

Fighting time: A qualitative analysis on the
impact
of lung transplantation in adults with Cystic
Fibrosis

Janet Mary McCarthy

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This candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

During the last decade lung transplantation has become an option for those with end-stage respiratory disease, including Cystic Fibrosis. However, there appears to have been very little written about the experiences of those who are on the lung transplant trajectory. Most of the previous psychosocial research in this field has focused on Quality of Life issues, functional outcome, and psychopathology. Moreover, most of the research uses quantitative methodology. Although there are a few descriptive papers in the literature, there do not appear to be any studies published that have used a rigorous qualitative methodology. Therefore, the aim of this study was to use Grounded Theory to explore the experiences of adult lung transplant candidates and recipients with Cystic Fibrosis. Fifteen semi-structured interviews were conducted. One participant was interviewed both before and after transplantation and one person had been accepted onto the active transplant list but had declined this offer.

Data analysis distinguished one core category, subsuming 11 conceptual categories and 31 sub-categories. The analysis has been conceptualised by way of the paradigm model (Strauss & Corbin, 1998), which is a method of incorporating both structure and process in a meaningful way.

The core category "Coping with living and dying" was identified as the central phenomenon which all the other categories either impacted upon or were directed at managing. Findings are discussed in relation to already established models of coping. Four other conceptual categories which appeared to be of most consequence to participants have also been considered, with reference to the literature from more diverse fields, such as oncology. These conceptual categories are: "Perception of health status," "Closeness of death," "Awareness of time," and "Medical management." In addition, the psychosocial stages of the lung transplant trajectory, as outlined by Worby and Smith (1997), have been expanded using data derived from the analysis. Implications for future research and clinical interventions are also discussed.

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List of abbreviations

Cystic Fibrosis	CF
Transplant	Tx
Lung transplant/ transplantation	LTx
Heart transplant	HTx
Heart-lung transplant	HLTx
United Kingdom Transplant Support Authority	UKTSA
Forced Expiratory Volume in one second	FEV ₁
Quality of Life	QoL
Quality of Well-Being scale	QWB
Nottingham Health Profile	NHP
Sickness Impact Profile	SIP
36 Item Short-Form Health Survey	SF-36
Diagnostic and Statistical Manual, 4th. Edition	DSM-IV
Cystic Fibrosis Quality of Life Questionnaire	CFQoL
Intensive Care Unit	ICU
Intra-venous	IV
Obliterative Bronchiolitis	OB

Chapter one: Introduction

"And then, that's when I started seeing people die then. And that's when it - it hit me then and I realised how- what Cystic Fibrosis is then."

(Int.5, male/ Tx recipient)

"...We, all of us, death is on the horizon... Its on the horizon, well in the distance is death for everybody, even those we see as over on the horizon. But when they tell you that you need a transplant suddenly that horizon literally, is right in front of your face. It's not over there any more..."

(Int. 4, female/ Tx recipient)

A famous politician once said "There are two certainties in life: death and taxes." Death is the one thing we can rely on. It's a sure bet. Yet the healthy amongst us would probably have great difficulty in comprehending it with regard to ourselves. Most of us expect to get old. We have pension schemes and worry about the ageing process. Death seems very far away. In contrast, one lung transplant candidate in this study had started her own funeral plan. She was 21 years old. Two other participants had written their wills. As one participant related:

"...and she just said to me "Oh, there is no old age in Cystic Fibrosis."

(Int. 2, female/ Tx recipient)

Cystic Fibrosis kills 25% of patients by the age of 20 (Mendeloff, Huddleston, Mallory, Trulock et al.,1998), with the majority not living passed 40 years of age (Jefferson & Davies, 1998). Even with this awareness, which adolescents with CF may or may not have, death may still seem very far off. When faced with the prospect of a lung transplantation, however, death is brought much closer. This is hard to comprehend at any age. Imagine what this must feel like when you are 25. This is the average age for lung transplantation for people with Cystic Fibrosis, in the United Kingdom at the present time.

1. Cystic Fibrosis and lung transplantation

"Cystic Fibrosis (CF) is the most common genetic disorder caused by a single gene defect" (Jefferson & Davies, 1998, p. 107) affecting one in 2500 live Caucasian births (Conway, Littlewood & Brownlee, 2000). It also carries the highest mortality rate due to respiratory failure. The gene defect results in increased sodium secretion

from the sweat glands and increased viscosity of exocrine gland secretions causing damage, blockage, and secondary infection principally in the lungs and gut. This results in difficulty in digestion and possible poor nutritional status due to pancreatic insufficiency, chest infections, lung damage, and ultimately respiratory failure. However, CF is a multi-system disease and can affect many other bodily organs causing infertility in the majority of males and possible difficulties in conception in females. There is also the possibility of liver failure, diabetes, delayed physical development, small stature, and increased risk of osteoporosis (Conway et al., 2000).

The condition is usually diagnosed in childhood and medical treatment aims at preventing and treating chest infections, maintaining adequate nutrition, and preventing blockage of the airways. Thus, the medication regime is extensive and regular chest physiotherapy is necessary (Jefferson & Davies, 1998). Although medical research has advanced sufficiently for gene therapy to be in the first stage of clinical trials, this form of treatment is not an option at the present time (Jaffe, Bush, Geddes & Alton, 1999).

Since 1985, in the United Kingdom (UK), lung transplantation (LTx) has been a possibility for people with CF (Ramirez et al., 1992; Yacoub et al., 1990). During the 1980's and in the early 1990's Heart Lung Tx (HLTx) was usually undertaken (Mendeloff, Huddleston, Mallory & Trulock et al., 1998). Nowadays, however, bilateral LTx is the treatment of choice at most transplant (Tx) centres thus leaving the patient with their own healthy heart (Conway et al., 2000). Indeed, between 1985 and 1995, 35% of LTx's were performed for fibrosing lung disease, including CF, in the UK (¹ UKTSSA: UK Transplant Support Authority, 2001). Improvements in functioning and survival rates of LTx recipients remain similar to that of HLTx patients (Hasan et al., 1995).

Between 1996 and 2000 there were only 100 LTx's carried out for patients with CF in the UK averaging 20 operations per year. Fifty-three of these were on male patients. The average age for LTx was 25 (UKTSA, 2001). On average, only 40% of patients who are eligible for a transplant in the UK will receive one (Conway et al., 2001) and in recent years there has been less donor availability, resulting in increased waiting times. Currently, the average wait for a first HTx or LTx in the UK is nine months (UKTSA, 2001), although patients can wait as long as two years or more. For this reason decisions regarding Tx need to be made approximately two years before it becomes imperative. Patients are generally considered for Tx when their Forced Expiratory Volume in one second (FEV₁) is less than 30% of predicted normal

¹ Statistics prepared by UK Transplant from the National Transplant Database maintained on behalf of transplant services in the UK and Republic of Ireland.

although other factors, such as Quality of Life (QoL) and speed of deterioration in lung function are also considered (Conway et al., 2000).

Post-Tx survival rates, at the centre participating in this study, have been cited as 80% at one year, over 70% in years two to four and over 60% at five years (Etherington et al., 1999, cited in Conway et al., 2000). These results appear to be better than other survival statistics cited for both the UK and the United States of America (USA). Between 1996 and 2000 in the UK the percentage survival Kaplan-Meier estimates for LTx, in CF patients, was 67.1% at one year and 30.9 % at three years. No data is available for five year survival for this time period (UKTSA, 2001). In the USA, survival rates provided in 1997 by the United Network of Organ Sharing cited a percentage survival of 77%, 58% and 43% at one, three and five years respectively. These statistics are important when patients are considering Tx surgery, as they look at these figures for indicators to their own mortality and to make an informed choice.

2. Literature review

(i) Psychosocial aspects of Cystic Fibrosis and lung transplantation

The nature and course of CF and LTx means that there are potential negative implications for the psychological functioning and quality of life (QoL) in these patient groups. However, most of the research in the field of HLTx or LTx surgery is medical, examining variables such as physical functioning, infection, and rates of survival (e.g. Mendeloff, Huddleston, Mallory et al., 1998). Less attention has been paid to the psychosocial aspects of HLTx or LTx. In recent years, however, there has been a proliferation of studies evaluating health related QoL at a more holistic level (e.g. Jefferson & Davies, 1998) and psychopathology. Having said this, although CF is a common indication for HLTx or LTx there still remains a paucity of psychological research in this area in the UK (Geddes & Hodson, 1989).

Rather than measuring only medical efficacy (e.g. surgical complications, survival rates), QoL research focuses on the patient's subjective outlook, thereby hoping to provide a more comprehensive view of Tx outcome (Caine et al., 1996). Health related QoL has been defined in a number of ways over the past two decades. The general consensus now is that it is "a multidimensional construct including several core dimensions (e.g. physical functioning and symptoms, psychological and emotional state, and social relationships)" (Quittner, 1998, p. 326), and that the evaluation of this construct comes from the patient's subjective experience, not the health professionals. Therefore many of the instruments used to measure QoL are in the

form of self report questionnaires which contain a number of sub-sections covering some, or all, of the dimensions cited above.

Generally, QoL research is quantitative in nature using a range of measuring instruments. These measures generally fall into three main groups: utility measures which aim to compare different treatments or evaluate the impact of different diseases on QoL (e.g. the Quality of Well-Being Scale (QWB)); health profiles which are generic to different diseases so that comparisons can be made (e.g. the Nottingham Health Profile (NHP); the Sickness Impact Profile (SIP); and disease specific measures which are tailored to particular illnesses (Quittner, 1998).

(ii) Quality of life in CF

Since 1989 a number of studies have investigated QoL in CF patients using generic health and utility scales. This research is undertaken on patients with CF who are not ill enough to be on an active Tx list and the results would reflect this. For example, Congleton, Hodson & Duncan-Skingle (1996) used the NHP on 240 adults with CF. The NHP is a two part measure assessing physical, emotional, and social well being as it relates to health, as well as the impact that the illness is having on daily functioning such as work and home life. QoL in patients with CF was found to be analogous to QoL in those with minor, non-acute conditions such as hernia, varicose veins, and even pregnancy, although no formal analysis was done on this data (only means were reported) so results must be interpreted with care. These authors are not, however, proposing that CF is comparable to minor ailments. Instead they hypothesise that patients with CF have adjusted well to a chronic condition. In addition, they highlight the dangers of comparing disparate patient groups using a generic health measure. For this reason it may be problematic to extrapolate from studies looking at other groups of Tx recipients, including heart transplant (HTx) patients, to LTx patients with CF. CF patients are also more likely to be a younger age and therefore at a different life stage from many HTx patients or from other patient groups having LTx's. They may therefore have different expectations about life quality. These differences may become lost, however, within quantitative analysis, especially when generic health measures are used.

Reports using utility QoL scales, such as the QWB, which overly focus on function, suggest a positive correlation between lung function, exercise tolerance, and QoL (Kaplan, Anderson & Mathews et al.,1989; Orenstein, Nixon, Ross & Kaplan,1989). Other studies have also focused on functional status of the patient (e.g. Shepherd, Hovell & Slymmen et al., 1992), equating QoL with physical and social functioning. In contrast, when more disease specific measures were used, very little association has been found between lung function and QoL (Weir, Freeman, Roberts &

Stableforth, 1991). Again, looking at functional status, Gotz, Eichler & Gotz (1997) examined the relationship between objective health measures and employment in 41 adults with CF. Their findings indicate that those whose illness was more severe were less likely to be working full time. This is in line with similar research from the UK (Walters, Britton & Hodson, 1993).

Gender differences have also emerged in CF adults (Congleton et al., 1996). In comparison to a healthy community sample, males reported more problems in the areas of social isolation, pain and energy levels whilst females had difficulties with emotion, sleeping and pain. Interestingly, there was a trend towards poorer QoL scores as the age of the men increased whilst QoL scores for the older women in the sample were often better than age related norms.

Unfortunately, most of the QoL research in CF uses generic health scales that were not designed or validated with the CF population in mind (Abott, Webb & Dodd, 1997). Quittner (1998) suggests that many of the QoL measures used may be inappropriate for patients with CF as they may not be specific or sensitive enough to change, may overly focus on physical function, exclude emotional and psychological well being, and not allow for the fact that CF is a multi-system illness.

(iii) Quality of life in Tx candidates and recipients

Whilst there is a plethora of QoL studies on HTx recipients little research appears to have focused specifically on the psychosocial issues of LTx, especially in this patient group. Moreover, due to the nature of the illness, much of the research is oriented towards the child or adolescent population, rather than adults. However, studies focusing on LTx or HLTx patients suggest that, in general, QoL improves post-Tx, once the person has recovered from the traumas of surgery. For example, Gross, Savik, Bolman & Hertz (1995) evaluated health status and QoL in 98 LTx candidates and recipients. Their findings show a huge improvement in health and QoL measured at least one year after surgery. However, for those people who developed Obliterative Bronchiolitis (OB) (i.e. "narrowing of the small airways...which can cause end-stage lung disease") (Conway et al., 2000, p. 55), this did not hold and QoL decreased. This was mainly in the physical, social, and pain dimensions (Gross et al., 1995). Gross and Raghu (1997) suggest that concern for the future will have a marked affect on perception of health status in these patients.

The NHP, a generic health measure, has been used to assess QoL in LTx patients on a number of occasions, often in conjunction with other measures (e.g. Busschbach, Horikx, van der Bosch et al., 1994). Dennis, Caine, Sharples and Smyth et al. (1993) used the NHP to assess QoL before and after HLTx in 31 patients with CF. The authors found a significant improvement in areas of QoL with the largest

improvement in the patient's mobility and energy levels and least improvement on the pain dimension. The results are in line with other research in this area which suggests that QoL, as well as functional outcome including respiratory function, improves three to six months after Tx (e.g. Caine, Sharples, Smyth et al., 1991). O'Brien, Banner, Gibson et al. (1988) measured QoL in HLTx patients, using the NHP, at three, six and 12 months following Tx. Temporal changes were not significant suggesting that QoL increases in the first three months post-Tx and then remains stable.

Caine, Sharples and Dennis et al. (1996), in a prospective study of adults undergoing HLTx, also report highly significant improvements on all areas of functioning on the NHP at both three and six months post-Tx, although only 35% of their cohort had a diagnosis of CF. However, the authors acknowledge that the NHP is a generic health measure which may not be sensitive enough to change in the CF population. They therefore combined this with other measures to increase sensitivity.

A more recent cross sectional study, using both general and lung specific measures, also demonstrates that QoL improves overall post LTx, except in the area of physical pain (Stavem, Bjortuft, Lund et al., 2000). Lanuza, Lefaiver and Cabe et al. (2000) undertook a prospective pilot study on functional status and QoL before and after LTx in ten adult patients, four of whom had a diagnosis of CF. Their measures included generic health measures plus a number of other instruments and physiological tests. Patients were assessed when on the waiting list and at one month and three months post-Tx. Their findings suggest that improvements across QoL dimensions was not equal. Whilst physical health, respiratory function, and satisfaction with QoL showed significant improvements, three months following Tx this did not apply to psychological status measured by the Brief Symptom Inventory (BSI) and the SIP. However, this may have been due to a ceiling effect in that the study participants were only a little dissatisfied with their psychological well being prior to Tx. In HTx recipients research suggests that QoL improves after Tx when measured at four months post-Tx, increases for the next two years, and then levels off (Fisher et al., 1995). This seems similar to the gains made by LTx recipients, at least in the initial stages following surgery, with overall QoL considerably improved by three to four months post-Tx. (e.g. Lanuza et al., 2000; O'Brien et al., 1988; Ramsey et al., 1995; Stavem et al., 2000; Ten Vergert et al., 1998). The main areas of improvement are physical health and mobility with least change observed in the psychological, emotional, and social domains (e.g. Limbos, Chan & Kesten, 1997). Limbos et al. (1997) suggest that "there are a number of factors that continue to impair a return to normal QoL..., such as side effects of medication and complications of Tx" (p.1165). They suggest that QoL means more than health and functional status as it includes a number of other factors that may not improve post-Tx. For example, they found that female patients

continued to have a less positive body image post-Tx, and that sex drive decreased in women after Tx surgery, contrary to what one would intuitively expect with increased mobility and fitness.

