

CHALLENGES AND OPPORTUNITIES:
ADJUSTMENT TO LIFE POST TRANSPLANT
FOR ADULTS WITH CYSTIC FIBROSIS AND
THE IMPACT ON THEIR PROFESSIONAL
SUPPORT NEEDS.

SAMANTHA CAROLINE COCHRANE

Submitted in partial fulfilment for the award of
Doctorate in Health Psychology

QUEEN MARGARET UNIVERSITY,
EDINBURGH

2013

Abstract

Lung transplant can improve both quality and quantity of life for a person with Cystic Fibrosis (CF) at end stage respiratory disease. However, life post transplant can be challenging both medically and psychologically due to the need to adjust to a significantly changed health status, as well as understand and manage the side effects and medical complications of transplant.

This study questioned, whether from a service perspective, the support needs of adults with CF changes with transplant and how a specialist CF centre should accommodate this. In order to do this, a more detailed understanding of the experiences of a post transplant group was sought utilising qualitative methodology. Eleven participants or sixty-five percent of adults with CF post transplant who attend one of Scotland's largest specialist CF centres participated in semi-structured interviews.

Framework analysis was chosen as the method of analysis due to its relevance in a health care setting. A framework was generated consisting of four broad areas of post transplant adjustment: Recovering; Adjusting and realising; Redefining and pursuing and; Managing the issues of post transplant life. Each area has activities and key factors which provide more information about post transplant adjustment life as well as factors that may account for individual differences.

In general, and in the absence of medical complications, participants adjusted to transplant with the support of partners, families and local CF and transplant services. They did not indicate the need for dedicated post transplant services in their local CF centre, but found communications between service providers to be inefficient. When

faced with medical complications especially rejection, participants reported needing more psychosocial support.

Recommendations include an increased awareness of the processes of psychosocial adjustment post transplant for health professionals, psychological intervention at times of crisis and more efficient communication between transplant and local CF services.

Keywords: Cystic Fibrosis, lung transplant, psychological adjustment, professional support.

Word Count: 25 186 (Abstract 299)

Acknowledgements

I would like to offer my most grateful thanks to my Director of Studies, Dr Vivienne Chisholm and my Second Supervisor, Dr Michele Hipwell for the time and effort they have spent in supporting me not only with this study, but in the Doctorate in Health Psychology. Their support, understanding and encouragement are very much appreciated.

My grateful thanks also to the participants of this research project who gave up their time to share experiences of their lives post transplant; as well as to the Scottish Adult CF Service multi-disciplinary team for their expertise and support in this project.

On a personal level, I would never have managed to make the progress I have without the unwavering support, encouragement, calming influence and practical advice of my partner Sandie to whom I express my very grateful thanks. I am also grateful to my parents and godmother for their support and belief in me.

Contents

Abstract.....	1
Acknowledgements.....	3
Chapter 1: Introduction.....	8
1.1 Overview of Cystic Fibrosis.....	8
1.2 The journey to transplant.....	10
1.3 Post transplant support needs.....	14
1.4 The relevance of qualitative studies.....	16
1.5 “Owning one’s perspective”.....	16
1.6 Summary.....	18
Chapter 2: Literature review.....	19
2.1 The lung transplant journey.....	19
2.1.1 Stage based approaches vs. normative and non-normative development....	21
2.1.2 The Family Systems Illness Model.....	23
2.2 Coping styles of people with CF.....	24
2.2.1 Coping styles post transplant.....	25
2.3 Professional support –roles and responsibilities.....	27
2.4 The psychological impact of transplant.....	29
2.5 Summary.....	32
2.6 Aims and research questions.....	33
Chapter 3: Methodology.....	35
3.1 Motivation for study.....	35
3.2 Research design.....	35
3.2.1 Rationale: Choice of methodology.....	36
3.2.2 Choice of qualitative methodology.....	38
3.3 Description of sample.....	42

3.3.1	Inclusion and exclusion criteria.....	43
3.3.2	Method of recruitment.....	43
3.4	Procedure.....	44
3.4.1	Ethical issues, confidentiality and informed consent.....	44
3.4.2	Development of interview guide.....	45
3.4.3	Interviews and transcription.....	48
3.5	Data analysis.....	48
3.6	Summary.....	50
Chapter 4: Results.....		51
4.1	Participant characteristics.....	51
4.2	Framework of how adults with CF conceptualise their lives post transplant.....	52
4.3	Areas of post transplant adjustment	55
4.3.1	Area 1: Recovering.....	55
4.3.2	Area 2: Adjusting and realising.....	59
4.3.3	Area 3: Redefining and pursuing.....	65
4.3.4	Area 4: Managing the issues of post transplant life.....	74
4.4	Summary.....	78
Chapter 5: Discussion.....		80
5.1	Considering the results in the light of the extant literature.....	80
5.1.1	Adjusting to a major medical event and significant change in health status.....	80
5.1.2	Adjusting to a “new” chronic condition.....	82
5.1.3	Moving forward developmentally.....	83
5.1.4	The developmental perspective.....	85
5.1.5	The systemic perspective.....	86
5.2	Considering the results from the perspective of the research questions.....	89
5.2.1	Research question 1: How do people with CF who have had a lung transplant conceptualise their lives post transplant?.....	89

5.2.2	Research question 2: How does lung transplant affect the service needs of people with CF post transplant?.....	91
5.3	Clinical implications.....	94
5.4	Limitations of research and future research directions.....	95
5.5	Summary.....	97
Chapter 6: Conclusions.....		99

List of Tables

Table 1:	Overview of participants.....	52
Table 2:	Framework of how adults with CF conceptualise their lives post transplant	54
Table 3:	Tasks post transplant according to stages of the illness life cycle outlined in the FSIM.....	88

Chapter One

Introduction

This thesis addresses the question of how to conceptualise the experiences of adults with Cystic Fibrosis (CF) who have had a lung transplant in order to understand whether this group of unique individuals have specific needs of the specialist CF service they attend. It also considers the relationship between health care provider and a person with CF, with the question of what psychological support would be most useful to them. This chapter introduces these ideas and how this study will explore them further.

1.1 Overview of Cystic Fibrosis

Cystic Fibrosis (CF) is the most common, life threatening recessively inherited disease in the UK. It is a multi system disease that primarily affects the respiratory and digestive systems. Other complications may include CF related diabetes, male infertility, chronic liver disease, CF arthropathy and reduced bone density (CF Trust Standards of Care, 2011).

There is currently no cure for CF, so medical treatment is palliative as opposed to curative, focusing primarily on the treatment of lung disease to reduce the impact of infection, inflammation and subsequent lung injury (Doring, Flume, Heijerman & Elborn, 2012). A multi disciplinary approach is strongly advocated (CF Trust Standards of Care, 2011) as the only way to provide sufficient expertise to offer maximal treatment and support to this group and involves input from physicians, physiotherapists, specialist dieticians, clinical psychologists and specialist nurses.

In the UK, there are currently 9749 people with CF, of which 4598 (47%) are adults (CF Registry, 2013) with a median age of 18. This reflects the trend of steadily improving survival rates: In 1969 a child with CF in an industrialised country had a

mean survival of 14 years (Doring et al., 2012) compared to the median predicted survival in 2011 of 41.5 years (CF Registry, 2013). A child born with CF in 2000 could be expected to live to 50 years (Dodge, Lewis, Stanton & Wilsher, 2007). Having said that, the current median age at death in UK adult services is 26 years (CF Registry, 2013) which reflects the fact that it will take time for these positive trends in paediatric services to be seen in adult services (Dodge et al., 2007). There is also no evidence of a particular age being a crisis point where mortality rises sharply which illustrates that people with CF do not deteriorate uniformly chronologically at the same time (Dodge et al., 2007). This means that while survival rates are improving, people with CF can still face end stage respiratory disease in early adulthood.

The gene underlying CF was discovered in 1989 (Griesenbach & Boyd, 2005) and although the first clinical gene therapy trials began in 1993, to date no effective gene therapy has been discovered. CF remains a progressive disease with no cure where pulmonary damage ultimately leads to respiratory failure and death. At the present time therefore, the only option for people with advanced CF lung disease to extend both quantity and quality of life is lung transplant (Meachery et al., 2008).

The number of people receiving lung transplants is increasing worldwide (Dilling & Glanville, 2011). In the UK in 2011, 47 people with CF received a lung transplant, an increase of over 40% from the previous year (CF Registry, 2013). Whilst lung transplants have not had the same survival rates as other solid organ transplants, for example heart, liver and kidney (DeVito Dabbs, Kim, Hamdan-Mansour, Thibodeau & Mc Curry, 2006; Dilling & Glanville, 2011), rates of survival post lung transplant have been improving.

In an article outlining the outcomes of lung transplantation at one of the major transplant centres in the UK, Meachery and colleagues (2008) describe survival rates post lung transplant in the CF population as 82% survival at 1 year, 70% at 3 years, 62% at 5 years and 51% at 10 years. This means that half of the people with CF receiving a lung transplant will have their lives extended by at least 10 years as a result of the procedure.

People with CF have been identified as a group that do particularly well with lung transplants in terms of improved quality of life compared with other disease groups (Meachery et al., 2008; Limbos, Joyce, Chan & Kesten, 2000; Choong & Meyers, 2004). The reason for this is not entirely clear, although a study by Weiss, Merlo and Shah (2009) points to better outcomes for younger patients. On average CF patients are 15-20 years younger than other lung transplant recipients, with the average age of those receiving a transplant being between 25 and 30 years old (Pochettino et al., 2007). Havermans, Matossian, van den Bergh, Knoop and Dupont (2008) suggest that people with CF adapt more quickly to their new situation than older transplant patients, a finding echoed by Smeritschnig et al., (2005) who hypothesize that the relative youth, physical condition and greater life expectations of this group may be the reason for them doing better than other groups. Transplant therefore seems to be an effective treatment intervention for people with CF both in terms of extending quantity and quality of life.

1.2 The journey to transplant

A person is listed for transplant when they have reached end stage respiratory disease, where they have a marked decline in functional capacity with significant restrictions in both leisure and work activities (Barbour, Blumenthal & Palmer, 2006).

This marks the beginning of a psychosocial journey (Yorke et al., 2006) that includes the realisation of the necessity of a transplant and its implications in terms of potential life expectancy; referral to a transplant centre and the rigours of a transplant assessment, followed by acceptance onto a transplant waiting list. Once on the waiting list, a potential transplant recipient has to manage the stress and uncertainty of waiting for an organ, whilst having to manage deteriorating physical health, facing the possibility of not surviving long enough to receive a transplant and well as having to manage “false calls” that is potential organs that are found to be not suitable. These are clearly psychologically challenging times (Barbour et al., MacDonald, 2006) and set the scene for understanding the “starting point” of people with CF who successfully receive a lung transplant.

Life post transplant can be a mixture of both challenge and opportunity (Savitch, Gilmore & Dowler, 2003). A successful transplant provides the time for recipients to develop and fulfil life goals that they may never had the chance to consider without the life saving intervention (Choong & Meyers, 2004). At the same time, there are numerous challenges that occur over time, unique to a post transplant group, that need to be managed (Stilley, Miller, Manzette, Marino & Keenan, 1999). These can include medical, rehabilitation, psychological and vocational challenges, all of which can affect outcome and survival post transplant (Savitch et al., 2003).

From a medical perspective post transplant complications can range from acute rejection resulting from surgery (Stewart, Fisbein & Snell, 2004), to chronic rejection, immunosuppressant toxicity, and secondary malignancy (Meachery et al., 2008). Non pulmonary non-infectious medical complications could include renal failure, diabetes, and cardiovascular conditions, for example hypertension (Lyu & Zamora, 2009).

People with CF still need ongoing treatment for the impact of CF on other organs in spite of having a lung transplant and transplant may cause or worsen other CF related conditions, for example CF related diabetes (Valour et al., 2012). Thus, lung transplant confers the unquestionable benefit of greatly increased lung and exercise capacity but this may come at a price.

From a psychological perspective, there is some evidence that lung transplant significantly improves quality of life and psychological health (Choong & Meyers, 2004, Smeritschnig et al., 2005, Kugler et al., 2005).

Quality of life studies show a positive association with lung transplant, especially in the short and medium term and in the absence of significant medical complications (Smertischnig et al., 2005, Kugler et al., 2005; Goetzmann et al., 2005, Limbos, Joyce, Chan & Kesten, 2000). Depressive symptoms generally remain low post transplant (Fusar-Poli et al., 2007) while levels of anxiety drop significantly, although they still remain higher than the population norm (Kunsebeck et al., 2007). This points to a much improved psychological profile for people with CF post transplant.

Significant medical complications however such as chronic rejection can have a negative impact on quality of life and mood (Fusar-Poli et al., 2007, van den Berg et al., 2000, Vermeulen, Groen, van der Bij, Koeter, & TenVergert, 2004). The degree of negative psychological impact though, is influenced by the amount, type and severity of these medical complications.

By providing the opportunity for extended survival, lung transplant enables a person with CF to continue with their life path. This could involve changes in relationship status, moving out of the parental home or setting long term goals (Matossian, Havermans, Claes, Dupont & Cloop, 2007).

This in itself may well be viewed as “normal” from a developmental perspective, but even so may be stressful and the individual may potentially need psychological support if difficulties are encountered with these changes, especially in the context within which they occur (Williams, Burker, Kazukauskas & Neuringer, 2012; Savitch et al., 2003). For some returning to work, being able to consider going to work for the first time or establishing a career is also possible (Savitch et al., 2003). Clearly this is dependent on the age of the person at transplant, but in the absence of medical difficulties, a lung transplant often clears the way for a person with CF to move forward with vocational ambitions.

This can be both exciting and daunting especially for those whose illness has prevented them from developing a career. Managing these challenges requires the ability to cope and adjust, which raises the question of how people with CF cope and what support they may need if they have difficulties in coping.

Abbott (2003) has extensively researched the coping skills of people with CF. Based on Lazarus & Folkman’s (1984) transactional model of stress and influenced by Holohan & Moos’s (1987) and Moos & Schaefer’s (1993) work relating to the focus and method of coping, Abbott (2003)’s research has shown that people with CF utilise both approach and avoidance coping strategies adaptively. This she believes enables them to manage the complexities of the condition by focusing attention on CF at times when a situation is controllable and amenable to problem solving (approach coping), whilst utilising avoidance coping when a situation is uncontrollable. This enables people with CF to have the time to adapt, control and deal with a specific situation in their own way which enables them to maintain their psychological well being during this time (Abbott, Dodd, Gee & Webb, 2001).

Abbott, Hart, Morton, Gee and Conway, (2008) have identified four major coping styles utilised by people with CF which are: optimistic acceptance, hopefulness, distraction and avoidance. Lowton and Gabe (2003) had similar findings in their research, stating that people with CF control their health by maintaining a positive attitude towards the disease which becomes a way of controlling it.

These coping skills will undoubtedly help people with CF manage the challenges and opportunities post transplant, but where and how important is support from others in this process including health professionals.

1.3 Post transplant support needs

Thomsen & Jensen (2009) found that support was highly rated by people post transplant and was provided mainly by friends, relatives and in some instances other transplant recipients. From the perspective of professional support, many people with CF have long standing relationships with members of CF multidisciplinary specialist teams who have been closely supporting them pre transplant (MacDonald, 2006). Matossian and colleagues (2007) found that people's support needs, including that from their CF team, changed with transplant depending on their circumstances and goals post transplant. This leaves the question of whether multidisciplinary professionals working in CF services understand what these changes are and whether they have adjusted support services accordingly. This study will explore this further.

In a study that sought to understand post transplant support needs across several transplant groups including CF, Ullrich, Jansch, Schmidt, Struber, and Niedermeyer (2005) found that respondents were generally satisfied with the professional support they received (unless it was fragmented by frequent staff changes) but felt that information about how to access psychological services would improve the delivery of care.

A psychological service evaluation for a Regional CF Unit in Leeds, found that some participants reported unanticipated problems post transplant, but did not access the Unit's psychology service as they felt that they were "now well" and therefore shouldn't be utilising the CF Unit's resources (Miller, Harris, Latchford, Conway & Peckham, 2010). These findings seem to suggest that psychological services post transplant are not well defined enough which may mean people with CF post transplant are not accessing psychological support should they need it.

Understanding the psychological needs of people with CF post transplant is limited by the small numbers of studies that focus specifically on this group. Some attempts have been made to conceptualise transplant from a developmental perspective as a trajectory with different stages with particular psychological challenges for example Worby (1997) but often these are not very detailed especially from a post transplant perspective. Other studies focus more on psychopathology or quality of life, which although important does not add to the understanding of the processes of psychological adjustment post transplant. This results in an under-developed understanding of how CF services should best support their patients especially from a psychological perspective, except by being able to treat anxiety and depression once it reaches clinical levels and concern is raised.

This study aims to address this gap by utilising qualitative research to gain detailed insight into the experiences of a cohort of people with CF post transplant attending a specialist CF service. The objective is to gain a more detailed understanding of what adjustment to transplant entails and what this means in terms of the need for psychological support. This will allow the generation of recommendations which can influence the development of services to ensure this group has access to useful and effective support.

1.4 The relevance of qualitative studies

The post transplant group within the CF population is a small, but growing proportion of adult services that warrants research in its own right. Qualitative studies are useful in enabling a fuller understanding of life post transplant by richly illustrating the lived experience of this group and the “highs and lows of life” post transplant (Lowton, 2003). As Stilley et al., (1999) put it: “Studying the experience of transplantation from the patient’s perspective rather than by diagnosis may equip medical and mental health professionals to better plan and coordinate pre and post operative care across transplant services.”

1.5 “Owning one’s perspective”

Elliot, Fischer and Rennie (1999) recommend, as one of the guidelines for good practice in qualitative research, “owning one’s perspective”. In practice, this means being committed to reflexivity which is a process whereby a researcher is aware of what he or she brings into a research project, as well as an awareness of the impact of his/her contribution to the research relationship. This section will situate the author’s perspective and experience as it relates to this study.

The author is a clinical psychologist and family therapist who has been qualified for fifteen years. For the first seven years, she worked in a mental health setting including both primary and secondary care. In the past eight years she has worked in a variety of physical health settings, including being the clinical health psychologist attached to the Scottish Adult Cystic Fibrosis Service. She has also worked in oncology, palliative care and clinical genetics services.

As a member of the multi disciplinary professional team attached to the Scottish Adult Cystic Fibrosis Service, the author was part of discussions that sought to consider whether, due to the increasing numbers of people with CF in the service

who have received a transplant, there should be more “post transplant specific” services made available to this group. An example of this would be post transplant clinics as opposed to the current way of offering clinics that do not distinguish on the grounds of transplant status.

The author observed that the multidisciplinary team offered a comprehensive and effective service to people with CF pre transplant with a measure of confidence that was not necessarily the same post transplant. This led the author to wonder about the team’s understanding of the psychosocial challenges post transplant and how they conceptualised their role with people with CF post transplant.

As part of her role as CF team psychologist, the author had experience of seeing people with CF post transplant from a professional perspective, and had some understanding of these psychosocial issues. It was also very clear to the author that due to the idiosyncratic nature of these issues (influenced by medical, psychological and social factors) that it could be difficult for the wider team to conceptualise the possible range of issues people with CF post transplant could face. This was also due to the varied nature of the post transplant group attending the service in terms of amount of time post transplant, as well as type and number of complications post transplant and their effect.

This led the author to want to participate in the question of whether the needs of the post transplant cohort were being met, but from a psychological perspective, with the aim of “feeding back” into the team a framework with which they could consider where people were at in terms of psychological adjustment post transplant and hence this study.

1.6 Summary

Lung transplant is used as a treatment option for end stage respiratory disease in CF with increased frequency and success. A successful lung transplant is associated with challenges and opportunity. Opportunity relates to the ability to pursue life goals that wouldn't have been possible without transplant. Challenges refer to issues relating to adjusting to and managing life post transplant from a psychological and medical perspective.

While the role of support in managing these challenges is clearly useful (Savitch et al., 2003), it is unclear who should provide this support and how multi-disciplinary professionals attached to transplant or CF teams should approach this.

