literature concentrating on decision making following completion of treatment, whilst other evidence centres around the psychosocial impact of cancer once young people try to move forward with their lives (Wakefield *et al.*, 2010; Stern *et al.*, 2010; Zebrack and Isaacson, 2012). Evidence which considers the period prior to completion is not evident, further evidence which focuses on choice and control at this time is absent. This is an important time period for young people during their cancer journey, a time when in my experience they were eager to get 'back on track' and move forward in their lives. They spoke on more than one occasion about feeling as

though they had fallen behind and were worried that their friends and partners would finish their university education before them. There was an indication here that they wished their lives to once again be as they were, be 'normal' as such (Fern *et al.*, 2013). Evidence of their personal agency was strong in this phase and whilst they needed some support they very much took the lead in determining their future actions.

There were still some peaks and troughs, however, they were able to reach higher levels of personal agency and therefore made more progress with their independence. This time in their trajectory was important as they used some of the benefits of their experience such as being positive, not missing out on life opportunities and adopting a more mature attitude in order to implement their plans (Wicks and Mitchell, 2010). This data would benefit from further exploration to enable mechanisms to be implemented which enable much earlier planning and support for the time following the completion of treatment whilst firmly making sure that young people if they feel able to can lead these actions, confirming their right to agency and independence as they move back to their developing lives.

8.6.1 GETTING BACK TO EVERYDAY BUSINESS AND MORE

Each of the young people experienced improving health during the data collection as they came closer to the completion of their treatment, particularly Ellen who made significant progress after her spell in the intensive care unit. Unfortunately Leah's health deteriorated towards the latter stages of interviewing and so she was not able to make plans. The other four participants all had quite complex paths to manage in order for them to continue with their lives. Ellen and Sam made plans to return to university and had to cope with the myriad of form filling and contacting their institutions to organise their return. The literature comments on how this can be difficult for some young people as they worry about their symptoms returning as well as fitting in with their peer group once they resume their lives (Lewis *et al.*, 2013). This did not appear to be the case with this group, rather they recognised that their lives were 'different' but this did not appear

to deter them. This ability to recognise that their lives were different and to articulate this appeared to be beneficial to their wellbeing and enabled them in my view to make positive progress. I began to refer to the group as 'different but determined'. They all had clear plans about what they wanted to do following treatment and my interpretation was that levels of optimism about the future were high. This was also evident with reference to their treatment. As they began to feel more in control of the side effects of their treatment, they appeared to demonstrate far more personal agency in treatment decisions. Ellen for example whilst she was troubled by the effects of the steroid therapy she was having (her consultant confirmed that she could refrain from taking it if this helped her), was keen to 'get on with it' and insisted that she be given the steroids. In this consultation her mother was present and did not intervene with regard to this decision. Although Wicks and Mitchell (2010) talk about 'benefit finding' in the context of their study the data here took this a step further. There was what could be described as 'the young person being liberated by the experience' in some sense. This in turn led to a more determined stance in their lives to achieve success. William for example had not thought about playing at a higher level in cricket, however, following his amputation he had been inspired by the Commonwealth Games which had been televised during his illness and was confident that he could now reach national level in his chosen sport.

8.6.2 THE EXPERIENCE OF RELATIONSHIPS AT THIS TIME

Throughout the cancer experience the importance of those close to each young person was transparent. This was reflected as parental support, peer support and professional support, which was viewed as central to the young people (Woodgate, 2006). Nevertheless as treatment progressed the desire of the young people to 'take back' their lives sometimes presented tensions for those who would rather the young person had taken a course of action that significant others suggested but was not always subsequently agreed with (Grinyer, 2004). Whilst there was evidence of collective agency again the young people were keen to manage issues themselves and whilst it is acknowledged that shared decision making is preferable at least for children (Coyne *et*

al., 2014) also comment that this lack of full control can lead to frustration in the experience of older age groups (Wicks and Mitchell, 2010).

Although parents and health professionals gave their support, one could not help feeling that they had some serious concerns about some of the decision making that was taking place regarding the young people and the reclaiming of their lives. This was not unexpected, however, the young people's perspective was that whilst they knew that those close to them might not be happy, in Sophie's words it was about getting back to normality. Equally for Sam and Ellen their desire to live independently was strong as was William's desire to leave home as soon as he could.

The need to put in place strategies which might help with this stage of reclaiming life is paramount. This type of activity spans much further than just one group of professionals helping. Rather an interdisciplinary approach is required in thinking about how best to support young people as they transition towards life after completion of treatment (CLIC Sargent, 2012; CLIC Sargent, 2013). The recommendations stemming from these aforementioned pieces of work, reflect the need for this type of action to help young people who are trying to reclaim their future. At what stage plans about what to do on completion should be introduced needs to be further debated. It is clearly the case that in the early stages of treatment young people can be very unwell and as we have seen are happy to hand over control of their decision making. However, perhaps having strategies in place which ensure that they are not just empowered but have some firm plans that they are able to pursue, albeit in a restrictive way, would be useful. This approach might also give parents and those close to young people some reassurance about their pursuance of other plans at an early stage to allow them time to readjust to life after their child's cancer.

8.6.3 SUMMARY

Crucial to the realignment of agency at this stage is the recognition that increasingly, young people want to lead in their plans for life after completion of cancer treatment. Whilst support is vital it is nevertheless something that in this study proved very important

to them. 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. Support specifically tailored to each young person, at an early stage in their treatment, needs to be further explored as well as thinking about how involving significant others in a way that is led by the young person can be beneficial to both the young person and their family.

8.7 THE CONTRIBUTION TO KNOWLEDGE: TRAJECTORIES OF AGENCY IN TEENAGE AND YOUNG ADULT CANCER

Demonstrably, there is a growing body of evidence which examines aspects of the cancer journey in this age group and this has contributed to the current knowledge base. This evidence comprises although not exclusively, multiple perspectives and illuminates limited examples of experiences prior to diagnosis, treatment issues, survivorship and palliation. Equally choice and control in decision making in this age group has formed part of the literature, however, this has focused primarily on specific treatment issues. Nevertheless elements of decision making which consider other aspects of life is minimal. Further detailed examination of the period prior to diagnosis from the voice of the young person is sparse.

The theoretical concepts of agency and structure are widely debated in the sociological literature. These theories are centred primarily on the traditional discourse of the duality of the two concepts, which translates to the recursive nature of the freedom to choose a particular course of action at the level of the individual coupled with society restricting that intentionality and choice. This stance on agency and structure has been applied in healthcare for example in relation to health and lifestyle issues and health related behaviours (Cockerham, 2005; Holman and Borgstrom, 2015). The prominence of this debate should not be underestimated, however, there are other arguments which concentrate more on the temporal nature of agency and the importance of the idea of the social embeddedness of the theory as a more persuasive argument (Emirbayer and Mlsche 1998). This use of agency and structure in an adapted way by viewing structure

as family, healthcare workers and the system and the treatment itself as restrictive against agentic power has helped to frame this study. This is situated in the context of the experience of the young person and those who are close to them and have been involved in their care. It has provided a backdrop by which we can reflect the young person's level of control through the interpretation of their experience relating to their cancer care.

This is therefore the first study of its kind which has simultaneously considered the journey of cancer from the development of symptoms through diagnosis and towards the end of treatment using the theoretical framework of agency and adapted theory of structure. The critical focus of the discussion which accompanies this adds further in that it considers the intentionality, motivation, freedom, choice and control in individual decision making against the backdrop of fluctuating agency.

The application of trajectories in this context can assist in demonstrating the temporal nature of the journey of young people, highlighting the changes in their situation in terms of choice and control in their decision making. These trajectories can be exemplified at an individual level and collectively where there are commonalities between cases. Trajectories are not new and these are commonly utilised to illuminate healthcare experience. One of the most recognised of these in healthcare qualitative research is perhaps that of Corbin and Strauss (1985) which was discussed in the opening chapter and provides a starting point for the consideration of trajectories in healthcare. In the years that followed their work, evidence has proliferated relating to the use of trajectories in healthcare to map the paths of those experiencing a wide range of illnesses. As was outlined in Chapter one, Corbin and Strauss (1985) make reference to the complex nature of trajectories and their discussion is not limited just to the physiological nature of the experience. Rather, they make reference to other aspects of 'work' in the life of patients, which include everyday and biographical features of their trajectories. Their so-called 'work' of patients also takes into account the contribution of others in this process.

Robinson (1990) discusses the nature of trajectories using terms which have some resonance with those described above, 'personal narratives of illness, social careers of sickness and physical courses of disease' (pg. 1173) in trying to determine the complex journey through chronic illness. This again determines the range of considerations in the experience of disease. Allen *et al.*, (2004) however, articulate some limitations of the Corbin and Strauss original contribution relating to trajectories by pointing out that these are referred to as 'illness trajectories' rather than 'trajectories of care' (pg.1011). Murray *et al.*, (2005) are able to note the benefits of trajectories in their study. They suggest that when clinicians use trajectories in palliative situations they can be helpful in planning care. Furthermore, they assert that if patients and those caring for them have knowledge of trajectories of care they will all perhaps be in a better position to exert better control in managing their situations. Another important feature in the representation of trajectories written about by Bury (1982) and pointed out by Corbin and Strauss (1985) points to the repeated biographical disruption that those who are chronically ill experience. Although a study of older people and of those who have experienced chronic illness for very long periods of time, Larsson and Grassman (2012) highlight the repeated number of times that patients experience biographical disruption. This can and sometimes does translate to young people's experience, as their cancer journey may last for many years particularly if they suffer a recurrence of their disease. Hannigan and Allen (2013) also espouse the usefulness of trajectories in helping to understand the complex nature of the experience of care in the field of mental health, arguing that the way in which these are shaped can be unique in this area.

The trajectories in this study are unique for two reasons. Firstly they concern the temporal nature of agency in three phases, 'life then', 'life interrupted' and 'life reclaimed' in teenage and young adult cancer specifically (and there is no other evidence of this type of trajectory) and it is situated at a time of development which is also different to any other time in the life cycle.

The recognition of the interruption to life and life being put on hold is recognised in teenage and young adult cancer. The concept of trajectories are utilised as a tool here, which is the result of detailed examination over time of these experiences in the life course as a whole, providing new insights into not just the experience alone, rather the following is highlighted:

- The way in which young people manage their symptoms and make decisions through the assertion of agency prior to diagnosis.
- Their response to severely restricted agency both in treatment and in their lives more generally but still demonstrating small peaks in agency during treatment as they manage decisions.
- Their ability to exercise agentic power in determining their actions in difficult circumstances.
- The strong need for the freedom to plan and make decisions about their future pathways as their health improves.

The illumination of trajectories gives the opportunity for those involved in the care of young people to have a crystallised view of the peaks and troughs of choice and control in decision making through the notion of agency and structure.

In these trajectories, levels of agency were categorised into the three phases in the same way as each of the findings chapters, 'life then', 'life interrupted' and 'life reclaimed'. For the most part these experiences were recorded in real time as is advocated in case study research (Yin, 2009) apart from the retrospective data prior to diagnosis. This would have been clearly impossible to record in real time as the young people would not have been identifiable. Indeed it was only once the study began and they gave me thick descriptions of their experience at this time that I was compelled to include them in analysis. These descriptions provided a really useful informative lens of their high levels of agency during

the time leading up to diagnosis. The separate elements of the trajectories are thus categorised into three phases reflecting the findings chapters. Further exploration of the individual trajectories of each young person through publication in future work will contribute more understanding of specific examples of the maintenance, loss and reclamation of agency. The findings in the study also provided some commonality across the five cases. The two tables below outline an example of an individual trajectory (Ellen) and a collective trajectory of agency by way of a selection of the nuances of each phase of the young people's journey, which were present in the majority of participants. These stemmed from the findings identified in each young person's individual story (Figure 8.1 and 8.2).

Individual Trajectory of Agency in Teenage and Young Adult Cancer (Ellen)		
<i>Life then</i>	<i>Life interrupted</i>	<i>Life reclaimed</i>
<i>Flying the nest to attend university and live away from home, possessing high levels of agency.</i>	<i>Personal agency severely restricted compared to 'life then' following diagnosis e.g. the lack of choice for fertility preservation.</i>	<i>As Ellen's condition improved, she asserted her agency in organising a large fundraising event and made many decisions alone as she would have done prior to her illness.</i>
<i>Maintaining agency during the onset of symptoms in seeking medical advice.</i>	<i>Serious reaction to treatment at an early stage rendering Ellen with a complete absence of agency.</i>	<i>Collective agency in decision making utilised in terms of a return to university.</i>
<i>Progression of symptoms, advice given from others but agency maintained and plans to finish the university term and complete examinations continued.</i>	<i>High levels of proxy agency as parents and staff are required to take control and make choices in decision making for significant numbers of decisions.</i>	<i>Trying to exert agency in making a return to university but faced with a number of challenges due to logistics of living away after experience of a serious illness and complications following treatment.</i>
<i>Diminishing levels of choice and control in agency as adjustments are made to try and cope</i>	<i>Some evidence of agency in decision making as recovery takes place e.g. deciding to continue with steroid therapy, despite</i>	<i>Looking forward and determined to reclaim her life. Ellen continued her relationship and made plans to return to her</i>

<i>with progression of symptoms.</i>	<i>the consultant stating that Ellen could take a rest from this medication.</i>	<i>programme. She looked forward to being in control of her life following her treatment</i>
<i>Agency surrendered as father intervenes to establish a diagnosis.</i>		

Figure 8.1. Individual Trajectory of Agency in Teenage and Young Adult Cancer (Ellen)


<p>Across case collective trajectories of Agency in Teenagers and Young Adults with Cancer</p> 		
<i>Life then</i>	<i>Life interrupted</i>	<i>Life reclaimed</i>
<i>High levels of agency in decision making.</i>	<i>Personal agency severely restricted compared to 'life then' following diagnosis.</i>	<i>Regaining levels of personal agency as the recovery process continues and treatment nears completion.</i>
<i>Needing to maintain agency in order to achieve goals.</i>	<i>Examples of proxy and collective agency in decision making changing the emphasis of choice and control.</i>	<i>Still a requirement sometimes for high levels of collective agency in planning futures.</i>
<i>Help from others who are close however, decision making remains with the individual, utilising personal agency.</i>	<i>Some evidence of personal agency relating to treatment decisions but with limitations on choice and control.</i>	<i>Trying to reclaim full control but sometimes faced with challenges which limit this e.g. change in physical status in light of cancer treatment.</i>
<i>Diminishing levels of choice and control in agency relating to decision making as symptoms progress.</i>	<i>Loss of choice and control in relation to future aspirations.</i>	<i>Looking forward to having higher levels of personal agency in pursuit of aspirations in work and education.</i>
	<i>Striving to maintain some personal agency in respect of everyday decision making.</i>	

Figure 8.2. Across case collective trajectories of Agency in Teenagers and Young Adults with Cancer

8.8 WORKING WITH PARTNERS IN PRACTICE

As the data analysis gathered momentum in the study, I decided to share some of my early findings with colleagues (senior nurses) working in the field to ascertain their views on the timeline of the young person's experience in relation to decision making. Early indications of the usefulness of trajectories were encouraging. Their feedback particularly in the life interrupted and the life reclaimed stage suggested that the notion of being able to perhaps predict when they might benefit from being able to independently make choices and times when they needed support or guidance could be helpful in meeting their needs for higher agency more effectively. Following further discussions when the analysis was complete, I was able to consider more contributions from colleagues. These included a psychologist, a specially appointed well-being co-ordinator for young people with cancer, a social worker a service development professional and senior nurses. They kindly suggested some ideas to support the use of trajectories. These are as follows:

- The need to consider the period prior to diagnosis in thinking about what is currently available in terms of education, particularly in those over 16 years for example at university freshers' weeks and as part of drop in services targeted at health promotion.
- The use of social media platforms to engage young people in general health monitoring and the emergence of worrying symptoms.
- Through specialist psychological support consider how modes of independence could prior to diagnosis be reinstated at an early point during treatment when young people are at their most vulnerable.