Returning to work also appears to be a common difficulty for individuals post HTx with 47% of respondents not back in full-time employment or education at five-year follow up (Fisher et al., 1995). A number of hypotheses have been suggested to account for this. Fear of loss of insurance benefits and natural retirement from employment due to ageing are two such propositions. However, the former would not apply to the UK population and the latter is not relevant to the age group under study. Moreover, these are only tentative suggestions. A person whose self concept is that of a chronically ill person may have difficulty in re-defining themselves as "well". Perhaps employers are also reluctant to employ someone who has had a Tx due to concerns about future sick leave. Littlefield, Abbey and Fiducia et al. (1996) compared the QoL in patients following Tx of the heart, liver and lungs. They report improved QoL overall in all three patient groups although LTx recipients fared better than the other two groups in all domains. Improvements were mainly in physical activity and energy levels with less improvement noted in social and intimate relationships. Moreover, LTx recipients scores were equal to, or better than, norms for the general population on all sub-scales of the SF-36 (Medical Outcome Study 36 Item Short Form Health Survey). This was especially notable for vitality and mental health. Other measures used to evaluate QoL in patients with either HTx, HLTx, or LTx include the Psychological Adjustment to Illness Scale (e.g. Caine, et al., 1996); the SF- 36 (Cohen, Littlefield, Kelly, Maurer & Abbey, 1998); the Standard Gamble Interview (e.g Ramsey et al., 1995); the Rand-36 Health Survey, Body Cathexis Scale, Derogatis Sexual Functioning Inventory, the Rosenberg Self-Esteem Scale (e.g Limbos, Chan & Kesten, 1997); Quality of Life Index and Rating Question Form, the Heart Transplant Symptom Checklist, the Heart Transplant Stressor Scale, and the Jalowiec Coping Scale (e.g. Grady et al., 1996, 1998).

Most studies detail the reliability and validity of their chosen instruments and all appear reasonable in this regard. However, due to the number of measures used to assess QoL, it is difficult to compare across studies. In addition, there are few studies that have focused solely on LTx candidates, even fewer that are prospective in design, and many of them have small numbers of participants. Unfortunately, these difficulties are inherent in this field of research due to the seriousness of the patients' condition and the lack of availability of donor organs.

Moreover, much of the QoL research on LTx recipients is North American. Because of the differences in the health care systems between the UK and North America, it is difficult to generalise from these studies to the UK population. For

example, US citizens often have to pay for their own Tx or have appropriate insurance cover. High payments are also involved in the evaluation phase of the Tx process with no guarantee that they will be accepted. The distances in the USA are huge so patients often have to relocate, frequently having to leave their families behind. Some insurance companies will not continue to pay for expensive medication long-term. Furthermore, the different health systems may mean that some patients get surgery earlier than others and, as surgical success depends on where the Tx is performed, insurance companies can dictate the Tx centre to be used (Smolin & Aguiar, 1996).

QoL measures are varied but all aim to be patient-centred in that it is the patient's perception that is important rather than their objective health status. Having said this, one person's idea of good QoL will not be the same as another in the same circumstances. Indeed, some individuals may give very different definitions of this concept. For example, a person who has been chronically ill with CF will probably have a different idea of quality of life than someone who became ill more acutely, although they may be pooled together for research purposes.

In summary, research to date indicates that overall functional status and QoL improve significantly by three to six months after Tx and then levels. However, lung function and QoL do not necessarily correlate when more sensitive instruments are used. Moreover, as functioning is relative and dependent on context, this does not necessarily mean that QoL is *good*. Thus, the instruments used to measure QoL give some idea of patient functioning pre and post-Tx but, unfortunately, do not explore patients' experiences, affect, beliefs, and cognitions to any depth.

(iv) Psychological functioning in patients with CF

The coping mechanisms, psychological status, and knowledge level of patients with CF are important factors as they, no doubt, influence the person's evaluation of QoL and their ability to cope with the different stages of the Tx process. For example, being told of the need for a Tx may be quite unexpected and overwhelming if the person's perception is that their health status is relatively good or if they are already in psychological distress.

Studies that have looked at psychological functioning in adolescents and young adults with CF show mixed results. A number of studies suggest that psychiatric disorders are much more prevalent in CF patients than in the general population although not all used clinically valid instruments (e.g. Boyle, di Saint' Agnese & Sack et al., 1976; Strauss & Wellisch, 1981). For example, Boyle et al. (1976) used a battery of projective tests (which have inherent problems of validity and reliability) to assess the psychological impact of CF in adolescents and young adults. Participants in the study were found to be managing their lives quite well, generally keeping up with

studies and employment, but had impairments in the emotional realm. Anxiety and depression were found to be common. The most problematic areas were found to be concerns about physical appearance, problems in social interaction and relationships, including marital difficulties, discord with parents (e.g. over protection by mothers), and concerns about the future.

However, more recent studies suggest that young people with CF are not dissimilar in psychological functioning to their healthy peers (e.g. Blair, Cull & Freeman, 1994; Kellerman, Zeltzer, Ellenberg et al., 1980; Moise, Drotar, Doershuk & Stern, 1987). Cowen, Corey and Simmons et al. (1984) found that their research participants generally coped well with life's demands. Although they also report higher levels of emotional disturbance, especially in women, which increased with age (after aged twenty) severity of the illness did not equate with degree of emotional disturbance. This implies that very ill patients were still functioning adequately. Socially they also appear to perform well, although much of their social group can consist of other CF sufferers (Shepherd, Hovell, Harwood, Granger et al., 1990).

Coping skills used by people with CF have been discussed in a number of papers (e.g. Cowen et al., 1984; Moise et al., 1987; Strauss & Wellisch, 1981; Zelter & Kellerman et al., 1980). The main responses to illness appear to be that of denial, minimisation, avoidance or, conversely, increased health monitoring and focusing on the illness. These can all serve an adaptive or maladaptive function depending on context (Aspin, 1991). Thus they may either help the person control emotional distress or increase likelihood of non-compliance with medical treatment (cited in Aspin, 1991).

Overall, adolescents and young adults with CF appear to cope very well with the limitations of their illness and their uncertain future. Day to day functioning appears to be similar to that of their healthy peers, especially at school or work. There are mixed reports regarding level of psychological distress and psychopathology although methodological shortcomings cast some doubt on the more negative findings.

(v) Psychological functioning in Tx candidates and recipients

Other studies have looked for evidence of psychopathology or emotional difficulties pre and post-Tx, how this affects QoL and in turn, Tx survival rates. Squier, Ries and Kaplan et al. (1995) measured QoL and depression using the QWS and the Beck Depression Inventory (BDI) respectively. They found that quality of well-being, rather than depression or length of time on the waiting list, was the best indicator of survival in both the pre and post-LTx groups. Other studies indicate that poor compliance with the medical regime can be predicted by high levels of anxiety,

poor social support, and dysfunctional coping mechanisms in HTx recipients (Dew, Roth & Thompson et al., 1996) and that this affects post-Tx survival rates (e.g. Rodriduez, Diaz & Colon et al., 1991).

Many studies include self-esteem scales and measures of depression and anxiety (e.g. Caine et al., 1996; Fisher et al., 1995). The Diagnostic and Statistical Manual, Fourth Edition (DSM IV) (American Psychiatric Association (APA), 1995) provides guidelines for assessment and diagnosis of mental disorders by way of one of five axes. Axis I disorders include clinical disorders such as depression and anxiety whilst Axis II disorders include personality disorders and mental retardation (APA, 1995). Reportedly both Axis I and Axis II disorders have been reported in HTx candidates and co-morbidity is high (Chako, Harper et al., 1996). Freeman, Westphal and Davies et al. (1995) also report high levels of Axis I disorders (30-40%) in people waiting for HTx, although improvements were noted post-Tx. Depression and anxiety are the most common psychiatric disorders identified (cited in Manzetti, Ankeny & Miller, 1997). Most find that many patients are mildly to moderately depressed before HTx but that this decreases after surgery with the majority of patients classified as not depressed four months post operatively (Fisher et al., 1995). Fisher et al.'s study demonstrated that low depression ratings and increases in QoL scores were maintained over a five year period. Indeed, as psychiatric morbidity is thought to be due to the enormous amounts of stress induced by having a life threatening and disabling medical condition (Chacko et al., 1996), one could possibly expect some psychological change if health status decreased significantly post-Tx. This could be especially significant for LTx patients who rarely obtain a second Tx. Indeed, as already mentioned, Gross et al. (1995) found that QoL ratings fell in patients with OB as their future became more uncertain.

A cross sectional study by Cohen, Littlefield, Kelly et al. (1998) found that psychological status pre-LTx can predict adjustment and QoL post-Tx as measured by the 36-Item Short Form Health Survey (SF-36). Multiple regression analysis demonstrated that state anxiety decreased after Tx whereas higher pre-Tx trait anxiety scores were associated with poorer QoL scores and adjustment post-Tx on all but one of the subscales of the SF-36. In contrast, pre-Tx depression scores using the BDI did not predict QoL post-Tx.

LeHeuzy, Isnard, Lambert et al. (2000) assessed seven patients with CF, aged 13 to 30 years, before Tx and at one and two years post-Tx. It was found that mean anxiety and depression scores decreased post-Tx although remained significant in two of the seven patients studied. In addition, a positive correlation was found between pre and post-Tx anxiety and between pre-Tx anxiety and depression post-Tx. However, this study was very small making it difficult to generalise.

Most of the psychopathology and QoL measures are in the form of self report questionnaires and hence subject to the usual difficulties associated with such measures, e.g. minimisation or social desirability bias. Indeed, Carnike, Lance, McCracken and Aiken (1996) indicate that many patients are reluctant to reveal psychopathology pre-Tx for fear of rejection by the Tx team. This is especially so when the questionnaires are used as part of a pre-operative evaluation. Although minimisation, as measured by the Marlow-Crowne Social Desirability Scale, may also be a risk within an interview context, Carnike et al. suggest that the effect is lessened and more easily identified (e.g. by the interviewee displaying incongruent non verbal and verbal behaviour). This demonstrates the advantages of using a semi-structured interview instead of self report questionnaires.

In interviews with 30 HTx patients in the UK, Greaves (1997) found that patients were very open about their experiences. They acknowledged periods of depression, difficulties in re-integration of their identity from having someone else's heart inside them, the need for constant medication, difficulties in maintaining a healthy lifestyle, and emerging hostilities within the family which were kept hidden prior to the Tx. Unfortunately, the author gives little indication as to how the data was collected and does not report the method of analysis used, so it is impossible to evaluate the validity of her conclusions. However, it does provide some insight into the type of problems patients may experience pre and post-Tx.

In most of the studies focusing on psychopathology in Tx patients the participants did not fall exclusively into one diagnostic category (e.g. Caine et al., 1996). Therefore, participants could not be considered an homogenous group in terms of their illness. Consequently, it is conceivable that participants' responses may, in part, reflect the impact that their illness has had on their life in terms of diagnosis, length of illness, age, and causal attributions. In CF, for example, which is a life long medical condition, patients may have adapted well to their illness over time so that they will rate their QoL higher than an objective observer might. It could also be speculated that patients with CF, who are generally diagnosed early in life, may be resigned to the idea of LTx given that end stage lung disease kills the majority of patients with CF by the age of 40 (Jefferson & Davies, 1998). They may therefore cope relatively well in comparison to other groups of patients when Tx is first mooted.

Having said this, patients' perceptions of their own health status may not coincide with that of their doctors. Indeed, past research supports this speculation (e.g. Strauss & Wellisch, 1981). A more recent study by Abbott, Dodd & Webb (1995) found that CF patients and the person closest to them underestimated their disease severity, even when health was deteriorating. Included in this sample were eight patients who had been assessed for Tx. They also believed that their health was

better than average. The authors suggest that patients may be using denial as a form of self protection. However, they express concerns that this can give rise to problems when important decisions regarding treatment need to be made.

In similar vein, Conway, Pond, Watson & Hamnett (1996) found that patients' knowledge of CF was good in many respects but that there were some important areas in which they were uninformed. This lack of knowledge may therefore feed into their overly optimistic health perceptions so that LTx may be a form of treatment that they may never have considered.

(vi) The process of lung transplantation

There is a proposed common pathway that patients apparently follow when having a LTx. This seven stage Tx trajectory is outlined below (Worby & Smith, 1997; Worby, 1998).

1. Tx proposed.
2. Referral to Tx team (assessment for Tx suitability).
3. Accepted on to the active waiting list (up to 2 years).
4. Peri-operative and postoperative care.
5. Rehabilitation (up to 3 months post-Tx).
6. Getting on with life, trying to establish normality.
7. Irreversible decline and death.

Worby (1998) states that the patient must address different psychosocial tasks as they go through the trajectory, although these are not well defined. The tasks are both intra-psychic and inter-personal, involving not only the patient but also their significant others and the Tx team. Most psychosocial studies do not address the first two stages of this process but focus instead on the pre- and post-Tx phase, often only up to two years after surgery (Arcasoy & Kotloff, 1999). However, Smolin & Aguiar (1996) provide a useful, descriptive account of stages one to five of the LTx trajectory, although this appears to be an anecdotal report as the authors do not report any research methodology. It does, though, provide some understanding of the patients' experiences when undergoing Tx. Stage one is when the Tx is proposed. Smolin & Aguiar report feelings of shock, hope, uncertainty, and denial. Benefits and risks may need to be evaluated or patients may feel that they have no other option. Stage two is the evaluation phase when the Tx assessment is carried out. This involves many medical procedures and psychosocial assessments which can be physically exhausting and very stressful. There may be a sense of being out of control and worries as to whether or not they will be accepted onto the Tx list. The patient then moves into stage three of the Tx process. This may involve a long wait which can give rise to a host of painful

emotions: preoccupation with their place on the list, coping with the knowledge that someone must die in order for them to live, use of black humour, dealing with other patients dying, worrying that they will die whilst waiting for a Tx, and putting life "on hold" (p.298). Stage four is the peri-operative and immediate post operative stage. This starts when "the call" from the Tx centre comes to tell them that a donor organ is available. Feelings expressed were anxiety, excitement, and fear. A false call, when the patient is called but the organ is subsequently found to be unsuitable, is disappointing but can prepare the patient for what to expect next time. After the Tx some patients feel overwhelmed by all they must do and learn before going home (e.g. exercises, new medication regime). They may also worry about leaving the safety of the hospital to return to normal life. Stage five is the rehabilitation phase when the patient and their family must learn to adjust to normality, their new roles and deal with the side effects of the anti-rejection drugs which can be unpleasant.

Due to its anecdotal nature it is difficult to evaluate the validity of Smolin & Aguiar's findings. However, their account bears many similarities to another descriptive paper by Bright, Craven & Kelly (1990). The latter also describe how hospital support groups helped patients cope with the pre-Tx phase.

(vii) Coping mechanisms in transplant candidates and recipients.

Smolin and Aguir (1996) and Bright, Craven and Kelly (1990) mention some coping mechanisms used by LTx patients. These included denial, the use of black humour, and support from other patients with whom they can share information and express their concerns. Miurhead, Meyerowitz and Leedham et al. (1992) also discuss the benefits, for HTx candidates, of keeping a positive attitude and gaining social support. This is supported by the work of Cupples, Nolan, Augustine and Kynoch (1998). They found that humour, positivity, trying to sustain normality, belief in God, and distraction, were the main coping strategies used by a group of HTx candidates, although this changed over time. This was in contrast to more fatalistic coping strategies (e.g. acceptance and escapism) used by HTx patients in Grady, Jalowiec & White-Williams' study (1996). In a Scottish study, Kaba & Shanley (1997) described the coping mechanisms used by HTx recipients. Coping was evaluated using an American coping scale entitled the Family Crisis Oriented Personal Evaluation Scales (F - COPEs) which, as the authors acknowledge, has not been validated for the UK population. Nevertheless, the Scottish sample were found to use more passive coping strategies (e.g. watching television, belief in luck, waiting for problems to disappear) than the American normative sample. The authors suggest that patients who use this coping style will have more psychological distress which will negatively affect their

QoL. However, psychological distress was not measured. In addition, the comparison group being North American raises problems for interpretation of scores as the culture of the USA is very different from that of the UK.

(viii) Summary

Most of the psychosocial research in LTx candidates focuses on functional outcome and QoL. All show overall improvements post-Tx. However, many of the measures used may not be appropriate for patients with CF. In addition, as so many different instruments are used, it is difficult to compare across studies. Moreover, few studies focus specifically on LTx in CF patients. Depression and anxiety appear to be common responses in the pre-Tx phase although this could be considered a normal response to a very difficult situation (cited in Manzetti, Ankeny & Miller et al., 1997).

The experiences of people undergoing LTx have also been described in regard to the LTx trajectory. Although these papers provide useful insights into the patients' experiences, the authors do not describe their research methodology and are therefore difficult to evaluate. Perceived psychological stressors and coping mechanisms of patients with CF have also been described. These experiences will, no doubt, affect their perception of the Tx process and therefore provide important contextual information.

3. Information regarding the present study:

(i) Qualitative research methodology

During the course of the literature search no published articles using qualitative analysis were found on the experiences of LTx candidates and recipients (although this may indicate that journals are reluctant to publish qualitative research). In contrast to quantitative analysis, qualitative methodology is flexible so that unusual or unexpected avenues can be explored, meaning elicited, and findings explicate the participants' perspective. Quantitative research tends to use structured questionnaires. This does not allow participants' free expression of their feelings and thoughts as areas considered to be important are already fixed by the questionnaire format.

As qualitative methodology explores patients' experiences in depth, it was thought to be an ideal methodology for a relatively new area of study where theory development is limited. It is also considered that the use of this methodology will help identify important aspects of patients' experiences that have been previously overlooked. Lyons (1999) states; "Qualitative research methods enable an incorporation of the social world into health research... and in this way allow insights into individuals' perspectives that are rendered invisible in quantitative research" (p. 242).