Research in this area is scant and the studies that have been carried out have largely focused on quality of life or psychopathology post transplant (Choong & Meyers, 2004, Fusar-Poli et al., 2007). This has left a gap in the literature in understanding the detail of what psychological support should consist of post transplant. This study aims to utilise qualitative methodology in order to better understand adjustment to a lung transplant in a CF population as this methodology can yield greater insight. It further aims to clarify what needs people with CF post transplant see themselves having within a CF service as well, which includes what psychological support would be most meaningful in a post transplant context.

Chapter Two

Literature Review

This literature review seeks to describe and evaluate literature specifically relating to adults with CF in an attempt to increase our understanding of the extant literature relating not only to what the psychosocial challenges are for this group post transplant, but from a wider perspective of how to contextualise these challenges in terms of what the literature reveals about the coping strategies and support needs of people with CF.

The author is mindful that much of the literature relating to lung transplant includes other disease types apart from CF for example COPD. These studies are successful in being able to make generalisations about lung transplant recipients as a group, but do not always provide an in depth understanding about specific disease groups, for example adults with CF. The author has reviewed the extant literature relating to lung transplant as well as other solid organ transplants where relevant, but due to restraints in the word count of this study, as well as a desire to focus as specifically as possible on issues relating to people with CF, these studies are not included in this review unless specifically relevant.

This review has also been informed by a systematic review, carried out by the author, relating to the psychological impact of chronic rejection for adults with CF who have received a lung transplant, which has assisted with focussing the literature as well as providing a deeper understanding of the psychological impact of chronic rejection.

2.1 The lung transplant journey

It may be useful to consider lung transplant as a journey in a similar way to other medical areas such as cancer have, as this has helped alert health professionals to key

transition points where input may be needed, as well as understand the journey in its entirety.

When considered this way lung transplant can be described as a “trajectory of experiences” (as described in Yorke et al., 2006) that range from the point of having the need for a transplant, waiting for a transplant to become available, receiving and living with a lung transplant, with each point being associated with specific psychological challenges and transitions. Several authors have attempted to do this as illustrated below:

<u>Worby(1997)</u>	<u>McCarthy(2001)</u>	<u>Ullrich(2008)</u>	<u>Kurz(2001)</u>
Transplant proposed	Telling: is this real, am I that ill?	The decision to have a transplant	The transplant event
Referral to transplant team (assessment for transplant suitability)	Assessing: Will I be accepted on the transplant list? Do I want to be?	The waiting period	Cocooning
Accepted onto active waiting list (up to 2yrs)	Will I get a transplant in time?	The transplant and hospital stay	Normalizing
Peri-operative and post operative care.	Being called: will this really go ahead? What should I be thinking?	Rehabilitation at home	Branching out
Rehabilitation (up to 3 months post transplant)	Dealing with the aftermath of false calls. Will I get another chance?	Challenges	Settling down
Getting on with life, trying to establish normality	Surgery: will I survive?		
Irreversible decline and death.	Going home: Can I manage? What now?		

These ideas may be useful in terms of conceptualising lung transplant as a complex process with differing psychological demands at various points. Ullrich (2008); Worby(1998); Worby and Smith(1997) and McCarthy (2001) all conceptualise transplant from a chronological perspective and Kurz (2001) identifies five stages post transplant from the perspective of well spouses after lung transplantation.

However, there are differences in terms of breadth, level of detail and focus which result in divergent approaches that leave no real possibility for cohesion or depth of understanding about the psychological tasks relating to the transplant trajectory.

One reason for this may be because they are focusing on a significant number of processes that may happen over the course of many years. Thus by attempting to describe the entire transplant trajectory, they lose the detail necessary to understand some of the key issues at certain points in the journey, for example post transplant and what key factors health professionals should consider when offering psychosocial support.

An example of this would be comparing the psychological issues faced by a person with CF pre transplant versus post transplant – pre transplant the person may be struggling with keeping well enough in the face of life threatening deteriorating health in order to stay on the transplant list (MacDonald, 2006) whilst post transplant they may be trying to manage issues relating to moving forward developmentally or adjusting to life post transplant in terms of their immunosuppressant regimen (Durst et al., 2001). These are clearly very different issues.

This suggests that focusing on specific stages of the transplant journey will deepen our understanding of the psychosocial issues relating to transplant. This study seeks to do this by focusing on the needs of people with CF post transplant, being mindful that “post transplant” is a term that incorporates a broad spectrum of medical and psychological experiences that can happen over many years, and therefore warrants research and focus in its own right.

2.1.1 Stage based approaches vs normative and non-normative development

Worby (1997), McCarthy (2001) and Ullrich (2008) have all mentioned “stages” post transplant but haven’t considered these from an epistemological perspective which

could be seen as a weakness in their work. Stage based approaches originate from developmental psychology where the nature of developmental change is considered as either continuous or discontinuous (Keenan & Evans, 2009). Notions of development as a series of distinct and separate stages with a starting and ending point view change as discontinuous, whilst continuous theories view development as an incremental process. Sternberg & Okagaki (1989) challenge the “either-or” debate suggesting that development has aspects of both continuous and discontinuous change and focus should rest on how this occurs rather than whether one or the other does. Change therefore happens in different ways and for different reasons.

When applied to lung transplant this points to the fact that whilst lung transplant may be seen as a trajectory of experiences, considering these experiences as discrete stages may not be appropriate as it would be hard to identify where each stage began and ended, especially in the light of the complexity of the medical aspects of lung transplant. For example, someone may be discharged from hospital and re-establishing themselves at home which could be seen as the “next stage” whilst still dealing with some minor medical complications related to transplant surgery which relates to the “previous stage”.

What seems more relevant are ideas Keenan & Evans (2009) discuss ideas relating to a life span approach to the study of development where non-normative life events (that is unanticipated and not relating to expected life events) can occur alongside normative life events (for example moving away from the parental home, making vocational decisions or forming intimate relationships), both of which can have a major impact on the life course and which need coping skills and strategies to manage. This means that lung transplant can be seen as a non-normative event that can occur alongside other normative psychological stages of development.

What this points to is that people with CF may well be dealing with two different “types” of psychological issues – normative developmental challenges and opportunities, as well as the non-normative developmental issues relating to adjusting to having a lung transplant and the issues this raises. Psychological professionals within CF specialist teams are in a unique position to be able to understand these processes once they have been delineated, because they understand CF specific issues as well as a broader developmental perspective. Therefore adopting a developmental perspective when conceptualising life post transplant for people with CF may be very useful from the perspective of normative and non-normative developmental tasks.

2.1.2 The Family Systems Illness Model

The Family Systems Illness Model (FSIM) developed by Rolland (1994) views illness not only from a wider systemic perspective, but also in a developmental context, where illness related events occur within the context of individual’s and families’ developmental processes. This develops the ideas discussed in the previous section by being able to contextualise normative and non normative life events as part of one model. The benefit of this is to enable health professionals understand specific illness related events from the perspective of “what else is going on”, that is individual and family developmental tasks.

This perspective may be useful when conceptualising the psychological needs of people with CF post transplant as it points to the fact that depending on where an individual is developmentally, and what events are occurring in his/her family, may affect how he/she may cope with a particular health challenge and what professional support they may therefore need. Thus, it may not be the actual health challenge that

necessitates the need for further professional support, but the meaning of the event and context within which it occurs.

2.2 Coping styles of people with CF

Having considered the broader developmental perspective, it may be useful to outline relevant research relating to the coping styles and strategies of people with CF in a broad sense, as well as relating more specifically to a post transplant context.

As stated in the introduction, Abbott (2003) has made a major contribution to understanding the coping styles and strategies of people with CF. Describing people with CF as a group with “remarkable resilience”, Abbott (2003) considers the role of coping in chronic disease as an important mediating variable between life stressors and psychological adjustment. This means that the way people cope can be an important determining factor as to how people adjust to the challenges of chronic illness which includes post transplant.

In this regard, Abbott (2003) utilises the theoretical principles of Lazarus & Folkman’s (1984) transactional model of stress where a twofold process of appraisal takes place when faced with a stressful situation. This consists of a primary cognitive appraisal, to initially understand the impact of the stressor. This is followed by a secondary appraisal, to consider whether enough resources are available for meeting the demand generated by the stressor. Coping is understood as the process that occurs where people try to identify and manage the perceived discrepancy between these demands and the resources available. Coping can also alter the nature of the problem or regulate the emotional response to the stressor and is therefore a crucial process in responding to the challenges transplant can bring (Sarafino, 2008).

Coping can take many forms, but the two broad and generally accepted categories of coping that include most coping strategies are approach and avoidance coping

(Ogden, 2007). Approach coping embraces coping strategies where attention is focused on a stressor (or disease in the case of CF), whilst avoidance coping focuses attention away from the stressor that is CF (Holohan & Moos, 1987; Moos & Schaefer, 1993). Examples of approach coping include styles that are optimistic, positive and problem focused, whilst examples of avoidance coping styles include passivity, distraction, avoidance and emotion focused coping (Abbott et al., 2008).

2.2.1 Coping styles post transplant

In a study that compared coping styles across transplant groups that included CF, Stilley, Miller, Manzetti, Marion & Keenan, (1999) state that that organ transplant is a unique experience that differs from other chronic and terminal illnesses. They identified that an optimistic attitude correlates most positively with more effective and adaptive coping styles and therefore better psychological functioning across transplant groups. This would point to approach coping being a better style of coping for managing psychological stresses post transplant.

Abbott et al., (2008) concur with this but add that evidence has shown that in a CF population including transplant and non-transplant groups, avoidance coping is not necessarily negative and maladaptive as it can be useful for short term problems or uncontrollable situations. They state that adults with CF face both chronic and short term difficulties of varying controllability and complexity and so may find both approach and avoidance coping strategies useful. Indeed, Abbott et al., (2008) have identified four major coping styles utilised by people with CF with the most prominent coping style being optimistic acceptance followed by hopefulness, distraction and avoidance. All of these styles have been found to be useful for people with CF from a psychological perspective (Abbott et al., 2001; Abbott, 2003; Abbott et al., 2008) even avoidance. This allows people with CF to adapt, control and deal

with a specific situation in their own way which enables them to maintain their psychological well being (Abbott et al., 2001).

Lowton & Gabe (2003) have approached how people with CF cope from a sociological perspective, taking the position that coping with CF involves a complex construction of concepts of health in CF and coping styles. They have identified four concepts of health in CF that operate in a cyclical fashion as: health as 'normal'; health as controllable; health as distressing and health as release. They believe that the concept of health is dynamic and changes over the life course and so depending on what event a person with CF is dealing with they can locate their particular approach at different points in the cycle. For example a person with very few symptoms may see their health as 'normal' whilst small amounts of treatment may make it manageable, whereas major health events may be distressing. Interestingly, Lowton and Gabe's (2003) study revealed that people with CF post transplant identified their concept of health as 'release' as they felt very liberated from the treatment burden focused on the lungs pre transplant.

Lowton & Gabe, (2003) have identified three coping strategies people with CF use, namely comparison with others; acknowledging and minimising loss of spontaneity and maintenance of a positive attitude. Maintaining a positive attitude to CF is similar to Abbott et al's., (2008) coping style of optimistic acceptance. This relates to an approach of controlling health by not giving into it and being positive about having CF and being able to manage it.

These studies illustrate the fact that people with CF use a mixture of approach and avoidance styles of coping to manage CF from a psychological perspective, with the predominant style being optimistic acceptance or maintenance of a positive attitude.

2.3 Professional support – roles and responsibilities

Whilst an individual's coping style and strategy is a key variable in managing stressors, support from others is acknowledged as an equally important component of being able to cope with a long term physical illness (Sarafino, 2008, MacDonald, 2006; Ullrich, Jansch, Schmidt, Struber, & Niedermeyer, 2005; Thomsen & Jensen, 2009).

The FSIM (Rolland, 1994) conceptualises the family or care giving system as the central unit of care with health care professionals playing an integral part of providing support but not taking total responsibility for it. This means a complex but useful relationship of shared responsibility consisting of a series of interconnected relationships between the patient, healthcare provider, and family.

In a CF post transplant context, Matossian et al., (2007) found that people's support needs reduced and changed post transplant as a result of improved health and independence. However, as Meachery et al., (2008) illustrate complications post transplant may be very common which can cause psychological distress. This suggests health professionals need to find a balance between offering psychological support when necessary whilst at the same time understanding that the person with CF post transplant needs to "get on with their lives" when things are going well.

At the same time it has been suggested (Woo,2008) that close follow up and strong medical/clinical suspicion can be very important strategies in reducing morbidity and mortality for those post lung transplant which is clearly very important. This involves frequent clinic visits in an outpatient setting post discharge as well as the need for frequent and open communication between the patient, transplant team and referring physician (in this context the CF physician).

This indicates the acceptance of joint responsibility that is transplant and CF consultants taking medical responsibility for the person with CF post transplant, with the post transplant patient also taking responsibility in complying with medical advice and treatment. This underscores the development of a collaborative relationship between patient and health care provider.

De Vito Dabbs, Kim, Hamdan-Mansour, Thibodeau & Mc Curry, (2006) conceptualise this from the perspective of health locus of control, stating that a “dual health locus of control” (that is both clinician and patient taking medical responsibility) makes most sense in a post transplant context.

Health locus of control (HLC) is a construct that is defined as the extent to which individuals believe that their health is controlled by internal or external forces (Wallston, Stein & Smith, 1994). If a person believes they have control over their own health they have ‘internality’ or an internal locus of control orientation whilst those who believe their health status is influenced by others has ‘externality’ or an external locus of control orientation. HLC is significant in a health context because it is believed to be a factor that can influence health behaviours.

This is significant in a transplant context as non adherence to immunosuppressant medication can be a cause of chronic rejection post transplant (Abbott & Gee, 1998). De Vito Dabbs et al., (2006) believe that high internality and externality in terms of HLC that is both the patient and the health care provider to sharing responsibility for post transplant health makes most sense in a post transplant context. Therefore a collaborative relationship where each party’s responsibilities are clear seems to be of most use in a post transplant context.

Therefore multi disciplinary health professionals in a CF team need to have a strong collaborative relationship with people with CF post transplant where good

communication is paramount. They also need to understand and appreciate some of the adjustment issues faced by people with CF post transplant so that they can converse meaningfully about these issues as part of a routine clinic appointment, rather than only raising them if the patient is in obvious distress and needing psychological intervention.

2.4 The psychological impact of transplant

Transplant heralds a major change in lifestyle for a person with CF. As has been stated earlier, a person is listed for transplant when they have reached end stage respiratory disease, where they have a marked decline in functional capacity with significant restrictions in both leisure and work activities (Barbour, Blumenthal & Palmer, 2006). Transplant potentially reverses this and provides the opportunity to live longer, and significantly improve pre transplant quality of life.

This major change has implications - people with CF who receive a lung transplant need to adjust psychologically to the medical consequences of transplant. This is what the author conceptualises as the psychological tasks of transplant – adaptive tasks that need to be addressed by people with CF directly relating to and as a consequence of transplant.

Furthermore, whilst treating psychopathology post transplant may be the domain of a trained mental health professional such as a clinical psychologist, the author believes that broadly understanding psychological issues post transplant is the role of all health professionals working in a CF and transplant setting. The focus of this literature review will now shift to reviewing studies that illustrate the psychological tasks post transplant for adults with CF.

Broadly speaking, quality of life studies provide strong evidence that lung transplant significantly improves quality of life and psychological health (Choong & Meyers,

2004; Smeritschnig et al., 2005; Kugler et al., 2005; Fusar-Poli et al., 2007) especially in the short and medium term and in the absence of significant medical complications (Smertischnig et al., 2005; Kugler et al., 2005; Goetzmann et al., 2005; Limbos, Joyce, Chan & Kesten, 2000). Conversely, and depending on their type and severity, significant medical complications negatively impact on quality of life and mood and increase anxiety (Fusar-Poli et al., 2007, van den Berg et al., 2000, Vermeulen, Groen, van der Bij, Koeter, & TenVergert, 2004). This suggests that lung transplant potentially has both a positive and negative effect on a person's psychological functioning depending on the occurrence and significance of medical complications.

Lowton (2003) points out that it is qualitative research not quality of life questionnaires or measures of anxiety and depression that provide us with more information and detail about what the psychological tasks are for people with CF post transplant. Qualitative research can capture experiences post transplant and therefore illustrate in detail how individuals manage life and what difficulties they may encounter.

Although there is a relative paucity of literature in this area, some studies (Ullrich, 2008, MacDonald, 2006, Lowton & Gabe, 2003, Durst et al., 2001) do enhance our understanding by suggesting three broad areas of adjustment post transplant, each of which have potential psychological ramifications. They are: a) adjustment to a major medical event and significant change in health status that is a lung transplant b) adjustment to having a "new" chronic medical condition that is being a person with CF who has had a lung transplant and is now immunosuppressed and c) how people with CF post transplant move forward with their lives from a developmental perspective. Each of these areas will now be discussed in more depth.

A. Adjustment to a major medical event and significant change in health status that is a lung transplant.

The first major change post transplant relates to actually having a transplant and engaging in recovery and rehabilitation. This includes the transition from the intensive care unit to a general ward to discharge. Participants in Ullrich's (2008) study describe emotional lability as part of this process with moods fluctuating from euphoria to depression. This is consistent with evidence of an elevation of subclinical psychological symptoms and distress initially post transplant for recipients of cardiothoracic transplants (Dew & DiMartini, 2005).

B Adjustment to a "new" chronic condition

This is followed by the second major change which is the adjustment to a "new" chronic "condition" that is being a person who still has CF, but where the focus of treatment is no longer the lungs and who is now immunosuppressed. This means significant changes to treatment regimens, learning about new medication as well as developing new routines that may take into account being aware of risks to immunosuppression that is infection (Ullrich, 2008). This could be a time of anxiety in terms of adjusting to being immunosuppressed, as well as conceptualising what being well or unwell is where the lungs are not the main focus.

Linked to this is the question posed by Lowton (2003) and Ullrich (2008) as to whether the major medical event of a lung transplant changes the way people with CF see themselves in terms of their disease. A study by Lowton & Gabe, (2003) revealed that post transplant people felt a sense of release from poor health, a return to spontaneity and state of "near normality" in terms of health with a far less restrictive medication regime than pre transplant. A similar study by Lowton (2003) described people with CF no longer feeling 'experts' in CF since their transplant.

Ullrich (2008) addressed this slightly differently with the question “...are you still ‘chronically ill’ after the transplant?” Receiving a wide range of responses to this question, he points out that people with CF (as compared to other lung transplant recipients included in his study) have viewed CF as part of their identity and existence. Responses show that transplant can have an impact on an individual’s identity but this seems to be linked to the degree to which CF was part of their identity pre transplant.

C Moving forward developmentally

The third major change focuses more on how people “pick up” their lives again and move forward from a developmental perspective. Durst et al.’s (2001) study illustrates this by describing five key psychological goals expressed by a group of adolescents and adults with CF (age range 14-28) post transplant. These are: the need to control as many aspects of their lives as possible and set long term goals while dealing with parental over-protectiveness, adjustment to a new life style, managing the fear and anxiety of rejection and uncertainty regarding the future.

These all relate to lung transplant recipients starting to realise the opportunities transplant has provided from a developmental perspective, whilst also needing to manage the potential complications transplant may bring. This may involve a change to social roles and inter-personal relationships, as both Ullrich (2008) and MacDonald (2006) observed.

2.5 Summary

This chapter has considered ways of conceptualising the psychological tasks for adults with CF who have had a lung transplant. It initially considered lung transplant as a trajectory of experiences that should be viewed from a developmental perspective as a non normative event that occurs alongside normative life events.

The Family Systems Illness Model (FSIM), (Rolland, 1994) was suggested as a way of conceptualising chronic illness (including lung transplant) from a systemic and developmental perspective that situated the event of a lung transplant alongside other individual and family developmental processes.

What support health care professionals need to offer was also discussed from the perspective of health locus of control, where in a post transplant setting, a dual locus of control and collaborative relationship between transplant recipient and healthcare professional is suggested.