- At local levels, 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.
- Systematic early planning about what the young person intends to do following treatment. Support is important but the offer of the young person leading and progressing with future plans should be firmly in place at an early stage.

Undoubtedly, the strengths of the study design and the data generated as a result was central to the development of the contribution to knowledge.

8.9 STUDY STRENGTHS AND LIMITATIONS

This study commenced at a time when limited evidence was available which explored in detail the experience of young people in the context of the cancer experience and all types of decision making (Coyne *et al.*, 2013). This provided the opportunity, having explored the available literature, to pay detailed attention to the experience of decision making during their cancer experience. User and expert consultation and engagement as identified in Chapter Three was a strong feature of the early part of the work which ran concurrently with the literature searching and was extremely helpful in framing the study in a context that would have clear and helpful application to practice. Relevance to practice was also highly desired and meeting and talking to experts in the field as well as those affected by cancer was instrumental in achieving this aim. User consultation and engagement strategies in trying to find the best 'fit' for research are now becoming part of established practice and can be extremely beneficial in providing useful findings. These ultimately have the power to benefit patients. Some support the idea that involvement is also ethically sound and is a democratic way to proceed (Barnes, 1999). Whilst these beneficial strategies found their early use in the discipline of mental health (Syrett, 2011) there has been further development of these approaches in other fields of healthcare which have further confirmed the positive role that consultation and

collaboration can play in 'finding the right fit' for effective research (NHS Plan 2000; Staley 2009; Cotterell *et al.*, 2011).

The development of such initiatives in the field of teenage and young adult research have also made ground but this has arguably taken more time, possibly due to the identification of the so called vulnerability of the group and the barriers sometimes encountered through ethics permissions where the researcher is seeking collaborative engagement rather than consultation. It must be acknowledged that the nature of these permissions and the time available did in part lead to the selection of only one site for data collection (a subsidiary site had to also be approved) but this was only because outpatient appointments for one case, William, took place in another health board. However, the number of participants in a multiple case study of individuals is normally no larger than seven (Yin, 2009). Added to this the study was first of its kind in the country of investigation.

When referring to the sample size, the nature of this in case study research allowed me to 'drill down' from each case rather than consider the breadth of cases as is the approach with larger studies. Within the sample size I was still able to adopt a strategy of maximum variation in a purposive sample and this allowed me to choose four of the most common cancers in teenagers and young adults aged 16-24 as identified by cancer research UK (2013) in their incidence data. The idea to include a young person with a rare cancer was the suggestion of the consultant who acted as one of the gatekeepers of the study. It was proposed that because the outcome for someone with a rare cancer may be less predictable, their journey with reference to choice and decision making would it could be argued consist of different dimensions of experience.

The chosen age group linked very closely to criteria in current service provision in the UK, with those aged between 16 and 24 years being cared for in specialist cancer settings and therefore has a high degree of application to practice. A challenge could be

instigated which would argue that in terms of cognition there are a potentially wide range of differences in decision making ability between 16 and 24, however, once young people with capacity reach 14 years of age, generally there is agreement they are judged to be able to make decisions in the same way that an adult can. This is despite the fact that some of the key research in this area used artificial situations to judge decision making (Weithorn and Campbell, 1982; Scherer, 1991; McCabe, 1996). Situational perspectives and life experience were of course different but this could be applied to any number of samples in research settings.

The in depth study of the young person's account of their experience throughout the cancer journey largely in real time, strengthens the data set as a whole because the events are close to the reporting providing better recall and much needed evidence in this vein (Gibson *et al.*, 2013). In interviewing the key participants on three occasions I was able to undertake this at particular junctures in their care, further there was more information offered by the young people as we got to know each other and as demonstrated in the transcripts, thus providing increasingly rich data. The findings most importantly provide more than just a snapshot of the experience in terms of choice and control, rather they offer a time line and trajectories of the fluctuation of agency against structure during the duration of the study.

The use of multiple methods provided the opportunity to refrain from relying on the accounts given in interviews alone. Instead real live negotiation and decision making was observed and I was also able to capture the tripartite nature of this in all but one case as parents and in one case a girlfriend were present at all other appointments. Concerns about the impact of my presence on the interaction were noted and accepted as potentially leading to bias. One must accept that those involved in the consultation may be influenced by the presence of the researcher. Equally the ability of the researcher to remain objective and not refer to their own personal terms of reference was challenging. The third and final method was to undertake a documentary analysis of the

evidence contained in medical notes which provided another way of retrieving relevant data. However, this recording of interactions was not standardized and varied widely between not just the record itself but who wrote in the record. Nevertheless data retrieved from the record complimented or added to existing knowledge in each case, providing in some elements at least a strong triangulation of data.

The data set was significant in size, and produced extensive information about the five young people and their experience of cancer. It was therefore impossible to detail each individual story as I would have liked. This was especially apparent in Chapter Four, where I could only make brief reference to each of the identified themes in individual cases. Nevertheless it was important to provide illustrative examples of each journey with reference to their agency in decision making.

Within these multiple methods, whilst young people were at the centre of the investigation, there were other participants who provided further evidence of choice and control in decision making which resulted in a number of perspectives through which I was able to analyse the experience of participants. Trustworthiness was also enhanced by retrieving information from both multiple sources and methods.

As with the consultation and engagement at the early stages of the study with reference to experts in the field, this continued throughout the project, thus strengthening and reaffirming that through the study I had retrieved, analysed and presented the findings in a way that could be helpful to practice.

8.10 CONCLUSION

The key aim of this chapter was to summarise and illuminate the key findings of the study. The complex interplay of both the individuals involved, the methods utilised and the context of serious illness provided a rich palate for discussion. The three identified themes provided highlights of the findings which linked to the original questions in the study and either added to or denoted something that was new in the context of the

existing literature. This resulted in the subsequent development of trajectories of agency during teenage and young adult cancer. These trajectories set out to provide the basis for considering how young people might best be given the opportunity for choice and control of their decision making set against the sometimes restrictive nature of the structure as was adopted for this study. The final concluding remarks which follow will succinctly summarise the thesis and provide ideas for future research connected to the context of this study.

9. CONCLUDING REMARKS

9.1 INTRODUCTION

Cancer in teenagers and young adults is uncommon. Nevertheless it is a serious disease and its occurrence at this time is known to have a significant impact upon an important transitional period when young people are in the stage of developing their early adult life platforms. The transitional period can be an exciting and optimistic time, when the pursuance of new goals brings many new and rewarding experiences. Despite the clear and sometimes lengthy disruption that cancer can bring to the lives of young people affected by the disease, coming towards the end of the treatment period formulates the emergence of a sometimes different but determined young person. Nevertheless with the support of a good network and the encouragement towards empowerment in their decision making this group can begin to re-engage in building their future lives.

This study originated from an interest in children's consent and refusal of treatment as part of an LLM qualification in medical law. At the outset, ideas linked to those previously studied were proposed but with reference to cancer treatment. For a variety of reasons, these early ideas did not develop further. The rationale which led to rethinking the ideas about consent and refusal of medical treatment included a number of considerations. These included the examination of existing literature, the difficulty of sufficient data generation relating to the topic area and importantly the sensitivities of the subject matter associated with protecting participants from harm. Thus, further discussion and reading took place to determine a useful and workable project. It transpired that there was much to explore that was exciting and novel which attended to elements of decision making in the much broader spheres of young people's lives and this is what drew me to the project.

9.2 THE STUDY

Once determined, the study sought to explore the experience of all types of decision making in young people aged 16 to 24 years who developed and were subsequently treated for cancer. It also examined the views on this issue from those who were close to the participants and included parents, friends, boyfriends and girlfriends nominated by

the young person and healthcare professionals. This data generation was undertaken by initiating three interviews with the young people over an average period of six months and for the majority of this the data was generated in real time. Other participants were interviewed once. Additional methods include observation at outpatient appointments on two occasions for each young person and a documentary analysis of each of their medical notes. Within case and cross case analysis was undertaken using a six step thematic approach and three overarching themes were identified thus providing the backdrop for the findings chapters. The subsequent discussion highlighted and theorised the key elements of the findings with reference to existing literature and this was underpinned by the theoretical framework of agency and an adapted framework of structure.

9.3 THE KEY FINDINGS AND CONTRIBUTION TO KNOWLEDGE

Findings in the form of new knowledge and further contributions to existing knowledge were presented in each of the three categorised findings chapters, 'life then', 'life interrupted' and 'life reclaimed'. In the 'life then' chapter the notion of holding onto control of life events was well demonstrated and this went further than existing literature in that there appeared to be what can only be described as a compulsion to continue with life goals and professional and educational deadlines. Some young people went past what have been usefully described in the literature as threshold points (Gibson *et al.*, 2013) and in the extreme put themselves in potentially dangerous situations in terms of their health status. The 'life interrupted' stage brought considerable challenges, where vulnerability was most marked. However, despite disruption young people were able to exert small measures of agentic power whilst being restricted by the structures of family, healthcare professionals and the treatment itself. In contrast to one key piece identified in the literature (Wicks and Mitchell 2010), young people found more restrictions in their everyday life and social decisions and had to accept diminished levels of agency in pursuing their interests. In treatment decisions they appeared to be able to exert choice when they were not in agreement about aspects of this part of their life. The same

aforementioned research was influential in the 'life reclaimed' chapter as not only did there appear to be 'benefit finding' in the experience of cancer but the young people in this study appeared to experience a transformative stage where they emerged as 'different but determined' in their quest to move forward in their lives. This of course was not without a number of challenges. Added to this, planning and decision making about the future was taking place not after the completion of treatment but as young people's health was improving even where treatment or side effects had been particularly significant. Existing literature tends to focus on this type of decision making following the completion of treatment.

The support of those close to the participants remained constant throughout their experience, with a different dynamic between parents and those who were nominated to take part namely friends, boyfriends and girlfriends. The ever present support of parents was unflinching in trying at all times to protect their children through decision making despite some disagreements along the way and thus restricting agentic power in the young person. The relationship with partners and friends was as one would expect, different. Here illuminations of peer support, staying together and helping but respecting the young person's actions were evident. This notion of helping and respecting actions was also present in the role of healthcare professionals. These interactions during the study period were both unique and special.

Most importantly, these findings served as a continuum across time which resulted in the development of trajectories of agency, both individually and across cases in decision making relating to the experience of teenage and young adult cancer. This detailed the temporal fluctuation of choice and control in the manifestation of the disease from the onset of symptoms to the subsequent diagnosis and treatment, through to either the completion or the later stages of treatment. As a result of this it was possible to anticipate unmet needs in this group with reference to their agency in terms of choice and control in decision making. Despite the existence of trajectories in many aspects of life and those

of course identified in healthcare perhaps most famously by Corbin and Strauss (1985), there is no evidence of such trajectories which are mapped against the agency and decision making experience of cancer in teenagers and young adults. No one has investigated healthcare or illness trajectories of choice and control in decision making over time with a particular focus on agency in this field.

9.4 FUTURE WORK

This study has created the opportunity to undertake an in depth examination of the agency in decision making in teenage and young adult cancer. The ultimate formulation of these trajectories provide the first step in examining the fluctuation of choice and control over a large part of the cancer journey. Further exploration of these trajectories needs to be first of all tested in practice. This would be to ascertain if they could assist in development of mechanisms in practice which may be able to help identify when young people might want to lead in terms of their choice in decision making. Alternatively they may want to negotiate support at some points. At others, there might be a wish on their part to relinquish personal agency in favour of either proxy or collective approaches. In determining such research, mapping the individual and collective trajectories against recent expert guidance could be a way to determine how these models could be tested (see Appendix 12). These trajectories would have most application perhaps in hospital settings although some treatments do take place largely in day unit settings and so it could be useful there. This would be during the diagnosis and treatment of cancer in the interrupted and life reclaimed phases. The 'life then' phase may be helpful in primary care settings in home and work contexts during the development of symptoms when some young people do not seek help. Continued efforts to maintain and increase awareness raising, for example amongst university or further education populations, are required. Equally, other areas of life, perhaps relating to leisure facilities or popular places frequented by young people could also be targeted. The trajectories may also have transferability in terms of exploring dynamic agency both in survivorship and in end of life care. These are both projects where it might be possible to seek further funding.

The findings chapters which were set against the idea of a three act play triggered the idea of discussing the development of the work using the concept of ethno drama. This is where transcripts could be developed into scripts with the added idea of asking participants to be part of a project group to develop the performance of monologues relating to their stories using actors. This could with all the appropriate permissions, anonymity of course and careful, sensitive planning be produced for educational purposes. However, the opportunity to consider this commercially with a production company is something else I would like to consider. This also might produce the option to work collaboratively with other academics with humanities backgrounds either within or outside of the university where the research was undertaken.

A number of papers could be reasonably argued for resulting from the study. Papers outlining research protocols are becoming increasingly popular and there is no reason why this could not be the case in this instance. The use of multiple sources in research is interesting, however, the direct nomination of friends, boyfriends and girlfriends and friends in cancer experience in this age group is not present. A methods paper which focuses on this approach would be interesting. In the same vein a paper outlining the skills required in interviewing teenagers and young adults with cancer could also prove useful. There is still room for further legal debate and the relevance of frameworks which are currently in place which focus on young people's rights in decision making. A collaborative legal paper might add further to this discussion.

In terms of the research findings there is certainly space in the literature for evidence of the experience of young people in the pre diagnostic phase as there is little written in this area. In terms of this phase of treatment more attention could be directed to agency in everyday life decision making and the challenges that are faced by young people in keeping this part of their lives under their control. In moving towards the end of treatment, there are again elements of this part of the journey which are not discussed prior to the completion and here I refer to decision making in pursuance of future life plans. However,

in this study there was much activity in terms of planning at this time especially in those who had received the most intensive treatment or had experienced the most serious side effects. Partners and friends of the young people could be a source of writing in respect of methods, however, I think there is an opportunity here to report their response, support, fears and help towards the young people they love when they develop cancer.

9.5 ...AND FINALLY

This work stayed very close to the participants, reporting verbatim stories and supporting these with evidence from those who were close to them or involved in their care. This undoubtedly formed the fundamental backdrop for all that has gone before in this thesis. Further and very importantly, the number of experts 'behind the stage' provided informed advice in which to frame the study setting it in a context which had the capability to uncover new and exciting knowledge. It is passionately hoped that elements of this work can be developed to further understand and support this age group of young people in working with them through their experience of cancer.