The method of qualitative analysis used here was "Grounded Theory" (Glaser & Strauss, 1967) which practices rigorous and systematic analytic techniques (Strauss & Corbin, 1998). Although there are a number of different methods of conducting qualitative analysis, I have decided to use Grounded Theory as it has been well established in other disciplines, and is being used more and more in psychology (Henwood & Pigeon, 1992). More importantly, its analytic techniques are rigorous and systematic and an ideal methodology to use in an area where theory development is limited.

Grounded theory was originally developed by sociologists Glaser and Strauss (1967). It describes both the method of analysis and the principles of theory building. It is an inductive methodology whereby the theory, or model, emerges from the data rather than using data to support or "test" a theory. Moreover, the theory generated remains close to, or grounded in, the data (Henwood & Pidgeon, 1995). It involves three main phases (Chamberlain, 1999): sampling, in which the researcher obtains data relevant to the research question; coding, in order to conceptualise the meaning of the data; and theory development.

There is a constant interplay between each phase as new data is collected. Data gathering continues until little more is added to the emerging theory. Data analysis is aided by the use of memos. Memos are "written records of analysis that vary in type and form...containing the products of analysis or directions to analysis. They help keep the analysis grounded in the data and maintain the awareness of the researcher" (Strauss & Corbin, 1998, p. 217-218).

Grounded theory analysis is conducted on textual data. In the present study, data was generated by way of semi-structured interviews. An interview format was used so that LTx candidates and recipients could "have space to describe and validate their experiences" (Mathieson, 1999, p. 118). This was thought to be the best way of gaining information about individuals' own subjective experience rather than, for example, analysing patients' hospital notes. As opposed to a structured or unstructured interview, a semi-structured interview allows the researcher to formulate questions around certain ideas and follow up interesting leads. At the same, this allows the participant free expression of their experiences so that in depth information can be gathered (Mathieson, 1999).

(ii) Summary of research rationale and aims

Although CF is a common reason for LTx (Geddes & Hodson, 1989), adults with CF are an under-studied group as regards transplantation. Indeed, research into the psychosocial aspects of LTx is fairly new and the area is still relatively unexplored. Moreover, the paucity of research in this area is most notable in the UK. Although

there are a number of North American studies, it is difficult to generalise from these to the UK population due to cultural and health care differences. There is also a dearth of qualitative research investigating the experiences of adult LTx candidates and recipients with CF. Hence, the aims of the current study are as follows:

1. To explore the experiences of adult LTx candidates and recipients with CF.
2. To increase understanding of the psychological processes involved in the Tx trajectory and to identify areas of importance that may have been omitted by previous research.
3. To construct a theoretical model of the processes involved in the experience of LTx for patients with CF.

Chapter two: Methodology

1. Brief overview of the research project

This research project was set up with the aim of interviewing 20 participants: ten people waiting for LTx and ten who had already one. However, given the length of the initial interviews, which were between one to two hours long, it was decided to reduce the total number of participants to 14. Moreover, there were only seven potential participants who were on the Tx waiting list. In addition, I hoped that there would be the opportunity to interview at least one participant both before and after surgery.

2. Information about the researcher

Recent guidelines for the publication of qualitative research recommends that the researcher is open about any background experiences, interests or values that may have influenced their interpretation of the data. "Owning one's own perspective... helps readers interpret the researcher's data and understanding of them, and to consider possible alternatives" (Elliott, Fischer & Rennie, 1999, p. 221). It is also for this reason that qualitative research is often written in the first person, as is done here. I will therefore outline my background and include any other information that seems relevant to the present study.

Prior to starting my career in Clinical Psychology I was a Registered General Nurse. I was therefore familiar with the hospital environment, the communication style of medical and nursing staff and medical regimes. I therefore felt that I had a sense of where participants were "coming from" when they talked about medical issues and life in hospital. I had also worked as a school nurse which involved working with adolescents, and had spent time with young adults on adventure type activities overseas. In addition, when a nursing tutor, most of my students had been young adults and I was aware of the issues that they had experienced difficulty with (e.g. in relationships). I therefore felt that I had some sort of comparative "base line" when conducting the interviews.

Presently, I am a Psychologist in Clinical Training at Leeds University and this research was conducted over the 2nd. and 3rd. year of the course. During my training I have had lectures on developmental stages, health psychology and bereavement issues and am currently on clinical placement in a health psychology department. The theoretical models with which I am familiar include Cognitive Behavioural and Psychodynamic. Indeed, during the early stages of the analysis the data appeared to be leaning towards a Cognitive Behavioural model, and I found that I was also looking for

evidence of defensive mechanisms in the participants. As I began to feel that I was being overly biased by my psychology training I therefore sought to curb this tendency by looking at alternatives (i.e. imagining what another person would find if they were in a different occupation). I was also aware of this bias during the interview process (e.g. I would ask about what sort of thoughts ran through their mind).

3. Ethical considerations

(i) Ethical approval

In order to protect the psychological well being of potential research participants all psychological research undertaken by the University is subject to ethical approval. Guidelines set down in the British Psychological Society's (BPS) Code of Conduct, Ethical Principles and Guidelines (BPS, 2000), specify what is considered to be acceptable research practice. This includes issues such as informed consent, debriefing, confidentiality, the right of participants to withdraw and avoidance of harm. I used these recommendations to guide the written and verbal information given to potential participants, in gaining informed consent and in the way in which I carried out the research. The latter included provision for any possible distress to participants arising from the interview itself. An ethics form and the research proposal was submitted to the participating hospital in November 1999 before any approach was made toward potential participants. Ethical approval was given that same month by Chairman's Action (Appendix 1).

(ii) Dealing with sensitive issues

After ethical approval had been given I sent potential participants postal information about the nature of the research. In this information sheet I informed participants that the interview would be conducted in a sensitive manner and that they had the right to withdraw at any time (Appendix 2).

Due to the nature of the study it was likely that emotionally sensitive topics (e.g. the possibility of early death) would be discussed. For this reason it was important that I conduct the research in a sensitive manner and in a place where participants felt comfortable. Sensitive areas were discussed later in the interview process when some rapport had been established, rather than at the beginning of the interview. This was unless the participant brought the topic up themselves. I also reminded participants that they could stop the interview at any time or ask me to turn off the tape recorder. I also informed them when the tape was recording. None of the participants stopped the interview or asked me to stop taping although I emphasised this option on one occasion, when the discussion appeared to become particularly distressing for the participant.

At the beginning of each interview I informed participants that I was there as a researcher, rather than as a psychologist, but that the interview could raise some potentially distressing material for them which they might feel the need to discuss further. For this reason I gave them a list of staff telephone numbers who they could contact for support. This included the contact telephone number of a qualified clinical psychologist working in the CF unit where they received treatment, (Appendix 3).

(iii) Informed consent

Due to the potentially sensitive nature of the material to be covered during interview the consent form aimed to cover all aspects of the interview process, including audio-taping, and the use of the material in research reports. Informed consent is especially important in qualitative research as it is necessary to use verbatim quotes to illustrate points. For this reason issues regarding the write-up of the research, was also included in the consent form (Appendix 4).

I sent out the consent form with the information sheet so that potential participants could see exactly what was involved prior to making a decision as to whether or not they would like to participate. However, they were not expected to return the consent form immediately but, instead, I asked them to sign it in my presence just prior to the interview taking place. I also gave participants the opportunity to ask questions about the research at the beginning and end of each interview when I could clarify any outstanding queries.

(iv) Confidentiality

In the information sheet and consent form (Appendix 2 and 4 respectively), I informed participants that the interview tapes would be kept in a secure place and that, when transcribed, identifying names or places would be changed. Furthermore, I informed participants verbally that the transcriptions would be undertaken by a secretary but that she had signed a confidentiality agreement (Appendix 5). The consent form also stated that their name would not be used in any reports or publications. They were also made aware that feedback would be given to medical staff but that this would also be kept anonymous and that participation would not interfere in any way with their medical care.

4. Participants

(i) Recruitment context

The hospital from which I recruited participants is a large University teaching hospital located in a city in the United Kingdom. It has a specialised unit for adults with CF and this particular service has a regional catchment area. All patients are under

the care of one of two consultant physicians. A meeting was arranged with the members of the CF team to discuss the aims of the research and the method by which it would be conducted. The consultants were very enthusiastic about the project and gave it their full support.

(ii) Selection criteria

As the mean age of Tx for people with CF at the participating hospital is 24 years (Conway et al., 2000), the focus of this research is adults with CF rather than children. This was also for practical reasons in that there would have been an insufficient number of children involved in the Tx process who would have been available for interview. Therefore all potential participants were to have a diagnosis of CF and be aged 16 or over, this being the age at which their medical care is transferred to the adult unit.

Those in the pre-Tx group had to have been accepted onto the active waiting list for LTx although they need not have agreed to the surgery following assessment. All the participants would therefore have been through a similar assessment procedure irrespective of the Tx centre at which they were assessed. They will have been provided with information regarding the risks and benefits of Tx and will all be aware that they are unwell enough to need a Tx regardless of their varying health status at the time of interview. Patients who had been fully assessed, and considered suitable for Tx, but were not ill enough to need one at the present time (i.e. on the provisional waiting list), were not considered. I felt that this difference could potentially confound the analysis and therefore not give a true picture of the experience of those who were actively waiting for a donor organ. However, for piloting purposes I interviewed a patient from the provisional list. This was because I had concerns that there may not have been sufficient people on the active waiting list for the main study. Moreover, the purpose of the pilot study was to test the interview schedule rather than to analyse its contents. For this reason, it seemed appropriate to interview a patient from the provisional list as they would have undergone the assessment procedure.

In general, patients are referred to a Tx centre for assessment when their forced expiratory volume in one second (FEV₁) is 30% of normal predictions. Other factors such as QoL and speed of deterioration of lung function are also taken into account. Patients are usually referred by the consultant physician at the participating hospital about two years before the need for Tx becomes imperative. This allows time for full assessment at the Tx centre and increases the chances of lung donor availability.

In order to control for possible gender differences, I recruited seven females and seven males, making the gender balance as even as possible between the two groups. For the same reason, cited above, I considered a spread of ages to be

desirable. This was done in order to obtain as wide an overview of experience as possible. For example, feelings about having the surgery itself may alter depending on life stage, life roles, and background.

On the basis of research requirements such as gathering information on diverse experiences, the demographic information I obtained at previous interviews was used in selection of other participants so that similarities and differences could be explored. In order to do this, I found it necessary to obtain some pertinent information from the consulting physicians. For example, one person had been accepted for the active waiting list but, at the time of the interview, had decided not to be put on it. Length of time since Tx varied from between four months to seven years seven months. Some patients were relatively well whilst others had been beset by complications. Two of the women had children. This said, pragmatics influenced the selection criteria. This was especially so in the pre-Tx group as there were only seven patients initially on the active waiting list.

5. Recruitment procedure

I recruited participants with the help of one of the consulting physicians of the CF unit and his secretary. Names, addresses and phone numbers were provided of all eligible patients and I was kept informed of any changes to the list. The consultant also sent a letter to each patient informing them about the research and indicating his support for it (Appendix 6). I then sent a follow up letter to each patient informing them about the research. It also outlined factors such as ethical considerations, issues of confidentiality, anonymity and the right to withdraw from participation at any time (Appendix 2). A consent form was also enclosed (Appendix 4). Letters were sent initially to 29 patients.

Two weeks after this letter was sent, I telephoned potential participants to find out if they were willing to participate and to give them the opportunity to ask questions. This was done in stages so that not everybody was contacted in the same time span. Staggering of initial contact with participants was so that information obtained at previous interviews could be used in selection of other participants, as outlined above. For example, following an interview with a participant who had children, a second person who also had children, was contacted so that their experiences could be compared. For practical reasons those people who were known to be more unwell were also interviewed earlier where possible. This was based on information provided by the medical staff at the participating hospital. As I hoped to follow at least one person through the Tx trajectory, from pre- to post surgery, I also made endeavours to make early contact with people who were on the waiting list. This was because availability of donor lungs is scarce and unpredictable and patients can be called for Tx

at any time. Early contact, therefore, gave me more opportunity to follow a participant through the Tx process. However, this was not always possible due to their unavailability when contact was initiated. If someone refused to be interviewed, no reason for this was requested as I felt that this may have been considered coercive and overly intrusive. Appointment dates for an interview were then agreed with those individuals who were willing to take part.

As telephone contact was carried out in stages, I only found it necessary to telephone 21 people to obtain sufficient participants. Of those verbally invited to take part, six people were unobtainable by telephone and one person died before I could establish contact with them. Of the 14 people I was able to contact, one person died before I was able to interview them and three people refused to participate although they did not give reasons for their decision. As the Tx waiting list was updated five further people were contacted, four of whom were interviewed.

6. The participants:

(i) Demographic information

Fifteen interviews were conducted. Table 1 shows the demographic characteristics of each participant. In order to protect identity, participants were assigned a number which reflects the order in which I interviewed them. Therefore, Table 1 does not list participants in numerical order. I interviewed three males and four females in the pre-Tx group and four males and four females in the post-Tx group. I interviewed one of the participants twice: six months prior to surgery (Int. 9) and five months afterwards (Int. 15). The gender spread of participants would appear to reflect the general CF population as the risk of acquiring CF is not gender dependent. As mentioned in the introduction, the average age for LTx in the UK for the CF population is 25. In this sample, the mean age of Tx candidates was 24.7 years and mean age of Tx recipients was 32.7. In the post-Tx group the age range spanned 31 years which was a much wider range than the pre-Tx group. Only one adult patient from the participating hospital has refused to consider Tx as a treatment option in the last year.

A number of other factors also had important implications for the data content and its subsequent analysis. The most significant variables appeared to be participants' differing health status and the length of time they had been on the waiting list. I interviewed three people in hospital, two of whom were in bed at the time. Of the seven people I interviewed prior to Tx, two had been waiting a year or more and one person had been accepted onto the active waiting list 18 months previously, although he had decided against having a Tx at that time. In contrast, one of the participants had only just been accepted on to the active waiting list. Sadly, two of the participants died during the course of the research and their interviews were coded post-humously.

The Tx recipients I interviewed were between four months and seven years seven months post-Tx. Two of them were experiencing difficulties with their health at the time of interview. They had also suffered major complications after Tx so that both these factors impacted upon their outlook and sense of well-being. In addition, five of the eight people I interviewed were almost five years post-Tx or more: five years being a significant marker for LTx patients due to the implications of LTx statistics. Only two of this group had received recent Tx's (i.e. within the last six months) and one of these had suffered significant complications in the initial post-operative phase.

Table 1: Characteristics of study participants

Interview number	Gender	Age	Length of wait at time of interview
Int. 12	M	34	Refused Tx (a)
Int. 10	M	23	< 1 week
Int. 14	F	30	< 1 month
Int. 7	M	20	2.5 months
Int. 9	F	18	4.5 months
Int. 8	F	27	12 months
Int. 3	F	21	2.3 years
Interview number	Gender	Age	Time since Tx
Int. 6	M	24	4 months
Int. 15	F	19	5 months (b)
Int. 2	F	50	1.3 years (c)
Int. 5	M	27	4 years
Int. 13	F	35	4.11 years
Int. 1	M	33	5 years
Int. 4	F	44	6.3 years
Int. 11	M	30	7.7 years

(a) Participant accepted onto active waiting list 18 months previously but he declined to go on the Tx waiting list (Note: the term " Refused Tx" has been used in the results section to describe this participant. It does not imply that he was refused a Tx by medical staff).

(b) Participant was interviewed twice: six months prior to surgery (Int. 9) and five months afterwards (Int. 15).

(c) Participant diagnosed with CF aged 45. All other patients diagnosed shortly after birth or during childhood.

Participants in the post-Tx group also gave retrospective information on their experiences pre-Tx. Prospective data was only available on one participant. She also reported retrospectively on the intern period between the first interview and the second, including details of the peri-operative phase. Only one other participant received a Tx during the time that the research was being conducted but, sadly, she did not survive the operation.

All but one participant was diagnosed with CF shortly after birth or in childhood. Therefore, most had lived with the knowledge of a potentially shortened life span for a number of years. As CF is such an integral part of their lives it was difficult to separate out their feelings about CF from the Tx process. Indeed it seemed artificial to do so as CF had implications for how they felt in regard to Tx. Therefore, I have made no attempt to do this.

(ii) The Cystic Fibrosis Quality of Life Questionnaire

I administered The Cystic Fibrosis Quality of Life Questionnaire (CFQoL) (Gee, Abbott, Conway & Etherington, 2000) (Appendix 7) in conjunction with the semi-structured interview as a means of situating the sample. In contrast to other QoL questionnaires, the CFQoL Questionnaire is a recently developed measure which was specifically designed with the CF population in mind. It has demonstrated reliability and validity and contains eight sections: social functioning, treatment issues and chest symptoms, emotional functioning, concerns for the future, interpersonal relationships, body image, and career concerns. The highest (most positive) obtainable score is 100, whilst the lowest is zero. Transformed scores of 50 or less suggest that the person is finding that area problematic (Gee et al., 2000).