In terms of the psychological benefit of lung transplant, quality of life studies have shown that lung transplant confers a significant improvement to quality of life and psychological health. More specific studies relating to the psychological tasks post transplant have pointed to three major areas that illustrate the psychological tasks post transplant which include adjustment to a major change in health status, adjustment to a “new” chronic condition and a possible change in illness identity, and the strong desire to move forward developmentally and pursue life goals whilst managing uncertainty regarding the future.

However, this literature review has highlighted the paucity of research in the area of psychological adjustment to transplant for adults with CF. Furthermore there is a gap in the literature to specifically understand the psychological needs for adults with CF post transplant that this study aims to address.

2.6 Aims and research question

The aims therefore of this study are as follows:

1. To gain an understanding of the experiences of people with CF who have received a lung transplant.

2. To investigate what psychological support people with CF post lung transplant want from specialist CF services

In order to achieve these aims, the following research questions will be asked:

1. How do people with CF who have had a lung transplant conceptualise their lives post transplant?
2. How does lung transplant affect the support needs of people with CF post transplant?

Chapter Three

Methodology

The aims of this study were to gain an understanding of the experiences of people with CF who have had a lung transplant in order to identify what psychological support is needed from a health service perspective. This chapter focuses on the rationale for the methodology used in this study, followed by a description of the sample, procedure followed and data analyses.

3.1 Motivation for study

The motivation for this study came out of a context of a specialist CF service that offers multidisciplinary treatment and support for a significant proportion of Scotland's CF population. This service recognised that the number of patients attending the service with a lung transplant had increased to the extent that they now represented 13% of the total patient group. This led to questions about whether this specific group had specific needs and whether these were being adequately met by the service. As part of this, the researcher, who was a member of the team offering psychological input, considered this question from a psychological perspective questioning what level of psychological support was needed by this group regarding the challenges they may face post transplant.

3.2 Research design

A cross sectional design incorporating a qualitative methodology was utilised in this study in order to be able to access a deeper understanding of the lived experiences of adults with CF who have had a lung transplant and attend one of the largest specialist CF services in Scotland.

3.2.1 Rationale: Choice of methodology

Quantitative and qualitative research have fundamentally different ontological and epistemological positions, with qualitative approaches being based on interpretivism and constructivism as opposed to the positivist assumptions underlying quantitative approaches (Sale, Lohfeld & Brazil, 2002). A qualitative approach emphasizes process and meanings in the context of a specific researcher-participant relationship at a particular period in time. This focus on the lived experience of participants and the changing nature of reality created through people's experiences is very different from a quantitative perspective where there is one objective reality independent of human perception (Sale et al., 2002). Both approaches can yield useful data and so a choice of approach may ultimately be determined by the method best suited to answering a particular research question as well as the ontological and epistemological position of the researcher.

Due to the fact that numbers are often small in a CF context, research involving a post transplant group often includes other disease groups who also receive lung transplants for example COPD. However, as Dew et al., (2005) point out, in the drive for seeking generalisations with regard to understanding psychological issues post transplant, an "average" pattern can conceal sub groups which have different styles of adaptation to transplant. There is also a significant difference in the profile between groups, for example people with CF and COPD (Ullrich, 2008) not only differ in terms of age differences at transplantation, but have a different disease profile for example CF develops from birth whereas COPD is diagnosed much later in life and often as a result of lifestyle choices.

Quality of life measures have been gaining popularity in post transplant studies which offer the patient's subjective perspective of their psychological state in a

holistic context that is alongside their functional status and physical symptoms. These measures can be generic or disease specific and are multidimensional usually including four core dimensions namely: disease state and physical symptoms; functional status; psychological and emotional state and social functioning (Quittner, Buu, Messer, Modi, & Watrous, 2005). These measures have gained popularity because they provide important information following a specific treatment or intervention even when the intervention hasn't been termed a complete medical success, which can have relevance for conditions where there is no cure (Quittner et al., 2005). They may also be easier and less time consuming to administer as part of a routine clinic appointment compared to more in depth qualitative interviews. They would therefore be more appropriate to be used following a specific health crisis for example an episode of rejection or post transplant medical complication rather than when trying to understand the lived experiences of a particular group.

In a study that compared using a standardised self report measure versus qualitative research in a heart transplant population, Abbey et al., (2011) found that qualitative methods yield information that would otherwise remain unobserved if just using a standardised questionnaire. There may therefore be a case for smaller qualitative studies to provide a different perspective relating to more detailed and in depth information regarding specific disease groups to complement quantitative studies that seek to understand the lung transplant group as a whole, or yield quality of life and mood data in more specific sub groups.

It was therefore decided that in order to answer the research questions of this study, accessing the specific lived experience of this group utilising a qualitative approach would be most appropriate.

3.2.2 Choice of qualitative methodology

Qualitative research is a broad term that describes a number of different approaches to a particular type of research that involves an interpretative approach in a naturalistic setting that is trying to understand people's experience in terms of the meanings they attach to it (Denzin & Lincoln, 2000). More specifically it involves the researcher choosing from a variety of methods in order to gain the most appropriate access to the rich material of an individual's lived experience (Snape & Spencer, 2011). These methods can include observation, in depth individual interviews, focus groups or bibliographical methods, with semi structured interviews being the most widely used method of data collection (Willig, 2004).

When considering the aims and objectives of this study, the researcher decided that in depth individual interviews would be the most appropriate method of data collection to utilize as this would enable participants to describe their experiences of transplant in detail. Focus groups could have been useful in this study to understand a group perspective, but not possible due to people with CF being actively discouraged from meeting each other due to the risk of cross infection which has an adverse effect on survival (Koch, 2002).

Interpreting and analysing qualitative data using a qualitative perspective does not necessarily follow one agreed method or protocol (Spencer, Ritchie & O' Connor, 2011). Instead a variety of approaches can be chosen depending on the epistemological assumptions and the aims and objectives of a research study. Different approaches include content analysis, conversation analysis, analytic induction and discourse analysis, grounded theory, interpretative phenomenological analysis (IPA) and framework analysis.

As discussed, this study originated in a health setting where the researcher was a member of a specialised CF team offering psychological support to people with CF. It was originally conceptualised as a service audit that is considering whether the service was successfully meeting the needs of those adults with CF who had received a lung transplant. The researcher however identified that there was a gap in the literature in understanding the psychological needs of people with CF post transplant and sought to find a qualitative methodology that could encompass both of these aims.

It could be argued that grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998) or interpretative phenomenological analysis (Smith, 2003) could be considered potential methods of qualitative research in this study. IPA (Smith, 2003) is a qualitative methodology grounded in a phenomenological perspective whereby a researcher accepts the impossibility of gaining access to research participants' world views and that understanding is always an interpretation of participants' experience (Willig, 2004). Although there are different versions of grounded theory, in general it uses an inductive process to generate theory from coded data (Willig, 2004). Charmaz's (2006) social constructionist version has latterly gained popularity compared with earlier positivist versions.

The framework method is a fairly new research methodology developed by the National Centre for Social Research as a method to analyse qualitative data in applied policy research in the 1980's. It is particularly suited to a health care setting where a research brief can be commissioned with highly focused aims and objectives (Smith & Firth, 2011). As a result, the process of identifying a thematic framework is made up of *a priori* areas (areas that are informed by the original aims and research questions) as well as emergent areas (areas that are raised by participants in the

interviews) and analytic areas (areas that arise from the recurrence or patterning of particular views and experiences) (Ritchie & Spencer, 1993).

The process of analysis is therefore both inductive and deductive which is fundamentally different from grounded theory and IPA which are both inductive (Pope, Ziebland & Mays, 2000). IPA, for example, works with transcripts of semi structured interviews following a series of steps that guide a process of interpretation with as little imposition of meaning by the researcher as possible. At the end of the process areas are produced that can be traced back to the data which form the researcher's best interpretation of a participant's experience. Framework analysis in contrast to this approach is not aligned with a particular epistemological approach, but is seen more as a flexible tool that is aligned with thematic analysis which aims to identify commonalities and differences in qualitative data (Gale, Heath, Cameron, Rashid & Redwood, 2013).

The Framework approach also has a particular application in a healthcare setting where pre-set aims and objectives can drive a study with a specific outcome that has relevance in clinical practice. This had considerable applicability to the aims of this study which included actively considering whether a service in a healthcare setting needed to be changed based on the results of the study, as opposed to primarily understanding participant's experience of lung transplant.

In this study the researcher wanted to go beyond generating the themes that IPA would yield or theory that grounded theory would generate, and produce a framework that could be used as a guide to understanding the key psychological factors that need to be taken into consideration when working with people with CF post transplant as well as considering the practical service needs of this group.

This was particularly relevant as the experiences of people post transplant can be quite different depending on the amount and type of complications as well as other factors, including the age and stage of the person when they received a transplant, amount of time on the list and so on. A framework that can outline the various psychological tasks post transplant, together with an appreciation of factors that can influence adaptation to these tasks would be most appropriate and useful in this setting.

A framework approach enables analysis by both case and theme adding another layer to qualitative analysis. This approach may be able to illustrate the challenges and opportunities post transplant, but still be able to point out factors that account for individual differences. For example a person in their 20's who has had very few post operative complications, may adjust more readily to getting home for the first time than someone in their 40's with other physical health issues who also has had considerable post operative issues. The framework approach could be particularly useful in this study as the cohorts of people with CF who have had lung transplant are very diverse – there may be differences in terms of amount and degree of post operative complications; differences in terms of age at transplant as well as differences in terms of the number of years that have elapsed since transplant occurred.

By enabling analysis by case and theme and allowing the generation of a framework or matrix, the author hoped that psychological issues post transplant would be able to be conceptualised in a way that outlines the general processes that all people experience post transplant whilst allowing for variation in terms of the complex factors surrounding lung transplant that makes the experience unique for each individual. This would allow understanding of the broad phases whilst allowing room for individual variation.

It was with this in mind that the research design was chosen – a cross sectional design utilising the framework method of qualitative analysis.

3.3 Description of sample

Elliott et al. (1999) underscore the need for situating a sample as part of guidelines that demonstrate good rigor in qualitative research. This section accordingly, describes and situates the sample used.

Participants in the study were drawn from a specialist CF centre in Scotland, the Scottish Adult CF Service, which offers ongoing care and support to 185 people with CF over a wide geographical area including Edinburgh and the Lothians, the Borders, Dumfries & Galloway, Fife and Dundee, and Inverness. 132 people with CF attend clinics in Edinburgh and it was this group who were identified as potential participants in this study. Of this number 17 people or 13% have had lung transplants and were invited to participate in the study.

In the UK, once people with CF have had a lung transplant their care becomes “shared” between the transplant centre and the CF centre. This means in practice that the transplant centre remains responsible for all matters relating to transplant, while the CF centre continues to care for the post transplant patient for all their medical care relating to CF. The CF patient post transplant does not usually attend CF clinics for 6 months post transplant as the focus during this period is stabilising them medically primarily in terms of their transplant and immunosuppressant medication as well as managing any early side effects or complications relating to transplant.

3.3.1 Inclusion and exclusion criteria

Inclusion criteria: Any adult over 18, who has Cystic Fibrosis, has had a lung transplant and attends CF clinics in Edinburgh.

Exclusion criteria: Any adult over 18 who has CF, who has not had a lung transplant or attends clinics in centres other than Edinburgh.

3.3.2 Method of recruitment

People who met the inclusion criteria were sent a letter (See Appendix 1) asking if they would like to participate in a small study to understand the experiences of lung transplant in people with CF with a view to improving the services offered to people post transplant. The letter made reference to their next clinic visit and suggested that the research interview could be held either before or after clinic.

Participants were given the option of responding directly to the researcher or via the CF Clinical Nurse Specialists (CNS) with whom all people with CF attending the Scottish Adult Service are very familiar with and speak to on a routine basis.

This was put in place as the researcher was also the specialist team's clinical psychologist and so giving a choice of ways to respond to the invite letter could make it easier for participants to choose whether they wanted to participate or not and for no one to feel that it might be difficult to access the psychologist in the future if they said they did not want to participate in the study. The CF group are very used to research and audit and are generally understood to be an assertive group that will only participate if they choose to (Lowton, 2005).

3.4 Procedure

3.4.1 Ethical issues, confidentiality and informed consent

The British Psychological Society (BPS) Code of Human Research Ethics (2010) and the Health and Care Professions Council (HCPC) Standards of Conduct, Performance and Ethics (2012) set out principles of best practice applicable to all research contexts.

i) Ethical review

These include the need for research protocols to be properly evaluated by reviewers with appropriate expertise to ensure that research proposals are of a high standard and pose no risk to participants. Opinion was sought as to whether this study was classified as a service audit or a research project needing ethical approval from the Scientific Officer from the South East Scotland Research Ethics Service. The response was that the study was deemed to be a service evaluation and as such it did not require NHS ethical review (See Appendix 2).

ii) Confidentiality

The BPS Code also stresses the need for confidentiality to be strictly observed and for research participants to be confident that what they say is confidential. To ensure participant anonymity, all identifiable information was removed and each interview ascribed a number for example Int 1, Int 2 etc.

iii) Safe storage of data

Recordings and transcriptions were kept in a secure place in a locked office on NHS premises. Two medical secretaries working within the NHS transcribed the recordings.

Both transcribers were familiar with confidentiality and safety criteria as part of their duties as medical secretaries working in the NHS. The researcher went over safe storage of data procedures with each transcriber and they each signed a confidentiality agreement (see Appendix 3) whereby they agreed to keep the interviews in a secure place, not let anyone else listen to them and return both the transcription and original recordings to the researcher and destroy any other material they may have relating to the interviews.

iv) Consent

Obtaining the consent of participants is equally important. With this in mind, the researcher gave all potential participants the choice to opt into the research following receipt of the initial invitation letter. Once participants had indicated whether they wanted to be part of the study, the researcher telephoned them to fully explain the procedure. This included their rights in terms of consent and the right to withdraw from the study at any point without any impact on their medical treatment. During this telephone call, participants were given the opportunity to ask any questions or have any aspects of the research process clarified.

When the researcher subsequently met each participant for the research interview, she went over their rights and gave participants the opportunity to ask any questions. Following this, participants were asked to give their consent to the procedure. In this way participants had several opportunities to consider whether they wanted to be part of the study and thus give informed consent.

3.4.2 Development of interview guide

Interviews were designed to be semi structured which would give a mixture of structure and flexibility. With this in mind, the researcher developed an interview guide, which would broadly direct the interviews, but also left space for participants

to raise any experiences or issues that had not been covered as well as for participants' answers and perspectives to be explored (Legard, Keegan & Ward, 2011).

The interview guide was developed with guidance from the extant literature, questions raised by the CF multidisciplinary team, as well as the researcher's own clinical experience as a clinical psychologist working with the CF service for over 7 years.

The literature points to three main areas of change post transplant, namely: a) a general adjustment to a significant change in health or major medical event, b) adjustment to a "new" chronic medical condition and c) how people with CF post transplant move forward with their lives from a developmental perspective. Some literature has also suggested stages or phases post transplant which led the researcher to wonder whether there were specific "milestones" that participants experienced post transplant that were significant to them.

Research has also pointed to psychological difficulties being experienced by those who have experienced significant medical complications post transplant which the researcher wanted to explore further in the interviews.

During the research planning process, the researcher engaged the CF multidisciplinary team as part of a consultative process. This was to include the wider CF team in the research process, which is in line with a framework approach. The CF service wanted to consider whether participants were in favour of services that were more specifically focused on people post transplant that is specific post transplant clinics as opposed to people post transplant coming to general CF clinics, as well as being broadly supportive of the researcher's aims.

The interview guide was thus developed with guidance from these areas and resulted in seven broad areas, with prompt questions as follows:

<u>Area</u>	<u>Prompt questions</u>
1. Experience of transplant	What do you remember of the time when you had your transplant? Post op complications, any aspect traumatic? Did you have enough support and info (who from).
2. Going home and first year	What were your feelings going home? How long did it take you to recover from surgery and feel back to normal? What changes were there? New routine/medications? Concerns about rejection or complications? Support (who from and enough?) Emotionally how did you find it?
3. Life post transplant	How has your life changed since having a transplant? Challenges/Opportunities?
4. Stages/Phases/Milestones	Have there been stages or phases you have gone through since transplant for example after the first year, after 5 years etc. Milestones? What have they been? How would you define them? Different support/info needs? Support (Who from and enough?)
5.Rejection & Medical Complications	How did you cope? Were some harder to cope with than others and if yes why? Impact on QOL? Did you expect the ones you got and

surprised you didn't get others? Warned -
Expect them? Protect against them? How much
do you worry about rejection and medical
complications? Enough info and support about
rejection and medical complications?

6. Professional Support

Shared Care, How have you found this? Do you
think you have different needs in terms of the
CF service post transplant? Suggestions as to
how we can improve the services offered to
post transplant CF pts? Would you have liked
more support/input from clinical psychology –
Edinburgh/Newcastle? When? What?

7. The future

What does the future hold for you? How do you
see the future?

Any other comments.

3.4.3 Interviews and transcription

The interviews were carried out over a period of a year between August 2011 and 2012. Interviews were recorded in full on a digital voice recorder and transcribed verbatim from the voice recordings. Interview length varied from 34 to 74 minutes (average 41 minutes per interview).

3.5 Data Analysis

Data analysis is a continuous and iterative process that involves two broad stages: managing the data and making sense of the evidence through descriptive or explanatory accounts (Spencer et al., 2011).

Data were analysed according to the five key stages of framework analysis, a matrix based analytic method with a thematic framework as outlined by Spencer and colleagues, (2011) as follows: 1. Familiarisation, 2. Identifying a thematic framework, 3. Indexing, 4. Charting and 5. Mapping and interpretation.

1. Familiarisation:

This stage involved two parts; firstly becoming very familiar with the data by reading and re-reading transcribed interviews. This was followed by noting key ideas and possible areas in the margins with the relevant section of text highlighted (see Appendix 4). An initial list of possible codes/ areas was generated for each interview and then collated for all 11 interviews where attention was paid to recurring areas (See Appendix 4). (Please note, the author decided not to include a section of original transcript in Appendix 4, as the material gained during the interviews was so individual and the sample so small, there were concerns that including part of an original transcript would enable participants to be identified and therefore breach confidentiality.)

2. Identifying a thematic framework:

The next task involved identifying a thematic framework or index from the recurring areas as well as *a priori* areas that may have informed the interviews through the topic guide (Ritchie et al., 2011, Gale et al, 2013). This involves sorting and grouping areas into higher order categories or main areas and putting them into the framework (See Appendix 5).

3. Indexing:

Once a preliminary framework has been developed, indexing takes place where the framework is applied to all interviews.

This is done by considering all the areas and raw data in the light of the framework and considering its applicability. This process often results in a refinement of the framework as there may be important categories to add, group together or collapse (Ritchie et al., 2011). Appendix 6 outlines this process.

4. Charting:

This stage involved setting up thematic charts according to each area and sub area. Each interview is assigned a row on each chart and a process of summarising the key points of each piece of data is carried out in the thematic matrix. This could also be a direct quote from each participant relating to each area or sub area in order to ensure a strong link with the original data. See Appendix 7 for an example.

5. Mapping and interpretation:

This final stage involved reviewing the charts to map and interpret the data as a whole and further refine the framework. It involves summarising and synthesizing the data and concludes the process of analysis by seeking meaning and interpretation as well as exploring the relationship between major areas and the established literature. This will be further discussed in the Results chapter.

3.6 Summary

This chapter has outlined the rationale behind the decision to utilise a cross sectional design utilising qualitative methodology to answer the research questions in this study. Furthermore it has outlined the suitability of the framework method as the chosen qualitative approach to analysis due to its relevance in a health care setting and its use as a method that is both inductive and deductive that can influence service design.

Chapter Four

Results

This chapter outlines the results of this study which has sought to understand the experiences and service needs of people with CF who have had a lung transplant and attend a specialist CF service in Scotland. More specifically the aims and research questions of this study were as follows:

Aims:

1. To gain an understanding of the experiences of people with CF who have received a lung transplant.
2. To investigate what psychological support people with CF post lung transplant want from specialist CF services.