9.6 EPILOGUE

At the time of writing, I have not yet visited Leah's parents but plan to do this as they indicated that they would like some feedback on the study. I know that these will be difficult visits but feel that if they wish me to talk with them then this is appropriate. The four remaining young people are progressing with their lives. I am aware that Sophie is doing extremely well back in her job and enjoying life. Ellen is still planning to go back to university, although she is sadly unlikely to go back to her original place of study. Instead, she is planning to go somewhere nearer to home, the last word I had was that she was still in a relationship with Nigel. William is playing cricket again and has raised money for a specific sports prosthesis to enable him to play to his full potential and Sam as was his way is keeping his own counsel and has not been in touch!

Many, many thanks again go to these young people and those close to them who took part in this study, I wish them all well for their futures.

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APPENDIX 1: PAPER PUBLISHED IN JOURNAL OF ADVANCED NURSING APRIL 2015

This Appendix is a copy of a discussion paper published as a result of the initial literature search undertaken in 2012.



DISCUSSION PAPER

Autonomy and dependence: a discussion paper on decision-making in teenagers and young adults undergoing cancer treatment

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Abstract

Aim. A discussion which aims to explore the diversity of decision-making during teenage and young adult cancer treatment. The discussion will be related to the concepts of autonomy, dependence and decision-making in this age group.

Background. The experience of cancer involves a significant series of treatment decisions. However, other non-treatment decisions also have to be made which can relate to any aspect of everyday life. These decisions occur against the backdrop of young people's disease experience.

Design. Discussion paper.

Data sources. A literature search for the period 1990–2013 was undertaken. This included searching the following databases: Cumulative Index for Nursing and Allied Health Literature (CINAHL), SCOPUS, Medline, DARE, Applied Social Sciences Index and Abstracts (ASSIA), (Psych Info) and The Cochrane Library.

Implications for nursing. There is a lack of evidence into the experience of everyday decisions made by young people during cancer treatment. This may affect them in the form of unmet needs that nurses, or other professionals, fail to appreciate.

Conclusion. Further exploration of how teenagers and young adults experience the range and process of decision-making during cancer treatment could be useful in helping to provide effective supportive care for this age group.

Keywords: adolescence, autonomy, cancer, control, decision-making, dependence, independence, nursing, teenagers, young adults

Introduction

Cancer in teenagers and young adults (TYA) is unique because it occurs at a significant stage in the developmental trajectory. Making the transition from childhood to adulthood is an important event in the human life cycle. It

is a time when the young person is moving from dependence to independence. Decision-making forms a central part of this process. The complexity of decision-making is such that it is commonly referred to in decision-making models by several steps which enable understanding of the processes involved (Byrnes *et al.* 1999). In using these steps,

Why is this research or review needed?

- There is limited evidence concerning the experience of decision-making in the 16-24 year age group with cancer, in particular decisions related to everyday life. These decisions can be influenced by the impact of treatment and the disease.
- Young people have to make decisions at this time which may affect their long term future and more needs to be learnt about this.
- More knowledge of the experience of all types of decision-making during cancer treatment may assist health and social care professionals to provide helpful approaches in care.

What are the key findings?

- The paper illuminates the need to consider issues such as autonomy and independence in teenagers and young adults with cancer.
- Key issues identified include: the period of cancer treatment as a time of 'suspension', the implications of moving towards independence during cancer treatment and the difficulties involved in ongoing life decisions which have to be made at this time.
- This discussion suggests that further insight is required into young people's needs relating to decision-making during cancer.

How should the findings be used to influence policy/practice/research/education?

- There is a need for greater awareness in practice, policy and research of the decision-making challenges facing young people with cancer.
- This could involve the development of knowledge relating to autonomy or dependence in young people's everyday lives while undergoing cancer treatment.

which include identifying the possible options, identifying the possible consequences which might follow these options, evaluating the desirability of these consequences, assessing the likelihood of those consequences and combining the aforementioned according to some decision rule (Furby and Beyth-Marom (1992, pp. 3-4)). They describe two types of decision-making models applied in adolescence, normative and behavioural. They identify the same steps outlined above for each as advocated in the decision-making literature. However, the former is concerned with how decisions should be made and the latter with the reality of decision-making and how it actually takes place. Developing autonomy is generally experienced as young

people mature. Leffert and Peterson (1999) comment on the increasing capability of young people in decision-making as they grow towards adulthood, and how this increasing autonomy shifts responsibility from the parent to the young person. However, young people will still look to others to help them in decision-making and sometimes they may return to a state of being dependent when they have a serious illness (Grinyer 2003). Models of decision-making are therefore bound up with the concepts of autonomy and dependence during adolescence and beyond.

The occurrence of cancer in this age group has the potential to make a significant difference to life choices and the decision-making that young people engage in when being treated for the disease (Smith & Case 2012). Our aim in this paper is to review literature and promote the discussion of the need to better understand the interrelationships between autonomy, dependence and decision-making in young people with cancer.

Cancer continues to be a challenging range of disease processes, which affects individuals across the life span. Treatment for cancer often takes place over a considerable period of time resulting in many people experiencing its impact in the form of a long term condition (Department of Health 2007). This experience requires a significant series of treatment decisions, depending on the stage of the disease and its treatment. However, other decisions also have to be made and these can be related to any aspect of a young person's life. These can range from what could be viewed as minor, such as what to wear or what to eat, to those relating to relationships or issues concerning future education and career options. The emergence of a wider expert network on an international level, The European Network of Teenage and Young Adult Cancer (ENTYAC), are taking account of these needs. They focus not just on treatment and outcomes but also on the involvement of teenagers and young adults in their care and this is an important development in this field.

This process of choice occurs against the backdrop of young people's disease experience. Having cancer constitutes a key event at any time during the lifespan; however, in young people a unique range of factors exist relating to their development needs that have to be considered. These factors may make an important difference to the experience of cancer care and treatment but also to life thereafter. Importantly, they can also affect goals related to physical, emotional, psychological and social development, which may result in a unique cancer experience for this age group.

Background

The experience of emerging maturity involves a complex series of transitions. These are related to legal ethical, social and developmental issues and are often overlapping in nature. This discussion therefore reflects that complexity.

It has been well documented that during adolescent development, young people commonly acquire a greater degree of autonomy in decision-making as they make the transition to adulthood (Smith *et al.* 2011a). They also desire more independence from immediate families or carers and, at the same time, create strong links with peer groups (Marris *et al.* 2011). The period of adolescence is not always clearly identified, however, there is some consensus that it can span between the ages of ten and twenty years (Smith *et al.* 2011a). This constitutes a relatively long period during which the development of cognitive and life skills will vary significantly. This highlights the wide variation in experience among young people in non-cancer, and cancer, contexts.

TYA is a widely used term in the UK and other European countries in this context. It is acknowledged that this group are also referred to as adolescents and young adults (AYA) in the United States and some other countries. For this paper the term TYA will be used, encompassing AYA.

Once young people reach the age of 18, parents no longer have legal responsibility (in England and Wales) and therefore have no control over the decisions made by their children. However, young people still need support as they can be vulnerable and inexperienced at his stage of their lives (Grinyer 2003). Those between the ages of 16–18 years can consent to medical treatment if they are competent to do so under The Family Law Reform Act (1969) and this was extended to those under 16 years in the later 'Gillick' principle established in 1986. However, refusal of medical treatment has been managed differently in the legal context with only a small number of cases being referred to the courts. This usually happens when refusals in those under 18 years, that are supported by parents, have been denied by judges who can order treatment to be undertaken, [*Re E (Minor)* (1990), *Re S (a minor) (consent to medical treatment)* (1994)]. The parameters of what generally constitutes 'a young adult' currently lacks consensus with some definitions spanning as far ahead as 39 years in terms of upper age limit (Zebrack *et al.* 2010).

The incidence of cancer in adolescence is relatively rare and has shown a progressive rise from 14.4 per 100,000 populations for those aged 15–19 years and 22.6 for 20–24 year olds (Kelly & Gibson 2008). These cancers account for 11% of deaths in this age group, resulting in

cancer as the second most frequent reason for death in young people aged 15–24 years after accidental causes. More recent United Kingdom figures based on data extracted from the Information Services Division Scotland, the Office for National Statistics in England, the Welsh Cancer Intelligence and Surveillance Unit and the Northern Ireland Cancer Registry state that less than one per cent of cancers are identified between the age of 15–24 years. This accounts for an average of 2234 young people who were diagnosed per year in the UK between 2009–2011. This can be further divided into 1153 males and 1081 females (ISD Scotland 2013, Northern Ireland Cancer Registry 2013, Office for National Statistics 2013, Welsh Cancer Intelligence & Surveillance Unit 2013). Estimated figures documented by Cancer Research UK (2013), which are sourced from the International Agency for Research on Cancer suggest that there were around 173,000 cases of cancer in Teenagers and Young Adults diagnosed worldwide in 2008. The drivers that are required to improve diagnosis and care for this age group are grounded in the formulation of policy and guidance, based on incidence and needs, which can then be applied to practice.

Recent UK policy and guidance emphasizes the requirement to understand the specific needs of this particular age group in relation to cancer treatment and the care offered. The National Institute for Health and Care Excellence (NICE) published guidance which recognized that the needs of children and young people with cancer were different from those of older adults with the disease (NICE 2005). They commented, for example, that during childhood and adolescence there are several physical changes that will occur. These may impact in different ways including: the type of cancer present, how it needs to be treated effectively and how well the treatment is likely to work. Children and young people's emotional response to cancer might be affected due to the psychological changes they are also experiencing (NICE 2005). Similarly and more recently, a consensus document known as The Blueprint of Care has been published by the Teenage Cancer Trust in collaboration with young people which sets out practical advice and guidance for those working in the field (Smith & Case 2012). In earlier work the priorities and unique challenges in meeting the needs of young people undergoing cancer treatment has been clearly highlighted (Smith *et al.* 2011b).

Data sources

A literature search was undertaken to retrieve articles published between 1990–2013 using the following databases:

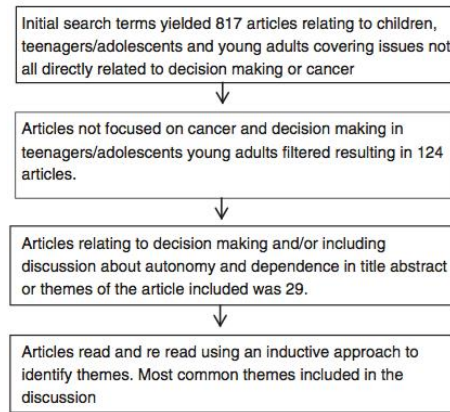


Figure 1 Article selection process.

Cumulative Index for Nursing and Allied Health Literature (CINAHL), SCOPUS, Medline, Databases and Abstract of Reviews of Effectiveness (DARE), Applied Social Sciences Index and Abstracts (ASSIA), (Psych Info) and The Cochrane Library. Only papers written in the English language were retrieved but these were not limited to those published in the UK. Keywords were used in combinations and included: adolescent; teenagers; young adults; cancer; autonomy; dependence and decision-making. The aim was to identify evidence in the literature outlining teenage and young adult experience of the different types of decision-making during cancer treatment. Initially 817 articles were retrieved. The articles included reports of original research using a variety of methods (primarily interviews, focus groups and observation), commentaries and opinion papers. Some single articles focused on children, adolescents/teenagers and young adults with cancer and while an attempt was made to exclude all materials that referred to those under 16 this was not possible in sources of this type. These materials also covered a wide range of issues other than decision-making and some were concerned with chronic illness generally in young people. These were then filtered for relevance to focus only on those who had experienced cancer treatment. This resulted in identifying 124 articles. Again there were several issues relating to elements of care and management other than decision-making, for example health promotion, education and treatment issues. The articles were further reduced by focusing on those where either decision-making and autonomy and dependence were in the title or the abstract and/or there were themes in the publications which related to these concepts. This resulted in 29

articles being considered for discussion. These were read and re read using an inductive approach to identify themes and the most common themes were included in the discussion section of the paper (Figure 1).

There are some important legal and ethical frameworks which are relevant to young people and four further sources were used to support the discussion. Guidance recently published by the Health Foundation was also used as this provided evidence for current participation in healthcare decision-making.

Discussion

This paper is concerned with identifying and discussing issues relating to the experience of decision-making during and beyond treatment and arguing that limited evidence exists which explores decision-making that is not linked to treatment. The literature provided several themes, which relate to treatment decision-making in cancer. These include: making decisions about whether to enter into clinical trials (Chappuy *et al.* 2008, Read *et al.* 2009), decisions concerned with palliative and end of life care (Hinds *et al.* 2001, 2005, Tomlinson *et al.* 2011) and fertility treatment issues (Quinn *et al.* 2011, Peddie *et al.* 2012). There is also literature available which explores the decisions made relating to risk taking once cancer treatment is complete (Hollen *et al.* 2007, Stern *et al.* 2010). Parental perspectives on treatment decision-making also form part of the literature (Holm *et al.* 2003, Hokkanen *et al.* 2004, Stewart & Pyke-Grimm 2012). A recent Cochrane review explored the promotion of participation in shared decision-making relating to children with cancer, which revealed the lack of research in this area. However, it is acknowledged by the authors that the review was limited to randomised controlled trials. This review was also concerned with treatment decisions rather than those which take place outside of treatment. Nevertheless it exposed a gap in the evidence relating to the promotion of shared decision-making in childhood cancer care (Coyne *et al.* 2013).

The perspective of the young person is considered in some of the literature but not all and several studies were undertaken using samples across a much wider age range, which includes those under the age of 16 years. Despite glimpses of the differences in everyday life in terms of a loss of independence and control, (Smith *et al.* 2004, Hollen *et al.* 2007, Palmer *et al.* 2007, Morgan *et al.* 2010, Treadgold & Kuperberg 2010, Wicks & Mitchell 2010, Wakefield *et al.* 2011/12, Fern *et al.* 2013), specific studies in the literature on decisions other than those concerning treatment are not evident. More particularly studies about this

issue, which consider the views of young people and significant others over a period of time during treatment are limited. Interestingly, The Health Foundation recently published a review of the usefulness of shared decision-making in health settings and commented that few studies had been undertaken considering the views of children and young people (The Health Foundation 2012).

The uniqueness of the 16-24 year age group means that there are potential challenges with reference to the degree of autonomy a young person might desire, contrasted with their need for dependence at some other points in their cancer treatment. The legal framework is designed to act in a protective way to those under the age of 18 years in this area but also serves to add further complexity to what is already a difficult and sometimes challenging situation. For those who are over 18 years (who are legally adults), there is evidence in some studies that parents still feel the need to take some control of decision-making when cancer is diagnosed (Grinyer 2003). Three themes were identified as a result of inductive reading: a time of suspension, moving towards independence and life decisions, all of which involved several complex overlapping issues. These themes are discussed below

A time of suspension

Several papers identify the unique period of adolescence and make reference to teenagers and young adults as a distinct group (Palmer *et al.* 2007, Treadgold & Kuperberg 2010). This is a time when human development is at a key stage as the young person makes the transition from child to adult. Many activities normally experienced can be suspended while cancer treatment takes place and the typical processes which involve the making of independent decisions at this age are slowed down or halted completely. Planning for a future adult life is interrupted, while health care takes priority (Stern *et al.* 2010). In some cases this can be for long periods of time as cancer treatment can sometimes be protracted. While this is a time of growing independence, or indeed when full independence has been achieved, the young person might retreat and become dependent on others.