I administered the questionnaire after each interview. However, only ten questionnaires were completed: six by Tx candidates and four by Tx recipients. This was because some participants had only just completed the questionnaire in clinic and did not want to fill out another one, or because of time restraints. Unfortunately, there is currently no comparative data available as the results are in the process of being written up for publication by the authors.

I have provided the mean scores and range of responses for each section of the questionnaire in Table 2. Strauss and Corbin (1998) suggest that "the researcher is looking for dimensional range or variation of a concept...in order to maximise similarities and differences" (p. 210). As can be seen from the table, the range of

responses is wide. This suggests that respondents experiences are diverse and that the population sample is broad.

Table 2: Mean scores and range for the CFQoL Questionnaire

Section	Means (all)	Mean (pre-Tx)	Mean (post-Tx)
	(N = 10)	(N = 6)	(N = 4)
1. Physical functioning	61.2	51.3	89
2. Social functioning	63.83	64.16	77.14
3. Treatment and chest symptoms	63.99	65.34	77.14
4. Emotional functioning	72.75	69.1	78.13
5. Concerns for future	44.5	54.16	30
6. Interpersonal relationships	52.2	49.33	56.5
7. Body image	61.31	59.3	63.33
8. Career concerns	45.5	43.33	48.75
Section	Range (all)	Range (pre)	Range (post)
1. Physical functioning	97 (4-100)	83 (4-86)	29 (72-100)
2. Social functioning	101 (0-100)	96 (0-95)	47.7 (53.3-100)
3. Treatment and chest symptoms	81 (20-100)	39.58 (51.42-90)	81 (20-100)
4. Emotional functioning	78.5 (22.5-100)	73.5 (22.5-95)	63.5 (37.5-100)
5. Concerns for future	66 (5-70)	31 (40-70)	61 (5-65)
6. Interpersonal relationships	79 (18-96)	67 (18-84)	65 (32-96)
7. Body image	74.4 (26.6-100)	54.4 (26.6-80)	61 (40-100)
8. Career concerns	96 (5-100)	51 (20-70)	96 (5-100)

7. Data collection

(i) Interview design: structure and content

Dialogue with participants was guided by a semi-structured interview format. I constructed this in consultation with the consultant physicians in the CF unit and the research supervisors. The latter included a clinical psychologist whose expertise is in the area of CF.

Literature pertaining to CF and both LTx and HLTx was used in construction of the interview schedule. Most of the relevant research is quantitative in nature, generally focusing on QoL issues and psychopathology. I therefore explored these topics during the interview process by open-ended and closed questioning (e.g. "How would you describe your life now?"; "Do you work at the moment?"). As media coverage about

Tx was thought to be potentially influential this is reflected in some of the questions asked (e.g. their feelings about having another person's organs inside them).

The questions were therefore designed to cover the main areas of interest. These were: their current life and how they were generally feeling, ways in which they described themselves and how others described and responded to them, being told of the need for a Tx, their experience of waiting for a Tx, thoughts and feelings about the Tx and the future, the most difficult parts of the Tx process and what helped/didn't help. Prompts were used to help elicit meaning when necessary (e.g. "I'm wondering what sort of thoughts ran through your mind then"). Early questions were more general and aimed at establishing rapport as well as gaining information. I asked more sensitive questions later in the interview unless the topic was brought up earlier by the participant. Ending questions were more neutral (e.g. their feelings about the progress of CF research). This was done so that the interview did not end in a distressing way for the participant. After the tape was switched off I continued the process of containment by encouraging general "chat" and by asking if the interview process had raised any further queries about the research project.

I conducted a pilot interview (see Section IV: pilot interview) in order to test the interview schedule (Appendix 8) and adapted the interview schedule subsequently (see Appendix 9 for final interview format). The schedule also underwent subtle changes throughout the data collection. For example, I dropped the question regarding participants' feelings about CF research after five interviews as responses were all very similar. There was also a need to reduce the length of the interviews as they were overly long, some of them being nearly two hours in length. Therefore, Question 4 was abandoned (i.e. "Just to put me in the picture a bit, could you tell me a bit about yourself such as where you were brought up, your living situation now, and a bit about your family and friends?"). I found that this information was often brought up by the participant as a matter of course throughout the interview. The way in which I asked questions also changed depending on responses of previous participants and emerging topics (e.g. questions relating to feelings about the death of others with CF). When trying to understand how participants felt about this I asked "What are the advantages and disadvantages of having a lot of friends with CF?" As many people with CF have friends that have died this question usually brought up the subject of death and allowed gentle exploration of this area.

(ii) The interview process

I conducted all but three of the interviews in the participants' homes. Interviews seven, 12 and 14 were conducted in private hospital rooms as this was convenient for the participants at the time. I interviewed participant eight in the

presence of her partner. The partner of the first participant was also present for part of his interview. Although partners' contributions were interesting, their comments have not been reported as the focus of the research was the patient. I interviewed all the other participants on their own. Participant seven was interviewed twice due to tape failure; first in hospital and then at home. The second interview felt more relaxed in that the home environment appeared to be more comfortable and relaxing for the participant. It was also the second time that I had met the participant so rapport had already been established. Therefore, the second interview seemed to flow better than the first.

During the interview, I was sensitive to participants' non-verbal as well as verbal behaviour. If participants seemed to be very uncomfortable about a particular topic I asked more neutral questions so that participants would not feel threatened. Mathieson (1999) suggests that "discovery and interpretation are critical to the interview context" (p.129). It is suggested that this is done by reflecting back and summarising the information heard so that the researcher is actively engaged in the interview process. Reflecting back and summarising were used intermittently in some of the interviews. I did this in order to move the interview along, encourage the person to open up, or to clarify points when I was not sure that I had understood something correctly.

I elicited meaning by probes such as "In what way was that helpful?" or "How did you deal with that?" With those participants who found it difficult to talk to me, or who found it difficult to describe their feelings and experiences, I used more closed-ended questions. Although not ideal, this seemed to result in fuller responses than some of the open-ended questions and, at times, appeared to be the best way to gain information.

Each interview was audio-taped. The tape was left to run unless the interviewee left the room (e.g. to answer the telephone). I informed participants when the interview was finished and when I turned the tape off. All participants were extremely helpful and generally appeared to be very open about their experiences and feelings. Interviews lasted between 40 and 120 minutes with the majority of interviews lasting about 80 minutes.

(iii) Transcription

The tapes were transcribed by a secretary at the University who had signed a confidentiality statement (Appendix 5). Pauses in speech, unless marked, were not recorded. However, the laughter of participants was noted so that the use of humour could be put into context. Identifying names and locations were changed to preserve anonymity. This was of special importance in this patient group as many of them

know each other well and would be able to recognise each other from initials. Line numbers were included in the transcripts as this allowed me to identify information quickly and easily during analysis.

The tapes were kept at my home and were not accessible to anyone else. They were identifiable by an interview number and date and the participant's initials. The transcript was also saved on floppy disc and these were also kept in a safe place. Patient information on the hard drive will be removed when the research is complete and tapes and floppy discs destroyed. Transcripts were checked against the audio-tape to ensure accuracy and were corrected where necessary. An example of interview transcript is provided in Appendix 13.

(iv) Pilot interview

One pilot interview (Appendix 8) was conducted prior to the main research interviews. It was conducted in order to assess the clarity and content of the information sheet and consent form, to test the interview schedule and my questioning style, and to obtain feed-back from the interviewee. The person interviewed was a 25 year old male who was on the provisional Tx waiting list. This meant that he was too well to be considered for Tx but had undergone the full Tx assessment. The 30 minute interview was audio-taped and held in a private room of the hospital as he was undergoing medical treatment at the time. The tape was not transcribed but was listened to by myself and my supervisors.

Most of the changes after the pilot interview concerned my questioning style rather than the actual interview schedule *per se*. For example, it was noted that I had a tendency to jump in and ask the next question without pausing. More space between questions was therefore allowed so that participants had more time to think and give a fuller response. Other questions or statements such as "That must have made you feel down at times" was considered leading and therefore avoided during subsequent interviews. In addition, I did not always explore fully the meaning of some statements where language can mean different things. For example, the use of the term "*a normal life*" was used by the interviewee but I did not clarify what he actually meant by this. I kept this in mind at subsequent interviews so that my questioning could elicit further meaning when necessary.

I did not alter the information sheet and consent form but the interview format was slightly modified. I re-phrased some questions to help elicit information or to increase clarity. For example, Question 4: "How would you describe yourself as a person?" was changed to: "If you had to describe yourself, say to a new pen pal, what would you say?" (Question 5): "How would other people describe you do you think?" was changed to: " How would your best friend describe you, do you think?" Ordering

of questions was also changed so that enquires into participants' present health (Question 2 in the pilot interview) became the first question as this seemed a more gentle and natural way to start the interview. Some of the prompts used in the pilot interview were changed to open ended questions so that important information would not be overlooked. For example, under Question 7 one of the prompts asked: "Some people have described having unusual worries and beliefs about transplantation. Do you have any worries and concerns about it?" This became: "What are your thoughts about (the possibility of) having someone else's lungs inside your body?" (Question 18).

As the pilot interviewee was quite reticent in his responses, this is reflected in the modifications to the interview schedule (i.e. more use of probes). The final interview schedule is given in Appendix 9. Where participants were more forthcoming I adhered to the interview schedule less strictly, as the responses to some questions also covered answers to subsequent questions in the schedule and also led on to different topics. For example, the fourth participant began to discuss how her beliefs about alternative therapy helped her cope with Tx. Following this interview I incorporated more explicit questions about belief systems into subsequent interviews. Participants' feelings about death were not addressed directly but were raised in all but one of the interviews by the participants. Following Interview three, when the participant made reference to the large number of close friends with CF who had died, I included a question about the possible benefits or negative aspects about being close to other patients with CF. This question appeared to tap a number of different themes and it was therefore incorporated throughout all the following interviews unless the subject was highlighted by the participant first.

8. Analysis.

(i) Data gathering

It was initially intended that the analysis would be conducted hand in hand with the data gathering, as recommended by Strauss & Corbin (1998), so that emerging themes could be explored in subsequent interviews. This was in order that participants' responses could be constantly compared and similarities and differences noted. Although this would have been ideal, it was not pragmatic given the health status of the participant group. As patients on the Tx waiting list can be called for surgery at any time it was necessary to try and interview them all quite quickly. This was so that a participant could be interviewed both before and after surgery should the opportunity arise. In addition, the numbers of the people on the waiting list for Tx was very small and a number of deaths reduced that number further. Moreover, the time

taken to transcribe the interview tapes meant that it would have been very difficult to move forward with the research had the analysis been conducted in this way.

Due to difficulties in making contact with the Tx candidates, the first three interviews were with Tx recipients. I analysed four transcripts prior to the other interviews taking place. Thereafter, further analysis took place after I had conducted the next nine interviews.

(ii) Open coding

A line by line analysis of the data was conducted by a process of open coding (Strauss & Corbin, 1998). This means that I examined each line of transcript for emerging themes and wrote these in the margin of the transcripts so that a large number of potential categories were identified.

When the first inspection and initial coding of the transcript was complete, I developed an index system. This consisted of a collection of index cards. Written at the top of each card was the name of one specific category, the interview number and date of analysis. Written beneath the category title were the verbatim quotes (i.e. the "Meaning units") of participants that pertained to that category. A meaning unit may be one word, one sentence or a whole paragraph. This is because a meaning unit is defined by its content rather than by the length of the utterance (Henwood & Pigeon, 1992). I therefore placed meaning units that contained a similar theme together under one category. In order to identify where each meaning unit appeared in the transcript, line numbers were also recorded. This was so that I could return to the original transcript for more contextual information or clarification if necessary. If a meaning unit appeared to fit into more than one category, I wrote the quote out again onto another index card headed by that other categories title and cross referenced it. Below are examples of two quotes under the category "Weighing the odds":

"fifty fifty . Should I come off the list or not, live my life to what I've got. I might have the Tx and that might be the end anyway".

(Int. 1, male/ Tx recipient)

"...taking on board that if I don't have the Tx I'm not going to live."

(Int. 4, female/ Tx recipient)

Each interview produced from 15 to 39 categories. Initially I analysed each transcript separately so that a separate list of categories was produced for each interview. Following the tenth analysis (Int. 6) meaning units were able to be assigned to categories that had already been identified. Forcing meaning units into already

identified categories was avoided. If there was any ambiguity, I wrote out the meaning unit on a separate index card for further examination later in the process of analysis before assigning it to a particular category.

Following analysis of nine interviews, a large amount of categories were produced. In order to reduce this data to manageable proportions I collapsed similar categories together and gave them an amended label that better described the phenomena contained within it. At this point, I re-checked each individual meaning unit to ensure that it fitted conceptually with the composite category to which it had been assigned. To give an example, the categories "Feeling special or different from others " and "Self Concept" were collapsed into one category re-labelled "The changing self". This was later re-named "Change in self." This latter title seemed more descriptive of the sub-categories it finally contained and which evolved later in the analytic process.

Some meaning units were moved to different categories that explained the phenomena better. For example, the following quote was first assigned to the category "Attitude of others" but, on revision, appeared to fit better conceptually with the category labelled "The struggle for independence versus need for dependence".

"In some ways it might be good but other ways I'm dreading it. Mum and dad will be more protective than they've ever been after the Tx."

(Int. 3, female/ Tx candidate)

This category was later collapsed into a sub-category entitled "Life stage and roles" which emerged later in the process of analysis and was subsumed under the conceptual category "Change in self." As mentioned, I also amended the names of some categories so that they were more descriptive of the revised category content. For example the category "Communication and support" was re-labelled "Expressing to others how you feel and being heard." As I modified the categories further, cross referencing was carried out as described previously. Possible links between different categories were also recorded on the index cards at this stage. For example, although I found close links between the categories "Awareness of time" and "Closeness of death", there were subtle but important differences between them that warranted two separate categories. In order to exemplify these differences one meaning unit from each category is given below:

"I do have quite a strong fear of death as in I sort of assumed as well that if you face it once, then your sorted with it. But that's not true at all. Every single time that you

have sort of an instance of a chance that you might die, you have to go through exactly the same process again. So it doesn't actually get any easier."

(Conceptual category: Closeness of death) (Int. 13, female/ Tx recipient)

" ...I thought if I get a Tx tomorrow and it all goes wrong I could have still been alive, do you know what I mean? You know, like two more months or something but if something goes wrong then you've had it haven't you?"

(Conceptual category: Awareness of time) (Int. 9, female/ Tx candidate).

(iii) Theory development

Axial coding is "the process of relating categories to their sub-categories" (Strauss & Corbin, 1998, p.123). It helps define the structure of the categories and what is happening within them in terms of process. It tries to answer questions such as "What is going on here?", "Why is that happening?", "What are the consequences of this?", and "When and where does this happen?" Thus, axial coding helps define categories by their properties and dimensions and identify links between them. It is from this process that theory development emerges.

Similar themes drawn from the initial open coding process were clustered together to form higher order (conceptual) categories. I then broke each conceptual category apart to produce lower order categories (termed sub-categories). This was done by re-examining in detail the meaning units that I had assigned to each conceptual category, using a process of "constant comparison" (Glaser & Strauss, 1967). Clusters of similar meaning units were then grouped together to form sub-categories. The title of each conceptual category therefore describes the sub-categories subsumed within it.

Writing of the results helped refine the analysis. It was part of the analytic process in that it enabled a clearer picture to emerge of the links between conceptual categories and sub-categories. For instance, certain meaning units were identified as fitting better with a conceptual category or sub-category that was not the one I had originally assigned them to. They were therefore moved. For example, I originally placed the following quote within the conceptual category "Closeness of death" but later removed it and placed it within the conceptual category "Awareness of time" (sub-category: "Time running out"). This was because the underlying theme appeared to be about making the most of time as the future was so unpredictable:

"...it's like anything, anybody could die. Anybody at any time. It's just that your life is so immediate. I live my life more immediately than anyone I know. I always have

done...It could just be a family trait but I wonder if it's because you know, having a child who's possibly going to die. Everybody's used to just doing immediate things.
(Int. 13, female/ Tx recipient)

In addition, I altered slightly the titles of some of the sub-categories in order to better describe its contents. For example, the sub-category "Feeling special versus feeling different" later became "Normalisation." In this sub-category, participants described a desire to be seen as similar to their healthy peers whilst, at the same time, wanting to have their illness acknowledged. On closer examination, however, it appeared that participants were actually describing the process by which they tried to achieve normality (e.g. keeping up physically with peers). I therefore re-named this sub-category, "Normalisation strategies."

Data analysis resulted in the formation of two models. Two models, rather than just one, seemed to give a clearer picture of the overall findings. Diagram 1 enables the reader to have a clear overview of the way in which the findings are structured, and demonstrates how the conceptual category's link together. As can be seen, it is not a hierarchical model. Rather, the core category: "Coping with living and dying" provides the back drop to the other categories. To show this more effectively would require a 3D model. In Diagram 2, I have broken up the conceptual categories into their sub-categories. This model demonstrates the processes involved in "Coping with living and dying."