Research questions:

1. How do people with CF who have had a lung transplant conceptualise their lives post transplant?
2. How does lung transplant affect the support needs of people with CF post transplant?

4.1 Participant characteristics

Of the 17 people asked whether they would like to participate in the study 65% or 11 people (6 male, 5 female) agreed. One person did not want to do a full interview that was audio recorded, but spoke briefly to the researcher during a clinic appointment. The researcher made brief notes after this interaction, but this person was not included in the sample. Five people chose not to participate.

Table 1 Overview of Participants

	Gender	Current Age	Age when received transplant	Years since transplant
	F	60	59	1
	M	48	45	3
	F	25	20	5
	F	35	28	7
	M	40	49	9
	M	36	25	11
	M	39	28	11
	F	51	39	12
	M	44	31	13
	F	38	24	14
	M	36	14	22
Mean		41 years	32.9 years	9.8 years
Range		20-60 years	14-59 years	1 – 22 years

4.2 Framework of how adults with CF conceptualise their lives post transplant

The framework approach allows for the development of a framework which encapsulates the main areas from data analyses which is presented on page 53 in tabular form (Table 2).

As has been described, the composition of a cohort of people with CF who have had a lung transplant varies greatly in terms of length of time of transplant, age at transplant and amount and degree of complications post transplant. At the same time, this group also shares certain commonalities.

The framework approach enables these similarities to be captured; in the framework presented below common experiences are organised into four broad areas of adjustment, each of which have key activities. These areas are organised chronologically and according to the key goals or milestones participants described post transplant.

In order to capture individual differences each area of adjustment has “key factors” in each area. These are specific factors that could increase the chance of potential difficulties developing in the post transplant adjustment process. For example, the age and developmental stage a person is at or the amount and severity of complications they may experience at a particular point could impact on the amount of difficulties they have and therefore the amount of support they may need.

Table 2: Framework of how adults with CF conceptualise their lives post transplant.

Key areas of adjustment	Recovering	Adjusting and realising	Redefining and pursuing	Managing the issues of post transplant life
Key Activities	Physical rehabilitation Participating in recovery Establishing a trusting relationship with the transplant service Gradual progress towards going home.	Getting home Realising new physical capabilities Moving away from pre transplant identity Regaining independence Adjusting to change in treatment regimen and different risks	Redefining and pursuing life goals: a) Career b) Other life goals Redefining key relationships: a) Partner and family b) Self as person with CF c) Donor d) Professional relationships	Managing rejection Managing post transplant complications Managing uncertainty re the future
Key factors	Complications post surgery Perceptions of complications post surgery	Age when transplanted Time on the list	Age and stage in life Time on list	Amount and type of complications

Each area will now be discussed in more detail. Quotations from participants have been used wherever possible to keep as close as possible to the original data. This is in line with Elliott et al's (1999) recommendation for qualitative data to be grounded in examples, ensuring coherence of data and presenting the results in the best way possible in order for the reader to understand and appreciate it.

4.3 Areas of post transplant adjustment

4.3.1 Area 1: Recovering

Key activities	Physical rehabilitation
	Participating in recovery
	Establishing a trusting relationship with the transplant service
	Gradual progress towards going home

From a chronological perspective this area of adjustment spans once a transplant occurs until recipients are discharged from hospital. During this time recipients realise they have actually received a transplant and there is a shift in focus from trying to keep alive and as well as possible in order to stay eligible to get a transplant to actively working with the transplant service to recover from surgery and build their new lives.

Physical rehabilitation

Participants described a variety of milestones they experienced relating to gaining strength and recovering from surgery, for example having their drains removed, coming off oxygen, and being able to walk unaided. These broadly followed the theme of starting to feel physically stronger and less dependent all of which seemed to happen gradually:

The first milestone I think was actually waking up from the transplant; you know actually having had the operation. And I guess the next one would be the oxygen being taken away. (Participant 10, lines 152-155)

Well for me it was -- for me it was getting drains out of my neck...that was the first big one to achieve was getting drains out of my neck. They are

terribly necessary but they're they're very uncomfortable, it's like heavy beaded dreadlocks that swing around your shoulder... Being able to walk on my own was another one, that was a few weeks down the line. Being able to cough for the first time which is really quite a pathetic thing to listen to. Being able to yawn for the first time. Being able to do my own drugs for the first time. You know there was a whole lot of these milestones, they are very small to begin with but they become more and more meaningful to you. (Participant 11, lines 91-95, 103-110)

Progress varied according to complications post surgery. All participants spoke of the process where they had to recover from major surgery stating that they did not feel "well" or significantly better for some time. This seemed to fall within two categories – being able to breathe deeply and realising the implications of this, as well as realising that they were needed to work on physical rehabilitation as many were very weak as they had been inactive and unable to do physical activity for a period of time whilst waiting for transplant.

Participating in recovery

A noticeable feature of participants' stories of recovery was how motivated they were to progress physically and that they felt a sense of pride in their progress.

Because I was actually walking about the hospital with one of the lung drains still in...I actually used one of the wicker baskets that the flowers were in, I put the flower in the bucket and take the basket and carried the lung drain about with me. So because I got up and walked about that aided my health rather than just sit there. So the quicker you get on your feet and the quicker you move about the better. (Participant 8, lines 168-173, 178-181)

Clearly, the amount of post operative complications is a key factor in this area – some participants described being up and mobile very quickly, whilst others took longer. The researcher was struck by how quickly participants seemed to relish being physically able and keen to participate in rehabilitation and improve their physical condition. This perhaps links in with the previous section on physical rehabilitation.

Establishing a trusting relationship with the transplant team

While working hard on physical rehabilitation, having a lung transplant signified the start of a new relationship with the transplant team and shared care between them and their local CF service. For many participants the hospital where they were transplanted was not close geographically to where they live or the CF service with which they had established relationships with their care providers. New relationships are thus developed as their care will now be shared between the transplant team and their local CF service.

Part of this new relationship is the need to develop a trusting relationship with new care providers that is the transplant service. One participant illustrated this in describing her insistence at wanting to continue to use breathing equipment (that had been a lifeline pre transplant) after her transplant:

...you have so much support when you're there and in hospital and like you learn to trust them with everything like when they said to me that my lungs would be fine and I was convinced it wasn't fine and then it was fine and when I went over I brought my bipap with me and I insisted on using it a few times after I had the transplant and eventually the surgeon came in and told me to throw it out and if he saw me with it again he would be very cross(laughs), but it was just learning to trust them and to trust that what they

said was right so by the time it came to going home I had learned to trust them...(Participant 3, lines 163-172)

Gradual progress towards going home

As their strength increased and their condition stabilised medically, participants described how they gradually started to move towards going home in a series of “steps” facilitated by the transplant service that helped them gain confidence whilst being close enough to the hospital to feel safe. These steps included moving from a high dependency ward to a general ward, then to a hospital flat, going out on day trips or weekend visits to home and then finally going home. The majority of participants commented on how useful this approach was where they could see themselves improve and progress, but at the same time be close enough to the transplant centre should there be any difficulties.

You know to build yourself up and eat your own food and know that support is still there and you're there handy enough for them still to be monitoring you and still to be taking bloods and to treat anything quickly that raises its head. And that's that's really is reassuring. And then of course you've gained that bit of strength and you've gained that bit of independence so the next thing is 'oh god I wish I could go home' you know. (Participant 11, lines 240-247)

... So I got out for the weekend to see how I would be over the weekend and then went back down on the Monday and they'd already moved all my stuff out the room, they were like 'oh we needed your room' so they were like 'we'll sign you out and you can leave'. So it was fine, I just had to go down every week for the first what was it? Month or so and then it became every two weeks and then a month, just until everything was stable sort of thing, to

get your bloods done and go to obviously the clinic and everything like that
so. (Participant 9, lines 158-167)

4.3.2 Area 2: Adjusting and realising

Key activities	Getting home
	Realising new physical capabilities
	Moving away from pre transplant identity
	Regaining independence
	Adjusting to change in treatment regimen and different risks

This area of adjustment broadly starts at the point of discharge from hospital where transplant recipients get home and continue to gain physical strength, whilst realising that their lives have been fundamentally changed. This occurs alongside significant changes to treatment regimens and the need to understand and adjust to new transplant related risks that is risks relating to being immunosuppressed. From a chronological perspective this area seems to span from the time transplant recipients get home to the time they have stabilised post transplant which means at least a year but can be longer depending on post transplant complications.

Getting home

All participants reported getting home to be a very significant milestone for them as well as their friends and family.

...going home was a big thing from the hospital... But I think it was more a big thing for my family... But obviously because I had a wee boy going home

to see him that was... that was my focus, obviously my wife as well, but going to see him and obviously seeing my family.” (Participant 5, lines 197-202)

Realising new physical capabilities

Once at home, participants continued to realise that they have more physical capabilities than they have had for a long time and the implications of this, as well as understanding and adjusting to risks post transplant and their new treatment regimen.

Many participants noticed improving energy levels, which enabled them to truly appreciate the difference in physical capabilities pre and post transplant.

I was desperate to clean my bathroom...Because I couldn't do...I mean I used... I had a cast iron bath so I had to bleach it and of course the last time I done that it just about wiped me out. (Participant 10, lines 183-187)

Just like putting my clothes on, having a shower, you know being able to go to the hospital and have a shower without... because you know things like that were just so difficult, even with the oxygen because I was so low and just every movement, as I say even brushing my teeth or brushing my hair, you know just doing that it... even the small, because it was exhausting. I was exhausted just lying still so as soon as you try and do anything, you know...And just as I say the smallest things, the smallest things. And then of course then realising as time goes on that you've a bit more freedom, that you know I could go out and I could get my car and I could drive again.” (Participant 7, lines 682-694)

...a lot of it was just because I hadn't used my legs for so long, I was weak. But that sort of... The amount I was eating I think I soon sort of got a big

stronger that way, so I mean for a while I was going out with the wheelchair and actually just pushing it and then with my mum and then when my leg sort of gave out I could sit down and she could push me back, but I was sort of using it like a zimmer or something just to support myself. But that was just as I say building up muscle again because my legs were like twigs, you know.” (Participant 7, lines 712-721).

Moving away from pre transplant identity

This realisation of new physical capabilities seemed to help participants start to move away from their pre transplant identity and grasp the opportunity of life with both hands. For some this involved realising how poorly or close to death they had come, which could be a very emotional experience.

I think one day I went down to the Outpatients and I was crying, why I dinnae ken, it's just the fact that, I don't know, it's just like you've actually realised that everything's gonna be... I'm no saying you're over the worst but you can actually walk about and do things and talk, like I'm talking now. Where before when you go back to a month earlier you're just about on death's door which is like the opposite of where you are now. (Participant 4, lines 247-254)

For some participants, it was returning pre transplant equipment that also signified this major change in their lives:

Ooh. It was fantastic to give my oxygen back. The big machine that I used more and more and more and more as I became more and more and more unwell, I trailed a great long green piece of tubing from it to me throughout my flat...So to go the other way and and it's a big ugly machine anyway, and to go the other way and to not have any tubing lying on my wooden floors.

And then the guy coming and immediately thinking I was dead and then being really happy that I wasn't dead. And him taking those machines away was fantastic (Participant 11, lines 329-332, 341-346).

All participants reported during this period becoming aware that they no longer had difficulties with breathing – something that had taken time as immediately post surgery taking a deep breath was hindered by significant surgical wounds on their chests and their new lungs not being fully inflated yet.

...if you've got a wee 1 litre Fiesta it's quite cold to start in the morning, you fit a V8 engine in, you know the difference, well that's it -because I could breathe that's the biggest issue, you know just breathing. And (the) energy kick because you can breathe is unbelievable (Participant 5 lines 197-202).

Because I never breathed like that in my life, no. That was...That took some getting used to because I didn't have to pull the air into my lungs and consciously breathe, it just happened and I'd never done that before (Participant 7, lines 638-641).

Regaining independence.

The move away from a pre transplant identity in terms of physical capability seemed to make way for all participants to regain independence and get back to normal or “get on with life” with renewed vigour. Interestingly, it seemed that what ‘normal’ was to each participant was different and often related to their age and stage in life.

I wanted to just go home and play with my friends and be able to join in, like because before I couldn't really...Yeah (...) I done everything and anything I could do as much as much as I could. All the time exercise type sports ...Fun and games that require a lot of eh breathing, so, but I was, I played every,

played tennis, played golf. I've I tried everything and just embraced everything because it was so, it was so amazing that I was able to do it (Participant 1, lines 84-93).

It was just incredible, I could plan things. You know I mean within a couple of weeks of being home I had planned a holiday...I think I just started by I mean getting out and about for about three months between transplant and the end of that year I don't think I had a weekend in my own house...I was out enjoying myself, I was out partying. It was amazing. And then by the December I think I had booked my first abroad holiday with my auntie, the following May after my transplant we went to Tenerife for a week (Participant 10 lines 215-217, 231-233, 235-238).

Change to treatment regimen

Participants all reported a significant change in their treatment burden. Apart from an immediate reduction in physiotherapy and chest based treatments, the main change was an increase in the number of tablets they need to take (could be up to 100 a day). Participants reported some anxiety with this initially, especially when they were still in hospital, where they benefited from support, but all reported settling down in time with the new medication regime, often finding it a lot less onerous than pre transplant treatment regimes.

From the start I suppose it was because you weren't quite fully compos mentis, I mean you were still a bit groggy and err some of the nurses and that helped you. But certainly after a while you just got into a routine...It's a case of now you almost shut your eyes and just do it now, off by heart... (Participant 2, lines 185-188, 190-191).

Well I mean all I've had since is taking the pills twice a day...huge difference yes, you don't feel nearly so tied to, you know, the day being set out and doing one thing and then doing another and you know before that it was getting up it was taking the nebuliser, physiotherapy, you know this that and the other, you know. Or coming in for hospital visits and never knowing you know how long you'd been in and out and all that sort of thing (Participant 7, lines 580, 605-611).

Adjusting to new risks

Participants were keenly aware initially of trying to keep away from sources of infection and follow the guidelines they had been given by the transplant service in keeping as well as possible. This signalled a process of becoming aware and managing different risks namely rejection as opposed to what they were used to pre-transplant.

I was worried about things like picking up infections in supermarkets or on planes. My brother bleached the whole shower, completely cleaned out the head of the shower and everything and I mean you could have eaten your dinner off the shower by the time I got home and he had it all ready for me. Ehm we were like using a new face cloth every time I washed my face, changing my bed every evening. Just probably completely over paranoid about infection and I was just worried about everything (Participant 3, lines 179-187).

However, like with changes to their treatment regimens, all participants reported that in time they became comfortable with the different risks associated with transplant, most specifically picking up infections from public places.

4.3.3 Area 3: Redefining and pursuing

Key activities Redefining and pursuing life goals

- a) Career
- b) Other life goals

Redefining key relationships:

- a) Partner and family
- b) Self as person with CF
- c) Professional relationships
- d) Relationship with the donor

This area of adjustment starts when participants have stabilised medically post transplant and the initial adjustment to transplant has taken place. This can often be about a year after transplant (depending on medical complications during the initial stabilisation phase). Where the previous area of adjustment is about realising and understanding new physical capabilities, adjusting to new treatment regimens, the focus now shifts to defining and actively pursuing the new horizons transplant has provided.

Key activities during this time are divided between redefining and pursuing life goals as well as redefining (and potentially pursuing) key relationships.

Redefining and pursuing life goals

In the last section, participants described starting to move away from a pre transplant identity of being so physically restricted that the most basic of tasks were physically exhausting.

Now, participants seem to have come to terms with their new physical abilities and describe a process of “getting back on track” with their pre- transplant lives. What “getting back on track” means can vary and is linked with the participants age and stage in life as well as the amount of time they were unable to pursue their life goals due to being so unwell pre transplant. Some of the areas discussed by participants will now be described.

Career

Participants in this sample showed a range in terms of occupational status. Some were at work or college at the time of transplant whilst others were not working at all either having had to give up work due to their poor health, or never having worked due to their health. Post transplant, some chose to commence working or re establish their careers post transplant, whilst others were keen to resume studies, compared to those who had either retired pre transplant or had never worked. Participants who had been involved in some form of training for example a college course pre transplant often continued with that after their transplant. The amount of time spent on the transplant list and the extent to which career goals were formalised seem to have a bearing on the extent to which participants managed to move forward again with their careers post transplant.

...well I was in the middle of doing a Diploma at the time so I'd done the first year and during the first term of the second year I went back to live with my parents. So, I just wanted to pick up where I'd left off (Participant 6, lines 107-110).

One participant who had spent a long period of time in very poor health prior to transplant spoke of having very little confidence in moving forward with a career and needed a lot of support from her local CF team.

...because I'd never been able to work and then I went on a course, I was put onto it through (name of CF nurse) through the clinic. It was mostly for women who'd you know been bringing up children or looking after parents and just wanted to get back into work...it was just sort of you know...what sort of job, the usual sort of thing, making up a CV because I had nothing to put on a CV and I was a bit... I did find it quite awkward, it was quite nerve-racking because I did feel so different from everybody. But I did have a very good sort of instructor who was, you know, sympathetic to you know the way I felt because I couldn't pick up a phone and talk, you know, I was really... I hadn't really been around people for a long time, you know, a long time I'd been at home and I'd been at clinics. I hadn't been able to socialise because of the oxygen and all sorts and I hadn't been able to talk properly because you know I was so short of breath. You know even just having a conversation was exhausting. So I'd been sort of... I felt I hadn't been out in the big wide world for a long time... (Participant 7 lines 727-731,733-748).

For others who were older or in a different life stage at transplant and had not worked for different reasons for example medical retirement or similar, pursuing a career did not have the same meaning and working was a means to paying the mortgage rather than creating and developing a career path. Clearly the financial position of participant's also influenced these choices.

The unpredictability of life post transplant, medical complications and treatment side effects also had an impact on the degree to which participants pursue their post transplant work careers:

Ehm when I started the job I was on a 5 day week now I'm on a 4 day week and that does help a lot but I still find it very physically demanding and if

I'm not 100% my job really takes it toll on me.... Yea they asked me recently where they saw me going and I said saw myself sitting in the same job for a long time (laugh)...which I do I've no interest in going any higher in there, not for the moment. I've other things I want to do with my life and spending all my time in work trying to impress the top men is not one of them. As long as I can hold down my job that's all I want to be able to do in there... (Participant 3 lines 724-725, 727-731, 741-744).

Other life goals

Once again depending on the age and stage participants were when they had their transplant, a process of moving forward with their lives involved them moving forward with other life goals.

These goals could be becoming more independent which included driving again, moving away from living with their parents, and changing their status in terms of partnerships. The researcher's understanding of this was that many issues had been put on hold pre transplant and that some participants even felt as though they had been "going backwards" in terms of their development pre transplant for example having to move back to live with parents when they had left home, or not addressing a poorly functioning relationship.

The situation often changed dramatically post transplant with participants often demonstrating great focus and motivation to move forward with their lives in whatever way was meaningful to them.

A different kind of role reversal

Some participants spoke of their experience of role reversal of a different kind. For many, years of declining health had meant that the gains that had been made in terms

of independence often seemed lost. This for some meant that a return to the parental home as they couldn't manage living independently any more. One of the first goals for these participants post transplant was to be able to regain this independence.

Some participants also noted that this return to 'the normal order' continued as their good health carried on post transplant enabling them to look after their own parents as they aged which was something they had never thought would be possible.

And it's actually the case now that I mean my father well is in his seventies now and he has a heart condition and it's me that does all the driving. I mean I've been away to college and I'm actually back living at home again and it's me that does all the driving so err. As my mother says I'm a vital part of the team. (laughs) I suppose it's swings and roundabouts, I mean they can rely on me now as I had to rely on them (Participant 2, lines 275-282).

Age and Stage

It is worth noting that out of the potential candidates for this research project two were juveniles at the time they received transplants. One agreed to be part of the study, whilst the other person agreed for the researcher to have a brief conversation with him about transplant, but did not wish to be recorded or have a separate research interview. The researcher noted a unique feature from these two participants namely that neither of them had any real perception of being at the end of their lives which was in marked contrast to those who were transplanted as adults. This also seemed to translate into a perception of not "seeing life in finite terms" as one participant noted. Clearly the numbers are too small in this project, but it would be an interesting research question to consider for future projects – the differences in perception of those who were transplanted as adults as opposed to those transplanted as paediatric patients.