Albritton and Bleyer (2003) question what happens to the young person who is in the throes of learning new roles either as a student, a newly employed person or perhaps less commonly as a young parent themselves. In their discussion paper, they pose several other questions that reinforce the consequences of their everyday life being suspended, all of which relate to anxiety as to whether or not they will be successful in their chosen endeavours

following treatment. They also make the point that thought needs to be given to how futures can be planned which might not happen.

On some occasions it is not only the treatment protocol but the effects of treatment that curtail everyday activities. It is reported that some young people on treatment may miss many social events, for example, due to fatigue following treatment. In terms of decision-making in this area, the suspension of social events is often made jointly with parents. However, sometimes parents can take over this responsibility, when normally these decisions would be made by the young person themselves (Wakefield *et al.* 2010).

The suspension of everyday activities has the capacity to adversely affect 'normality' in multiple ways Wicks and Mitchell (2010) and can sometimes result in a reticence to resume these once the young person recovers from cancer. There may also be fears about being involved in former activities after treatment is completed (Kelly *et al.* 2004, Gibson *et al.* 2005).

Moving towards independence

The desire for participation and thus a degree of individual autonomy in decision-making is clearly demonstrated in a study undertaken by Wicks and Mitchell (2010). They argue that one of the developmental goals of adolescence is independent decision-making and that a diagnosis of cancer in this age group has the potential to affect this activity. In their study they explored the cancer experiences of 10 young people aged between 16-22 years. Although some of the participants were over the age of 18, the average age at diagnosis was 16 years and 5 months. Of two key themes, one focused on loss of control. Participants were reported to be restricted in their everyday lives and subsequently lost control over life events. This led to feelings of anger and a wish to control the treatment process even in the smallest way. The young people reported a greater loss of control in terms of medical treatment in that they had to give over control to some of their doctors (Wicks & Mitchell 2010). Similarly, during the experience of cancer young people found it harder to gain independence and therefore make decisions due to heightened protection and control by parents (Hokkanen *et al.* 2004). Earlier work supports this also in that adolescent cancer patients do not always like being controlled by parents and also found it difficult to find their independence in terms of decision-making (Dunsmore & Quine 1995).

It has been reported that there may be reluctance on the part of the parents of young people with cancer to share

information with this age group in an attempt to protect them from what can sometimes be distressing news. This news can also come at a time that the young person may have troubling symptoms or might just have being diagnosed with cancer (Stegenga & Ward-Smith 2008). This protective tendency may be in part the reason that young people might find themselves isolated when medical communication takes place. In a recent study exploring communication with child patients in paediatric oncology, respondents consisted of children (aged 8-16), parents and survivors (aged 8-16 at diagnosis) (Zwaanswijk *et al.* (2011). Of the three respondent groups 71% preferred children to be involved in medical decision-making. This preference, however, was linked primarily with the patients' age, this was explained as an 'age dependent increase' relating to involvement in treatment decision-making. This study, however, did not extend to young adults.

This instinct to protect and therefore inadvertently perhaps restrict independence in this situation is again set against the backdrop of best interests. Paternalism is a complex concept, examples of which can include; coercion, manipulation, non-disclosure of information and even force (Beauchamp & Childress 2001). The range of decisions that young people make are potentially limited due to their age and so parents want to protect decision-making, even though they too may have little experience of decision-making in health care (Ross 1997).

From a legal perspective, Huxtable (2000) argues that English law has advocated equality, to demonstrate its commitment to justice. However, in relation to treatment decisions particularly related to refusal of medical treatment, he proposes that a status approach which is based primarily on age has been applied therefore discriminating against young people, which is unjustified. He believes that young people are compromised in terms of moral and ethical principles and that this area of law is inconsistent. Central to this legal commentary is the framework of competence. Sawyer (2010) argues that there is no agreement on the developmental pathway in relation to the achievement of competence and that the assessment of this issue is multi-faceted. She goes on to suggest that health professionals are possibly influenced by whether the young person makes the 'right choice' (the one in their best interests) rather than the wrong choice which thus raises doubt in the health professional about their competence. It is this comment which goes to the heart of the question of autonomy and dependence and allowing choice vs. protection, which emerges it is argued when a young person makes a decision on which the staff or indeed the parents disagree. Sawyer's argument raises ethical questions about

the appropriateness of altering the degree of autonomy with reference to how closely the decision of the young person meets with the health professional's view. In real life healthcare settings these decisions are likely to be emotionally charged. The young person's emotional behaviour may therefore have important implications for the way they may reason and weigh up the risks and benefits of treatments (Fundudis 2003).

Life decisions

The question of decision-making other than those which concern treatment is important to young people. Decisions which are made at this time can often form the basis for creating a platform that may last well into adulthood and have implications for the whole of someone's life. At this time young people will make decisions about whether they continue their education, begin a career or job, leave home, adopt a particular lifestyle, which may not be the same as their family, take up new hobbies and enter into more committed emotional relationships. (Albritton & Bleyer 2003, Stern *et al.* 2010) make reference to the notion that cancer, because of the treatment and disruption to their lives makes them different. This is not what young people want; rather their desire is to be aligned to their peer group. They also want to do the social things that others their age are doing. They may therefore, for example, want to have control in deciding to attend a social event and it is important to try wherever possible to strike a balance between their needs and the priorities of treatment. This again returns the argument to the legal framework, where those over the age of 18 can make treatment choices, which in the laws eyes must be adhered to.

In terms of psychosexual maturation Morgan *et al.* (2010) comment that at this time young people will experiment in the form of developing relationships. These could include sexual exploration and while they may experience a change in priorities when having cancer treatment, it is important to understand these matters even though this can be a difficult issue to raise. Morgan *et al.* (2010) comment, as an example that it is important to outline the differences here between fertility, which is talked about in the context of treatment and sexuality, which is completely separate from treatment issues and therefore requires a different discussion.

Making decisions about future education or work which might involve leaving home may have already happened before the cancer is diagnosed. For example, some young people may be diagnosed while at University and might have preferred to at least have been able to

consider available options in terms of their treatment centre.

In terms of more minor life decisions, which could be termed everyday decisions, it has been reported that the degree of flexibility in hospital environments can sometimes be limited (Palmer *et al.* 2007). Not everyone is treated in a designated treatment centre in the UK. This results in the experience of having to conform to particular ward routines in adult wards rather than being afforded the consideration of individual needs, which are cognisant with age.

Nursing implications

The process of decision-making in young people with cancer involves a range of complex issues which are neither standardized nor constant. Age, cognitive development and competence are certainly central factors. There is also a need to acknowledge and note individual differences. These issues can be challenging for nurses and others working with teenagers and young adults. The legal framework also provides what could be argued a confusing and contradictory approach to treatment consent and refusal in minors. Legal frameworks of course will differ between countries and as such this can further add to the confusion in the nursing management of patients.

Almost exclusively, the literature located and included in this article focus on treatment decision-making. Understanding other types of decision-making is central to the meeting the needs of young people during cancer treatment, which is what this paper adds to the existing literature. There are papers that make reference to the many areas of life where decisions will not be about cancer treatment. Nevertheless, there is limited evidence of studies which examine in detail the range of decision-making during cancer treatment coupled with the control, autonomy and dependence young people have in this process. This translates to a gap in the evidence and therefore a potential lack of knowledge in those caring for this age group. Thus, nurses and other healthcare professionals are not able to draw on evidence that may help them in managing issues around non-treatment decision-making. Guidance and policy referred to already in this discussion, however, is now readily available and this coupled with further evidence will provide a strengthening of knowledge in the experiences of decision-making in this specific age group.

Family-centred care has for many years been the cornerstone of children and young people's nursing practice in the UK and has been advocated as one of the central principles

of nursing in this field (Callery & Smith 1991, Smith & Dearmun 2006, Smith & Coleman 2009). In the limited available evidence relating to decision-making in this group, there are number of tensions between parents and young people. These stem mainly from paternalistic approaches to decision-making where parents are almost exclusively concerned with making decisions which are in the best interests of their child. The question could be posed as to how nurses work equally effectively with parents who want and need to be protective and young people who are struggling for independence.

Types of decision-making can add further complexity to the care agenda. Hokkanen *et al.* (2004) identified six categories relating to decision-making, which included joint decision-making and independent decision-making. One could argue that the concept of autonomy has limitations for all age groups as individuals are not freely able to make choices in all situations and therefore are sometimes dependent. However, when an individual has the required knowledge, maturity, emotional stability and competence, then there is a case for allowing autonomy in decision-making to take place. Nurses need to recognize when individuals have reached this stage and enable young people to make independent decisions, thus meeting their individual care needs and helping them in their transition to adulthood.

Nurses must also of course provide non-judgemental approaches to care and 'keep in check' their own personal values and belief systems. Each individual is unique and will have lived in a different way to others (Wu & Volker 2011). It is therefore crucial that nurses are able to adopt appropriate approaches to such situations without personal judgement. In addition the support of the whole health and social care team working in this area will also be central to supporting the decision-making process.

Conclusion

Setting aside the presence of cancer, there are number of potentially life changing decisions which are made during this time including, work, further education, living independently and entering into intimate relationships. However, during cancer treatment young people are still faced with some, or all, of these decisions. During a time of increasing independence it is likely that young people will also wish to have some control in this decision-making. However, against the backdrop of cancer, decision-making may become a very different experience. The complexity of issues and the current gap in the literature, support the need for further exploration of decision-making in young

people's cancer care to understand how best to meet the needs of this age group.

There are several factors which could inhibit individual autonomy in teenage and young adult cancer care, although there is some clear evidence that the prime source and reason for these is to protect the young person. The way that independence in decision-making differs between the public and private space is interesting, since it is almost exclusively the family who normally regulate control for young people in the private setting (Bjerke 2011).

Contrastingly in the healthcare setting there are teams of health and social care staff who all may have a stake in decisions made by young people. This may escalate further the number of tensions experienced by the young person and may result in a range of contrasting views leading to frustration and sometimes anger on their part. This may be because they are now challenged in terms of some decisions that had they made prior to a cancer diagnosis would possibly not have been questioned. Such a situation is coupled with the developmental nature of adolescence where the fundamental emerging elements include the emergence of maturity, competence, emotional stability and the need for independence. The vulnerability of this group, therefore, alongside the myriad of factors discussed here, warrants further investigation of decision-making and autonomy during cancer treatment. By further exploring this experience it may be possible to better understand the needs of young people with cancer in relation to all aspects of decision-making at this critical juncture in their lives.

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Conflict of interest

No conflict of interest has been declared by the author(s).

Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the IC-MJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;

- drafting the article or revising it critically for important intellectual content.

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APPENDIX 2: KEY: FOR PSEUDONYMS OF ALL PARTICIPANTS

Case study subject one

Young person (case study subject), Ellen

Father, Phillip

Mother, Christine

Boyfriend, Nigel

Ellen's nurse

Case study subject two

Young Person (case study subject), Sam

Mother, Linda

Girlfriend, Harriet

Sam's Nurse

Case study subject three

Young person (case study subject), William

Mother, Julie

Father, Martin

Friend, Nathan

William's nurse

Case study subject four

Young person (case study subject), Leah

Mum, Janice

Father, Kevin

Aunt

Leah's consultant

Case study subject five

Young person (case study subject) Sophie

Mum, Brenda

Friend, Pip

Sophie's nurse

APPENDIX 3: INTERVIEW SCHEDULES: CASE STUDY SUBJECTS

This Appendix provides an outline of the interview questions which were utilised when working with the five young people in the study. Other schedules were developed for each of the other participants including, healthcare professionals, parents or carers and nominated friends/girl friends or boyfriends.



Interview schedule for teenagers and young adults

The interview schedule for teenagers and young adults has been designed with the help of young people; some of whom have had cancer and some who have not.

There will be three interviews for each TYA aged between 16 and 24 years old and having cancer treatment. These will be semi structured and follow a conversational style and will use standard prompts and probes to help ensure consistency.

Length of interview: 90 minutes (maximum).

Venue: To be selected by teenager or young adult.

First interview: Introductory.

Topic to be discussed: The background of the teenager or young adult and their diagnosis of cancer.

Specific question guide:

1. Can you tell me something about yourself?

Prompts and probes will include: who they are, their age where they come from, who they live with, what they have experienced in their life so far, whether they are at school, university or work, what their hobbies or interests are.

2. Could you tell me about your family?

Prompts and probes will include: their family size, who makes up their nuclear family and their extended family, what are the roles of other family members?

3. I would like to know a little about the other important people in your life, can you tell me about who they are?

Prompts and probes will include: Who are your close friends? Other important people who might include a teacher, a priest or mentor of some kind.

4. Can you tell me a bit about what happened before you were diagnosed?

Prompts and probes will include: When did you begin to feel unwell? When and how did you make a decision to report the symptoms? What decisions were made by you, by others?

5. When you first started treatment what sorts of decisions did you make?

Prompts and probes will include: the decisions about treatment, the decisions about other aspect of your life e.g. school, university, work, social

6. Can you tell me about decisions you have made on your own and decisions you have made with others?

Prompts and probes will include: freedom to be autonomous. How was collaborating with others? The importance of others in decision making

Length of interview: 90 minutes (maximum).

Venue: To be selected by teenager or young adult.

Second Interview: Exploration of decision making.

Topic to be discussed: The teenage and young adult experience of decision making during cancer treatment.

Specific question guide:

1. How have things been since we last met?

Prompts and probes will include: How is treatment progressing? How are you, your family, significant others? What stage of treatment are you at now?

2. Can we talk about what treatment decisions have been made since we last met?

Prompts and probes will include: decisions relating to different aspects of treatment. E.g. investigations, interventions, treatment protocols, who was involved in the decision making.

3. What kind of decisions other than treatment decisions have you had to make?

Prompts and probes will include: decisions relating to other aspects of life such as school, work or everyday task such as eating, washing, dressing, rest and relaxation.

4. Tell me about who has been involved in the decisions that have been made since we last met?

Prompts and probes will include: the involvement of the teenager or young adult, health care professionals, parents or carers, significant others.

5. In any of the decisions we have discussed did you feel you had enough control? Can you tell me more about this?

Prompts and probes will include: The degree of control over the decision. Why did you want to control these decisions in particular? Did it help the way you felt if you had control over the decision?

6. In any of the decisions we have discussed did you feel any were either out of your control or did you prefer someone else to make them for you?

Prompts and probes will include: the types of decisions that you didn't want to make alone, where you felt others were 'taking over'. Why were they out of your control?

Length of interview: 90 minutes (maximum).

Venue: To be selected by teenager or young adult.

Third interview: Further information, clarification and closure.

Topic for discussion: Further exploration of decision making during teenage and young adult cancer treatment.