(iv) The Paradigm Model

As the analytic process developed it became apparent that the data could be explained by means of the paradigm model (Diagram 2). The paradigm model (Strauss & Corbin, 1998) is a pre-determined framework which aims to show the links between categories in relation to a specific phenomenon. The phenomenon is a central set of circumstances, happenings, or events that emerge from the data and to which all the other components of the paradigm model relate. The analytic process identified the central phenomenon as "Coping with living and dying." The components consist of:

- (a) Causal conditions which lead to the development of the phenomenon.
- (b) Intervening conditions that have a bearing on the strategies people use to manage the phenomenon
- (c) Action/interaction strategies are the processes people use to respond to the phenomenon.
- (d) Consequences are the outcome of these processes mediated by the causal and intervening conditions.

However, it was sometimes difficult to decide what was an intervening condition and what was an action/interaction strategy, or distinguish between action strategies and consequences in that action is usually a consequence of an event or condition. Being wary of forcing the model upon the data, I tackled these difficulties by detailed analysis, immersing myself in the material, and by keeping the model grounded in the data.

The paradigm model is, of course, a simplification of a very complex process. Most conceptual categories do not split neatly into the model's separate components. Assigning each conceptual category to only one part of the model appeared to be artificial, removed the context of the participants' experience, and not be a true reflection of the process. For example, one sub-category may be better placed under "intervening conditions" whilst another, from the same conceptual category, may be better placed under "action/interaction strategies" or "consequences." Hence, the sub-categories rather than the conceptual categories have been assigned to different parts of the model. For example, conceptual category nine: "Interaction with others" contains three sub-categories. Two of these, "Attitude and behaviour of others," and "Concern and care for others" are intervening conditions that result in action/interaction strategies. On the other hand, the third sub-category "Expressing to others how you feel and being heard," is considered an action/ interaction strategy as it describes a process.

In addition, some sub-categories could be assigned appropriately to two of the model's components. For example, "Making decisions" (which has been placed into the "consequences" component of the model) could also be considered an action/interaction strategy as it describes a process of decision making. "Concern and care for others" is, in itself, an intervening condition but also contains action strategies, such as putting on a brave face or being selective about the people with whom problems are discussed.

(v) Writing of memos

Memos are written aids that serve to remind the researcher of thoughts and ideas they had whilst undertaking the analysis (Strauss & Corbin, 1998). They help to identify links between categories and encourage more reflexive thinking. They can be of any length: from one or two lines to a number of pages. I wrote memos following interviews, after listening to the audio tape when checking transcripts, and during the process of analysis. Initially I wrote memos onto index cards and later into a large note book. On each memo a record was made of the date, interview number and category to which it referred. Memos helped to develop theory by aiding in the identification of links between categories and helped in comparison of data. It also reminded me of

thoughts I had as different themes emerged and helped me think in more diverse ways. An example of a memo is given in Appendix 10.

(vi) Category saturation

Strauss and Corbin (1998) state that "a category is considered saturated when no new information seems to emerge during coding..." (p. 136). Glaser and Strauss (1967) suggest that when a meaning unit has been coded to the same category a number of times the researcher should stop coding the incident unless it is a negative example, and that this is then compared. In the present analysis, each conceptual category and sub-category contained a large number of meaning units. Table 4 (Appendix 12) shows which participants contributed to which category. Where individual participants have contributed five or more incidents to a category I have reported this. An "incident" is equivalent to one meaning unit.

9. Enhancing the analysis of the data

This was done by : a) employing a graduate to validate the titles of the conceptual categories and b) discussion with supervisors.

(i) Validation of categories

I asked another clinical psychology trainee who was unfamiliar with the subject area, but who had experience of using grounded theory to validate the categories. As she was unfamiliar with the literature on CF or Tx's I considered that she would be less biased in her interpretation of the material. Moreover, unlike myself, she had not been immersed in the data and was therefore unaware of the context of each individual quote. Thus, she was able to be more objective. The purpose of the validation exercise was for the trainee to match a random sample of quotes from each conceptual category with that category (Appendix 11). Prior to the validation exercise taking place I typed out a list of the titles of the final 11 conceptual categories and their sub-categories. Three quotes were taken at random from each category by a process of "lucky dip" (i.e. the index cards were in 11 envelopes. Each envelope was labelled with the category title and contained all the cards that pertained to that category. Therefore, quotes were used from which ever card was drawn out of the envelope). However, I did try to ensure that individual quotes were drawn from all the participants' interviews. Therefore, if two cards drawn out were from the same participant I replaced it in the envelope and drew out another card. The three quotes were then put together on the same sheet of paper (i.e. in groups of three).

This exercise took the trainee approximately 40 minutes. I was present whilst it was being conducted but tried not to bias her responses by my verbal or non-verbal

behaviour. All quotes were correctly matched with the relevant category although the trainee commented that she had found the exercise difficult. This was because there were some subtle differences between categories which caused some uncertainty. This was especially so between the categories "Perception of health status" and "Medical management" and between "Closeness of death" and "Awareness of time." Working out these subtle differences was aided by having the titles of the sub-categories also listed. This served to "operationalise" each conceptual category. When text is "carved up" for the purposes of analysis important context can be lost. The trainee therefore found it helpful, and more realistic, to have quotes grouped in threes, rather than individually.

(ii) Use of supervision

At times, it was difficult for me to see how the conceptual categories linked together due to my immersion in the material. Therefore, supervision was invaluable for helping make sense of the data and in identifying links between categories. This was especially so following the open coding process and towards the end of the analysis. Having an experienced and "fresh eye" to view the data was useful in clarifying ambiguity and helping to identify structure and process.

Chapter three: Results

"I've lived with these [lungs],with CF, for 30 years and having these taken away, it's like having your arm chopped off or your favourite teddy bear taken away and you know I've lived with it. I've lived to cope with it and watched how to cope and that and it's going to be strange having someone else's lungs...it's just like having something taken away from you. I don't want that taken - you know it's like having your mum taken away from you basically..."

(Int. 14, female/ Tx candidate)

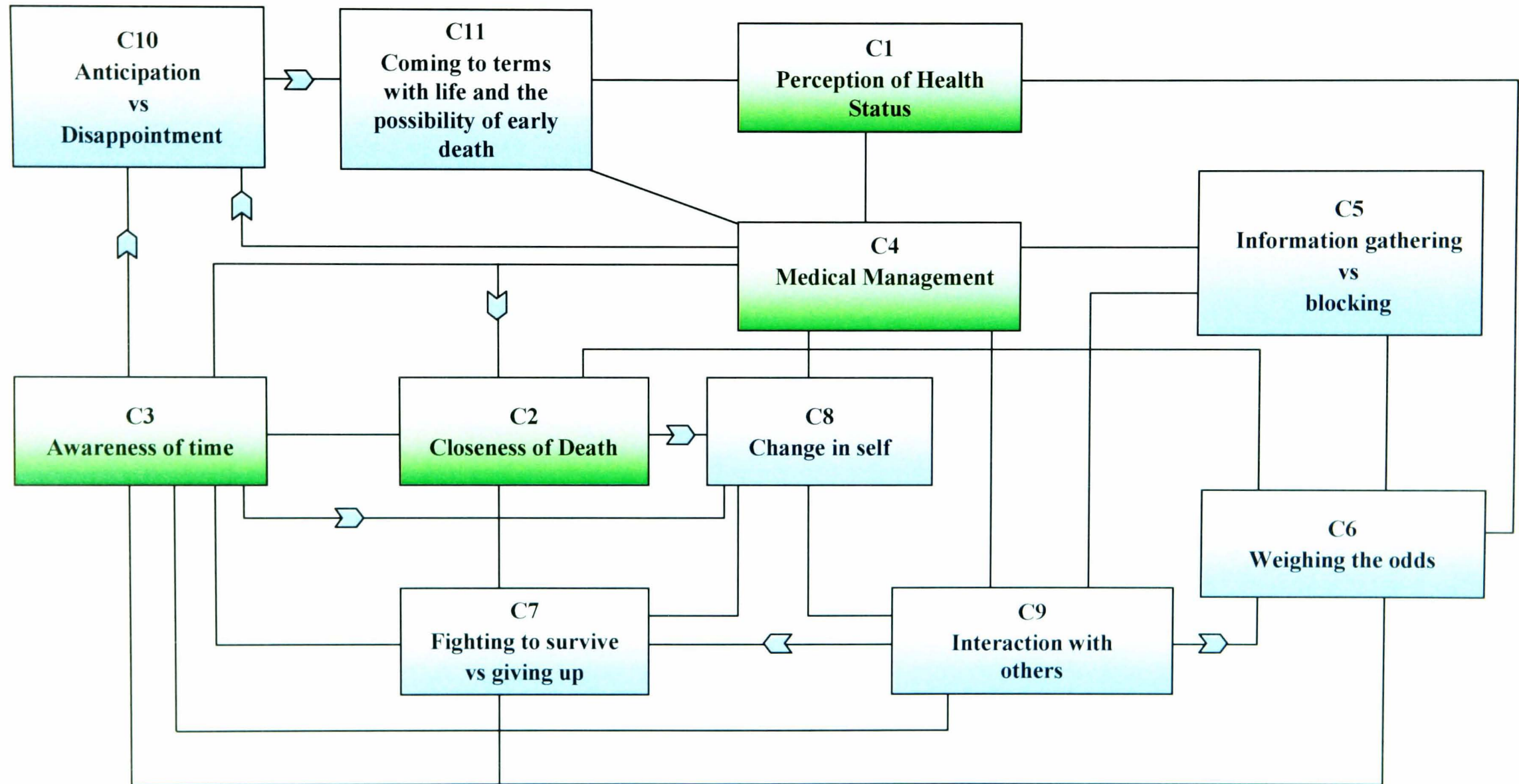
1. Overview

In this chapter I will firstly provide a description of the categories developed from the analysis of the data and the models created. Secondly, I will present an integration of the analysis by way of the paradigm model (Strauss & Corbin, 1998) around the central phenomenon of "Coping with living and dying." A table showing which participants contributed to which sub-categories is provided in Appendix 12.

2. Introduction to the Analysis

Analysis of the data identified one core category under which all 11 of the conceptual categories are subsumed. Each conceptual category contains a number of sub-categories within them. The conceptual categories will each be summarised and its sub-categories discussed in relation to their properties and dimensions, using quotes from the text to illustrate points. Diagram 1 demonstrates how all the conceptual categories link with one another. However, the links between the conceptual categories and the core category "Coping with living and dying" is not visually presented in this model. This is because the model is not hierarchical. Rather, "Coping with living and dying" is the back drop of every conceptual category. As each conceptual category contains both structure and process this is better exemplified by the paradigm model (Diagram 2). Although I shall describe each conceptual category and sub-category there are four categories which seemed to be of particular importance. These categories appeared to have the greatest psychological implications for participants and were often the most emotive. They are: "Perception of health status," "Closeness of death," "Awareness of time," and "Medical Management."

Diagram 1: Overall model demonstrating how the conceptual categories link



 Green denotes major conceptual categories

No arrow indicates 2 way interaction

(i) Core category "Coping with living and dying"

"Coping with living and dying" is the thread that runs through every category and sub-category. It is therefore defined by all the categories and sub-categories which it subsumes. In essence, participants had to cope with living with end-stage CF, the possibility of early death and major surgery. Each category pertains to the factors that impact upon "Coping with living and dying" (e.g. "Medical management"), the strategies that participants used to cope (e.g. "Fighting to survive versus giving up") and the outcome of these strategies.

(ii) Conceptual categories which were central to the analysis

The conceptual categories which were central to the analysis are highlighted by the colour green in diagram 1. The most striking feature of the interviews was how all the categories pivot on the conceptual categories of "Closeness of death" and "Awareness of time." These issues appeared to be uppermost in the minds of most participants although it seems that many hide their feelings for fear of upsetting loved ones and to prevent themselves becoming depressed. However, the relative ease with which these fears and anxieties were tapped suggests that they were fairly close to the surface. Only one person, who had just been accepted onto the Tx list, was unwilling to discuss these issues and he did not bring them up spontaneously. This may have been too raw for him to discuss and was therefore not pursued. One other Tx candidate also seemed to have little concern about death and dying. She was very positive on first interview (having been interviewed twice: before and after surgery) and felt that she had very little to cope with. "Perception of health status" was also considered to be a major conceptual category. It was a common theme and also the first step on the Tx trajectory. The conceptual category "Medical management" was also central to the analysis. It emerged as a prominent intervening condition in the paradigm model, affecting many other aspects of the participants' experiences including both other intervening conditions as well as action/interaction strategies.

3. Description of conceptual categories:

Conceptual category 1: Perception of health status

Perception of health status is the participants' subjective view of how well they are in comparison to the views of the medical team whose assessment of health status is measured by objective physiological tests. I have gone into detail in this category because health perception is closely linked to so many other categories, not least "Closeness of death" and "Awareness of time." "Perception of health status" is

mediated by "Medical Management" in that this had an influence upon how participants saw their health. It also links with "Coming to terms with life and the possibility of early death" and "Weighing the odds." Psychologically, it also appears to be the first step in the Tx trajectory. This category contains three sub-categories: "Thinking that they are not that ill," "Feelings of shock and disbelief when the gravity of the situation is realised," and "Health monitoring."

(i) Thinking that they are not that ill.

Eight people contributed to this category. When told initially that they would probably need a Tx and should go for assessment they did not feel that they were that poorly and therefore did not need to go on the Tx list. Indeed, two of the participants were actually not placed on the active waiting list immediately as they were too well at the time of initial assessment. Others were less accurate in their perception of their own health status and had difficulty understanding that they needed a Tx, even when their physical capabilities were quite low in comparison to healthy people and to their previous physical health status. "Thinking that they are not that ill" appears to be a form of defensive denial. For example:

"I mean at one point when I was first on the Tx list I used to say to X [boyfriend] that I didn't need to go on it or I didn't think I needed it. I always thought "Are they sure they've got it right?" cos. I always felt well except when I got me infections. And I could still get round and do things. I had difficulty in walking distances but I could still do stuff...I could still get about."

(Int. 8, female Tx candidate)

Interestingly, one patient stated:

"...it's fairly well known that people with CF consistently underestimate how ill they are. So I would actually say, "oh I'm actually feeling pretty good," but I'm sure you know - if you went and spoke to, you know Dr. X he'd say "Oh well, actually he's quite ill". But by my standards I'm fine."

(Int. 12, male / refused Tx)

Generally comparisons were made between their own previous health states and those of others with CF, who they considered to be more ill than themselves. However, once it is taken on board how ill they really are, the response is often one of shock and disbelief.

(ii) Shock and disbelief when the gravity of the situation is realised

Eleven participants contributed to this category. Coming to the realisation that their health was so poor that they needed a Tx, and that they would die without one was extremely difficult. Therefore, even though all but one of the participants had grown up with CF, the full implications of what it meant for them were not always realised. One participant, who had long realised the ultimate outcome of CF, still found the news difficult to hear :

"The issue was that I was dying so its facing that for the first time. Which is something you always grow up knowing, at some stage its going to happen earlier than most people. But to come face to face with it like that, its a really horrendous realisation."

(Int. 13, female/ Tx recipient)

Moreover, not only was it a shock realising that they were seriously ill but it was traumatic realising that a Tx was not the whole answer, that it is in fact palliative, and that major complications can, and do, occur. One person made this comment about somebody they knew who died post-Tx:

"I think before he died I assumed that most Tx people, once they'd sort of got past the initial post-op stages that you know it was fairly much plain sailing. But it was then that I realised that you know, you can get hit at any time...it made me realise that a Tx isn't, wasn't, the fantastic cure all that perhaps I thought it was."

(Int. 6, male/ Tx recipient)

Nine of the participants mentioned feeling "shocked" even though all but one of them had been diagnosed with CF since a young age. For example, when told that he needed a Tx:

"I were a bit shocked and worried then because its like another face of death - you think "oh god - I need a Tx, your gonna, your nearly dying again, so its a bit worrying."

(Int. 5, male/ Tx recipient)

Very few people had ever anticipated needing a Tx. If it had been thought about the perception was that people who receive Tx's needed to be much more ill than they felt

they were. For some who had thought about it previously, however, the news appeared to be slightly easier to cope with and less shocking.

(iii) Health monitoring

Ten participants talked about ways in which they monitored their health. This was evaluated by a number of criteria such as: cough and ease of breathing, infection rate, the number of admissions to hospital, their length of stay, observing pre-Tx that they improve less and less after each bout of illness and how they slowly go down hill, that their "blows" (lung function) are decreasing, and needing an intra venous canula (IV) in place for frequent administration of antibiotics. For example, one person who had received a Tx remembered how he had been before:

"I mean, at one point...when I actually had to go on like a ventilator, the bronch pack, I can't remember, it like helps you breathe and that. And that were when Dr. X asked me then [about a Tx]. That were the worst I'd ever been. I knew I were, so."

(Int. 11, male/ Tx recipient)

Most also undertook self-care strategies once accepted onto the Tx list. For example, avoiding people with infections, careful monitoring of symptoms and reduction in alcohol intake. Health monitoring was done by both the pre- and post-Tx participant groups. However, for the post-Tx group, this was more salient if they had complications or when they were approaching, or had passed, the five year marker.