Redefining relationships

Transplant has a major impact on relationships including that of the transplant recipient and their partner, parents and family, as well as relating to the CF team. This section explores these changes.

Partner and family

Clearly transplant has a major impact on not only the recipient but also their family. Roles in partnerships and families changed as the person post transplant gained strength and moved forward with their lives. For the transplant recipient this involved 'the task' of redefining relationships.

...I think that was a big shock to the family alone because there's no IV's you don't have to do all that anymore. Just literally take tablets, get up, there's no physio or anything like that. So I think it was a big like culture shock to everyone until it all pretty much evened out and things like that so.....and then obviously there's my mum she's lost a daughter and then she's also got a daughter whose went through a transplant so it was hard for her, 'cause she's cared for us both since we were both born. So she's been a carer for what twenty odd years of her life and then all of a sudden nobody needs her as well, so it's a big change for her (Participant 9, lines 311-317, 301-307).

Redefining partnerships was also described by participants to varying degrees – for some this involved feeling able to pursue finding a partner, while for others it involved changing existing partnerships:

...as I was going into transplant my husband and I had only been married since the August before...and things were going rapidly downhill. So I had

my transplant in the June following the wedding and on our first anniversary I went to the solicitor to file for divorce”(Participant 10, lines 243-248).

For others having a transplant meant they were now able to seek a partnership and start dating again.

Self as a person with CF

Participants described how their identity of themselves as a person with CF also experienced some redefinition. They described feeling different - not that they didn't have CF anymore, but felt different to those with CF who hadn't had a transplant.

...sometimes when I sit there (*at clinic*) and see someone with CF who looks really ill I think oh I'm so lucky and then I feel guilty that that ehm I'm a lot better than they are and I know what's going to happen to them in 2 or 3 years (Participant 1, lines 569-572).

...I find it very hard to believe that that was me. Sometimes I have to remind myself that that was me and I was the one who was coughing up a lung first thing in the morning on the ward or doing nebulisers and I feel quite out of touch with what CF's have to do now...hm and I look at some of them and I feel sorry for them in a way that they might not get the chance that I've had and that they are so sick and they look so sick and they're really struggling to breathe, and yeah...It seems like a completely different life time ago (Participant 3, lines 800-812).

I obviously feel different because I can breathe better and sometimes if you're sitting in the same area as somebody who hasn't had a transplant you know straight away because of their breathing, and that's kind of like Oh god

I would hate to be back there but you also with them because you know you know what they're going through... (Interview 10, lines 514-519).

'Relationship' with donor

The researcher observed that all participants were aware and felt some sort of connection to their donors. This was in a pragmatic sense of acknowledging that without the donor's lungs (or heart and lungs) they would not be alive. Participants varied to the extent that they celebrated transplant anniversaries or the extent they thought about their donor in spite of having very limited information about this person.

But...I do always remember it, it's umm my dad sometimes he'll buy me a bunch of flowers or something, he sort of ... he's the one that still remembers the day as such but umm, yes it's still it's always on my mind that day that you know that events back then of what happened that day and you know and always a wee thought for my, you know, obviously my donor, you know, because I'll always think his family must be, you know, it's a significant day for them as well.... You know you're having all this good fortune but somebody, some other family somewhere are going through hell. So it's not just pure exhilaration and it's not just, you know... you're sort of anniversary's not just a celebration, you know... (Participant 7, lines 12-20, 418-422).

It's just a weird thing, you can be sitting watching the television that is one of the things about the police, you know, and motorway cops or something like that and there'll be a car crash on it and they'll say it's a fatality and it's a young boy. So I'm like, you automatically think well is that what happened to him. Or just maybe somebody will say something to you and for whatever

reason it sparks it and I know, obviously I knew his first, 'cause they only tell you his first name, so whenever I hear that first name getting mentioned, whether it's in a conversation, obviously a conversation about somebody totally different, but the name then lodges in and you think about him ken. And you, you don't say a wee prayer but you say a wee thanks (Participant 5, lines 379-391).

I've never celebrated it. Err, again it's just a thing I've... I suppose I'm just glad of every day I've got I suppose. I mean I've never been a person... We've never been really a family or a person sort of have big birthday bashes and all this sort of thing (Participant 2, lines 396-400).

Professional relationships

Most participants attended their transplant centre very frequently in the first 6 months post transplant, after which time in the absence of significant complications, these appointments became less frequent (although still regular) and participants started re-attending their local CF centre. In effect, their care became shared between the transplant centre for matters relating to their transplant and their CF centre for matters relating to CF. This necessitated the development of relationships with the multidisciplinary team at the transplant centre. For those who had post transplant complications, a further set of relationships was developed with other specialist services, for example renal. Professional relationships therefore needed some redefining.

As has been discussed in the first area, developing a trusting relationship with the transplant service was a key task that seemed to commence immediately post transplant. Participants were very positive about the follow-up service provided post transplant both in terms of literature provided to them, and contact with health

professionals. However, lines of communication between the transplant service and the local CF service were criticised by most participants as being very slow. Participants also commented on the fact that they often have to develop relationships with other specialities for example renal which can potentially complicate issues further in terms of advice regarding medication and communication.

...every time I go to the renal clinic my renal consultant says “why are you on 4mgs and 3mgs and not on 3.5 and 3.5” and I don’t know the answer and then she writes to (the transplant service) and (the transplant service) obviously have their reasons for it and it just goes around every time I go to see her she says the same and I don’t know the answer (Participant 3 lines 527-533).

However all participants seemed clear about the boundaries of responsibility in terms of transplant, their CF and other issues for example renal and diabetes.

4.3.4 Area 4: Managing the issues of post transplant life

Key activities	Managing rejection
	Managing post transplant complications
	Managing uncertainty re the future

This area of adjustment refers to the challenges unique to having a transplant, namely rejection and medical complications post transplant as well as how participants manage the future especially as their life expectancy and survival post transplant is unspecified.

Managing rejection

All participants managed early episodes of rejection in a very positive way, which seems to be directly influenced by the transplant centre preparing them in advance, normalising early rejection and being very optimistic about treating it. Participants described early episodes of rejection as entirely normal and manageable. This was contrasted to those who had episodes of rejection once this acute stage had passed.

For those, these episodes of rejection were anxiety provoking and very unsettling, with some participants mentioning feeling quite anxious both during the episode and afterwards in terms of having to settle down again in terms of day to day life.

I mean I rejected twice when I was still at (transplant service/hospital) but they they don't worry about rejection, they just pump you full of drugs and three days later you're fine. So they say 'we'll not worry about you rejecting' so that's fine. And in the nine years I've had one bad session where at first I didn't know what was wrong and that then comes to mind was 'is this as far as it goes now 'cause they don't know what's wrong with me, are the lungs packing in'. But it turned out I had one infection on the top of my right lung and a different kind of infection on the bottom of my left lung and they were fighting against each other, so it taken them a couple of month to suss out what was going on, got that sorted so. Once I got that out the way I thought well that's... you've come through that wee hurdle and it was quite a major one because at first as I say they didn't know what was wrong, so once I got that out the road and it was a case of well we just, we just go along now and just every day we take it as a bonus (Participant 5, lines 427-445).

Yes, yeah. Because up to that point I was very comfortable with knowing when I have a cold, or sort of my own sort of reaction to things, you know. This last week I've had a bit of a sore throat and things and I'm sort of quite happy with that and don't feel that I need to come in here and see a doctor every time I have a sore throat and things like that ...so it sort of unnerved me a bit (Participant 6, lines 401-403, 407).

I also think it's got something to do with rejection from what was said to me when I was there in November. I came out of the doctors room a bit kind of I suppose shocked. Radiotherapy was mentioned and rejection was mentioned (Participant 10, lines 418-421).

Due to the great variation of the incidence and severity of rejection and its implications, it is hard to generalise results in this area from this cohort. However, a common theme throughout is that rejection after the initial post operative period is unsettling, anxiety provoking and frightening. This may well be a time for psychological support to be considered and where participants were most positive towards it.

Post transplant complications

I think there's the initial stage where you obviously have your transplant and every day you're feeling better and better and better and that goes on for about a good 9 months I think at least and then I think you sort of have a year or so of you're still in disbelief and you still feel amazing and you are just taking the drugs and your kidneys are doing fine and everything is doing fine and then I think you sort of little things just start to happen, the little complications but then it seems like the farther out you get the bigger the complications are getting (Participant 3, lines 587 – 595).

All participants had experienced post transplant complications and to a large extent these were not unexpected. However, how they were perceived varied. One participant had had complications that included skin blemishes which she found very distressing in terms of body image as well as needing a hysterectomy for cancerous cells. Others managed complications like high blood pressure with minimum distress.

A high proportion of participants reported having renal complications which necessitated them linking in with the renal service. Some participants struggled with this, mainly in terms of the different culture of renal teams in comparison to CF teams, often finding them less collaborative or understanding about their particular situations:

...when I was referred to the dialysis people and they whipped me in to have a look at their dialysis machines and that scared the living daylight out of me (Participant 3, lines 372-374).

... it was a nightmare.

CC How so?

P1 Just because of the way they do things so different. And they're very poor at explaining stuff to the patient, they just expect them, expect you to say yes sir, no sir three bags full sir (Participant 1, lines 446-452).

Managing the future

How participants managed the future was directly related to time post transplant and the amount of complications they have had. For some who had been very close to death pre transplant, having a transplant signifies a future where there previously had been none.

Well you've got a future, but prior to that I wouldn't have had a future, the end was nigh, you're looking at if I see next summer I'll be lucky rather than... which is most folk would have if they've got a big problem I think. And now you do plan things (Participant 4, lines 620-624).

Others conceptualised the future in terms of the amount of complications they had had:

Although I've had a fantastic 12 ½ years. I've had an...I've had an up and down year with several things this year, it just hasn't been a good year all round. But next year's round the corner so who knows... I suppose in the not too distant future working less hours and just doing what I can, taking each step as it comes and learning to live with what's going to happen... (Participant 10, lines 390-393, 443-445).

Whilst others had a fatalistic view of the future:

No you just take the day as it comes. If something's gonna happen it's gonna happen it's no good saying what's gonna happen or not, you cannae... if you worry about something that's not happened then that's not the thing (Participant 4, lines 346-349).

There was a clear difference between participants who had considerable complications which had negatively impacted on their quality of life and those who had only experienced minor complications or those that did not negatively impact on their freedom and quality of life.

4.4 Summary

This results chapter has presented a framework that has outlined four major areas of adjustment experienced by participants post transplant which are: recovering,

adjusting and realising, redefining and pursuing and managing post transplant life. Each of these areas have activities associated with them that participants described pursuing, as well as key factors that can influence the individual circumstances and response to each theme. The next chapter will discuss these results in terms of the extant literature.

Chapter Five

Discussion

This chapter will consider the results presented in the previous chapter in the light of this study's research questions and the extant literature. It will also consider the clinical implications of the research, limitations and future research directions.

5.1 Considering the results in the light of extant literature

As has been discussed, there is a relative paucity of studies relating to psychological adjustment post lung transplant. Of the existing studies, those focusing on psychopathology or quality of life indicate a general improvement in mood and quality of life post transplant (for example Choong & Meyers, 2004; Fusar-Poli et al., 2007). Participants in this study generally echoed these findings, unless they had significant post transplant complications.

As was stated in the literature review, the qualitative literature relating to adjustment post transplant can be broadly divided into three areas: adjusting to a major medical event and significant change in health status; adjusting to having a "new" chronic medical condition and moving forward from a developmental perspective. These areas will now be revisited in the light of the results of this study.

5.1.1 Adjusting to a major medical event and significant change in health status

Participants in this study describe four key activities relating to the first area of adjustment: "recovering", namely physical rehabilitation; participating in recovery; establishing a trusting relationship with the transplant service and gradual progress towards going home. Some participants described emotional lability consistent with Ullrich's (2008) and Dew and DiMartini's (2005) findings of an elevation of subclinical psychological symptoms and distress initially post transplant.

In the current study, one participant spoke of feeling very emotional for no apparent reason after his transplant, whilst another spoke of feeling very distressed in the post operative period. Both of these participants had had their transplants less than 3 years ago, and so it may be that the memory of distress post transplant was more vivid for them because the event occurred fairly recently.

However, transplant is clearly an emotional time both for recipients and their families. All participants spoke of being very relieved that they had received a transplant, often reflecting on how close they had come to death whilst on the transplant waiting list. Participants in this study have therefore all described experiencing a wide range of emotions in the immediate post transplant period and especially during the first year.

A feature of all participants in this study was how eager they were to actively participate in their recovery and physical rehabilitation post transplant, often expressing a sense of pride at how quickly they were recovering in spite of having major surgery. This may well relate to the age at transplant of participants. Schmeritnig and colleagues (2005) noticed that people with CF do better than other lung transplant recipients from different disease groups for example COPD as people with CF are often transplanted 15-20 years younger than other lung transplant recipients (Pochettino et al., 2007).

The need to develop a trusting relationship with the transplant team and gradually progressing towards home were a key part of this period, a finding that resonates with Moos and Schaefer (1984)'s framework that describes developing appropriate relationships with medical teams as one of the adaptive tasks of coping with a health crisis.

In their work, Moos and Schaefer (1984) used the concept of a health crisis in a broad sense to mean an unexpected health event which needs to be confronted and coped with, a definition that could easily include lung transplant. They propose seven challenges that an individual needs to overcome in order to cope successfully with the challenges that the health crisis brings. These include learning to detect and manage symptoms; dealing with hospital procedures; developing appropriate relationships with staff; managing upsetting feelings while maintaining hope for the future; preserving a competent self image; maintaining relationships with family and friends to provide support and preparing for an uncertain future. This framework has a clear applicability to describe the adaptive tasks post transplant, especially those covered by the first two areas described in this study's framework.

5.1.2 Adjusting to a “new” chronic condition

Moos and Schaefer's (1984) framework of adaptive tasks also has applicability to this theme in the literature, as well as to the first two areas described in this study namely 'recovering' and 'adjusting and realising'. This area of the literature focused on transplant recipients adjusting to changes in their disease 'profile' that is getting used to being immunosuppressed; not having the lungs as the key area of disease and disability as well as learning new medication or treatment regimens.

Participants in this study echoed Ullrich's (2008) finding of some initial anxiety about risk of infection when immunosuppressed, for example going to a supermarket late at night in order to avoid large numbers of people and keeping bathrooms scrupulously clean. However, this settled down, with all participants gaining confidence in this area after a short period of time. Participants also expressed pleasure at the change to their post transplant medication and treatment regimen, stating that in spite of having to take a large number of tablets post transplant, there

were many treatments that they now did not have to do for example physiotherapy or nebulised treatments and that this was very liberating.

This study's findings also illustrated participants' pleasure at moving away from pre transplant levels of physical ability, where they had very little energy, spontaneity or ability to pursue their life's goals. This is consistent with Lowton and Gabe's (2003) finding that people with CF post transplant expressed their health as a release, celebrated a return to near 'normality' and described a return of spontaneity.

5.1.3 Moving forward developmentally

The third theme in the framework presented in this study highlights people with CF post transplant's strong desire to redefine and pursue life goals which may include vocational aspirations; as well as redefining key relationships. These relationships include those with key family members who could be parents or a partner, as well as their own identity as a person with CF, their 'relationship' with their donor as well as professional relationships. Aspects of this theme resonates with research carried out by Ullrich (2008) and MacDonald (2006) who refer to changes to roles and relationships as a result of transplant.

Bury (1982) conceptualises chronic illness as a disruption to everyday life, and the future, as well as a disruption to the normal rules of reciprocity and mutual support in relationships. Lung transplant seems to fundamentally change the course of a chronic illness like CF by offering the promise or hope of a period of 'normality' for a person with CF from a respiratory perspective, instead of them having to face death. This means the ability to "regain" some of the losses in terms of life goals, independence and mutual support in relationships.

Clearly how people with CF who have a lung transplant choose how to move forward in terms of life goals may be dependent on not only their own age and stage

in life but also their personal circumstances, values and ambitions. This is therefore a highly individualised process. However, Rolland (1994) provides some guidance as to how we can conceptualise this by suggesting a developmental perspective that takes into account where a person is in terms of their own individual life stage or cycle as well as a person's circumstances in terms of their families and at what stage the family is at from a family life cycle perspective. This may provide some clues as to how someone may choose to move forward in terms of re-setting their life goals.

The seven stages of individual psychosocial development put forward by Erikson in the 1950's and described by Crain (2011) outline the key challenges that individuals face in their development at certain stages in their lives. The stages relevant to this cohort would be that of early adulthood (age range from 19 – 35) and middle adulthood (age range from 35 – 65). In early adulthood, individuals are usually motivated by the need to form intimate and loving relationships, find a career path and establish their first major life structure. In middle adulthood, the focus is often on work and parenthood where individuals are developing their careers, raising children and participating in activities that provide a sense of purpose.

Carter and McGoldrick (1989) have described families as also having stages or life cycles that they progress through which broadly speaking are: leaving home/single young adults; the joining of families through marriage/the new couple; families with young children; families with adolescents; launching children and moving on and families in later life. In the same way as where an individual is in his/her own stage in life individually, where they are in terms of their family life cycle can have relevance in terms of moving forward developmentally post transplant.

Participants in this study illustrated these findings – those who were clearly in the stage of early adulthood without a life partner described having moved 'backwards'

prior to transplant when they had to give up their independence and move back home with their parents due to their ill health. Their most significant initial milestone post transplant for this group was to regain independence and re-establish life goals as soon as they could. This is echoed in Durst et al's (2001) study where setting long term goals and moving away from parental over protectiveness were key areas of adolescents and adults post transplant.

Other participants who were older and in more committed relationships, some with children had a different focus developmentally. For parents, the focus often was to be able to do more physically with their children and get back to fully and actively participating in family life. Some participants spoke about just getting back to normal and enjoying the relative freedom compared to their lives immediately pre transplant, while younger participants clearly seemed to test the boundaries of what they could do and almost "make up for lost time" by taking every opportunity to travel and experience a social life that pre transplant had been impossible before settling down.

5.1.4 The developmental perspective

The literature review considered ideas where transplant was considered from a developmental perspective as a trajectory of experiences (Yorke et al., 2006) as well as considering some of the ways this trajectory has been described (Worby, 1998; Worby & Smith, 1997; Ullrich, 2008 and Kurz, 2001). The researcher argued in this study that more specific focus needs to be given to the post transplant trajectory because focusing on the entire transplant trajectory covers potentially a long period of time and very different issues meaning and not enough attention is paid to either pre or post transplant.

This study considered transplant from a chronological trajectory with areas emerging that were broadly similar to those suggested by previous authors, but has added

significant detail and focus. It has also added ‘key activities’ and ‘key factors’ which outline the main activities post transplant from an adjustment perspective, as well as key individual factors that need to be considered which could influence psychological adjustment.

5.1.5 The systemic perspective

A systemic perspective was considered in the literature review to mainly be able to contextualise the individual in terms of their family and professional support. This is because there is a growing amount of literature that demonstrates that both relational and professional support is significant in helping those with chronic illness have better treatment and psychological outcomes, findings that have been applied to a post lung transplant population (Savitch et al, 2003).

Family support

From the perspective of family support, all participants in this study spoke of the support they had received from their partners, parents or friends in the post transplant period. They also spoke of their pleasure at their own support needs changing and their increased abilities to be able to offer support to their own relatives for example parents as they aged. This seemed to have a specific significance for two participants who spoke of it feeling as though ‘the natural order’ had been restored.

Kurz (2001) considered ‘stages’ that well spouses of transplant recipients go through post transplant, namely: the transplant event; cocooning; normalising; branching out and settling down; which indicate some progression and change in terms of the nature of a spousal relationship post transplant. Whilst the focus of this study has not been to consider the impact of transplant on ‘significant others’ post transplant whether that be a spouse, boyfriend or girlfriend, partner or parent, it is clear from

the transplant interviews that transplant as an event affected more than just the person who received the transplant.