Specific question guide:

1. How have things been since we last met?

Prompts and probes will include: How is treatment progressing? How are you, your family, significant others? What stage of treatment are you at now?

2. Can you tell me about any treatment decisions that you have been made since we last spoke?

Prompts and probes will include: decisions relating to different aspects of treatment. E.g. investigations, interventions, treatment protocols. Who was involved in the decision making?

3. Other than treatment decisions are there any decisions you have made since we last met that you can tell me about?

Prompts and probes will include: decisions relating to other aspects of life such as school work or everyday task such as eating, washing dressing, rest and relaxation

4. Can you tell me more about your thoughts on how decision making has been for you during your cancer treatment ?

Prompts and probes to include: Are decisions out of your control? Have you had the autonomy to make decisions? Have you felt dependent on others during the decision making process?

5. Can you tell me if this experience has made you feel any differently about decisions you might make in the future?

Prompts and probes to include: increasing autonomy, confidence. Do you take a more measured approach now? Are you cautious about your decision making now? What about uncertainty?

APPENDIX 4: INCLUSION AND EXCLUSION CRITERIA FOR YOUNG PEOPLE

This Appendix details the inclusion and exclusion criteria in the study protocol for young people.

Participants	Criteria for inclusion	Criteria for exclusion
<p>(n=5) cases</p> <p>Four cases with one of the more commonly occurring cancers</p> <p>One case with a rare cancer in this age group</p>	<p>Teenagers and young adults aged 16-24 years (inclusive)</p> <p>Receiving treatment for either one of the more common cancers or a rare cancer in the 16-24 year age group</p> <p>Receiving treatment for two months or more</p> <p>Willing and competent to consent</p>	<p>Receiving treatment in the first two months following diagnosis</p> <p>Receiving palliative care</p> <p>Outside the ages of 16 to 24 years</p> <p>Already completed treatment</p> <p>Unwilling or not competent to consent</p>

APPENDIX 5: INTRODUCTORY LETTER , INFORMATION SHEETS AND CONSENT FORMS FOR PARTICIPANTS

This Appendix contains the introductory letter and information sheets given to participants by the senior nurse and key contact prior to their agreement to take part. Also contained are the information sheets for other participants and consent forms.

School of Healthcare Sciences, Cardiff University



Chief investigator: Mrs. Jane Davies
Supervisory team: Professor Daniel Kelly and Dr. Ben Hannigan

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Study title: Decision making in teenagers and young adults having cancer treatment

REC reference number:

Dear

I would like to invite you to take part in a PhD research study, which will explore the experiences of decision making in teenagers and young adults aged between 16 and 24 years who are having treatment for cancer.

Enclosed is an information sheet explaining more about how the study will be undertaken. Before you decide, I would like you to understand why the research is being done and what it would involve for you. I would be happy to meet with you to go through the information sheet and answer any questions you may have or you can contact me as indicated above.

Your participation is completely voluntary. If you think you might be interested in taking part, or would like to chat to someone to explain more about the study, please return the Expression of Interest form in the prepaid envelope and I will contact you.

Kind regards,
Jane Davies

School of Healthcare Sciences

College of Biomedical and Life Sciences

Participant information sheet for teenagers and young adults

Decision making in teenagers and young adults having cancer treatment

I am an experienced children's nurse and would like to invite you to take part in a PhD research study looking at the decisions you make during cancer treatment. Before you decide whether or not you want to take part, I would like to explain why the study is being done and what it will involve for you.

Please take the time to read the following information carefully. You might want to talk to other people about the study and you may have questions that you want to ask. If you have any questions or want to know more, please contact me on the number given at the end of this information sheet.

What is this study about?

This study will explore the experience of decision making during cancer treatment in teenagers and young adults aged between 16 and 24 years. When growing up, you may begin to gain independence from your families or carers and part of this change means that you make more decisions for yourself in many aspects of life.

Decisions may be made about things such as further study, career choice, joining new interest groups or sometimes leaving home. In addition to these areas, you will also need to make decisions relating to your cancer treatment.

It is important that we listen to your views about life at this time, so we can better understand how some decisions might present challenges for you. Alternatively there may be some decisions that you feel able or would prefer to make on your own. It is this that I want to explore.

With your permission, I will also be inviting your parents or carers and one of the health or social care team who is caring for you to take part. You will also be asked to nominate one other person who is 16 years or older, of your choice, to take part in the study. This could be a friend, brother or sister, or teacher, for example. The study will also involve me being present at two of your outpatient appointments to observe any decision making which takes place. I will also read your medical notes, to look for examples of written decision making. These last two activities will be carried out to explore the nature of face-to-face decision making in clinical settings and to examine how such processes are recorded.

Why have you been invited to take part?

I am inviting you to take part because you are aged between 16 and 24 years, currently having cancer treatment and you have been receiving treatment for two months or more.

Do you have to take part?

No. It is entirely your decision whether or not you want to join the study. If you are interested, I will describe the study to you and go through the information sheet again. If you agree to take part, I will ask you to sign a consent form confirming your agreement to be involved in the study. If you want to withdraw from the study, you can do so at any time and you do not have to give any reason for this decision. This will not affect the standard of care you receive. If you decide to withdraw from the study, with your permission I would like to keep and use any information that you have provided whilst taking part in the study.

What will happen to you if you take part?

The senior nurse at the unit where you are receiving your treatment has contacted teenagers and young adults who are currently undergoing treatment so that I can invite five of you to take part in the study. The study will take place during your treatment but not over a period of more than 12 months. During that time I would want to conduct an interview with you on three occasions, which will be audio-taped. These interviews can take place at a venue of your choice and will last for no longer than 90 minutes on each occasion. At each interview I will ask you a small number of questions relating to the decisions that you have made during treatment, which you will then be able to discuss. I would also like to attend two of your outpatient appointments to observe any decision making that takes place during this time. Finally I will need access your medical notes so that I can look for written examples of decision making during your cancer treatment. With your permission, I will write to your GP so that they are aware that you are taking part in the study.

What are the possible disadvantages and risks of taking part in the study?

There are no significant risks or disadvantages for you if you take part in the study. If you find any of the discussion upsetting we can stop the interview immediately. It might be that some of the information that you discuss will be sensitive and personal to you. However all the material collected for the study will be confidential and when the study is written your name will be changed to protect your identity. All of the information collected in the study will also be securely stored and subsequently destroyed, using the guidance for storing research information set out by Cardiff University.

What are the possible benefits of taking part?

Taking part in this study may not be of any direct benefit to you. It will however provide the opportunity for your views on decision making to be shared, which could contribute to the future care of teenagers and young adults with cancer.

What will happen to the results of the research study?

It is important that you know your identity will not be revealed in any publication, conference presentation or PhD study without your consent. At the end of the study the results will be published in nursing and medical journals and the study will be presented at nursing and medical conferences. The completed PhD will be submitted to the University and examined both internally and outside of the University. I would like to retain the results of the study with a view to being able to carry out a secondary study, present the findings at conferences and use the materials for teaching with your consent. I will also provide a report of the findings from the study for everyone who takes part.

Who is organising and funding the research?

The funding has been arranged so that the study can operate for three years. This funding was awarded by Cardiff University. The study will be supervised by two senior and experienced staff, one of whom is Professor Daniel Kelly and the other Dr Ben Hannigan who also work at Cardiff University.

Who has reviewed this study?

All research in the NHS is checked by an independent group of people called a Research Ethics Committee. The job of this committee is to protect your interests. This study has been reviewed by the West of Scotland (4) Ethics Committee who agreed that the study was ethically acceptable.

Further information and contact details

You may want some more general or specific information about this study. You may want to talk to other people who can advise you about getting involved. Healthcare professionals who are part of the team treating you are in a good position to give you advice about getting involved in the study. The Teenage Cancer Trust are also a good organisation to give advice.

If you decide to take part in the study and you are unhappy at any point about your participation, please contact the concerns manager:

Address removed

Thank you for considering taking part in this study. If you need to contact me you can do so at the address and number below

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Participant information sheet for parents or carers

Decision making in teenagers and young adults having cancer treatment

I am an experienced children's nurse and would like to invite you to take part in a PhD research study looking at the decisions teenagers and young adults make during cancer treatment. Before you decide whether or not you would like to take part I would like to explain why the study is being done and what it will involve for you.

Please take the time to read the following information carefully. You might want to talk to other people about the study and you may have questions that you want to ask. If you have any questions or want to know more please contact me on the number given at the end of this information sheet.

What is this study about?

This study will explore the process of decision making during cancer treatment in teenagers and young adults aged between 16 and 24 years. When growing up, they may begin to gain independence from their families and carers and part of this change means that they make more decisions for themselves in many aspects of life.

Decisions may be made about things such as further study, career choice, joining new interest groups or sometimes leaving home. In addition to these areas, they will also need to make decisions relating to their cancer treatment. It is important that we listen to your views about your children's lives at this time so we can better understand your perspective as parents on decision making during cancer treatment. It could be that some decisions might present more challenges for them. Alternatively there may be some decisions that they feel able or would prefer to make on their own. It is this that I want to explore.

I will also be inviting a health or social care professional involved in the care of the teenager or young adult and a person/friend nominated by each teenager or young adult to participate. The study will also involve me being present at two of their outpatient appointments to observe any decision making which takes place. I will also read their medical notes, to look for examples of written decision making. These last two activities will be carried out to explore the nature of face to face decision making in clinical settings and to examine how such processes are recorded.

Why have you been invited to take part?

You are a parent or carer of a teenager or young adult aged between 16 and 24 years of age who is currently having treatment for cancer and who has agreed to take part. I have been given permission by the teenager or young adult to contact you.

Do you have to take part?

No. It is entirely your decision whether or not you want to join the study. If you are interested, I will describe the study to you and go through the information sheet again. If you agree to take part, I will ask you to sign a consent form confirming your agreement to be involved in the study. If you want to withdraw from the study, you can so at any

time and you do not have to give any reason for this decision. This will not affect the standard of care your child will receive.

What will happen to you if you take part?

The senior nurse at the unit where the teenager or young adult is receiving treatment invited five patients to take part in the study.

The study will take place during their cancer treatment but not for a period of longer than 12 months. During that time I would want to conduct one interview with you, which will be audio-taped. This interview can take place at a venue of your choice and will last for no longer than 90 minutes. At the interview I will ask you a small number of questions relating to the decisions made during cancer treatment, which you will then be able to discuss.

What are the possible disadvantages and risks of taking part in the study?

There are no significant risks or disadvantages for you if you take part in the study. If you find any of the discussion upsetting, the interview can be stopped immediately. It might be that some of the information that you discuss will be sensitive and personal to you. However all the material collected for the study will be confidential and when the study is written your name will be changed to protect your identity. All of the information collected in the study will also be privately stored and subsequently destroyed, using the guidance for storing research information set out by Cardiff University.

What are the possible benefits of taking part?

Taking part in this study may not be of any direct benefit to you. It will however provide the opportunity for your views on decision making to be shared, which could contribute to the future care of teenagers and young adults with cancer.

What will happen to the results of the research study?

It is important that you know your identity will not be revealed in any publication, conference presentation or PhD study without your consent. At the end of the study the results will be published in nursing and medical journals and the study will be presented at nursing and medical conferences. The completed PhD will be submitted to the University and examined both internally and outside of the University. I would like to retain the results of the study with a view to being able to carry out a secondary study, present the findings at conferences and use the materials for teaching with your consent. I will also provide a report of the findings from the study for everyone who takes part.

Who is organising and funding the research?

The funding has been arranged so that the study can operate for three years. This funding was awarded by Cardiff University. The study will be supervised by two senior and experienced staff, one of whom is Professor Daniel Kelly and the other Dr Ben Hannigan who also work at Cardiff University.

Who has reviewed this study?

All research in the NHS is checked by an independent group of people called a Research Ethics Committee. The job of this committee is to protect your interests. This study has been reviewed by the West of Scotland 4 Research Ethics Committee who agreed that the study was ethically acceptable.

Further information and contact details

You may want some more general or specific information about this study and you may want to talk to other people about being involved in the study, healthcare professionals who are involved in your care for example. They are in a good position to give you advice about getting involved in the study.

If you decide to take part in the study and you are unhappy at any point with any aspect of the study, please contact the concerns manager:

Address removed

Thank you for considering taking part in this study. If you need to contact me you can do so at the address and number below

Jane Davies
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Email: daviesjp11@cf.ac.uk

School of Healthcare Sciences

College of Biomedical and Life Sciences

Participant information sheet for health or social care professionals

Decision making in teenagers and young adults having cancer treatment

I am an experienced children's nurse and would like to invite you to take part in a PhD research study looking at the decisions teenagers and young adults make during cancer treatment. Before you decide whether or not you would want to take part I would like to explain why the study is being done and what it will involve for you.

Please take the time to read the following information carefully. You might want to talk to other people about the study and you may have questions that you want to ask. If you have any questions or want to know more please contact me on the number at the end of the information sheet.

What is this study about?

This study will explore the experience of decision making during cancer treatment in teenagers and young adults aged between 16 and 24 years. When growing up, they may begin to gain independence from their families and carers and part of this change means that they make more decisions for themselves in many aspects of life.

Decisions may be made about things such as further study, career choice, joining new interest groups or sometimes leaving home. In addition to these areas, they will also need to make decisions relating to their cancer treatment. It is important that we listen to your views as a health or social care professional so we can better understand your perspective when caring for this age group. It could be that some decisions might present them, or you, with more challenges. Alternatively there may be some decisions that they feel able or would prefer to make on their own. It is this that I want to explore.

I will also be inviting the parents or carers and a person/friend over the age of 16 years nominated by each teenager or young adult to participate. The study will also involve me being present at two of their outpatient appointments to observe any decision making which takes place. I will also read their medical notes, to look for examples of written decision making. These last two activities will be carried out to explore the nature of face to face decision making in clinical settings and to examine how such processes are recorded.

Why have you been invited to take part?

I am inviting you to take part as you are a health or social care professional who is involved in the care of a teenager or young adult aged between 16 and 24 years who is currently having treatment for cancer and who has agreed to take part. I have been given permission by the teenager or young adult to contact you.

Do you have to take part?

No. It is entirely your decision whether or not you want to join the study. If you are interested, I will describe the study to you and go through the information sheet again. If you agree to take part, I will ask you to sign a consent form confirming your agreement to be involved in the study. If you want to withdraw from the study, you can do so at any time and you do not have to give any reason for this decision.

What will happen to you if you take part?

The senior nurse at the unit where the teenager or young adult is receiving treatment invited five patients to take part in the study.

The study will take place during their cancer treatment but not for a period of longer than 12 months. During that time I would want to conduct one interview with you, which will be audio-taped. This interview can take place at a venue of your choice and will last for no longer than ninety minutes. At the interview I will ask you a small number of questions relating to the decisions made by the teenager or young adult who you have cared for during cancer treatment, which you will then be able to discuss.

What are the possible disadvantages and risks of taking part in the study?

There are no significant risks or disadvantages for you if you take part in the study. It might be that some of the information that you discuss will be sensitive and personal to you. However all the material collected for the study will be confidential and when the study is written your name will be changed to protect your identity. All of the information collected in the study will also be privately stored and subsequently destroyed, using the guidance for storing research information set out by Cardiff University.