In all three of these categories there was a theme of realisation. Coming to this awareness seems to be the first step in the Tx process. Unsurprisingly, sudden awareness appeared to result in more distress and difficulty in coming to terms with their situation. The minority who had anticipated needing a Tx in the foreseeable future seemed to find the news easier to cope with and accept. This realisation gave rise to thoughts about death. It therefore links into the second and third conceptual categories: "Closeness of death" and "Awareness of time."

Conceptual category 2: Closeness of death

"Yeah, I've got CF but forget about it. I'm me. But when he [the doctor] said that, and I realised that, you know, well this is serious and it doesn't feel good. It's not a nice feeling to think about your own mortality. I think its not - it's not nice."

(Int. 6, male/ Tx recipient)

This category had contributions from twelve participants. For some, this theme dominated the interview. However, a few people found the subject too uncomfortable to discuss in any depth. Once participants realised how ill they really were their thoughts turned to the possibility of their own death. Thoughts about death and dying seemed to give rise to a sense of time running out and wanting to make the most of the time they had. It therefore has considerable overlaps with the category "Awareness of time". When friends with CF died the reality of their own situation was brought into focus so that their own death felt even closer. Therefore, "Strategies used to deal with the death of others" and "Thoughts about their own death" are closely linked, with one impacting upon the other. It also links with the conceptual categories "Medical management" and "Change in self." Closeness of death is a difficult concept for people to come to terms with. It contains two sub-categories:

(i) Strategies used to deal with the death of others with CF

Twelve participants contributed to this category. Many of the participants had close friends with CF and many of them knew each other from hospital visits. Everyone interviewed knew people with CF who had died. Many of the participants had also been in the hospital ward when a death occurred. Therefore, they are close to death in a very concrete way.

When friends died participants described feelings of disbelief, devastation, or upset. Although three participants said: "*you get used to it*" (Int.'s. 1, 3 and 7), they also expressed distress at the death of close friends. One of the participants who had made this comment later stated: "*You never get used to it*" (Int. 3). Other passive styles of coping included distraction (e.g. music, football), acknowledging that there is nothing they can do and that nothing will bring them back, and putting on a brave face. Others tried to shrug it off with remarks such as "*Oh well, never mind*" (Int. 4). Four people stated that they tend to avoid contact with others with CF. One person expressed her reluctance to form strong attachments to others with CF because they do die. Indeed, this was acknowledged by most people as being the downside of having friends with CF.

More active coping involved going to see the body in the hospital room in order to say "*good-bye*" and reach some form of "*closure*" (Int. 7), talking to each other about the person and remembering them, talking to "*them up there*" [the people who had died] (Int. 3), talking to the nursing staff, positive self-talk, and the use of humour. One Tx candidate stated:

"I think we just - we tend to make a joke of it on the ward...not joke at them but just talk about what- about how they used to be by remembering them there, remember them as they used to be...Like we joke about when you know when we're going to go and stuff like that. And you think, well, you know, cos it will happen one day and its gonna be really sad but we still do it."

(Int. 7, male/ Tx candidate)

(ii) Thoughts about their own death

Ten participants contributed to this sub-category which includes participants' thoughts about their own death, and the way in which the death of others influenced this. This included the death of friends and family without CF. For example, one participant discussed how the death of an older family member had adversely affected her after she had attended the funeral. Another participant gave a speech at her friend's funeral whilst, at the same time, wondered if they would be attending hers next. Moreover, participants felt that the death of others with CF brought home the reality of death for themselves. Therefore, the death of others made participants think more about their own mortality, especially with the realisation that Tx's do "give out" (Int. 6). Three participants expressed relief that it was not them that had died, whilst knowing that it could well be them in the future:

"Part of you thinks "Oh, thank God its not me". Part of you thinks, you know, "I'm not going to get that ill" and you know you are, but you hope your not - your're gonna get a Tx before that."

(Int. 7, male/ Tx candidate)

For some then it seemed difficult to conceptualise their own death, even when they were very ill. They seemed to know that they would probably not live long but could not really believe this. One participant, who was on the waiting list and, sadly, died shortly after I interviewed her, said:

"I don't ever think I'm going to die - but I don't know. I thought - well when X [patient] I thought - he wasn't even on the Tx list - why's he died?"

(Int. 8, female/ Tx candidate)

In contrast, another participant described his fear of going to sleep in case he did not wake up when he was at his most ill (prior to Tx). This concern is similar to that of another Tx recipient who was frightened to go to sleep after his Tx surgery for the same reason. Eight people talked directly about fear of death. Fears involved the

dying process (e.g. suffocation, not surviving the Tx operation), images of death, and fear of losing life rather than of dying *per se*. This applied to both the pre- and post-Tx groups. In the pre-Tx group, being told of the need for Tx brings death more sharply into focus. For example, one participant who had been on the waiting list for four months, described her thoughts about death which she had frequently.

"It's not the actual, of being poorly and just going to sleep and dying. I don't like the thought of being put into that body bag, zipped up, taken somewhere and then put into that box and going into the car and I don't relish that thought at all. It does frighten me a lot and I just can't get past thinking I'm going to be in that box and I've got to go in that car and then going into cremation part. I don't like that part."

(Int. 14, female/ Tx candidate)

In addition, the waiting period can become more stressful over time with increasing thoughts about death, hence the links with conceptual category "Awareness of time." One participant who had been on the Tx list for over two years and who, sadly, died, not long after I interviewed her had just started her own funeral payment plan. She described her experience in the following way:

"...It's like being on death row and never knowing when your going to get a reprieve and get out or whether your going to go down that long road. And it is. I mean you can sort of empathise with those that are on death row the way it feels.."

(Int. 3, female/ Tx candidate)

Rather surprisingly perhaps, people in the post-Tx group seemed to think more about death than people waiting for Tx. This is especially so if they had experienced complications and if they had their Tx for over four years. This is because they know statistically that survival rates decrease over time and the chances of them getting another Tx are slim. The exception to this were the two people who had their Tx's for a long time (six years and three months; and seven years and seven months) and were still well. They spoke more about their fears of death pre-Tx. Those who had only received a Tx four and five months previously were also very positive about the future. Some of the Tx recipients had been encouraged by the hospital to make out their will. This process was found to be very frightening. It reminded them that they would have an early death, even if relatively well at the present time, and it put death in the forefront of their minds. The closeness of death, however, also seemed to shift people's perspective on what is important in life and how precious life is with feelings that it should not be wasted. This was mentioned by six participants.

This category therefore contains themes of dealing with the realities of death and dying, both of their own death and other people's. It is intertwined closely with the concept of time: as time passes death comes closer and vice versa.

Conceptual category 3: Awareness of time

The concept of "time" was mentioned by all the participants. "Awareness of time" links with the conceptual categories "Change in self." (e.g. in attitude to life due to a fore-shortened future), "Anticipation versus disappointment." (e.g. not planning ahead in order to avoid disappointment) and "Medical management."

(i) Timing

Twelve people contributed to this sub-category. It refers to the appropriate timing of medical information and when they receive the Tx. Two patients (Int.'s 1 and 5) commented upon the fact that they were told of their need for Tx at a time when they were very ill. They felt that they had been too ill to take in such difficult news and that this could have waited until their health condition improved. The main thrust of this sub- category, however, is when people will receive their Tx. Many people seemed to feel that they were not ready for a Tx for some time after acceptance onto the active waiting list. This was because they either felt too well or because they had not yet come to terms with needing one. They felt that they "*needed time to take it on board*" (Int.'s 2 and 4). One participant who was still on the waiting list after one year said:

"I'd have definitely said "no"...I mean if I got called a year ago I'd have probably been really dubious about going through the op. I'd have probably...I mean at one stage I did say...I'll probably end up jumping off the bleeding table cos. I don't - I don't think I needed it that bad."

(Int. 8, female,/ Tx candidate)

With the knowledge that survival rates post-Tx decrease over time many participants also felt that they wanted optimum time with their own lungs so that this would ultimately increase their life span. One Tx recipient summed this up:

"I was sort of more thinking "I hope they don't call me up too quickly" I was wanting more time before hand really... more time, just life really. The more time you got before hand...it extended the whole thing so completely, if you know what I mean."

(Int. 2, female/ Tx recipient)

(ii) Time running out

A sense of time running out was applicable to both Tx candidates and recipients, with nine participants contributing to this sub-category. Prior to Tx there is an awareness that they may have only two years to live without a Tx (as patients are generally accepted onto the waiting list two years before a Tx becomes imperative). Therefore, time running out became more salient as time passed, as health deteriorated, and as they become more desperate for a Tx. Therefore, this was more noticeable in the two Tx candidates who had been on the waiting list the longest. It also became more important for relatives and partners. One Tx candidate, for example, who was very ill at the time of interview, related how her mother was spending much more time with her than previously. Retrospective reporting by Tx recipients suggested that their main fear was that they would not be called in time. The participant who had refused to have a Tx was also counting down time, but in a manner that bore more similarities to Tx recipients. However, instead of counting down from the Tx surgery, he was counting from when he was told he needed one.

Surprisingly perhaps, the sense of time running out was more noticeable in the Tx recipients. The following statement was from a 27 year old male, four years post-Tx .

"...you know you can have a right good day and you can think "Oh, how many more of these am I gonna have?"

(Int. 5, male / Tx recipient)

It is not dissimilar to the sentiments of the seven others who contributed to this category, only two of whom were waiting for a Tx. For people post-Tx, the limited time left was very important. It was counted down by milestones such as birthdays or anniversaries including that of the Tx operation. Three Tx recipients (Int.'s 1, 13 and 5) said that they used these markers as something to aim for. However, this also increased anxiety as the deadlines approached. They also tended not to plan too far ahead but lived life from day to day. One participant who had received his Tx five years previously said:

"Well, we live day by day anyway. We don't even book holidays...Well, we always book our holidays only two to three months before we go. We never book one year from one year, never...It's too long. It's too long, you know."

(Int. 1, male/ Tx recipient)

There were three exceptions to this. The two people who had received recent Tx's tended to look ahead much further, for example planning careers and holidays. They generally appeared to be much less concerned about the passage of time. One female participant who had received her Tx six years and three months previously was also very positive, although she still tended to live from day to day and wondered how long her Tx would last for.

It seems that feelings are quite dependent upon frequency and severity of complications, length of time on waiting list, and time since Tx. Those who had only been on the waiting list a short time and those who had only recently received a Tx seemed the most hopeful as regards time left. One participant who had been diagnosed with CF very late in life, had lived with the expectation that she would survive into old age. When she was informed that she needed a Tx, not long after her diagnosis of CF, this expectation was shattered. She was acutely aware of the passage of time although she was only 1.3 years post-Tx. She related:

"I said something about "How long? What sort of prognosis afterwards?" and she (doctor) said "Oh, there's somebody that's lasted eight years" and I remember saying "Eight years!" thinking, you know, "Gosh! I hope it's much longer than that" And she just said to me "Oh, there is no old age in Cystic Fibrosis."

(Int. 2, female, Tx recipient)

This is in contrast to another Tx recipient who had known her diagnosis of CF since the age of seven. She discussed how living with the possibility of early death had impacted upon her behaviour:

"It's the stress of how ill you are and how long you've got. Anybody at any time. It's just that your life is so immediate. I live much more immediately than anyone I know. I always have..."

(Int. 13, female, Tx recipient)

(iii) Time spent waiting

Thirteen people contributed to this sub-category. Participants described their feelings about having time on their hands and the impact of this on their mood, waiting around for medical tests during the assessment phase, waiting for nursing staff, waiting for confirmation that they were accepted on to the Tx list, waiting for the bleep to go off, and waiting to hear if the donor organ was suitable or available once they had been called for the actual Tx surgery.

Waiting for the bleep to go off or the phone to ring indicating that a donor organ had been found, created anxiety in itself. Participants tended to be both reassured and demoralised by false calls (i.e. when the Tx could not go ahead). When no calls were forthcoming over a period of time two participants said that they became worried that they had been forgotten (Int.'s 3 and 8). False calls also prepared people for "the real thing." Relief was also experienced if they did not feel ready for Tx. However, as their situation became more critical, false calls were experienced as devastating as hopes were raised and then dashed. One participant described her feelings when she experienced two false calls and how these changed over time:

" They rang me a couple of times. The first time they rang it was like "I'm really well at the moment. I don't need a Tx." I was actually out...When I got home, X [partner] said "The hospital rang" and I thought "Oh shit." I haven't got my bag packed. I'm not ready. I'm feeling quite well. I don't want a Tx, but they then rang back and said "No, sorry, things aren't okay but how are you?" I said, " oh, I'm fine thanks, great" you know. Then, when they did ring again, they said "we might have something for you" and it's like "alright, fine" and I had the bag packed by this time and there were some friends across the road and they came over and you know we all hung around together and about two or three hours later the hospital rang back and said "No, sorry. It's no go." And I was upset that time because I knew I was getting close."
(Int. 4, female/ Tx recipient)

Fears of missing the call affected their life in other ways by restricting activities (e.g. swimming or going out drinking with friends) (Int.'s 3 and 14). However, it seems that bleeps are sometimes forgotten, or turned off when the batteries run down and are then not replaced quickly.

To summarise, "Awareness of time" contains themes of time passing, time left, and, tied in with this, the timing of Tx.

Conceptual category 4: Medical management

The components of this conceptual category indicated that medical management had a major impact upon participants. All participants, except one, made contributions to this category. It was often discussed in depth, with some interviewees becoming quite emotive. For this reason it is considered to be a major conceptual category. It consists of three sub-categories that were all closely linked:

(i) Medical treatment within "the System"

This category relates to participants' feelings about their medical treatment and the Tx operation itself, hospital organisation and views about technology (e.g. using pigs' lungs for Tx). Twelve participants contributed to this category.

There was a mixture of positive and negative feelings about care at the Tx centre attended. For example, a number of participants commented upon the organisation of the ward and how the assessment procedure was conducted. Two participants (Int.'s 7 and 13) raised concerns about the assessment unit at the Tx centre as it was not specific to CF patients "*with no sense that it was a Tx zone.*" (Int. 13). This meant that there was a mix of patients with various illnesses, increased potential for infection, and staff who were not specialists in CF care. However, some found the experience of assessment and Tx very positive from an organisational point of view. As one participant stated:

" They were really good I thought. That's one thing I did notice about Hospital X. Really professional doctors and nurses and that... And I thought it were brilliant. They're brilliant ...and I felt at least when I went up there I felt I knew - I felt - I felt safe in a way."

(Int. 11, male/ Tx recipient).

Others were less positive and found the testing procedures unpleasant. For example:

"...I didn't really like my assessment. I hated it...They had to close up a ward and they couldn't get any blood off me and I didn't like the doctor up there...I didn't like my assessment at all and I got turned away the first time saying I was too well and I had to go back up again in six months...The second time wasn't as bad because they didn't need as much blood and stuff because they already had my tissue type and stuff but the first time, three days, it was awful. I didn't even need to stay up for three days cos they could have done it like in two days. I just wanted to go home."

(Int. 9, female/ Tx candidate)

Indeed, participants expressed anxieties about the unpleasantness of medical tests, such as having blood taken by inexperienced personnel, lack of preparation for the Tx assessment, and the stress of not knowing how ill they really were. Surprisingly, perhaps, only two Tx recipients complained about the side effects of medication (except for adverse reactions to anti-biotics and analgesia post-operatively), although these are known to be unpleasant. A number of Tx candidates alluded to the fact that, although

the amount of medication taken would increase after Tx, this was a small price to pay for not having to continue with their present gruelling medical regime.

(ii) Communication style and attitude of health professionals

Nine people commented directly on this area. Most people felt that there was no good way to tell someone that they needed a Tx. Some felt that it could have been conveyed to them in a different way but were unsure how. Use of humour by medical staff, as well as good interpersonal skills, was considered to be important. In the unit, where they know the nursing and medical staff, the feelings were all very positive. They felt supported, that people had time to listen to them and that staff were caring, concerned and knowledgeable, "*like a family*" (Int. 8). This is in contrast to situations where they did not know the staff and where the organisation of the ward was different and, perhaps, higher paced. Four participants emphasised the need for good explanations. Four were concerned about the uncaring attitude of some nursing staff and medics and their lack of time for them, due to staff shortages. For example, one Tx recipient had major complications from the side-effects of medical treatment. This was made worse by the apparent off-hand manner of both nursing and medical staff, leaving her feeling extremely angry and upset. Comments by three other participants suggested that they were unhappy with the attitude of junior medical staff who were not specialised in CF or Tx surgery. It was felt that they were sometimes disparaging and they did not give the patient credit for their knowledge about their own condition. For example, one participant commented:

*"They just think that they're the bees knees. They think they're great. You know, "I'm a doctor and you know nothing" kind of thing."
(Int. 6, male/ Tx recipient)*

In contrast, another doctor was commended on his style of conveying difficult information in a positive, hopeful way rather than being overly negative or pessimistic:

*"...He was very straight forward....It was just totally right what he did. You know, he wasn't all "lovey dovey" and he wasn't hard and cold but he was sort of factual without being, I don't know, horrible, do you know what I mean. I thought he did that very well actually."
(Int. 13, female/ Tx recipient)*

For two participants (Int.'s. 4 and 7) expectations of what they should do after Tx felt quite pressurising:

"...I mean even down at hospital X the first thing the professor asked me is what are you going to do after your operation. I goes "Oh, I don't know." And there was a really big emphasis on you know, well, you know, don't - don't waste it. And it sounds really bad but it's all the attitude of well you're gonna get a second chance and you're gonna be really healthy so you've got to think what you want to do, you know, you know they basically don't want you to just sit there and waste your life cos I think they've seen it happen quite a lot."