This may have special relevance when considering the fundamental uncertainty of transplant and the likelihood that all people receiving lung transplants will have some post transplant complications (Woo, 2008) which could be debilitating. Transplant may therefore encompass many different phases of wellness and illness, depending on these complications.

With this in mind, the FSIM may be relevant in this context by providing a framework to understand a typology of different illness related events that Rolland (1994) describes as the “illness life cycle” which describes the demands contained in each for an individual and their family. The three stages of the illness life cycle conceptualised by Rolland (1994) are crisis, chronic and terminal. Crisis is the period from the development of symptoms to the identification of a diagnosis and treatment plan; chronic signifies the phase where adaptation to the disease or illness takes place and lasts until the third phase which is called terminal which begins with the inevitability of death. Each of these phases requires different psychological responses from the individual and their family and potentially a professional system.

Applying this to a post transplant CF context, the development of chronic rejection (or a similar health crisis) is a crisis which matches the crisis phase of the FSIM. This crisis may resolve which then returns the individual to the chronic phase and the psychological demands relating to that. Should the rejection be so severe and result in imminent death, the terminal stage of the illness life cycle has relevance. The individual may also re-enter the chronic phase with additional treatment issues or less physical ability which would mean a period of adjustment to what the “new normal” is. Table 3 overleaf illustrates this further

Table 3. Tasks post transplant according to stages of the illness life cycle outlined in the FSIM (Rolland, 1994)

	Crisis	Chronic	Terminal
Individual tasks	Manage uncertainty and anxiety May feel very vulnerable May become hyper vigilant in terms of possible symptoms and their interpretation	Grieve for loss and move towards acceptance of illness related changes	Preparing emotionally and practically for death; Adjust to change from possibility to probability to inevitability of death
Tasks for family	Pull together to undergo short term crisis re organisation	Return to ways of functioning – “new normal” Adjust psychologically and organisationally to illness related changes.	Provision of emotional comfort; who do we tell? Preparing emotionally and practically for death.
Tasks for healthcare team	Illness management Reassurance Information	Less intense role. Help adjustment or reestablishment of “new normal”	Palliative care giving.

Rolland(1994) suggests that healthcare teams offer proactive support to individuals and their partners or families in order to be able to not only acknowledge and support them during these times, but to help them understand and manage the psychosocial tasks that each of these stages provides. This enables useful conversations with the healthcare team that can clarify what extra support patients and their families will most benefit from post transplant. The author considers this to be a very useful approach in a post transplant CF context.

5.2 Considering the results from the perspective of the research questions

5.2.1 Research question 1: How do people with CF who have had a lung transplant conceptualise their lives post transplant?

As is clear from the results of this study, participants clearly conceptualise transplant as a life-saving and life extending intervention that provides them with opportunities they would never have had. All participants reported progressing through a process of adjustment post transplant (as illustrated in the areas of adjustment discussed in the results) especially in the first twelve to eighteen months post transplant. This involved initial recovery from surgery and physical rehabilitation, adjusting to a different medication and treatment regimen, lifestyle changes commensurate with improving physical abilities which included re-alignment of life goals and changes in key relationships.

Participants reported this period to be one where they experienced a wide range of emotions including distress, anxiety, relief and happiness as part of this adjustment process. These emotions seemed entirely manageable without the need for any specific psychological input unless they had experienced any unanticipated difficulties or complications. However, many of the participants expressed surprise at

feeling so emotional during this time. This may point to the usefulness of developing some written material for post transplant recipients that normalises this.

The incidence and prevalence of medical complications that include rejection, as well as side effects of immunosuppressant treatment are very idiosyncratic and so participants varied in their experiences of these factors. In the immediate post operative period, participants were told by the transplant team to expect rejection and reassured that it was expected and treatable.

This reassurance made what could have been a very frightening time far more manageable than if they had not received this information. However, those who experienced an episode of rejection beyond this period found it frightening and anxiety provoking. Following successful treatment participants described feeling unsettled and anxious about their health for a period of time. Therefore, the period both during and after an episode of rejection, may well be a time where offering psychological support may be useful.

The same may be said for those whose experience of post transplant complications has either been individually hard to manage for example in terms of a specific complication or the cumulative effect of complications and its impact on their quality of life for example the effect of having daily dialysis for renal failure. Participants described an increase in anxiety, stress and at times frustration relating to managing post transplant complications that negatively impacted on their quality of life. This group may also benefit from more psychological support from either the transplant or CF team.

5.2.2 Research question 2. How does lung transplant affect the support needs of people with CF post transplant?

Lung transplant results in a major change to a person with CF's life especially when compared to their lives in the period immediately prior to transplant.

During this period they need intensive support from partners/families as well as their from multi disciplinary professionals in their local CF service (MacDonald, 2006). Participants support needs change with transplant insofar as initially they need intensive support from the transplant team from the time of surgery until they have stabilised medically, which can take up to a year post transplant.

Information provision

A large part of this support is the provision of information about their "new" condition to enable physical rehabilitation and adjustment to new treatment and medication regimens. In this study participants stated they felt very well supported from an information perspective as they were given a "folder" and booklets to read and refer to, as well as a helpline they could call in the event of any medical concerns or difficulties. This is in contrast to Ullrich et al. (2005) findings that in spite of being highly rated by participants as part of self management post discharge, good information was seen as lacking by participants.

Shared care

Participants seemed able to understand and manage the different foci of transplant and CF clinics although they bemoaned the amount of time it took to attend both, especially when they were well. No participants in this study wanted to have specific CF transplant clinics saying they did not see the point to this.

Therefore, even though people with CF post transplant might see themselves as different in a way to those with CF who haven't had a transplant, they still see themselves belonging within a CF service and not needing special services developed for them.

Participants' experience from a medical perspective outside of the CF and transplant service was altogether less positive. Examples were given of shock, frustration and irritation when being referred to other specialist services for example renal services, with participants feeling that the way they were treated was very different to what they were used to. More specifically this related to participants feeling the approach taken was not as collaborative as they were used to, their own knowledge of their condition not taken into consideration and treatment not adequately discussed.

Communications

From a communications perspective, participants spoke of delays in communication between the CF team, transplant team, other specialist services and their GP's which could be difficult as they may attend an appointment with one team that did not know about a development relating to another service. This could also relate to changes in medication. Participants felt that an improvement in the speed of communications and co ordination between the various stakeholders in their medical care would be welcomed.

Psychological morbidity

Pfeffer and Pfeffer (2003) have found that people with CF do not have a different psychological profile due to the fact that they have CF, until the disease becomes severe where there is an increase in the incidence and prevalence of anxiety and depression. This finding could be applied to the post transplant group insofar as the extant literature and the results of this study both point to the fact that the CF post

transplant group generally cope with the challenges of life post transplant with a mixture of optimism and fatalism without any significant psychopathology in the absence of significant complications.

However, episodes of rejection and significant complications can negatively impact on mood and quality of life and thus warrant psychological support.

Psychological support

All participants were aware of their local CF psychology service and felt well supported by their CF team from a psychological perspective. Very few had any direct contact with psychological services from the transplant service they attended, although this may be due to difficulties in service provision rather than the service not being offered to them. In general, participants did not feel the need for psychological input, with the exception of times of increased stress due to an episode of rejection or significant post transplant complications as times where more support would be beneficial. How this support should be delivered will now be discussed.

Ullrich et al (2005)'s participants spoke of their embarrassment asking to see a psychologist but broadly welcomed initial contact with one. This led Ullrich and colleagues (2005) to recommend that psychological professionals are regular members of a multidisciplinary post transplant team and that contact should be proactive. This is also in line with Rolland (1994)'s recommendations for psychological professionals to carry out a "psychosocial check up" whereby a psychological perspective is normalised and integrated into conversations with patients and their families in order to check how everyone is coping and provide additional support as needed. This approach is positive insofar as it does not wait for psychopathology to develop, but offers and normalises support during key times in order to ameliorate distress, promote optimal coping and prevent the development of

psychological difficulties. This may be relevant in the initial stages post transplant and at times of health crises, where normalising emotional lability may be a useful intervention, both for the person with CF but their partner and/or family as well.

How should this support be offered? Rolland (1994) describes the work of Doherty and Baird who describe how psychological involvement with families can occur along a continuum ranging from the minimal provision of medical information and advice to providing more support and systemic interventions. This is useful guidance as support needs may be highly individualised.

5.3 Clinical implications

The clinical implications of this study are as follows:

1. It is strongly recommended that specialist CF and transplant teams have adequate psychological representation in order to be able to offer psychological input to people with CF post transplant.
2. CF and transplant teams should have a greater understanding and awareness of the psychological adjustment process post transplant so that they can integrate this perspective into their discussions with patients at clinic and have a more holistic perspective about the impact of transplant and medical complications on people with CF.
3. People with CF post transplant should have the opportunity to have a regular “psychosocial check-up” where time is taken to reflect on how they are managing as well as clarifying if they are struggling in any areas and what support would be useful. This could take place with their partner, parent or significant other. This could be done by a member of the healthcare team with some psychosocial training.

4. Screening post transplant utilising well validated psychometric measures should be included in clinic review appointments to ensure that any psychopathology is detected. Measures such as the Hospital Anxiety and Depression Scale (Zigmund & Snaith, 1983) as well as a CF specific quality of life measure for example the Cystic Fibrosis Questionnaire (CFQ) UK version (Bryon, Buu, Davis, Watrous & Quittner, 2009) could be considered. Should there be any difficulties, this should be followed up by a face to face meeting with a psychologist.
5. Care needs to be taken to reassure patients especially after a significant post transplant health event, as this study has shown, that it takes time to settle and that health anxiety can be high after these events.
6. It may be useful to develop written materials for example a booklet that normalises emotional lability in the post transplant period; the adjustment process post transplant; as well as psychological services available in both the CF and transplant teams for patients as well as their key support persons.

5.4 Limitations of the research and future research directions

This research has focused on one specialist CF centre in Scotland in order to answer questions specifically posed by this service. The results are therefore highly specific to this service, as it is not clear as to whether other CF services would have similar findings. Including other CF centres therefore, or even considering a UK wide or international study would significantly increase the available evidence that could guide the development of psychological protocols in this area.

At the same time, by focusing so specifically on one service, and with the high degree of participation from the post transplant group in this study, lends credibility to the findings contained in this thesis. So too does the researchers role within the CF

service as she has not only been well placed to understand both the perspective of patients and the CF service but has also been able to validate the results with the post transplant population that attends this service following analysis. This is in line with Elliott et al (1999)'s recommendation of providing credibility checks in order to demonstrate good practice and rigor when utilising qualitative research.

At the same time the researcher wondered whether her position as a member of the CF service offering psychological support might have made it difficult for participants' to speak openly about their perceptions of the service – would they have spoken differently to a researcher who had no connection to the CF service?

The decision to focus on a qualitative methodology and not utilise a mixed methods approach that could have included quantitative measures could also be seen as a limitation to this study. An example of this could have been the inclusion of a validated measure of coping which could have added another dimension to these findings.

This study has also just focused on individuals. It is acknowledged that considering life post transplant from the perspective of family members or partners would have added to our understanding of the relational dynamics post transplant. In the same way, considering the experiences of health professionals that is members of the CF and transplant teams could also have contributed to our understanding of the patient-health professional dynamic. Clearly these aims would suit a larger study.

Finally, considering a longitudinal study that would be able to capture the experiences of people with CF post transplant over a period of years would clearly be beneficial and should be considered in future studies.

5.5 Summary

The results of this study support the existing literature relating to psychological adjustment post transplant in terms of a significant improvement in quality of life and absence of psychopathology post transplant in the absence of significant post transplant medical complications.

This study has added to these findings by providing more detail as to what the key areas and activities are post transplant for people with CF. In the immediate post transplant period, it is not uncommon for post transplant recipients to feel emotional and experience a wide range of different emotions. This is usually fleeting and at sub clinical levels. However, conceptualising this in terms of post transplant adjustment and normalising it to transplant recipients may well be a useful strategy to improve and enhance coping strategies.

Moos and Schaefer's (1984) conceptual framework that outlines adjustment to a significant health event is useful in understanding some of the key adaptive tasks transplant recipients need to manage post transplant. These include developing new relationships with the transplant team as well as becoming used to different symptoms, treatment and medication regimens.

People with CF who have a lung transplant are keen to move forward with their life goals from a developmental perspective. This usually involves a redefining of key relationships and goals. The FSIM is a useful model that conceptualises illness in terms of key development goals from both an individual and relational perspective and has some relevance to this context.

In terms of changing support needs, participants in this study felt well supported by their local CF team, but were less sure of how to access psychological support in transplant services. (This may be due to the lack of psychological services in

transplant services as opposed to lack of awareness of existing services.) Participants rejected the idea of having separate CF post transplant clinics, preferring to still be integrated into CF clinics as per normal procedure.

Times of post transplant health crises may well be the key times for psychological support post transplant, with access to psychological input also being useful in the first year post transplant.

Recommendations for clinical practice from this study are for psychological professionals to be integrated into multi disciplinary teams both from the CF and transplant perspective, and for these teams to have an awareness of the psychological implications of transplant. Psychological screening at post transplant clinic appointments and psychological involvement at times of post transplant health crisis are also strongly recommended. Finally, a booklet could be developed to provide information about psychological adjustment to lung transplant as well as how to access psychological support should it be needed.

Chapter Six

Conclusion

This study has sought to understand the experiences of a cohort of adults with CF who attend a Scottish specialist CF centre who have had a lung transplant. This has been with the aim of increasing understanding about the experiences of this group in order to consider whether the CF service needs to make specific service adjustments in order to better support this group.

This study has utilised a cross sectional design utilising qualitative methodology, more specifically the framework approach in order to gain this understanding. Framework analysis is an approach that is particularly suited to a health care setting where specific research questions are asked that will have a direct impact on the delivery of a specific service. This is because it is both an inductive and deductive approach that allows the inclusion of *a priori* areas to be integrated into the research process. It also allows the generation of a framework that can be used to consider results on both a case and theme basis.

The framework generated in this study consisted of four areas of adjustment which encapsulate the way people with CF conceptualise their lives post transplant. These areas are broadly chronological that is they follow the post transplant trajectory as it happens chronologically and highlight the common experiences of all participants. Each area of adjustment has a set of key activities which consist of what people with CF post transplant are focusing their energies on post transplant in terms of the adjustment process. Each theme also has a set of key factors, which outline how individual experiences and events can alter the psychological response and need for psychological input. This is useful as each person's individual medical journey is unique and by understanding the key factors that may influence adjustment at a

particular point, psychological professionals can be alert to offering extra support when needed.

In general people with CF post transplant manage the challenges that come with the opportunities that transplant brings. This changes however, if rejection is experienced or if post transplant complications have a negative effect on quality of life. In these instances psychological support is important.

Participants in this study, representing 65% of the post transplant group attending a specialist CF centre in Scotland did not see the need for specific CF post transplant services including clinics preferring to attend “mixed” CF clinics (that is a mixture of people with CF some of whom had had transplants and others who hadn’t). They expressed satisfaction with the support provided by the CF service as well as with the information provided post transplant by the transplant centre. They valued access to psychological support in their local CF service although noted that similar support was not available at the transplant service. Participants were happy with “shared care” arrangements between the CF and transplant services, although found that communication between the services could be slow. The situation became more complicated when an extra service became involved for example a renal service; with participants who had experienced this stating that they found contact with this service to be frustrating and that they were treated differently than they were used to being treated by their CF service. This was mainly to do with the professional-patient relationship which participants felt was not as collaborative as the relationship they have with their CF service.

The clinical implications of this study are for health professionals working with people with CF post transplant to be aware of psychological issues post transplant. It is strongly recommended that both CF and transplant services have adequate

psychological representation in order to be able to provide input to people with CF post transplant. This input can take a variety of forms: consultation to the team, direct contact to patients and their families or partners at times of health crises or times where they may be finding the adjustment process difficult; as well as development of written materials that normalise the experience of emotions post transplant.

This is a small study focusing in depth on one CF centre. Future research could involve more centres, as well as a wider view that is including the views of partners or significant relatives as well as health professionals, as well as including objective measures of coping. Longitudinal studies would also be of great benefit to providing a more in depth understanding of the post transplant trajectory for this important group. This would also enable greater understanding of those within the transplant group who have to manage considerable medical complications over a number of years.

References

- Abbey, S.E., De Luca, E., Mauthner, O.E., McKeever, P., Shildrick, M., Poole, J.M., Gewarges, M. Ross, H.J. (2011). Qualitative interviews vs standardized self-report questionnaires in assessing quality of life in heart transplant recipients. *The Journal of Heart and Lung Transplantation*, 30 (8), 963 – 966.
- Abbott, J. (2003). Coping with Cystic Fibrosis. *Journal of the Royal Society of Medicine*, 96 (Suppl.43), 42-50
- Abbott, J., Gee, L. (1998). Contemporary psychosocial issues in cystic fibrosis: treatment adherence and quality of life. *Disability and Rehabilitation*, 20 (6-7), 262-271.
- Abbott, J., Dodd, M., Gee, L, Webb, K. (2001). Ways of coping with cystic fibrosis: implications for treatment adherence. *Disability and Rehabilitation*, 23 (8), 315-324.
- Abbott, J., Hart, A., Morton, A., Gee, L., Conway, S. (2008). Health-related quality of life in adults with cystic fibrosis: the role of coping. *Journal of Psychosomatic Research*, 64, 149-157.
- Anderson, D.L., Flume, P., Hardy, K.K. (1995). Psychological functioning of adults with cystic fibrosis. *Chest*, 199, 1079-1084.
- Barbour, K.A., Blumenthal, J.A., Palmer, S.M. (2006). Psychosocial issues in the assessment and management of patients undergoing lung transplantation. *Chest*, 129, 1367-1374.
- British Psychological Society. (2010). *Code of Human Research Ethics*. Leicester: British Psychological Society.

Bryon, A., Buu, A., Davis, M.A., Watrous, M., Quittner, A.L. (2009). The CFQ-UK: cystic fibrosis questionnaire, a health related quality of life measure (English UK version 1). Bexley: Forest Laboratories UK Ltd.

Bury, M. (1982). Chronic illness as a biographical disruption. *Sociology of Health and Illness*, 4(2), 167-182.

Carter, E., Mc Goldrick, M. (1989). *The changing family life cycle*, In: E. Carter, M. McGoldrick. Eds. *The Changing Family Life Cycle: A Framework for Family Therapy*, 2nd Edition, Boston: Allyn & Bacon.

Charmaz, C. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. London: Sage.

Choong, C.K., & Meyers, B.F. (2004). Quality of life after lung transplantation. *Thoracic Surgery Clinics*, 14, 385- 407.

CF Trust (2011). *Standards for the clinical care of children and adults with cystic fibrosis in the UK*, 2nd edition. Bromley: CF Trust.

CF Registry (2013) *Annual Data Report: 2011*. Bromley: CF Trust.

Corris, P.A. (2008). Outcomes of lung transplantation for cystic fibrosis in a large UK cohort. *Thorax*, 63, 725-731.

Crain, W. (2011). *Theories of Development: Concepts and Applications*, 6th Edition. New Jersey: Pearson Education.

Denzin, N.K., Lincoln, Y.S. (2000). *The Handbook of Qualitative Research*. California: Sage.