What are the possible benefits of taking part?

Taking part in this study may not be of any direct benefit to you. It will however provide the opportunity for your views on decision making to be shared, which could contribute to the future care of teenagers and young adults with cancer.

What will happen to the results of the research study?

It is important that you know your identity will not be revealed in any publication, conference presentation or PhD study without your consent. At the end of the study the results will be published in nursing and medical journals and the study will be presented at nursing and medical conferences. The completed PhD will be submitted to the University and examined both internally and outside of the University. I would like to retain the results of the study with a view to being able to carry out a secondary study, present the findings at conferences and use the materials for teaching with your consent. I will also provide a report of the findings from the study for everyone who takes part.

Who is organising and funding the research?

The funding has been arranged so that the study can operate for three years. This funding was awarded by Cardiff University. The study will be supervised by two senior and experienced staff, one of whom is Professor Daniel Kelly and the other Dr Ben Hannigan who also work at Cardiff University.

Who has reviewed this study?

All research in the NHS is checked by an independent group of people called a Research Ethics Committee. The job of this committee is to protect your interests. This study has

been reviewed by the West of Scotland (4) Research Ethics Committee who agreed that the study was ethically acceptable.

Further information and contact details

You may want some more general or specific information about this study and you may want to talk to other healthcare professionals about participating as they may be in a good position to give you advice about getting involved in the study.

If you decide to take part in the study and you are unhappy at any point about your participation, please contact the concerns manager:

Address removed

Thank you for considering taking part in this study. If you need to contact me you can do so at the address and number below

Jane Davies
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School of Healthcare Sciences

College of Biomedical and Life Sciences

Participant information sheet for nominated person

Decision making in teenagers and young adults having cancer treatment

I am an experienced children's nurse and would like to invite you to take part in a PhD research study looking at the decisions teenagers and young adults make during cancer treatment. Before you decide whether or not you would like to take part I would like to explain why the study is being done and what it will involve for you.

Please take the time to read the following information carefully. You might want to talk to other people about the study and you may have questions that you want to ask. If you have any questions or want to know more please contact me on the number given at the end of this information sheet

What is this study about?

This study will explore the experience of decision making during cancer treatment in teenagers and young adults aged between 16 and 24 years. When growing up, they may begin to gain independence from their families and carers and part of this change means that they make more decisions for themselves in many aspects of life.

Decisions may be made about things such as further study, career choice, joining new interest groups or sometimes leaving home. In addition to these areas, they will also need to make decisions relating to their cancer treatment. It is important that we listen to your views as a person who has been nominated by someone with cancer so we can better understand decision making when caring for this age group. Your view will give a different perspective to the research as one of the young people in the study has specifically asked if you would take part. It could be that some decisions might present more challenges for them. Alternatively there may be some decisions that they feel able or would prefer to make on their own. It is this that I want to explore.

I will also be inviting a health or social care professional involved in the care of the teenager or young adult and the parents or carers of each teenager or young adult to participate. The study will also involve me being present at two of their outpatient appointments to observe any decision making which takes place. I will also read their medical notes, to look for examples of written decision making. These last two activities will be carried out to explore the nature of face to face decision making in clinical settings and to examine how such processes are recorded.

Why have you been invited to take part?

You have been nominated by a teenager or young adult, who you know, and is currently having cancer treatment. I am therefore inviting you to take part in the study.

Do you have to take part?

No. It is entirely your decision whether or not you want to join the study. If you are interested, I will describe the study to you and go through the information sheet again. If you agree to take part, I will ask you to sign a consent form confirming your permission

to be involved in the study. If you want to withdraw from the study, you can so at any time and you do not have to give any reason for this decision.

What will happen to you if you take part?

The senior nurse at the unit where the teenager or young adult is receiving treatment invited five patients to take part in the study.

The study will take place during their cancer treatment but not for a period of longer than 12 months. During that time I would want to conduct one interview with you, which will be audio-taped. This interview can take place at a venue of your choice and will last for no longer than ninety minutes. At the interview I will ask you a small number of questions relating to the decisions made by the person you know during cancer treatment, which you will then be able to discuss.

What are the possible disadvantages and risks of taking part in the study?

There are no significant risks or disadvantages for you if you take part in the study. It might be that some of the information that you discuss will be sensitive and personal to you. However all the material collected for the study will be confidential and when the study is written your name will be changed to protect your identity. All of the information collected in the study will also be privately stored and subsequently destroyed, using the guidance for storing research information set out by Cardiff University.

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What will happen to the results of the research study?

It is important that you know your identity will not be revealed in any publication, conference presentation or PhD study without your consent. At the end of the study the results will be published in nursing and medical journals and the study will be presented at nursing and medical conferences. The completed PhD will be submitted to the University and examined both internally and outside of the University. I would like to retain the results of the study with a view to being able to carry out a secondary study, present the findings at conferences and use the materials for teaching with your consent. I will also provide a report of the findings from the study for everyone who takes part.

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Who has reviewed this study?

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Further information and contact details

You may want some more general or specific information about this study and you may want to talk to other people about being involved in the study and who are in a good position to give you advice about getting involved in the study.

If you decide to take part in the study and you are unhappy at any point with any aspect of the study, please contact the concerns manager:

Address removed

Thank you for considering taking part in this study. If you need to contact me you can do so at the address and number below

Jane Davies

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CF24 0AB

Tel: 02920917715

Email: daviesjp11@cf.ac.uk

School of Healthcare Sciences

College of Biomedical and Life Sciences

Title of project: Decision making in teenagers and young adults having cancer treatment

Researcher: Jane Davies

Consent form for teenagers and young adults

Please initial box

1. I confirm that I have read the information sheet for teenagers and young adults (version number 1.2 14.11.13), for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I understand that my interview will be recorded on a digital recording device. I give permission for this.

☐

4. I understand that my medical notes and data collected may be looked at by responsible representatives from Cardiff University and name of Health Board for the purposes of monitoring and auditing the conduct of the research. I give permission for this.

☐

5. I understand that data collected will not be transferred to any commercial organisation but may be used anonymously for publication in healthcare journals, presentation at conferences, for teaching purposes and for future studies. This data will be securely stored for a period of 15 years. I give permission for this.

☐

6. I give permission to inform my GP by letter of my participation in the study.

☐

7. I understand that if I lose the capacity to consent, that I will be withdrawn from the study. I understand that any information collected from interviews/observations before the loss of consent will still be included in the study.

☐

8. I agree to take part in the above study.

☐

Name of Participant

Name of Person taking consent

Date
Signature

Date
Signature

School of Healthcare Sciences

College of Biomedical and Life Sciences

Title of project: Decision making in teenagers and young adults having cancer treatment

Researcher: Jane Davies



Consent form for parents and carers

Please initial box

1. I confirm that I have read the information sheet for parents and carers (version 1.2 14.11.13) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I understand that my interview will be recorded on a digital recording device. I give permission for this.

☐

4. I understand that data collected may be looked at by responsible representatives from Cardiff University and name of Health Board for the purposes of monitoring and auditing the conduct of the research. I give permission for this.

☐

5. I understand that data collected will not be transferred to any commercial organisation but may be used anonymously for publication in healthcare journals, presentation at conferences, for teaching purposes and for future studies. This data will be securely stored for a period of 15 years. I give permission for this.

☐☐

6. I agree to take part in the above study.

Name of Participant
Date
Signature

Name of
Person taking
consent
Date
Signature

School of Healthcare Sciences

College of Biomedical and Life Sciences



Title of project: Decision making in teenagers and young adults having cancer treatment

Researcher: Jane Davies

Consent form for healthcare or social care professionals

Please initial box

1. I confirm that I have read the information sheet for healthcare professionals (version 1.2 14.11.13) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I understand that my interview will be recorded on a digital recording device. I give permission for this.

☐

4. I understand that data collected may be looked at by responsible representatives from Cardiff University and name of Health Board for the purposes of monitoring and auditing the conduct of the research. I give permission for this.

☐

5. I understand that data collected will not be transferred to any commercial organisation but may be used anonymously for publication in healthcare journals, presentation at conferences, for teaching purposes and for future studies. This data will be securely stored for a period of 15 years. I give permission for this.

☐

6. I agree to take part in the above study.

☐

Name of Participant
Date
Signature

Name of Person taking consent
Date
Signature

School of Healthcare Sciences

College of Biomedical and Life Sciences

Title of project: Decision making in teenagers and young adults having cancer treatment

Researcher: Jane Davies

Consent form for nominated person

Please initial box

1. I confirm that I have read the information sheet for the nominated person (version 1.2 14.11.13) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I understand that my interview will be recorded on a digital recording device. I give permission for this.

☐

4. I understand that data collected may be looked at by responsible representatives from Cardiff University and name of Health Board for the purposes of monitoring and auditing the conduct of the research. I give permission for this.

☐

5. I understand that data collected will not be transferred to any commercial organisation but may be used anonymously for publication in healthcare journals, presentation at conferences, for teaching purposes and for future studies. This data will be securely stored for a period of 15 years. I give permission for this.

☐

6. I agree to take part in the above study.

☐

Name of Participant
Date
Signature

Name of Person taking consent
Date
Signature

APPENDIX 6: SIX STEPS OF THEMATIC ANALYSIS DESCRIBED BY BRAUN AND CLARKE (2006).

This Appendix provides the six steps utilised in this study as outline by Braun and Clarke (2006) in their paper advising the approach with a step-by-step guide.

Phases of thematic analysis.

PHASE	DESCRIPTION OF THE PROCESS
1. Familiarising yourself with the data	Transcribing the data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relating to the coded extracts (Level 1 (and the entire data set (Level 2) generating a thematic map of analysis.
5. Defining and naming themes	On-going analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back to the analysis of the research question and literature, producing a scholarly report of the analysis.

Braun and Clarke (2006) pg. 87


APPENDIX 7: EXAMPLE OF CODING (CASE STUDY SUBJECT 5 SOPHIE)

CATEGORY CODING	DEFINITION OF CODE	EXAMPLE
ADVICE	Any instance where the young person was in receipt of advice from anyone else during their cancer trajectory.	we went to the pub one evening and she had this tooth, tooth infection that wasn't healing obviously she had no immune system at this point and she was in a lot of pain and I said do you want to go to the pub and she said no I will come to the pub, so we went to the pub and I said you know you have got to go to the dentist or the doctor, you have felt crap for weeks you just need to sort it out and she was yeah I just need to sort it (Pip, friend).
DISAGREEMENT	Occasions of disagreement during any decision making interaction.	I felt completely fine umm and I was being told that no you can't you have got to stay here you have got to stay on intravenous antibiotics, you can't and it was unbearable because I was sort of going I was doing nothing you know. I had my little routine that I had before but obviously I was kind of more interested in that sort of routine at that point because I wasn't feeling so well whereas at this point I am feeling completely normal and actually it sounds like an awful thing to say but I had, I had quite really two sick people in my ward with me. (Sophie)

CATEGORY CODING	DEFINITION OF CODE	EXAMPLE
FULL CONTROL	Examples of where the young person had full control of decision making during their cancer trajectory.	and umm 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 (Sophie).
HELPING	Instances of how others helped with decision making and action during the cancer trajectory.	yes she came in with me pretty much holding me up later to see the GP and she said well we will order some tests but obviously we can't do that till Tuesday because it's bank holiday (Sophie).
NEGOTIATION	Evidence of how decisions were arrived at through aspects of talking to others and negotiating an outcome.	I wasn't hundred percent I didn't know what and also I wasn't really capable of making decisions at this point so it probably was a good thing that they were sort of I think you know pushing me in a way to come down here and they said just come down and have a look at everything (in the unit) so that was fine (Sophie).
NO CONTROL	Examples of where the young person was not in control of decision making in all aspects of their life including treatment.	She felt in her treatment, she wasn't in control of any of it. I mean you're not it is protocol you don't have a choice, there isn't a choice and she was aware of that and she, she didn't enjoy everything about when what how. This needs to be done, that needs to be done no you can't do that this needs to be done. Now she was aware that she wasn't making any decisions but she was also aware that she was in a situation where you can't (mum, Brenda).

APPENDIX 8: POSTER PRESENTATION JUNE 2015


This Appendix presents the poster for dissemination and discussion at the annual Aneurin Bevan Health Board conference which attracted over 300 delegates.



CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

AN EXPLORATION OF DECISION MAKING IN TEENAGERS AND YOUNG ADULTS WHO DEVELOP CANCER

Jane Davies: PhD Student
Supervisors: Professor Daniel Kelly & Dr Ben Hannigan
School of Healthcare Sciences, Cardiff University



BACKGROUND

The transition to adulthood is a time of increasing independence when young people commonly experience increasing autonomy as they build their early adult life platforms. Developing cancer at this time inevitably impacts on this transition. The experience of cancer in young people requires a significant series of treatment-related decisions, for example deciding how to manage future fertility. Other non-treatment decisions also have to be made and these can be related to any aspect of life for example education, work and relationships. This all occurs against the backdrop of young people's disease experience. This three year research study provides insights into experiences relating to all aspects of decision making when teenagers and young adults aged 16 to 24 years develop cancer.

RESEARCH DESIGN AND METHODS

- ❑ A qualitative exploratory case study design using an interpretive methodology was utilised to examine the views of five young people using a purposive sampling technique.
- ❑ Views were also gathered from family or carers, nominated friends and professionals involved in the care of each young person.
- ❑ Multiple methods were used including, three in-depth semi-structured interviews with the young people over a period of six months during treatment.
- ❑ One interview was undertaken with each of the other participants.
- ❑ Non-participant observations were undertaken on two occasions for each participant at out-patient appointments.
- ❑ Documentary analysis of each case was carried out through the examination of medical notes.

DATA ANALYSIS

- ❑ Thematic Analysis was utilised (Braun & Clarke 2006).
- ❑ The data set was examined iteratively highlighting key messages and phrases and six codes were subsequently developed through a process of refining and categorising.
- ❑ Within case and across case analysis was undertaken. Three cross cutting themes were identified relating to the cancer trajectory in teenagers and young adults (see below).

LIFE THEN

- ❑ Emerging adulthood
- ❑ Increasing independence
- ❑ Development of symptoms
- ❑ Holding onto control and choice
- ❑ Continuation of everyday life despite increasing deterioration in health

LIFE INTERRUPTED

- ❑ Prominence of treatment decision making
- ❑ Severely restricted choice in decision making
- ❑ Control of decision making by others
- ❑ Glimpses of control in treatment and everyday life
- ❑ Disagreement and negotiation

LIFE RECLAIMED

- ❑ Making progress and taking back control
- ❑ Challenges in reclaiming life
- ❑ Picking up the pieces
- ❑ Returning to work and education
- ❑ Living independently
- ❑ Building intimate relationships
- ❑ Developing a life as a young adult

CONCLUSION

- ❑ It is envisaged that a conceptual model of choice of control will be developed which 'charts' the trajectory of the development of cancer in teenagers and young adults.
- ❑ This model will provide a mechanism for supportive care enabling the identification of points in the cancer trajectory where choice and control fluctuates over time.
- ❑ The model will be tested as part of post-doctoral work.