(Int. 7, male/ Tx candidate)

Most people were not offered any form of professional counselling in regard to Tx and thought this may have been useful at various times during the course of the Tx process, especially for their parents or partners.

(iii) Feelings about the operation itself

Eight people contributed to this sub-category. Participants described a mixture of both positive and negative feelings about the Tx and feelings varied over time, hence the link with the conceptual category "Awareness of time". Feelings ranged from: apprehension, thoughts about being cut open, waking up on a ventilator and being in the Intensive Care Unit (ICU), excitement or exhilaration, terror, enjoying the attention, and fear of the unknown. Main concerns were not surviving the operation and rejection of the new lungs. Therefore, this sub-category has links with "Closeness of death." However, the general feeling was one of ambivalence:

"...a mixture of sort of being very, very scared and being very excited. It was just about fifty-fifty you know, being sort of half shitting yourself and half thinking "yeah, this is great. This is really what I want, so"...I was - it's not. It's sort of a bit hazy. It's cos - it was just so exciting. The adrenaline is really going and you're in the ambulance and your going "oh, oh. What am I supposed to be thinking now?" It's really strange knowing...I was thinking in the ambulance - "what should I be thinking about now? Should I be really happy or should I be really sad or should I be really scared?" and I couldn't decide which...that was the main thing."

(Int. 6, male/ Tx recipient)

The one person who was interviewed both pre and post-Tx had changed her feelings about Tx due to her difficult experience. Prior to Tx she did not express any major

concerns and viewed it in a very positive light. However, five months following Tx she was unsure if she could put herself through it again:

"All pain. I were in so much pain.... when they moved me it was awful. I always felt really heavy, me chest felt really heavy. And I felt like I couldn't breathe all the time...I mean I think it was worth it now cos like I'm really well now but I wouldn't do it again."

(Int. 15, female/ Tx recipient)

This view is in contrast to people who had no initial post-Tx complications. Not surprisingly, therefore, feelings about the surgery very much depend on the person's experience and, probably to some extent, on the amount of time passed since the Tx. However, one participant who did not experience major surgical complications in the immediate post-operative phase described his fear in ICU. He stated:

"I was fighting to stay awake and I shouldn't have been cos I was in Intensive Care for seven days...I didn't want to sleep just in case I didn't wake back up (laughs). That was what I was frightened of, that...I tried to stay awake. I think I must have gone to sleep quite a few times but I was trying and trying to stay awake. Most of my family were there as well, so I wanted to stay awake cos of them."

(Int. 1, male, Tx recipient)

The main themes in "Medical management" are therefore how the hospital system and medical care is managed, the attitude and communication style of health professionals, and feelings regarding Tx surgery. Of the three sub-categories, "Communication style and attitude of health professionals" was discussed in the most detail by a number of participants. The emphasis was on a supportive and caring attitude, time available for staff to talk and listen to patients, staff knowing what to say and how to say it, and preparing patients well for assessment, surgery, tests and treatment by conveying accurate information. This links with the next category: "Information gathering versus blocking."

Conceptual category 5: Information gathering versus blocking

All the participants contributed to this category which contains three sub-categories. These were: "Information received from hospital"; "Information seeking" and "Sharing information between patients." These categories describe the context and process of information gathering and how participants felt about the information

provided. It has links with "Medical management," "Weighing the odds." and "Interaction with others."

(i) Information received from hospital

Eleven participants contributed to this sub-category. Most people felt that they had been given all the information they needed by the Tx centre. Information about CF and Tx's are also sent out to patients by the hospital. Two patients commented that they did not read it as they found it distressing and did not want to think about it (Int.'s 1 and 5). One participant was concerned about his partner's reaction to the material, although she was keen to be kept informed.

A number of participants felt that they had not been prepared adequately for the Tx assessment by the referring CF unit. These people had seemed to find this evaluation stage of the Tx trajectory particularly distressing. Importantly, two participants had felt misinformed about their health status and long-term prospects (Int.'s 12 and 13), resulting in feelings of anger or hopelessness. For example, one participant had been unaware of how damaged his lungs were, and thought that he was not that severely affected by CF. He had, therefore, refused three monthly intensive IV anti-biotic treatment that had been suggested by the medical staff. In retrospect, he felt that he had made that decision without all the information available to him. However, not all participants wished to be overloaded with facts, especially in one go.

Patients can also be given a lot of information and feel that they have all the facts but can still find themselves unprepared when things go wrong. For example, one participant who was interviewed both before and after Tx, had initially felt that she was well informed as someone very close to her had also undergone the same procedure. However when interviewed five months after surgery she said:

"And plus I don't know if they told me all that could go wrong...I mean, I think they told me a lot of stuff but I kept thinking "Oh, they didn't tell me this" you know what I mean?"

(Int. 15, female/ Tx recipient)

Families and partners can also feel uninformed and often received information second hand, via the patient. Three participants discussed how useful it would have been for the medical staff to provide families or partners with information and/ or support by way of discussion (Int.'s 1, 7, and 8). Three participants (Int.'s 7, 9 and 8) talked about how difficult it was not knowing what had happened when someone they knew with CF was dying or not being informed that they had died. Although they understood the need for confidentiality, and realised that the needs of the family were

paramount, they felt they would like have had more detailed communication about what had taken place (Int.'s 7, 8, 3 & 9) and would like to find out directly rather than indirectly through the grapevine.

(ii) Information seeking

Nine participants contributed to this sub-category. In this sub-category, responses varied between participants. Most people did not feel that they needed to know any more than they had been told, whereas others actively sought out material (Int.'s 7 and 12). For example, one person expressed a wish to see a video of the LTx operation (Int. 14), whilst two others suggested a booklet be made available that was directly relevant to the Tx Centre and CF Unit involved. Two contrasting accounts are given below:

"I just really wasn't interested. I was happy with the way... I was perfectly happy with the treatment I was getting ...It seemed to worry them [the doctors] a little bit, that I wasn't interested...and I was like "I'm not interested thank you and I realise exactly what a Tx is. I would like one thank you ".

(Int. 6, male/ Tx recipient)

"And then, after I'd started doing some, a bit more research myself and finding out about, you know, what exactly having the operation entailed and what the long term prospects were for people who had the operation and who hadn't had the operation. And you know, the deeper I looked into it the more uneasy about the whole thing I became."

(Int. 12, male/ refused Tx)

Interestingly, three people (Int.'s 2, 3 and 6) said that they had not really known anything about CF, even though two of them had lived with the diagnosis since childhood. Two of them (Int.'s 5 and 6) were not information seekers and preferred to compartmentalise their illness and not think about it. Others sought information about CF, Tx and the donor (post-Tx participants). Most of the post-Tx group expressed some curiosity about the donor and a number of people had written a letter of thanks to the donor's family, although had found it difficult to know what to say. Those in the pre-Tx group were more ambivalent about this.

(iii) Sharing information between patients

Eleven participants contributed to this sub-category. "Sharing information between patients" was thought to be a good thing. In particular, to be able to talk to

other patients who had already received a Tx was seen by most of the participants as more beneficial than talking to a health professional as patients had "*been through it*" (Int. 7). Tx recipients also saw this as useful but were aware that information had to be balanced and to be more positive than negative so as not to frighten Tx candidates. It was also seen as being particularly difficult if the patient who imparted the information sustained major complications, or subsequently died, when they had previously been well. If the person remained well after Tx, participants saw this as a hopeful sign for themselves. If the person died or became ill they also realised that this could happen to them. Dealing with the latter involves a number of cognitive mechanisms, one of which is looking for differences between themselves and the other person. This is done by a process of comparison which also involves "Weighing the odds."

Conceptual category 6: Weighing the odds

All but one of the participants contributed to this category. Three sub-categories have emerged from the data: "Comparison with others," "Odds of surviving," and "Making decisions." Eleven, ten, and eight participants made contributions to each sub-category respectively. The categories describe a process of odds ratio, costs and benefits, and decision making. As mentioned, it links with the conceptual category "Information seeking versus blocking." It also has links with "Perception of health status" in that participants, in part, evaluated their health status by comparing themselves to others. "Weighing the odds" also links with "Closeness of death," and "Awareness of time" as time left and chances of living or dying are weighed up. In addition, "Fighting to survive versus giving up" involves a process of decision making: to carry on fighting or to give up.

(i) Comparison with others

In this sub-category participants carried out a process of upward and downward comparisons to others. They looked to other patients who were doing well and found this motivating. When other patients died they looked for differences between themselves and the other person. For example, they talked about the person being non-compliant with medication or smoking, that they had a negative attitude and believed they were going to die, that they went to bed and never got up again, or that they got fed up and then gave up. Although they realised that motivation and determination to live can only help patients survive up to a point, it was these personal factors that were usually implicated. One person commented that he liked to know why people died so that he could prevent it happening to him. Another participant stated:

"..I've got the same as what they've got and they've just died from it and I'm in the same predicament..."

(Int. 3, female / Tx candidate)

Comparisons were also made between themselves and the healthy population, with some jealousy or anger expressed. Some participants (Int.'s 7, 4, 5 and 13) found healthy people moaning about their state of health particularly irritating (e.g. people with colds, asthma, suicidal people). They also compared themselves to older people, finding it galling that many elderly people were more physically able than themselves. Downward comparisons were also made in that they considered themselves better off, or lucky, in comparison to some segments of the population (e.g. the disabled).

(ii) Odds of surviving

Participants were also very aware of the survival statistics and were able to weigh up their "Odds of surviving" both with or without a Tx. Candidates also weighed up the chances of actually getting a Tx based on their size and donor availability. With regard to this, participants were asked about how they would feel, or have felt, if others received a Tx before them. All of the nine people who were asked were aware of the fact that Tx was based on tissue typing and organ size and acknowledged that others could get a Tx first. Generally people expressed pleasure in someone they knew receiving a Tx. However, three female participants (Int.'s 13, 9 and 8) felt that this would be more difficult if a Tx was becoming more imperative for survival or if the person had been on the list a much shorter time than themselves, and were the same gender and a similar size to themselves. A few people also stated that they had heard others with CF venting feelings of anger at this situation.

Tx recipients counted down the milestones in years of expected survival, according to statistics, and compared this to other people who had died as well as to those they knew who were maintaining health. Before Tx they weighed up their reasons for living such as friends, family, and children. Most felt like they had no option but to agree to Tx but were also worried that they may not survive the operation:

"...cos to me it's like...so if I don't have it then, you know, I'm dead and if I do then at least its a chance so, you know - I'm risking everything but I'd rather go through that."

(Int. 7, male/ Tx candidate)

(iii) Making decisions

This sub-category embodies a theme of control or lack of control. This includes decisions about having the Tx, medication compliance (i.e. what are the consequences if they don't? Is it worth the effort?), following medical regimes, what to tell friends or potential partners about CF and when, how much their families would be upset if they did not have the operation, and concerns about upsetting people, including medical staff, if they do not comply. It also involved the decision of whether to fight to live or to die. In regards to the actual Tx surgery, everyone felt that the decision had been theirs although remarks made by participants suggested that they were also aware of the expectations of family or partners. For example, one participant became unsure of his decision to have a Tx after a friend of his died three months after surgery:

"...I think she'd been on the Tx list for about fifteen months then and she's only just had a Tx and she didn't make it, so I was thinking of maybe coming off the Tx list at the time ... It was you [speaking to partner] and my mam that persuaded me to stay on the list."

(Int. 1, male/ Tx recipient)

Conceptual category 7 : Fighting to survive versus giving up

"...and you know I'll do whatever it- whatever it took to stay alive to - so that I could get my Tx."

(Int. 6, male / Tx recipient)

"Fighting to survive versus giving up" outlines the processes used to keep going. All participants except one contributed to this category which is divided into four sub-categories: "Reasons to give up the fight and reasons to keep going"; "Positive thinking and self-talk versus negative"; "Taking physical action"; and "Beliefs that helped people cope." Responses were mainly concerned with the pre-Tx stage, but also to times post-Tx when participants experienced major complications (e.g. lymphoma) or as time passed since the Tx. This conceptual category therefore links with the conceptual categories "Closeness of death," and "Awareness of time," "Interaction with others" (e.g. other people were cited as reasons to keep going), "Weighing the odds" (e.g. fighting to survive included "beating the odds"), and "Change in self" (many participants described themselves as "fighters").

(i) Reasons to give up the fight and reasons to keep going

The nine people that contributed to this sub-category considered themselves "fighters" (e.g. Int. 1), but acknowledged that there were times when they felt like giving up. At these times they said that they did not care any more, that they were fed up with CF and did not want to take their medication, eat, or get up. They asked themselves "What's the point?" (Int. 13) and if the fight was worth it. Two people mentioned having had suicidal thoughts. Many said that every day seemed to be a battle and that tiredness was a major problem. Breathing and remaining alive were huge efforts and the whole day could be taken up with their medical regime. Many acknowledged feelings of low mood, anxiety, or depression at certain time points, especially when ill. For example, one participant stated:

"...Then I come home on my own or something like that and I think "God, I just can't - can't be bothered." Sometimes you get right low ... I never get that fed up that I think "Oh, I could end it all, I've had enough." I mean it goes through your head "Oh, I've had enough of this"...Just coping with CF I think is the general - is what mainly gets me down. Not being able to work."

(Int. 3, female/ Tx candidate)

"Reasons to keep going" involved thinking of others, looking back to when they were healthier, and looking forward to when they would be healthy again. Many wanted to keep going for friends and family and were helped by encouragement from partners and by not wanting to let others down.

(ii) Positive thinking and self-talk versus negative

Twelve participants contributed to this sub-category. They described how their thoughts affected their mood, and vice versa. Strategies used to keep going when they felt like giving up were telling themselves to "get on with it" (Int. 5), and to "keep going" (Int. 1), keeping the mind set on the goal of Tx and believing it will happen, having the Tx to aim for, keeping optimistic by remembering when they had coped in the past and using this knowledge to solve problems, not dwelling on the past, viewing CF and the problems with Tx as a challenge, and the use of humour, especially black humour. For example, one participant described how he tried to remain positive:

"Well by - by sort of just dealing the setbacks as they arise and, you know, put it to one side, move on, forget about it. And then - not sort of going back and going over

and over and over events in the past, which is - and that's - that really is what I was doing when I sort of started coming down with depression. I was stuck in the sort of - "if only " - you know, and there's no point cos you know, "if only I'd done that". I didn't do it so."

(Int. 12, male/ refused Tx)

The cognitive processes described above also affected motivation to carry out physical action.

(iii) Taking physical action

"Taking physical action" was mentioned by six participants. It involved making themselves eat when they were not hungry, making themselves get up out of bed, forcing themselves to take their medication, and struggling to keep fit. Negative thinking was more likely to occur when they were not occupied and therefore, when very ill. Thus, keeping positive also meant involving themselves in distracting activities such as television, music, computers, or by watching football, as one Tx recipient described:

"...if you're really poorly you - and you can't really do 'owt you must think more like that all the time so. Scary sometimes. So I think you need some'at just to keep your mind occupied all the time."

(Int. 11, male/ Tx recipient)

This sentiment was endorsed by a number of other participants (Int.'s. 4, 10 and 12), interestingly all males except one. Taking physical action also involved doing something instead of worrying, living day by day, and phoning people up for a talk.

(iv) Beliefs that help people cope

Eight participants discussed spiritual beliefs, belief in themselves, in the support of others, and in modern medicine, although only three people seemed to have spiritual beliefs. This included belief in God and in an after life, in the power of prayer and in a universal life force providing energy and healing and helping to prevent organ rejection. One person (Int. 5) commented that he needed to believe that there was something after death as he had a short life span. In contrast, another participant had completely rejected religion as she felt it had not helped her and had given her false hope in the past. Those who had no spiritual beliefs tended to place more faith in themselves, in their will to survive, in their fighting spirit, in others, and in aspiring to

be as well as other healthy Tx recipients. One participant described how her beliefs help her:

"Reiki, it's like hands on healing, it's like energy healing so you just lay your hands on people and it's like the universal life force that's all around us and it channels through me and through my hands...She [Reiki teacher] actually gave me the third degree Reiki...because she thought it would help me and I think it did, once she'd given me that and I used to practice nightly and, as I say, it kept the rejection down to a minimum."

(Int. 4, female/ Tx recipient)

Conceptual category 8: Change in self.