- De Vito Dabbs, A., Kim, Y., Hamdan-Mansoor, A., Thibodeau, A., Mc Curry, K. (2006). Health locus of control after lung transplantation: Implications for managing health. *J. Clin Psycho. Med Settings*, 13, 381-392.
- Dew, M.A., & Di Martini, A.F., (2005). Psychological disorders and distress after adult cardiothoracic transplantation. *Journal of Cardiovascular Nursing*, 20 (55), S51-S56.
- Dew, M. A., Myaskovsky, L., Switzer, G. E., DiMartini, A. F., Schulberg, H. C., & Kormos, R. L. (2005). Profiles and predictors of the course of psychological distress across four years after heart transplantation. *Psychological Medicine*, 35 (8), 1215-1227.
- Dilling, D.F., Glanville, A.R. (2011). Advances in lung transplantation: the year in review. *The Journal of Heart and Lung Transplantation*, 30 (3), 247 – 251.
- Dodge, J. A., Lewis, P. A., Stanton, M., & Wilsher, J. (2007). Cystic fibrosis mortality and survival in the UK: 1947-2003. *European Respiratory Journal*, 29 (3), 522-526.
- Döring, G., Flume, P., Heijerman, H., & Elborn, J. S. (2012). Treatment of lung infection in patients with cystic fibrosis: Current and future strategies. *Journal of Cystic Fibrosis*, 11(6), 461-479. doi:10.1016/j.jcf.2012.10.004
- Durst, C. L., Horn, M. V., MacLaughlin, E. F., Bowman, C. M., Starnes, V. A., & Woo, M. S. (2001). Psychosocial responses of adolescent cystic fibrosis patients to lung transplantation. *Pediatric Transplantation*, 5 (1), 27-31.
- Elliott, R.; Fischer, C.T.; & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.

- Fusar-Poli, P., Lazzaretti, M., Ceruti, M., Hobson, R., Petrouska, K., Cortesi, M., Politi, P. (2007). Depression after lung transplantation: Causes and treatment. *Lung*, 185 (2), 55-65.
- Gale, N.K.; Heath, G., Cameron, E., Rashid,S., & Redwood, S. (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*. 13:117.
- Glaser, B.G., Strauss,A.L. (1967) The discovery of grounded theory. Chicago: Aldine.
- Goetzmann, L., Scheuer, E., Naef, R., Vetsch, E., Buddeberg, C., Russi, E. W., & Boehler, A. (2005). Psychosocial situation and physical health in 50 patients > 1 year after lung transplantation. *Chest*, 127 (1), 166-170.
- Griesenbach, U., Boyd, A.C., UK Cystic Fibrosis Gene Therapy Consortium, (2005). Pre-clinical and clinical endpoint assays for cystic fibrosis gene therapy. *Journal of Cystic Fibrosis*, 4, 89-100.
- Havermans, T., Matossian, A., Claes, N., Van den Bergh, O., Knoop, C., & Dupont, L. (2008). Attitudes and quality of life after transplantation: Do CF patients differ from other transplanted patients? *Journal of Cystic Fibrosis*, 7, Supplement 2 (0), S109. doi:10.1016/S1569-1993(08)60417-8
- Health and Care Professions Council. (2012). *Standards of conduct, performance and ethics*. London: Health and Care Professions Council.
- Holohan, C.J., Moos, R.H. (1987). Personal and contextual determinants of coping strategies. *Journal of Personality and Social Psychology*, 52 (5), 946-955.
- Keenan, T., Evans, S. (2009). *An Introduction to Child Development*, 2nd edn. London: Sage.

Koch, C. (2002). Early infection and progression of CF lung disease. *Pediatric Pulmunology*, 34 (3), 232-236.

Kunsebeck, H., Kugler, C., Fischer, S., Simon, A.R., Gottlieb, J., Welte, T., Haverich, A., Sgrueber, M. (2007). Quality of life and bronchiolitis obliterans syndrome in patients after lung transplantation. *Progress in Transplantation*, 17 (2), 136-41.

Kugler, C., Fischer, S., Gottlieb, J., Welte, T., Simon, A., Haverich, A., Strueber, M. (2005). Health related quality of life in two hundred and eighty lung transplant recipients. *The Journal of Heart and Lung Transplantation*, 24 (12), 2262-2268.

Kurz, J. M. (2001). Experiences of well spouses after lung transplantation. *Journal of Advanced Nursing*, 34 (4), 493-500.

Lazarus, R.S., Folkman, S. (1984). *Stress, Appraisal and Coping*. New York: Springer.

Legard, R., Keegan, J., Ward, K. (2011). *Design Issues*, In: J. Ritchie and J. Lewis (Eds) *Qualitative Research Practice: A guide for social science students and researchers*, London: Sage.

Limbos, M., Joyce, D.P., Chan, C.K., Kesten, S. (2000). Psychological functioning and quality of life in lung transplant candidates and recipients. *Chest*, 118 (2), 408-416.

Lowton, K. (2003). 'Double or quits': perceptions and management of organ transplantation by adults with cystic fibrosis. *Social Science & Medicine*, 56, 1355-1367.

Lowton, K. (2005). Trials and tribulations: understanding motivations for clinical research participation amongst adults with cystic fibrosis. *Social Science and Medicine*, 61, 1854-1865.

Lowton, K., Gabe, J. (2003). Life on a slippery slope: perceptions of health in adults with cystic fibrosis. *Sociology of Health and Illness*, 25 (4), 289-319.

Lyu, D.M., Zamora, M.R. (2009). Medical complications of lung transplantation. *Proceedings of the American Thoracic Society*, 6 (1), 101-107.

Macdonald, K. (2006). Living in limbo--patients with cystic fibrosis waiting for transplant. *British Journal of Nursing*, 15 (10), 566-572.

Matossian, A., Havermans, T., Claes, N., Dupont, L., & Knoop, C. (2007). Lung transplantation and changes in importance of social support. *Journal of Cystic Fibrosis*, 6, Supplement 1 (0), S79.

McCarthy, J. (2001). *Fighting time: a qualitative analysis of the impact of lung transplantation on adults with cystic fibrosis*. Unpublished doctoral dissertation: University of Leeds, School of Medicine, Academic Unit of Psychiatry and Behavioural Sciences.

Meachery, G., De Soyza, A., Nicholson, G., Parry, G., Hasan, A., Tocewicz, K., Pillay, T., Clark, S., Lordan, J.L., Schueler, S., Fisher, A.J., Dark, J.H., Gould, F.K., Corris, P.A. (2008). Outcomes of lung transplantation for cystic fibrosis in a large UK cohort. *Thorax*, 63, 725-731.

Miller, C., Harris, C., Latchford, G., Conway, S., & Peckham, D. (2010). Are the psychosocial needs of cystic fibrosis patients being met post-transplant? *Journal of Cystic Fibrosis*, 9, Supplement 1 (0), S104.

Moos, R.H., Schaefer, J. (1984). *The Crisis of Physical Illness: An overview and conceptual approach*. In: Moos, R.H. (Ed), *Coping with Physical Illness*. New York: Plenum.

Moos, R. H., & Schaefer, J. A. (1993). *Coping resources and processes: Current concepts and measures*. In: L. Goldberger & S. Breznitz (Eds.), *Handbook of stress: Theoretical and clinical aspects*, 2nd Edition. New York: The Free Press.

Ogden, J (2007). *Essential Readings in Health Psychology*. McGraw Hill: Open University Press.

Pfeffer, P.E., Pfeffer, J.M., & Hodson, M.E. (2003). The psychosocial and psychiatric side of cystic fibrosis in adolescents and adults. *Journal of Cystic Fibrosis*, 2, 61-68.

Pochettino, A., Augoustides, J.G.T., Kowalchuk, D.A., Watcha, S.M., Cowie, D., Jobes, D.R. (2007). Cardiopulmonary bypass for lung transplantation in cystic fibrosis: pilot evaluation of a perioperative bypass. *Journal of Cardiothoracic and vascular anaesthesia*, 21 (2), 208-211.

Pope, C., Ziebland, S., and Mays, N. (2000). Qualitative research in health care. Analysing qualitative data. *BMJ*, 320 (7227), 114-116.

Quittner, A.L., Buu, A., Messer, M.H., Modi, A.C., & Watrous, M. (2005). Development and Validation of the Cystic Fibrosis Questionnaire in the United States. A Health-Related Quality-of-Life Measure for Cystic Fibrosis. *Chest*, 128 (4), 2347-2354.

Ritchie, J., Spencer, L. (1993). *Qualitative data analysis for applied policy research*. In: Bryman, A. & Burgess, R. (Eds), *Analysing Qualitative Data*. London: Routledge.

- Ritchie, L., Spencer, L., O'Connor, W. (2011). *Carrying out qualitative analysis*. In: Ritchie, J. & Lewis, J. (Eds) *Qualitative Research Practice: A Guide for Social Science Students*. London: Sage.
- Rolland, J.S. (1994). *Families, Illness and Disability: An integrative treatment model*. New York: Basic Books.
- Sale, J.E.M., Lohfield, L.H., Brazil, K. (2002). Revisiting the quantitative-qualitative debate: Implications for mixed-methods research. *Quality and Quantity*, 36, 43-53.
- Sarafino, E.P. (2008). *Health Psychology: Biopsychosocial Interactions*, 6th Edition. New Jersey: Wiley.
- Savitch, S., Gilmore, R., & Dowler, D. L. (2003). An investigation of the psychological and psychosocial challenges faced by post-transplant organ recipients. *Journal of Applied Rehabilitation Counseling*, 34 (3), 3-9.
- Smeritschnig, B., Jaksch, P., Kocher, A., Seebacher, M.D., Aigner, C., Mazhar, S., Klepetko, W. (2005). Quality of life after lung transplantation: a cross sectional study. *The Journal of Heart and Lung Transplantation*, 24 (4), 474-480.
- Smith, J. (2003). *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage.
- Smith, J., Firth, J. (2011). Qualitative data analysis: The framework approach. *Nurse Res*, 18 (2), 52-62.
- Snape, D., Spencer, L. (2011). *The Foundations of Qualitative Research*. In: Ritchie, J. & Lewis, J. (Eds), *Qualitative Research Practice. A Guide for Social Science Students and Researchers*. London: Sage.

- Spencer, L., Ritchie, J., O Connor, W. (2011). *Analysis: Practices, Principles and Processes*. In: Ritchie, J. & Lewis, J. (Eds), *Qualitative Research Practice. A Guide for Social Science Students and Researchers*. London: Sage.
- Sternberg, R.J. , Okagaki, L. (1989). Continuity and discontinuity in intellectual development are not a matter of 'either-or'. *Human Development*, 32, 158-166.
- Stewart,S., Fisbein, M.C., Snell, G.I. (2004). Non infectious pulmonary complications after lung transplantation. *Journal of Heart and Lung Transplantation*, 23(12), 1396-1404.
- Stilley, C. S., Dew, M. A., Stukas, A. A., Switzer, G. E., & et al. (1999). Psychological symptom levels and their correlates in lung and heart-lung transplant recipients. *Psychosomatics*, 40 (6), 503-9.
- Strauss, A., Corbin, J.M. (1998) *Basics of Qualitative Research*. London: Sage.
- Thomsen, D., & Jensen, B. Ø. (2009). Patients experiences of everyday life after lung transplantation. *Journal of Clinical Nursing*, 18 (24), 3472-3479.
- Ullrich, G. (2008). *Lung transplant through the patient's eyes*. Norderstedt :Books on Demand.
- Ullrich, G., Jänsch, H., Schmidt, S., Strüber, M., & Niedermeyer, J. (2005). Consulting the "experts": A pilot study on perceptions of professional support among lung transplant recipients and accompanying relatives. *Progress in Transplantation*, 15 (2), 115-122.
- Valour, F., Brault, C., Abbas-Chorfa, F.,Martin, C., Kessler, L., Kanaan, R., Mosnier-Pudah, H., Coltey,B., Nore-Josserand, R., Durupt,S., Colin, C., Durieu, I. (2012). Outcome of cystic-fibrosis related diabetes two years after transplantation. *Respiration*, 86 (1), 32-38.

- van den Berg, J.W.K., Geertsma, A., van der Bij, W., Koeter, G.H., de Boer, W.J., Postma, D.S., ten Vergert, E.M. (2000). Bronchiolitis obliterans syndrome after lung transplantation and health related quality of life. *Am J Respir Crit Care Med*, 161, 1937–1941.
- Vermeulen, K.M., Groen, H., van der Bij, W., Koeter, G.H., TenVergert, E.M. (2004). The effect of bronchiolitis obliterans syndrome on health related quality of life. *Clin. Transplant*, 18, 377-383.
- Wallston, K.A., Stein, M.J., Smith, C.A. (1994). Form C of the MHLC scales: A condition- specific measure of locus of control. *Journal of Personality Assessment*, 63 (3), 534-553.
- Walsh, F. (2003). Family resilience: a framework for clinical practice. *Family Process*, 42 (1), 1-18.
- Weiss, E.S., Merlo, C.A., Shah, A.S. (2009). Impact of advanced age in lung transplantation: An analysis of United Network for Organ Sharing data. *J Am Coll Surg*, 208, 400–409.
- Williams, L. W., Burker, E. J., Kazukauskas, K., & Neuringer, I. (2012). Lung transplant: Information and recommendations for rehabilitation counselors. *Journal of Applied Rehabilitation Counseling*, 43 (2), 9-16.
- Willig, C (2004). *Introducing Qualitative Research in Psychology: Adventures in Theory and Method*. Berkshire: Open University Press.
- Woo, M. S. (2008). Overview of lung transplantation. *Clinical Reviews in Allergy & Immunology*, 35 (3), 154-163.
- Worby, C. & Smith, C.M. (1997). Lung transplantation: A seven stage trajectory integrating biomedical and psychosocial variables. Abstracts: 21st European Cystic Fibrosis conference. Davos, Switzerland, pp.123.

Worby, C. (1998). The seven psychosocial stages in the lung transplant trajectory. Twelfth Annual North American Cystic Fibrosis Conference: Perspectives on the Psycho social Intricacies of Lung Transplantation: October 1998. Montreal: Cystic Fibrosis Foundation.

Yorke,J., Parle, M., James, M et al. (2006). Lung transplantation in adolescents and young adults with cystic fibrosis. *Progress in Transplantation*, 16, 343-354.

Zigmond,A.S., Snaith, R.P.(1983). The hospital anxiety and depression scale. *Acta Psychiatr Scand*, 67 (6), 361-370.

Appendix 1

Invite Letter - On Letterhead

Patients name and address

Dear

I am writing to you because you have had a lung transplant. Over the next few months I will be doing a small study to find out about the experiences of lung transplant in people with CF. The purpose of this is to try to understand what life has been like for you since having a transplant as well as consider whether we need to improve the services we offer post transplant.

I would like to invite you to have a brief interview before, during or after your next clinic appointment. This should last no longer than 30 minutes. The interview will be audiotaped. All tapes will be kept in a secure place and your details will be kept confidential. Audiotapes will be transcribed by someone who will be not able to identify your voice. All responses will be anonymised so you cannot be identified.

I see that you are due to come to clinic on the (date). I wonder if it would be possible to meet on that day at (insert time) pm. If this is suitable for you, I would be grateful if you would come to my office which is very near where you attend clinic. To find my office as you come up the stairs to go to clinic (which is held in Clinic A or B) turn left (instead of right) and follow the signs for Clinic E. My office is just near a big Clinic E sign. Alternatively if you would prefer, I am happy to come and meet you at clinic and we can go to my office together (please let me know if you would prefer this.)

If this time is not suitable for you, or you do not want to participate in this study, or you have any questions, please contact me on 0131 XXX XXXX, or the CF clinical nurse specialists on 0131 XXX XXXX. Otherwise I will look forward to seeing you on the (date).

Yours sincerely

Caroline Cochrane

Chartered Clinical Psychologist

Scottish Adult CF Service

Appendix 2

South East Scotland Research Ethics Service

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG



Name: Caroline Cochrane
Address: Cystic Fibrosis and
Clinical Genetics
c/o Edinburgh Adult CF Team
Ward 54
Western General Hospital
Crewe Road
Edinburgh
EH4 2XU

Date: 08/07/2011
Your Ref:
Our Ref: NR/1107AB08
Enquiries to: Alex Bailey
Direct Line: 0131 485 5879
Email: alex.bailey@nhslothian.scot.nhs.uk

Dear Caroline,

Full title of project: What are the service needs for CF patients post transplant?

You have sought advice from the South East Scotland Research Ethics Service on the above project. This has been considered by the Scientific Officer and you are advised that, based on the submitted documentation (What are the service needs for CF patients just post transplant8 07.doc and advice re a potential study.rtf), it does not need NHS ethical review under the terms of the Governance Arrangements for Research Ethics Committees in the UK. The advice is based on the following:

- *The project is an opinion survey seeking the views of NHS patients on service delivery.*

If this project is being conducted within NHS Lothian you should inform the relevant local Quality Improvement Team(s).

This letter should not be interpreted as giving a form of ethical approval or any endorsement of the project, but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements. However, if you, your sponsor/funder or any NHS organisation feels that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further. Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS.

You should retain a copy of this letter with your project file as evidence that you have sought advice from the South East Scotland Research Ethics Service.

Yours sincerely,

A handwritten signature in black ink that reads 'Alex Bailey'.

Alex Bailey
Scientific Officer
South East Scotland Research Ethics Service

Appendix 3

Confidentiality Agreement

I agree to keep all of the information regarding the research interviews private and confidential. The recorded interviews will be heard by myself and no others. I will keep the CD or memory stick (or whatever agreed method the research interviews are given to me) secure at all times that is not accessible to others and not left in the car etc. Once I have completed the transcription I will delete any copies of this on my computer and return the research interviews to the researcher Caroline Cochrane.

Signature

Date

Appendix 4

Summary of initial notes - Interview 1

Celebrating 21st anniversary of transplant

Family and friends also want to celebrate

Celebrating significant transplant milestones

False calls

Length of time on list

Memories of journey to transplant centre

Waking up from surgery

Length of time in hospital

Sensation of breathing with new lungs

Type of transplant – heart/lungs

Experience of giving away an organ

Keeping in touch with donors and recipients

Actions and ambitions with new lungs

Actions with new lungs

Impact of changes to medication

Attitude to change in medication

Impact of transplant over time

Episode of acute rejection

Episode of rejection after 9 years

No concern about rejection

Medical complications

Renal

Impact of renal complications

Curtail independence

Other complications – stroke

Unfairness of multiple complications

Impact of surviving a long time

Impact of complications on quality of life

Significance of age when transplanted

Difference between being a child or adult when transplanted

Expecting rejection

Unexpected complications

Support and information with complications

Support needed

Support from transplant centre

View of shared care

Communication between centres

Support from local CF centre

Support needs

Referral for support

Good communication

Need for good communication for all involved

Time delays – impact on communication

Support at key stages – new treatments and complications

Difficulties engaging with a new team- specialist service treated differently

Patient's own knowledge and experience

Help to manage new treatments for example renal

Way of explaining new treatments

Age and stage at transplant

Impact of transplant on finding employment

Thoughts about the future

Expected length of time post transplant

Feel different from other people with CF who haven't had a transplant

Worth it to have a transplant.