References

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Davies, J, Kelly, D & Hannigan, B (2015) Autonomy and dependence: a discussion paper on decision-making in teenagers and young adults undergoing cancer treatment. *Journal of Advanced Nursing* doi:10.1111/jan.12669 [E-pub ahead of print.]

Taylor, RM, 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, 832-846

Wicks, L & Mitchell, A (2010) The adolescent cancer experience: loss of control and benefit finding. *European Journal of Cancer Care* 19, 5, 778-785

APPENDIX 9: TIME LINE AND STRUCTURE OF WORK INCLUDING KEY DISCUSSIONS AND DISSEMINATION

September 2011: Discussion with Professor Daniel Kelly about possibility of study.

Advised to do some reading in relation to ideas discussed, with a view to applying for a full time studentship in September 2012.

August 2012: Selected for interview for funding through a Cardiff University three year studentship. Successfully awarded to begin study in October 2012.

September 2012: Meeting with quality lead nurses at Teenage Cancer Trust to discuss ideas and potential lines of inquiry to inform study ideas.

October 2012: Registration for full time PhD studies. Undertook preparatory reading prior to the formulation of research questions

November 2012: Poster presentation at Cardiff University, School of Healthcare Sciences Annual Post Graduate Symposium titled 'Decision making in teenagers and young adults having cancer treatment'.

January 2013: Began preparation for ethical and research and development approvals. Began user consultation and engagement with a range of individuals and groups to further inform ideas for study.

January 2013: Began discussion of early ideas for the production of a paper considering key ideas and themes retrieved from the literature.

January-June 2013: Continued user consultations with experts from Teenage Cancer Trust, including quality leads, specialist nurses and policy professional. Discussion with young person with cancer, mum and healthy sibling (16). Meeting with cancer survivor. Discussion with consultant involved in TYA cancer care.

April 2013: Attendance at the Curie Institute in Paris for a conference organised by The European Network for Teenage and Young Adults with Cancer network, an opportunity

to meet a range of disciplines working in the field and from a number of European countries.

July 2013: First submission of study protocol to university ethics committee. Amendments received. Resubmission of documents in August 2013, following which approval was granted to proceed with IRAS application for submission.

September 2013: Attended TYAC education day and annual conference in Leeds, which was a good opportunity to meet with colleagues from around the UK (also became a member of TYAC).

October 2013: Submitted IRAS application for proportionate review. Minor amendments received and documents resubmitted. Amendments accepted and ethical approval confirmed in November 2013. Simultaneously documents sent through the Welsh permissions co-ordinating unit to two NHS sites. Amendments received and documents re-submitted, approval agreed in early January 2014.

November 2013: presentation of progress at the Annual Post Graduate Symposium Cardiff University titled: Decision making in teenagers and young adults having cancer treatment. Also a co-organiser at this conference.

February 2014: Meeting with unit contact to discuss recruitment.

February 2014: Ellen first participant (Case study subject 1) recruited to the study, data set completed in July 2014.

March 2014: Sam (Case study 2) recruited to the study, data set completed in September 2014.

March 2014: William (Case study 3) recruited to the study, data set completed in August 2014.

May 2014: Meeting with unit contact to consider recruitment progress.

June 2014: Poster presented at annual Aneurin Bevan Health Board research and development conference titled: Developing a research protocol exploring decision making in teenagers and young adults who are having cancer treatment.

July 2014: Leah (Case study 4) recruited to the study, data set completed February 2015.

July 2014: Meeting with unit contact to update and discuss study progress.

July 2014: Poster presented at the International Teenage Cancer Trust conference titled: Developing a research protocol exploring decision making in teenagers and young adults who are having cancer treatment. An opportunity to meet experts in the field from around the world and discuss the study with a number of colleagues.

August 2014: Sophie (Case study 5) recruited to the study data set completed January 2015.

October 2014: Presentation of early findings at the inaugural conference at Ty Hafan's Children's Hospice titled: Decision making in teenagers and young adults having cancer treatment.

October 2014: Met with lead specialist cancer nurse from a nearby Trust to discuss study and possible future collaboration.

December 2014: Presentation of early findings to Childhood and Youth Research Group in the department of Social Sciences at Cardiff University titled: Decision making in teenagers and young adults having cancer treatment. This multi-disciplinary group constituted a number of different professions including primary education, the prison service and adult community education.

December 2014: Presentation to the all Wales children and young people's senior nurse forum titled: Decision making in teenagers and young adults having cancer treatment.

Lead nurses from all parts of Wales contribute to this meeting which is held on a quarterly basis.

February 2015: Meeting with unit link to discuss findings and seek views on the same.

April 2015: Meeting with specialist nurse from nearby Trust to discuss some of the early findings and seek views on the same.

April 2015: Publication of jointly authored discussion paper in Journal of Advanced Nursing :

Davies, JP., Kelly, D M. and Hannigan, B (2015). Autonomy and dependence: a discussion paper on decision making in teenagers and young adults undergoing cancer treatment. *Journal of Advanced Nursing*, 10.1111/jan.12669.

June 2015: Poster presented at annual Aneurin Bevan Health Board research and development conference titled: An exploration of decision making in teenagers and young adults who develop cancer.

July 2015: One month residency awarded at the Brocher Foundation Geneva, a centre for the development of ethical, social and medical research. The month was spent writing up the latter part of the study and networking with academics from a number of universities including those in Canada, United States, Finland, UK and Australia. The study was also presented here to other scholars.

August 2015: Further meeting with the unit link and the lead nurses, social worker, psychologist, wellbeing co-ordinator and service development officer from two units to discuss ways in which the developed trajectory may have usefulness and application in practice.

APPENDIX 10: REFLECTION FROM DATA GENERATION

This Appendix is a personal account following an interview with Ellen

Reflection case one (Ellen) interview two

This was Ellen's second interview and again she chose to undertake it at the unit, whilst she was undergoing her treatment. On the day that we met, her treatment plan included chemotherapy and a lumbar puncture. We met in the relaxation area and I checked with her where she would like the interview to take place. At our first meeting Ellen had opted to be interviewed in the treatment room. We were not interrupted in this room as when the door is closed, people automatically do not enter as they believe a treatment to be taking place. I do remember however the clinical environment struck me and made me think about the number of times Ellen had to have treatment in there.

On this occasion she opted for the parent's room as a place for the interview. I think that this may have also been influenced by the senior nurse who suggested that this might be better as the treatment room may be busy. I was a little concerned about the parent's room as I thought that we might be interrupted. Parents who are staying in the unit usually keep food there in the fridge and so it is likely that you will be interrupted. As I said in an earlier reflection, I am not sure how many people actually sit in the room as it is extremely small and I would imagine quite depressing, as it looks out to a quadrant of other buildings. We decided that we would make a do not display sign and go ahead in that room.

At the outset of this interview I outlined to Ellen that I wanted to learn more on this occasion about her decision making experiences and that these were not to be just confined to treatment decisions. I said that I would be really interested to hear about other decisions which were connected to her life but did not necessarily centre on her cancer. On this occasion, she seemed generally a little more relaxed and appeared keen to talk. Her father had said to me earlier that she had enjoyed talking to me at our first interview. I wondered immediately about whether the interview had created any therapeutic effect or whether it was just that she had welcomed the opportunity to tell someone her story who wasn't involved in her care.

I began by asking her about how she had been since I last saw her in terms of her health and her most recent treatment. She explained that she was continuing with her treatment but had developed a number of side effects recently. She talked particularly about pain and abdominal distension. She immediately seemed anxious about these side effects and very quickly told me that when the effects appeared, she decided to have a look at

a website called the 'online doctor'. She said that she made this decision because she wasn't sure if these effects were due to her cancer treatment or were unrelated. I think that this not knowing was a source of anxiety for her and that she found reassurance in visiting the site. I asked her if she initiated visiting the site herself but she said that it was her mother who initiated it (this was to become more interesting when I observed Ellen's outpatients appointment and she produced very lengthy lists of her side effects for the consultant to see). She did not seem to see this as any form of control on her mother's part and indeed said that if her mom looked it up then she didn't have to, she could instead just sit back and do nothing. She said that her mom was always very keen to get to the root of the problem so that she could cope.

What happened next was I think interesting as she went from saying that she was happy to sit back and let her mom take the lead to discussing the emergence of severe chest pain. When this happened she commented that she should have phoned 999 immediately. She followed this however with the fact that she did not make the decision to do this. When I asked her why she said that when she phoned the unit for advice they said that it was her decision, they said it was up to her. Instead she made the decision to try and control the symptoms by breathing deeply and sitting down and trying to relax. I assumed that she was very frightened when she had the chest pain but chose to try and reduce her symptoms rather than seek help. She did not talk at this point about her parents being involved in decisions at this time. I wondered whether this was about not wanting to cause a fuss, fear or the thought that this was not serious and that she could control it.

I was aware from the first interview that Ellen had been very sick following a reaction to Methotrexate. This made me think that she was very cautious on the one hand in case this was something serious again but fearing that she would have to go through something terrible again, she decided to 'play it down'. In the event she did not seek help and interestingly at a later date was told by the doctor in the unit that she shouldn't have ignored that symptom. This was interesting as it contradicted Ellen's account of being advised that calling an ambulance was her decision. Again interestingly when I was waiting at a later date to talk to Ellen I was in earshot of the senior nurse telling her that she must never worry about phoning the unit especially if she was worrying about things and not sharing them. The nurse repeated this three or four times and said that she must not so to speak 'suffer in silence'. Ellen moved on from this conversation quite quickly and began to talk about a completely different treatment effect. This I felt was my fault as I asked about other side effects at this time and thus led her off the path.

She said that she had decided to shave her head and had asked her dad to do it for her as he was used to shaving! In both this interview and the first interview, I sensed a very close relationship between Ellen and her father and that he had been fundamental in assisting her in a range of ways throughout her treatment. We returned to other treatment decisions.

I asked Ellen about her involvement with treatment recently and she commented that basically the treatment had been 'given to her' up until this point. She added that decisions had been made in relation to her protocol but that she wasn't involved in that decision making. She had reacted very badly to one drug and the medical team had decided to take her off this medication. Ellen said that they did inform her. She remarked that she was worried about the change in her protocol but that she was also worried that she would have to take the drug again at some point. She asked the consultant in charge of her care, who told her not to worry and that the drug in question would not be given again by the same route and that it would be given later in her treatment. I felt here that Ellen had tried to exert some control over the administration of the drug in question and whilst I didn't feel that she was particularly happy with the explanation she was given, she said that she was happy with the decision. However I couldn't help feeling that there was little choice in this aspect of her care.

We moved on from this to discuss the specific incident which was related to her drug reaction. This was an extremely serious situation some of which Ellen had no recollection of at all. It began when she felt unwell and approached her dad to say that she had lost feeling in her arm. When I interviewed him about this, he said he was in no hesitation about making a decision to take her to the local emergency department. He did ring the unit first but they advised the local department because of the acute symptoms (they also live 50 miles from the unit). Ellen said that her condition deteriorated very quickly and that she found it difficult to communicate by the time she arrived at the hospital. She felt that she 'had to shout' to make herself heard but that very quickly her jaw seemed to lock and she was unable to speak. From this point onwards she had no control in the situation and remembers very little about the events that took place. Ellen said that she was afraid that she was going to die.

Her parents were with her throughout this time and were very unhappy about the way in which she was managed. They had good knowledge of her condition and treatment and recognised that she was very unwell, however they did not feel listened to and were very anxious about the situation. It would seem that in this situation neither Ellen nor her parents had the power to do anything and have some control of the situation. They were,

after many hours transferred to the specialist unit and Ellen was admitted to the critical care unit. The family described the event as her having a stroke. Her recover has been gradual and Ellen said that she has been dependent on her parents for everything. In the early days of recovery she required assistance with washing and dressing and her mobility was very limited. She also commented that her intellectual capacity had been affected and that her father had helped her to practice simple maths for example in an attempt to stimulate her ability to make decisions again.

This incident caused me to think about how in some situations the patient and family will have little or no control in terms of what happens to a patient. Even if they have knowledge and might be in a good position to assist with information etc., they will not as in this case always be asked. This must be a very 'destabilising' experience, it is hard to be able to try and understand the feelings of those involved. The key words which come to mind include, fear, anxiety, frustration, anger and desperation.

We returned to the present and began to talk again about Ellen's current treatment. I asked her about her treatment protocol and how that worked each time she attended the unit. She said what bothered her most was that when she came for treatment, nobody told her what order the treatment would be in. I asked her why this was a problem and she said that some procedures frightened her more than others. She felt that if she knew what was coming and when then she could prepare herself more effectively mentally. She was particularly nervous about lumbar punctures and wanted to know when these would be done. She said that currently they told you and you just went with what they said. What struck me here was this wasn't just about control but was clearly linked to Ellen's wellbeing. If she could prepare herself for unpleasant procedures she felt better mentally and more able to cope. This control in the process could potentially then improve her experience of treatment.

She added that 'you don't really disagree with the treatment, you just plod on,' she commented that she didn't really feel that there was a choice but then said you either have it or you don't. This of course is a choice but that is not the way that Ellen viewed the matter. She added at this point 'do you go through the side effects or die?' Not a choice she would want to make I think.

We next talked about decisions which were related to treatment. We talked first about fertility issues. Ellen said that she had asked whether her eggs could be harvested but the consultant said that it was too late to go down that route and that she needed treatment straight away. Ellen said that she understood what this meant and that she could not wait for a few weeks because her disease was advanced. She said that she

felt shocked by this and that this shock continued for several days. She commented that she cried because she didn't have a choice anymore. She also understood that it was very likely that she would be infertile because of the intensity of her treatment. Before she arrived at the specialist centre, she had asked the same question about her fertility and said that they avoided answering the question. She repeated this issue about choice and having no option. I realised at this point the magnitude of this implication of treatment. I felt incredibly sad that the cancer treatment would in likelihood mean that she couldn't be cured, however the sacrifice that would have to be made in some ways was hard to quantify. Ellen ended this section of the interview by explaining that she knew she had to continue with treatment.

We returned to the 'knowing about what is happening' theme again. Ellen said that at first she felt informed by what was happening but there had been occasions when she had looked things up online in relation to how to manage side effects and had implemented something she had read, however this had not been correct. The example she gave was the use of heat pads to reduce joint pain, apparently this was something that you shouldn't do when taking the medication prescribed on the protocol. I asked her if she used the unit website but she said that no she didn't use this website as she did not think that there was any information there. This activity made me think about how Ellen was trying to take control of the side effects and manage things in her own way, however it was not an activity always undertaken alone, her mother often assisted her.

We moved on from these 'side' issues of treatment and began to talk about some wider decisions which would need to be made. I asked her about returning to university and she immediately acknowledged that this was a 'big' decision. She commented that she had been contemplating going back to university as she was concerned that she could only have two years off and she did not want to start from scratch again. She had thought seriously about changing her specialist unit to one near to her university base, which she knew had opened just last year. She then said quite quickly afterwards "or do I transfer to (university near home)"

I felt that there was some reticence here and some uncertainty about this decision. She said that she wanted to go back to her original university to finish what she started and of course Nigel her long term boyfriend was there. Interestingly then she said that someone would be disappointed by her decision, I asked her what she meant by this. She said that her parents would be worried sick if she went back and that she didn't think that they would want her to return, however they had not discussed this properly and when Ellen had asked about it they had said that they would discuss it at another time.