Possible codes/areas – Interview 1

Memories of being called and journey down to transplant centre

False calls

Being prepped for surgery

Waking up after surgery

Post op complications

Pain

Hallucinations

Initial medical difficulties

Length of time in hospital

First milestone

Milestones

Going home

Difference with new lungs/breathing differently

Milestone – living independently

Milestone – becoming independent

Concerns about risk of infection in first year

Episodes of rejection after the first 6 months

Coping and adjusting after an episode of rejection

Lungs as commodity

Getting on with it

Living on borrowed time

Heart/lung

Post transplant medication regime

Feel different to others with CF

Challenges

Early rejection experiences

Complications – renal

Complications

Perspectives of the future

Differences having transplant as a paed
Age and stage when had it/work/college
Timing of when had it/time on the list
Information
Psychosocial support
Family
Changing family roles
Local CF service
Place of post transplant support
Specific post transplant clinics at local CF centre
Shared care – general impressions
Shared care – communication
Shared care – plus renal
Think about donor
Links with donors family (both for recipient and also donor if gave heart)
The future
Way handle uncertainty
Milestones in years since transplant – one year
Milestones in years since transplant – five years
Milestones in years since transplant – ten years
Milestones in years since transplant – over 15 years
Milestones – moving forward in life – career
Milestones – moving forward in life – relationships

Initial areas/codes - Interviews 1 – 11

Adherence to new medication regime
Adjustment for family post transplant
Aim post transplant
Anxiety about complications
(Age at)Being a kid at transplant
Breathing with new lungs
Celebrating transplant anniversary
Challenges post transplant
Complications dermatology
Complications post surgery
Complications renal
Culture of different teams
Cumulative effect complications
Episodes of rejection
Expected medical complications
Experience of transplant surgery
False Calls
Feel different from other CF patients
First milestone surviving surgery and getting up
Impact of pre transplant poor health
Impact of rejection
Initial milestones getting on feet
Is it worth it balancing complications with extending life
Limitations of transplant
Limitations to moving forward
Linked to previous life cycle
Managing complications
Mentoring others with CF potential transplant
Distance from hospital
Less treatment
Milestone 5-9 years

Back to normal tasks
Career development
Day trip away from hospital
First visitors
First year
Five years
Getting back to normal
Getting better and better first year
Getting drains out
Getting home
Getting on my feet
Having children
Helping parents
Holidays
Making changes
Making progress
Moving forward plans
Moving out of parents home
Moving to flat in hospital grounds
Not tube fed
Regaining independence
Seeking relationships
Space to move on
Ten year milestone
Turning 40 with CF
Working your way to get back home
Bigger complications
Breaking away from hospitals
College
Getting active and out
Getting home and fit
Milestones hoped for

Milestones initial disbelief
Little complications
No more oxygen
Need to trust transplant centre
Needed support
New normal
Not knowing how long others have survived
Not sure what to expect medically first year
Perceptions of mortality
Post transplant CF clinics
Process of adjustment
Quality of life
Relief at getting a transplant
Sources of support
Speaking with others with CF
Support needed different teams
The risk of transplant
Thoughts of the future
Thoughts or contact with donors family
Time on transplant waiting list
Unexpected complications
Views on shared care

Appendix 5

Preliminary thematic framework

1.The Transplant	2.Getting home and on my feet (initial adjustment)	3.Settling down	4.Moving forward	5.Managing rejection and complications
Post Op	Adjusting to different symptoms; Adjusting to shared care; Adjusting to different risks;	Redefining CF identity: Post transplant difference – new lungs; Relationship with donor/family; Resetting goals Getting back to work or career.	Post transplant identity Managing complications Balancing benefits with complications Adjusting to risk of rejection/future Getting married; having children	

Appendix 6

Mapping draft framework onto areas from Interview 1

Areas: 1. The transplant, 2. Getting home 3. Settling down 4. Moving forward 5. Managing rejection

ST= sub theme

Memories of being called and journey down to transplant centre	Surgery
False calls	(Pre) surgery
Being prepped for surgery	Surgery
Waking up after surgery surviving surgery	T1 The transplant: ST
Post op complications	T1 The transplant :ST post op
Pain	T1 :ST post op
Hallucinations	T1 :ST post op
Initial medical difficulties	T1 :ST post op
Length of time in hospital	T1 :ST gaining strength
First milestone	
Milestones	
Going home	T1 : ST moving towards home
Difference with new lungs/breathing differently	T2 ST breathing differently
Milestone – living independently independence	T3 ST regaining
Milestone – becoming independant independence	T3 ST regaining
Concerns about risk of infection in first year risks	T2: ST adjusting to different
Episodes of rejection after the first 6 months	T5 ST:adjusting to rejection
Coping and adjusting after an episode of rejection	T5 ST: adjusting to rejection
Lungs as commodity relationships	T3 ST: redefining
Getting on with it	T2 ST: getting on with life
Living on borrowed time time	T3 ST: living on borrowed
Heart/lung	
Post transplant medication regime medication	T2 ST: adjusting to different
Feel different to others with CF	T2 ST: redefining CF identity
Challenges	T4 ST: challenges

Early rejection experiences	T5 ST: adjusting to rejection
Complications – renal complications: renal	T4 ST: managing
Perspectives of the future	T4 ST: managing the future
Differences having transplant as a paed	T2 ST: age at transplant
Age and stage when had it/work/college	T2 ST: age at transplant
Timing of when had it/time on the list t identity/	T2 ST moving away from pre
	Time on list
Information support	T3 ST shared care/prof
Psychosocial support support	T3 ST shared care/prof
Family	T3 ST redefining relationships
Changing family roles	T3 ST redefining relationships
Local CF service	T3 ST shared care
Place of post transplant support	T3 ST shared care
Specific post transplant clinics at local CF centre	T3 ST shared care
Shared care – general impressions	T3 ST shared care
Shared care – communication	T3 ST shared care
Shared care – plus renal	T3 ST shared care
Think about donor relationships:donor	T3 ST redefining
Links with donors family (recipient and donor if also gave heart)	T3 ST redefining relationships
The future	T4 ST: managing the future
Way handle uncertainty	T4 ST: managing the future
Milestones in years since transplant – one year	
Milestones in years since transplant – five years	
Milestones in years since transplant – ten years	
Milestones in years since transplant – over 15 years	
Milestones – moving forward in life – career	T3ST: redefining life goals
Milestones – moving forward in life – relationships	T3ST: redefining life goals

Updated draft framework:

Major Theme	1.The transplant	2.Getting Home: initial adjustment	3.Settling down	4.Moving forward and Managing
Key phrase	recovering	Looking after my new self	Regaining independence	The issues of post transplant life
<u>Sub areas</u>	<p>Surviving Surgery</p> <p>Post Op Issues</p> <p>Gaining strength</p> <p>Moving towards home</p>	<p>Adjusting to different medication</p> <p>Adjusting to different risks</p> <p>Getting on with life</p> <p>Moving away from pre transplant identity</p> <p>Age at transplant and time on list</p>	<p>Regaining independence</p> <p>Redefining CF identity</p> <p>Redefining relationships</p> <p>Redefining life goals</p> <p>Professional support/shared care</p>	<p>Managing the future</p> <p>Managing complications</p> <p>Managing rejection</p> <p>Challenges</p> <p>Opportunities</p>

Mapping draft framework onto areas Interview 1- 11

Theme	Major theme	Sub theme
Adherence to new medication regime medication	2.	Adjusting to different
Adjustment for family post transplant	3.	Redefining relationships
Aim post transplant	3	Redefining life goals
Anxiety about complications	2.	Adjusting to different risks
Being a kid at transplant	2	Age at trplant & time on list
Breathing with new lungs	2	Breathing with new lungs
Celebrating transplant anniversary donor	3	Redefining relationships:
Challenges post transplant	4	Challenges
Complications dermatology	4	Managing complications
Complications post surgery	1	Post Op issues
Complications renal	4	Managing complications
Culture of different teams	3	Profes support/shared care
Cumulative effect complications	4	Managing complications
Episodes of rejection	4	Managing rejection
Expected medical complications	4	Managing complications
Experience of transplant surgery strength	1	Surviving surgery and gaining
False Calls	-	pre surgery
Feel different from other CF patients	3	redefining CF identity
First milestone surviving surgery and getting up strength	1	Surviving surgery and gaining
Impact of pre transplant poor health	2	Age at tplant and time on list
Impact of rejection	4	Managing rejection
Initial milestones getting on feet	1	Surviving surg. getting on feet
Is it worth it balancing complications with extending life	4	Managing complications
Limitations of transplant	4	Managing complications
Limitations to moving forward	3	Redefining life goals

Linked to previous life cycle	2	Age at tplant and time on list
Managing complications	4	Managing complications
Mentoring others with CF potential transplant	3	Redefining CF identity
Distance from hospital	3	Profes support/shared care
Less treatment	2	Moving away from pre transplant identity
Milestone 5-9 years	4	Opportunities
Back to normal tasks	2	Getting on with life
Career development	3	Redefining life goals
Day trip away from hospital	1	Moving towards home
First visitors	1	Surviving surgery & gaining strength
First year	2	Adjusting to different risks
Five years	4	Transplant anniversaries
Getting back to normal	2	Getting on with life
Getting better and better first year	2	Moving away from pre transplant identity
Getting drains out	1	Surviving surgery and gaining strength
Getting home	1	Moving towards home
Getting on my feet	1	Surviving surgery and gaining strength
Having children	3	Redefining life goals
Helping parents	4	Opportunities
Holidays	4	Opportunities
Making changes	3	Redefining life goals
Making progress	1	Surviving surgery and gaining strength
Moving forward plans	3	Redefining life goals
Moving out of parents home	3	Regaining independence
Moving to flat in hospital grounds	1	Moving towards home

Not tube fed	2	Moving away from pre transplant identity
Regaining independence	3	Regaining independence
Seeking relationships	3	Redefining life goals
Space to move on	3	Redefining relationships and life goals
Ten year milestone	4	Transplant anniversaries
Turning 40 with CF	4	Transplant anniversaries
Working your way to get back home	1	Moving towards home
Bigger complications	4	Managing complications
Breaking away from hospitals	2	Moving away from pre transplant identity
College	3	Redefining life goals
Getting active and out	2	Getting on with life
Getting home and fit	1	Moving towards home
Milestones hoped for	3	Redefining life goals
Milestones initial disbelief	2	Moving away from pre transplant identity
Little complications	4	Managing complications
No more oxygen	2	Moving away from pre transplant identity
Need to trust transplant centre	3	Profes support/shared care
Needed support	3	Profes support/shared care
New normal	2	Moving away from pre transplant identity
Not knowing how long others have survived	4	Challenges
Not sure what to expect medically first year	2	Adjusting to different risks
Perceptions of mortality	4	Managing the future
Post transplant CF clinics care	3	Professional support/shared
Process of adjustment	2	Moving away from pre transplant identity

Quality of life	4	Opportunities
Relief at getting a transplant	2	Moving away from pre transplant identity
Sources of support	3	Profes support/shared care
Speaking with others with CF	3	Redefining CF identity
Support needed different teams	3	Profes support/shared care
The risk of transplant	1	Surviving surgery and gaining strength
Thoughts of the future	4	Managing the future
Thoughts or contact with donors family	3	Redefining relationships: donor
Time on transplant waiting list	2	Age at transplant and time on list
Unexpected complications	4	Managing complications
Views on shared care	3	Profes support/shared care

Grouped Areas from Interviews (1 – 11) as per theme

Theme 1:

Theme	Major theme	Sub theme
(False Calls	-	pre surgery)
Complications post surgery	1	Post Op issues
Experience of transplant surgery	1	Surviving surgery and gaining strength
First milestone surviving surgery and getting up	1	Surviving surgery and gaining strength
Initial milestones getting on feet	1	Surviving surgery and getting on feet
First visitors	1	Surviving surgery and gaining strength
Getting drains out	1	Surviving surgery and gaining strength
Getting on my feet	1	Surviving surgery and gaining strength
The risk of transplant	1	Surviving surgery and gaining strength
Making progress	1	Surviving surgery and gaining strength
Day trip away from hospital	1	Moving towards home
Getting home	1	Moving towards home

Moving to flat in hospital grounds	1	Moving towards home
Working your way to get back home	1	Moving towards home
Getting home and fit	1	Moving towards home

Theme 2:

Adherence to new medication regime	2.	Adjusting to different medication
Anxiety about complications	2.	Adjusting to different risks
Not sure what to expect medically first year	2	Adjusting to different risks
First year	2	Adjusting to different risks
Impact of pre transplant poor health	2	Age at transplant and time on list
Linked to previous life cycle	2	Age at transplant and time on list
Time on transplant waiting list	2	Age at transplant and time on list
Being a kid at transplant	2	Age at transplant and time on list
Breathing with new lungs	2	Moving away fpre transplant identity
Less treatment	2	Moving away f pre transplant identity
Getting better and better first year	2	Moving away f pre transplant identity
Not tube fed	2	Moving away f pre transplant identity
Breaking away from hospitals	2	Moving away f pre transplant identity
Milestones initial disbelief	2	Moving away f pre transplant identity
No more oxygen	2	Moving away f pre transplant identity
New normal	2	Moving away f pre transplant identity
Process of adjustment	2	Moving away f pre transplant identity
Relief at getting a transplant	2	Moving away f pre transplant identity
Getting active and out	2	Getting on with life
Back to normal tasks	2	Getting on with life
Getting back to normal	2	Getting on with life

Theme 3:

Moving out of parents home	3	Regaining independence
Regaining independence	3	Regaining independence
Space to move on	3	Redefining relationships and life goals

Thoughts or contact with donors family	3	Redefining relationships:donor
Adjustment for family post transplant	3.	Redefining relationships
Speaking with others with CF	3	Redefining CF identity
Feel different from other CF patients	3	Redefining CF identity
Mentoring others with CF potential transplant	3	Redefining CF identity
Limitations to moving forward	3	Redefining life goals
Aim post transplant	3	Redefining life goals
Career development	3	Redefining life goals
Having children	3	Redefining life goals
Making changes	3	Redefining life goals
Moving forward plans	3	Redefining life goals
Seeking relationships	3	Redefining life goals
College	3	Redefining life goals
Milestones hoped for	3	Redefining life goals
Culture of different teams	3	Professional support/shared care
Distance from hospital	3	Professional support/shared care
Need to trust transplant centre	3	Professional support/shared care
Needed support	3	Professional support/shared care
Post transplant CF clinics	3	Professional support/shared care
Sources of support	3	Professional support/shared care
Support needed different teams	3	Professional support/shared care
Views on shared care	3	Professional support/shared care

Theme 4:

Complications dermatology	4	Managing complications
Complications renal	4	Managing complications
Cumulative effect complications	4	Managing complications
Unexpected complications	4	Managing complications
Expected medical complications	4	Managing complications
Is it worth it balancing complications with extending life	4	Managing complications
Limitations of transplant	4	Managing complications

Bigger complications	4	Managing complications
Little complications	4	Managing complications
Managing complications	4	Managing complications
Episodes of rejection	4	Managing rejection
Impact of rejection	4	Managing rejection
Milestone 5-9 years	4	Transplant anniversaries
Celebrating transplant anniversary	4	Transplant anniversaries
Ten year milestone	4	Transplant anniversaries
Turning 40 with CF	4	Transplant anniversaries
Five years	4	Transplant anniversaries
Not knowing how long others have survived	4	Challenges
Challenges post transplant	4	Challenges
Helping parents	4	Opportunities
Quality of life	4	Opportunities
Holidays	4	Opportunities
Perceptions of mortality	4	Managing the future
Thoughts of the future	4	Managing the future

Example of bringing together sub areas:

Area 2: sub area -moving away from pre transplant identity:

Sub areas initially included in this sub theme from all interviews:

Breathing with new lungs

Less treatment

Getting better and better first year

Not tube fed

Breaking away from hospitals

Milestones initial disbelief

No more oxygen

New normal

Process of adjustment

Relief at getting a transplant

Sub areas summarised to:

Breathing with new lungs

Less treatment/Breaking away from hospitals

Process of adjustment

Third draft – framework.

Major Theme	1.The transplant	2.Getting Home: initial adjustment	3.Settling down	4.Moving forward and Managing
<u>Sub areas</u>	<p>Surviving Surgery</p> <p>Post Op Issues</p> <p>Gaining strength</p> <p>Moving towards home</p>	<p>Adjusting to different medication</p> <p>Adjusting to different risks</p> <p>Getting on with life</p> <p>Moving away from pre transplant identity</p>	<p>Regaining independence</p> <p>Redefining CF identity</p> <p>Redefining relationships</p> <p>Redefining life goals</p> <p>Professional support/shared care</p>	<p>Managing the future</p> <p>Managing complications</p> <p>Managing rejection</p> <p>Challenges</p> <p>Opportunities</p>
Key phrase	Recovering	Looking after my new self	Regaining independence	The issues of post transplant life

Appendix 7

Example of Charting as per area/sub area.

Moving away from pre-transplant identity (Major Area: 2 sub area 4)

Interview/ Case No	Breathing with new lungs	Less treatment/ breaking away from hospitals	Process of adjustment
Int No 1	Felt amazing, like breathing cotton wool.		
Int No 2	Realised capacity of new lungs when sneezed! Little things you couldn't do. Took time to realise and recover from surgery.	Notice going less and less to the hospital and feeling of breaking away from hospitals.	
Int No 3			Feeling better and better, still feel a sense of disbelief.
Int No 4	"Four weeks later and it's like 'oh wow'"		Dont want to sit still – so much to do. Felt a real sense of relief as life pre transplant such a struggle and realised close to death.
Int No 5	Strange sensation to be able to "just breathe". "The doctors and nurses were like just saying 'breathe' and it was like, if you take a breath...it just seems to go on forever...a weird sensation cause you've never been able to do that. And that was that, phwoah I'm fine I'm sorted."		Instead of thinking what can I do, can just go out and do physical exercise. Gradual improvement in physical ability.
Int No 6	Quite difficult and painful to breathe initially as recovering from surgery and lung capacity not at best yet.		
Int No 7	Felt had to learn to breathe, was huge change from pre-transplant, notice it in the smallest things that you can do compared with what you struggled with pre transplant.		Had real difficulty initially as was very physically deconditioned – "my legs were like twigs" very slow process building physical strength.
Int No 8	"...well i think it was...because I'm a mechanic, an engineer, if you've got a wee 1 litre Fiesta it's quite cold to start in the morning, you fit a V8 engine in, you know the difference. Well thats it- because i could breathe that's the biggest issue, you know just breathing. And energy kick because you can breath is unbelievable."		
Int No 9	Initially lungs tight and sore from surgery – took 3-6 months before full effect realised. Worked lungs more as physical fitness increased.	Able to stop being tube fed. Big culture shock for self and family to have less treatment.	Big culture shock for self and family as had revolved around ill health.
Int No 10	First breath not amazing because was sore from surgery. Realised could breathe in shower with water hitting back.	Initially felt like something was missing having so much less treatment to do, but got used to it quickly!	First year tested limits, went out partying etc. Had been so much couldn't do pre transplant so wanted to work out what could do then settled down.
Int No 11	"It was a natural thing to do was just to breathe normally but a couple of times during the night I woke up and panicked for a few seconds because my cannula wasn't up my nose and the you suddenly remember 'no you actually don't need it, you're breathing by yourself, it's ok. So it was a fabulous sensation"	Fantastic to give oxygen back – had felt so intrusive in my flat.	

Appendix 8

1. Reworked framework illustrating key activities post transplant and 2. Final framework.

Area	The transplant	The first year	Moving forward with life	Managing the issues of post transplant life
Key phrase	Recovering	Adjusting and realising	Redefining and pursuing	Managing
Key Activities	<p>Physical rehabilitation</p> <p>Participating in recovery</p> <p>Establishing a trusting relationship with the transplant service</p> <p>Gradual progress towards home.</p>	<p>Realising new physical capabilities</p> <p>Moving away from pre transplant identity</p> <p>Regaining independence</p> <p>Adjusting to change in treatment regimen and different risks</p>	<p>Redefining and pursuing life goals:</p> <p>a) Career b) Other life goals</p> <p>Redefining key relationships:</p> <p>a) Partner and family b) Self as person with CF c) Donor d) Professional relationships</p>	<p>Managing:</p> <p>Rejection</p> <p>Post transplant complications</p> <p>Uncertainty re the future</p>
Key factors	<p>Complications post surgery</p> <p>Perceptions of complications post surgery</p>	<p>Age when transplanted</p> <p>Time on the list</p>	<p>Age and stage in life</p> <p>Time on list</p>	Amount and type of complications

Final Framework:

Key areas	Recovering	Adjusting and realising	Redefining and pursuing	Managing the issues of post transplant life
Key Activities	<p>Physical rehabilitation</p> <p>Participating in recovery</p> <p>Establishing a trusting relationship with the transplant service</p> <p>Gradual progress towards home.</p>	<p>Getting home</p> <p>Realising new physical capabilities</p> <p>Moving away from pre transplant identity</p> <p>Regaining independence</p> <p>Adjusting to change in treatment regimen and different risks</p>	<p>Redefining and pursuing life goals:</p> <p>a) Career b) Other life goals</p> <p>Redefining key relationships:</p> <p>a) Partner and family b) Self as person with CF c) Donor d) Professional relationships</p>	<p>Managing rejection</p> <p>Managing post transplant complications</p> <p>Managing uncertainty re the future</p>
Key factors	<p>Complications post surgery</p> <p>Perceptions of complications post surgery</p>	<p>Age when transplanted</p> <p>Time on the list</p>	<p>Age and stage in life</p> <p>Time on list</p>	<p>Amount and type of complications</p>