Her boyfriend on the other hand was keen for her to go back and he had offered assistance in the form of driving her to appointments etc. She recognised that there would be problems with accommodation if she moved back as she would need to be near her University base and the hospital and rents were high in these areas.

She stressed at this point that she wanted to go away to university to find herself as a person and become independent and that she wanted that independence back. She felt that having been away from home she was more able to show she was stronger mentally and that this had helped her to cope with her cancer. She followed this immediately however with her fears about being able to cope and how her mom felt that her illness had been caused by stress in the first place. She talked about having bad days and that her parents would not be there to help. This was a fascinating section as there seemed to be a number of dilemmas here. The distance from home, the costs, independence, coping, completing what she started and maintaining a relationship. This presents a complex picture and there is clearly a challenging set of issues that Ellen needs to navigate in the coming months. She finished this section of the interview though by restating that her focus was getting back to her original university.

In the meantime she was trying to stimulate her thinking and considering doing an A level physics course to help her with her return to university, again taking control of her future by preparing herself for study once her treatment finished. She spoke about the stress of maintaining a relationship at a distance and commented that since her severe drug reaction she had not been able to travel to see Nigel. She said that if she wanted to do this her parents would probably accompany her and joked that this might prove to be a little awkward! She did understand their anxiety however and that they were only trying to protect her. She acknowledged her complete dependence on them at this time in terms of travelling particularly because she couldn't drive. She went further than this by saying that she also depended on them for living. It was interesting at this point because she had just been talking about the real desire to return to university but again it was accompanied by this heavy dependence on her parents. She also alluded to times when there was conflict relating to going out and needing to travel to get there. She said that she had little choice if she wanted to go out with friends, especially if she wasn't very well as there was nothing she could do if her father disagreed. She simply could not go out.

She again swung back following this discussion to needing to organise herself and return to university. She spoke about the university sending her materials and Nigel helping her with reading. She also spoke about a fundraising event which she was organising. I think

though that she did have some fears about her relationship as she said that Nigel did not always contact her especially around busy periods in university but she understood this.

We finally ended by once again returning to issues in the unit and how she did not want to phone them all the time and it was about knowing when to do it. She referred again to calling or not calling 999. She had been worried when the doctor told her on her visit to the unit that she should have phoned 999 when she didn't. She said that she didn't want to bog them down with phone calls. She talked about her forthcoming maintenance treatment and said that she wanted to know more about this. She also spoke about the fact that she didn't always know what her blood count was and that this was unhelpful when she wanted to go out. She spoke finally about dietary restrictions and how she adhered to these completely, she said I just stick to the rules.

The second part of the interview was really interesting as there was an almost constant 'swinging' between taking control , planning various things, needing independence and planning for the future, coupled with some significant dependence, accepting that she didn't have control and some conflict in terms of decisions which were made.

APPENDIX 11: ETHICAL APPROVAL LETTERS The following letters include all of the relevant ethical approval letters from the institution of study, IRAS, and the relevant Health Boards.

Cardiff School of Nursing and Midwifery Studies
Head of School and Dean Professor Sheila Hunt
Ysgol Astudiaethau Nyrsio a Bydwreigiaeth Caerdydd
Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt



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14 August 2013

Jane Davies
SONMS

Prifysgol Caerdydd
Ysgol Astudiaethau Nyrsio a
Bydwreigiaeth
4ydd Llawr, Ty Eastgate
35-43 Heol Casnewydd
Caerdydd CF24 0AB

Dear Jane

Re: 'Decision making for teenagers and young adults having cancer treatment

Thank you for your letter dated 18 July 2013 outlining the changes made in response to comments from the Research Review and Ethics Screening Committee.

I am pleased to inform you that the Committee is happy to approve your revised proposal. The Committee is pleased to see that this protocol is much strengthened and that the applicant has really taken on board all the comments from the panel. The only suggestion is that we now need a clear summary of the proposed project, particularly details of the methods/numbers of participants, right at the beginning, this should be one or two paragraphs in length. This will really help the reader to orient themselves.

Please remember that this committee (RRESC) is *not* a research ethics committee (REC), and is therefore not able to give you a favourable ethics opinion. In the view of RRESC your proposal will now need to be submitted for approval through NHS research governance and ethics review procedures. Further information can be found in the 'Research Ethics Guidance for Staff and Students' document, which can be downloaded from the School's Peer Review and Ethics website (<http://www.cardiff.ac.uk/sonms/research/peerreview/index.html>). Please note that if your project is then classified as 'not research' within the NHS (eg, if it is described and treated as a 'service evaluation'), *but* that you are presenting it as 'research' in other contexts (eg, for academic award purposes) then you should submit your project for approval through the School REC. Information on the School REC is also available on the School's Peer Review and Ethics website (URL given above).

We wish you well with your project.

Yours sincerely

Rosemary Williams
EO: Research Administration



Cardiff University is a registered charity, no. 1136855
Mae Prifysgol Caerdydd yn elusen gofrestredig, rhif 1136855



Mrs Jane Davies
Student
Cardiff University
Eastgate House (7th floor)
35-43 Newport Road
Cardiff
CF24 OAB

West of Scotland REC 4

Ground Floor, Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT
www.nhsggc.org.uk

Date 2 December 2013
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail Wosrec4@ggc.scot.nhs.uk

Dear Mrs Davies

Study title:	Decision making in teenagers and young adults having cancer treatment
REC reference:	13/WS/0293
Protocol number:	SPON 1248-13
IRAS project ID:	127124

Thank you for your email of 20 November 2013, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Ms Evelyn Jackson, evelyn.jackson@ggc.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	-	29 October 2013
REC application	13/WS/0293	28 October 2013
Protocol	1.1	10 October 2013
Summary/Synopsis	1.1	10 October 2013
Investigator CV	1.1	25 September 2013
Letter of invitation to participant	Teenagers or young adults, V1.1	10 October 2013
Other: Letter of invitation to other participants	1.2	14 November 2013
Participant Consent Form: Teenagers or young adults	1.1	10 October 2013
Participant Consent Form: Health or social care professional	1.1	10 October 2013
Participant Consent Form: Parents or carers	1.1	10 October 2013
Participant Consent Form: Nominated person	1.1	10 October 2013
Participant Information Sheet: Nominated Person	1.2	14 November 2013
Participant Information Sheet: Parents or Carers	1.2	14 November 2013
Participant Information Sheet: Teenagers and Young Adults	1.2	14 November 2013
Participant Information Sheet: Health or Social Care Professionals	1.2	14 November 2013
GP/Consultant Information Sheets	1.1	10 October 2013
Evidence of insurance or indemnity	-	26 July 2013
Letter from Sponsor	-	19 September 2013
Other: Letter of support from f r	-	12 October 2013
Interview Schedules/Topic Guides	Teenagers and Young Adults, V1.1	10 October 2013
Interview Schedules/Topic Guides	Parent and carers, V1.1	10 October 2013
Interview Schedules/Topic Guides	Nominated person, V1.1	10 October 2013
Interview Schedules/Topic Guides	Health or Social care professionals, V1.1	10 October 2013

Other: Letter re. SONMS review	-	17 June 2013
Other: Letter re outcome of SONMS review	-	18 July 2013
Other: Final decision letter of SONMs review	-	14 August 2013
Other: D M Kelly's CV	-	10 October 2013
Response to Request for Further Information	-	20 November 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

A handwritten signature in black ink that reads "Evelyn Jackson". The signature is written in a cursive style with a large, stylized 'E' and 'J'.

For Dr Jackie Riley
Alternate Vice-Chair

Enclosures: *"After ethical review – guidance for researchers"*

Mrs Jane Davies
Student
Cardiff University
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West of Scotland REC 4

Ground Floor, Tennent Building
Western Infirmary
38 Church Street
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G11 6NT
www.nhs.gov.uk

Date 13 December 2013
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail Wosrec4@ggc.scot.nhs.uk

Dear Mrs Davies

Study title:	Decision making in teenagers and young adults having cancer treatment
REC reference:	13/WS/0293
Protocol number:	SPON 1248-13
Amendment number:	AM01
Amendment date:	11 December 2013
IRAS project ID:	127124

Thank you for your letter of 11 December 2013, notifying the Committee of the following amendments:

- Consent Forms changed – information about how long study papers would be retained added.
- Consent Form for Teenagers and Young Adults changed – statement added regarding writing to their GP.
- Letter of invitation changed – Letter to be sent out by Jenny Labaton, from the Teenage Cancer Trust Unit.
- Protocol appendices updated as above.

The Committee does not consider this to be a "substantial amendment", as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Continued ../

Documents received

The documents received were as follows:

Document	Version	Date
Notification of a Minor Amendment	AM01	11 December 2013
Protocol	1.3	05 December 2013
Letter of invitation to participant	1.2	05 December 2013
Participant Consent Form: Nominated person	1.2	05 December 2013
Participant Consent Form: Parent or carer	1.2	05 December 2013
Participant Consent Form: Teenagers and Young Adults	1.2	05 December 2013
Participant Consent Form: Health or Social Care Professional	1.2	05 December 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

13/WS/0293:	Please quote this number on all correspondence
--------------------	---

Yours sincerely



Ms Evelyn Jackson
Committee Co-ordinator

Ms Jane Davies
Cardiff University
Eastgate House
35-43 Newport Road
Cardiff
CF24 0AB

Dear Ms Davies

**Study Title : 13/RPM/5791 : Decision Making In
Teenagers And Young Adults Having Cancer Treatment**

IRAS Project ID: 127124

The above project was forwarded R&D
Office by the NISCHR Permissions Coordinating Unit. A Governance Review has
now been completed on the project.

Documents approved for use in this study are:

Document	Version	Date
NHS R&D Form	3.5	Rec'd 05/11/13
SSI Form	3.5	Rec'd 05/11/13
Summary of research	1.1	10/10/13
Protocol	1.3	05/12/13
Participant Information Sheet: Health and Social Care Professionals	1.2	14/11/13
Participant Information Sheet: Teenagers and Young Adults	1.2	14/11/13
Participant Information Sheet: Parents or Carers	1.2	14/11/13
Participant Information Sheet: Nominated Person	1.2	14/11/13
Letter to GP	1.1	10/10/13
Invitation Letter: Teenagers and young adults	1.1	10/10/13
Invitation Letter: Other participants	1.2	05/12/13
Participant Consent Form: Health and Social Care Professionals	1.2	05/12/13

Participant Consent Form: Nominated Person	1.2	05/12/13
Participant Consent Form: Parents or Carers	1.2	05/12/13
Participant Consent Form: Teenager and young adults	1.2	05/12/13
Interview Schedules/Topic Guide: Teenagers and Young Adults	1.1	10/10/13
Interview Schedules/Topic Guide: Parents and Carers	1.1	10/10/13
Interview Schedules/Topic Guide: Nominated Person	1.1	10/10/13
Interview Schedules/Topic Guide: Health and Social Care Professionals	1.1	10/10/13

I am pleased to inform you that the UHB has no objection to your proposal and that it has been classed as pathway-to-portfolio. You have informed us that Cardiff University is willing to act as Sponsor under the Research Governance Framework for Health and Social Care.

Please accept this letter as confirmation of permission for the project to begin within this UHB.

May I take this opportunity to wish you success with the project and remind you that as Principal Investigator you are required to:

- Inform the R&D Office if this project has not opened within 12 months of the date of this letter. Failure to do so may invalidate R&D approval.
- Inform NISCHR PCU and the UHB R&D Office if any external or additional funding is awarded for this project in the future
- Submit any substantial amendments relating to the study to NISCHR PCU in order that they can be reviewed and approved prior to implementation
- Ensure NISCHR PCU is notified of the study's closure
- Ensure that the study is conducted in accordance with all relevant policies, procedures and legislation
- Provide information on the project to the UHB R&D Office as requested from time to time, to include participant recruitment figures

Yours sincerely,

PRIVATE AND CONFIDENTIAL

Mrs Jane Davies
Senior Lecturer/Full Time PhD Student
Cardiff University
Eastgate House
35-43 Newport Road
CF24 OAB

27th February 2014

Dear Mrs Davies

Letter of access for research

This letter confirms your right of access to conduct research through _____ for the purpose and on the terms and conditions set out below. This right of access commences on 27th February 2014 and ends on 30th September 2015 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at _____ has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to _____ premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through _____, you will remain accountable to your employer, Cardiff University, but you are required to follow the reasonable instructions of the head of the relevant NHS Department/research supervisor in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Mae'r Ymddiriedolaeth hon yn croesawu gohebiaeth yn y Gymraeg
This trust welcomes correspondence in Welsh

You must act in accordance with
available to you upi

t policies and procedures, which are
Research Governance Framework.

You are required to co-operate with ' in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<https://www.gov.uk/government/publications/confidentiality-nhs-code-of-practice>) and the Data Protection Act 1998 (<http://www.legislation.gov.uk/ukpga/1998/29/contents>). Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that ' accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of ' or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

' will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

I,

APPENDIX 12: OUTLINE OF FUTURE RESEARCH MAPPED AGAINST EXPERT GUIDANCE

Extracts from key messages published in the Blueprint of Care (Smith and Case, 2012) pg.6	Mapping against dynamic agency in teenage and young adult cancer
<ul style="list-style-type: none"> Understanding each young person as an individual, taking into account their interests, past experiences, relationships, future aspirations and coping strategies will enable teams to develop an individual care package that will support the young person effectively through the cancer pathway. 	<ul style="list-style-type: none"> Anticipating the changes ahead Utilising the 'life then' phase to establish the individual degree of choice and control in everyday life, prior to cancer diagnosis, to enable early mapping of needs which relate to work, education, intimate relationships, family relationships and living arrangements. Take into account the need for personal agency to enable the young person to maintain control of these aspects in their lives.
<ul style="list-style-type: none"> Allow and encourage negotiation and flexibility in routine and treatment regimes where possible. This can support autonomy and may encourage compliance with treatment regimes. 	<ul style="list-style-type: none"> Supporting the phase of maximum disruption Considering the 'life interrupted' phase, predict elements of treatment/side effects which may limit choice and control in decision making by putting in place supportive mechanism to manage this phase of treatment where vulnerability is significant. Consider the need for proxy and collective agency along with personal agency where it is desired. Anticipating the post treatment phase Utilise the information from the 'life then' phase to predict and support the individual needs of young people 'after cancer' illuminated in the 'life reclaimed' stage. Again drawing on the use of types of agency, whilst maximising agentic power.
<ul style="list-style-type: none"> Cancer in a young person can result in a fundamental loss of control regarding life choices and freedom to make decisions. Mutual goal setting between the young person and professional helps to promote a sense of control for the young person. 	<ul style="list-style-type: none"> Use the trajectories in their entirety as part of the overall care to signpost and predict potential 'peaks and troughs' in choice and control. This could enable early recognition of the loss of agency, choice and control in decision making, resulting in meeting unmet needs in this context.