All the participants contributed to this category. It contains four sub-categories: "Change in health status", "Self concept", "Normalisation strategies", "Emotional changes", and "Life stage and roles." It has links with the conceptual category "Medical management" in that medical intervention can effect health status. It also links with the conceptual categories: "Fighting to survive versus giving up" (e.g. self concept, seeing self as a "fighter"), "Interaction with others" (e.g. attitude and behaviour of others affecting how they felt about themselves), "Awareness of time" and "Closeness of death" (e.g. effects life stage and attitude towards the world).

(i) Change in health status

Thirteen participants contributed to this sub-category. Change in self appeared to be very dependent upon "Change in health status" which was where the most noticeable shifts took place. This was both prior to becoming ill, as health deteriorated, and changes following Tx. The main differences noticed from pre- Tx to post-Tx were in levels of physical activity and ease of breathing. Before becoming ill for the first time most participants felt that they had led a fairly normal life and managed to do what most of their friends did, if not more. Six people (Int.'s 3, 4, 5, 8, 13, and 14) felt that they had experienced a great life, felt lucky, or had lived life to the full. When ill, however, participants described the incessant IV's, the constant medical activity, constant oxygen, hospital admissions, difficulty in eating and sleeping, physiotherapy, chest pain, feeds, nebulisers, the constant grind to stay alive, picking up less and less after each bout of illness, and the gradual chipping away of their health and lung function. However, one Tx candidate described how becoming ill had made him re-evaluate what was important in life, and how this made him much more laid back. This, therefore, appeared to be a positive change.

In contrast, some months after Tx, participants could breathe, had no cough and noticed a silkier voice. They could also walk to the shops and wake up in the morning feeling fine. Although oral medication increased after Tx, Tx recipients had more time to themselves due to the lack of extensive medical regime. There were two exceptions to this (Int.'s 5 and 13). These people had suffered from major complications and were not as well as they had hoped to be following Tx. One participant who was nearly five years post-Tx, commented that her symptoms were just like having CF all over again:

"...The most sick thing of all is that Tx problems are exactly the same as CF problems. So rejection is exactly the same as having a CF chest so it does the same thing to you again. And its just like you go through exactly. - well I have gone through the same thing again... so its all - it's like its all come in a circle - twice."

(Int. 13, female/ Tx recipient)

Not all Tx candidates became totally debilitated prior to Tx although physical activity was still severely limited. Being on the Tx list and deteriorating health prevented certain activities such as going on holiday, being impulsive, visiting friends overnight, going out to night clubs, and generally enjoying social and active sporting activities. For example, interviewee 10, who had just been accepted onto the Tx list and thought that he was relatively well, found it difficult to keep up with his friends at night clubs, specially if smoke machines were in use. Restrictions are also imposed by the prospect of a Tx. For example, one Tx candidate described how she had stopped going out with friends, stopped going swimming, and ceased drinking alcohol for fear of missing the call from the hospital (Int. 3). Another Tx candidate had reduced drastically her alcohol intake and had decided to "*slow down a bit*" (Int. 14) now she was on the waiting list.

(ii) Self concept

In the sub-category, "Self concept" ten participants contributed. Tx recipients did not feel that they had changed very much following surgery, except in levels of physical activity, although a few had anticipated that they would. However, one Tx recipient said that she had coped with the Tx better than she thought she would and felt that the experience had made her stronger. Moreover, it made her realise how precious life was so that she became more appreciative of the little things in life. This was endorsed by another Tx recipient (Int. 15) who felt that life was now precious as she had been given a new start. She was therefore totally compliant in taking her

medication in contrast to how she was previously. Prior to Tx she had told me that she would become very slack if she was not constantly encouraged by her mother.

Most participants felt that they were generally positive people. They described themselves as having inner strength and as being determined. Interestingly, only one person (Int. 2) described herself as pessimistic. She said that she had always had this trait and that it was not a change brought about by the Tx.

Feelings about having donor lungs were closely tied up with feelings about the actual surgery, hence the link with the conceptual category "Medical management." Most participants felt comfortable about having someone else's lungs inside them and felt that they belonged to them. For example, one participant stated "*They're mine*" (Int. 4), although some found the concept "*a bit weird*" (Int. 9) before they had undergone surgery. When interviewed after the Tx, however, one participant commented: "*I know I thought it would be weird didn't I? But um - it's just - I mean I can - I can't tell they're not my own.*" (Int. 9/15). Others made jokes about coughing up somebody else's spit, especially if the donor had been a smoker (Int.'s 5, 7, 8 and 12). One person commented:

"Part of me has, you know, been in other places in the world and part of me hasn't"
(Int. 2, female/ Tx recipient)

Interestingly, three people (Int.'s 4, 10 and 14) had either thought more about the loss of their own lungs rather than how it felt to be getting someone else's or they seemed almost protective of them. As participant ten commented: "*...they're a bit knackered and I need some other ones... well they haven't done too badly.*" Another participant stated:

"...I suddenly thought about what they were actually going to do which was like cut me open, and take out my lungs and put in somebody else's. I didn't worry about that, it was like they were going to take out mine. It was like "mine aren't very good but they've all I've got at the moment..."
(Int. 4, female/ Tx recipient)

One participant stated that she would have been more concerned about changes in personality post-Tx had she been undergoing a HTx but this issue was not raised by other participants. She stated:

"If it were a heart I think I'd feel really weird. I don't know why but I'm not having a heart. I'm just having lungs and I think - some people say that like their personalities

change don't they, but I don't think that's true... but if it were someone else's heart, I'd feel a bit - you know cos. its like your heart, do you know what I mean, stuff in your heart is your own...with lungs I think it's just for breathing isn't it? There's n'owt of you in your lungs."

(Int. 9, female / Tx candidate)

Most participants described their personalities, and ways of interacting with others, in positive terms. However, one Tx candidate had noticed a negative change in herself as she became more ill:

"I was more outgoing really...I used to - well, I used to go into hospital for my treatment and used to have a laugh...and I can't even do that..."

(Int. 8, female/ Tx candidate)

(iii) Normalisation strategies

Nine participants contributed to this sub-category. There was a theme of Tx candidates feeling different from their peer group, a desire to be "normal" whilst, at the same time, wanting to feel special or different. Two Tx recipients discussed openly being overly aware of the symptoms of CF and how they felt different from their peers. Although two participants talked about CF in this way, many tried to cover up their illness and portray themselves as "normal". For example, they would say they were feeling fine when they were not, put on a brave face, would struggle to keep up physically with non-CF friends, not tell people about the illness, only see non-CF friends when well, and dismissed any sympathy expressed to them. At the same time, they also wanted people to take an interest in them when they were not well and be attentive to their difficulties. Thus, there was a differentiation between those who considered themselves to be "normal" (e.g. *"They [friends] treat me the same, don't act any differently, don't want them to."* and *"What's normal? Me. I'm normal"*) (Int. 9) and those who felt different from their peers, although the two also coincided (i.e. feeling that they were "normal" but sometimes feeling different from peers). One participant stated:

"Yeah, I think that's one of the hardest things actually. Feeling like you don't totally belong because you've got this thing and nobody else really understands, especially as I hid it a lot...but I never wanted anyone in the public to know that there was anything wrong with me."

(Int. 13/ female, Tx recipient)

(iv) Emotional changes

"Emotional changes" were very dependent on health status and on expectations for the future. Eleven participants contributed to this sub-category. On the whole participants felt that their mood was okay most of the time although acknowledged that this was not always the case. One person on the waiting list did not feel that she had any worries and said that she had never been depressed (Int. 9) although, when interviewed after her Tx, said that she had felt quite low as she became more unwell. Participant 14 did not feel that CF had really affected her life at all in that she had done most of the things she had wanted to with her life so far. Having said this, she had major concerns about what happened after death which caused her a lot of anxiety. Another participant stated:

"Oh yeah, I was depressed again [about rejection] instead of optimistic. The doctors said it was nothing to worry about and they could treat it...you do sort of think - oh you know."

(Int. 2, female/ Tx recipient)

Indeed, the majority of participants said that they felt lower in mood when ill and that their mood was normally fine when they were feeling healthy. When unwell there was more time to think, whilst at the same time feeling bored due to inactivity. Isolation from peers also appeared to exacerbate low mood although it often felt an effort to socialise, creating a vicious circle. Five participants described the effect that low mood had on their behaviour. This included irritability, aggressiveness, rudeness to others, crying, shouting, and suicidal thoughts. Although only four people appeared to have suffered from clinical depression, three of whom were taking anti-depressant medication, others acknowledged feeling very down at different time points (Int.'s 1, 2, 3, 5, 7, 8, 11, 12, 13 and 15). For some, this related to anticipated losses or thwarted life plans (e.g. inability to have children, career changes or cessation), lack of emotional support (e.g. from family). One participant described how it felt to be depressed:

"I think it manifests itself by me not wanting to talk or wanting to see anyone. Or I can't find anything that I want to do. I don't think I can describe what the feelings are like cos when I'm depressed I think it's all very woolly. I just feel really its like a ball of emotion that is probably a lot of different emotions so it ends up in being a sort of grey lump. But I'm sure when I'm depressed I'm really angry and really pissed off."

But its almost like I can't channel the anger into anything that's going to be positive, so you know, fuck it."

(Int. 13, female/ Tx recipient)

Four people (Int.'s 1, 7, 11 and 13) stated that having CF felt like a constant stress that they could never get away from and two people described feelings of anger about their illness. Other emotions described were anxiety, when waiting for the assessment results and a donor organ, frustration as plans are constantly thwarted, changeable moods/feeling moody, and "*feeling awful*" (Int. 13). In contrast, two people described having increased confidence and higher self-esteem post-Tx. This was attributed to two things: a change in self concept due to input from psychotherapy, and being able to go out more and mix with people without worrying what they thought of them.

(v) Life stage and roles

"Life stage and roles" was a concept that was alluded to by thirteen Tx candidates and recipients. It contained themes of employment, parenting, physical activity and interests, interpersonal relationships, and issues of dependence and independence. The majority of people had worked and/or undertaken academic studies but had to give up work or put courses on hold as their health deteriorated. Five out of the eight Tx recipients interviewed had tried to resume work post-Tx. One person had been plagued by complications and so had to give up her studies. One person had not managed to find work. He felt that this was due to the attitude of employers in that they did not want to employ someone who had received a Tx. Participant four, who had undertaken a considerable amount of studying, was forced to work due to loss of disability benefits. She had commented on what a "*great life*" she had before her Tx and had been happy not working. Another participant had not taken up work post-Tx due to concerns about financial problems if benefits were lost. Wanting to enjoy the time they had was also mentioned by three participants (Int.'s. 1, 2 and 5) although this appeared to be a type of "positive re-framing" of their unemployed status. Some participants, therefore, seemed to adopt a kind of early retirement, willingly or unwillingly.

Also salient was the struggle for independence. Four people in particular stressed the importance of independence and spoke of their fear of losing it should their health deteriorate considerably. Six people expressed irritation with parental over-concern. This was most exemplified by being nagged (seemingly by mothers) to take their medication whilst, at the same time, recognising that this was due to concern and that they needed pushing or they would lapse. In contrast, other

participants felt that their parents treated them as "normal" and had difficulty in recognising them as ill. The latter had both positive and negative implications (e.g. smoking in their presence). Ways in which participants tried to maintain independence was by living alone, working, continuing to shop for themselves even if this meant having to lean on a shopping trolley, or by getting up and doing things whilst trailing oxygen cylinders around behind them (Int.'s 4, 7, 11 and 12).

Increasing independence following Tx can feel uncomfortable for partners who have been the main carer when the person was ill. Although participants themselves did not generally envisage a change in feelings for their partners post-Tx, some were aware of their partner's concerns about this. Issues revolved around the partner's change in role, of not being needed anymore, and of the participant becoming too independent. Indeed, one Tx recipient (Int. 6) separated from his partner when he became well. He attributed this to less contact time together and of him being "*selfish*" in that he wanted to do everything that he had not been able to do before. Therefore, it does seem that concerns of partners/carers are real ones which can create some anxiety for both parties in a relationship. For example:

"...cos he said something like this the other day. He said "Once you've had your Tx you wouldn't want to know me. I said "Of course I will!" He said, "No you won't. You'll be up and about. You'll be gone." I said "I won't." I said "I'll still need you, no, cos we'll be able to do more things. More things together really, you know"... No I don't think anything will change. I think it will be either as strong as now or better."
(Int. 14, female, Tx candidate)

Observing similarities and differences between themselves and people of different age groups (e.g. in level of physical activity) suggested that this differentiated participants from their healthy peers. In some respects, it seemed to place them at a later life stage than would their chronological age. This seemed especially so for some Tx recipients. For example, one participant (Int. 13) felt that she could relate better to people 15 to 20 years her senior. Healthy people of her own age group had different concerns than herself and were in a younger life stage which she found hard to identify with. Expectations also seem to be lowered, perhaps seeming to be more fitting to a much later life stage, especially when complications had occurred. One Tx recipient, for example, had undergone radiation treatment, for post-operative complications. The treatment accidentally rendered her infertile so that she had to re-evaluate her anticipated life role of being a parent. Another Tx recipient of four years (aged 27) described his idea of QoL:

"Quality of life to me is just being on this planet really. That's enough quality of life for me. Just being here...as long as I'm around people who I love and everything. As long as I can go out and get in my car and go somewhere and go and get a bit of shopping and - you know as long as I'm not stuck in. As long as I'm not ill enough where I can't leave this house, then quality of life to me is just alright as it is now."
(Int. 5)

Another Tx candidate also described his idea of QoL in similar terms. For him it was being able to enjoy a shower without becoming exhausted. Four participants (pre- and post-Tx) looked back at their lives with nostalgia, regret, or a mixture of both. For these, and others, this involved a search for meaning as to when they had began to become ill (Int.'s 3, 4, 5, 8, 12, 13 and 14) with some attributing blame to themselves (e.g. going away on holiday against medical advice), to others (e.g. doctors), or to life events (e.g. marriage break-up). Looking back can also be considered a feature of people nearing the end of life.

Conceptual category 9: Interaction with others

All the participants contributed to this category. It contains three sub-categories which link: "Attitude and behaviour of others," "Expressing to others how you feel and being heard," and "Concern and care for others." The main themes centred upon family, partners and friends, staff, the general public, and media images of Tx. This conceptual category has links to "Medical management" (e.g. communication style and attitude of health professionals), "Weighing the odds," (e.g. comparison with others) "Change in self" (e.g. others attitudes and behaviour effecting them) and "Fighting to survive versus giving up" (e.g. having people to live for).

(i) Attitude and behaviour of others

"Attitude and behaviour of others" had ten contributions. Out of the six participants who discussed employment issues, all of them found employers, pre-Tx, to be extremely understanding and accommodating once they were made aware of the situation. Parents and other family members were also seen as supportive generally, although there were two exceptions to this. Fathers appeared to be more pragmatic or used humour to ease situations. Mothers seemed to take on more emotional responsibility and were seen as the person who encouraged participants to comply with medical regimes. Most participants felt that they were brought up "normally" and encouraged to do "normal" activities (e.g. horse riding) whilst a few people felt that there was a degree of over-protection. This manifested itself in behaviour such as being constantly nagged to take medication or not being treated as a responsible adult

(Int.'s 3, 9, 7 and 13). Sometimes participants observed both these apparently opposing behaviours in the same, or different, parental figures. This suggests that parents may struggle to tread the most appropriate path: wanting their children to lead as full a life as possible whilst, at the same time, being concerned and hypervigilant about their physical health.

Partners too were found generally to be protective and concerned. Indeed, those who had partners usually found them to be the main stay of support. In particular, with respect to her partner, one participant talked of the way in which other people's acceptance of her symptoms had helped decrease her feelings of shame about her condition. A small minority of partners (two out of nine) did not seem to understand fully the implications of having CF, or they appeared to have difficulties in coping with it (e.g. showing lack of understanding or an unwillingness to talk about CF, showing an apparent lack of awareness regarding the long term outcome of Tx, or encouraging the participant to do more than they were able to). This seemed to influence how they interacted with the participant. For example:

"...but sometimes I don't think he realises how hard it is to walk that extra hundred yards, swim that extra length..."

(Int. 3, female / Tx candidate)

In turn, this influenced the extent to which concerns and fears were shared. Having said this, partners were also seen as being supportive in other ways (e.g. giving practical help).

Although most they felt that non-CF friends treated them the same as everybody else, participants expressed the feeling that most of them did not really understand their situation. There was also the sense that non-CF friends tended to drift away as the participant's health deteriorated. This gave rise to feelings of isolation from their healthy peer group. Comments made were that non-CF friends would stop calling so that participants had to make the effort to contact them (Int.'s 5, 7, 8, 15, and 11). During the interviews participants made excuses for friends who drifted away although three people, directly or indirectly, expressed feelings of hurt, loneliness, and loss of confidence when this happened (Int.'s. 7, 11 and 15). For example, participant 15 described how she had felt prior to her Tx:

"...I felt a bit left out. I don't know. I didn't know 'owt what was happening in their life and stuff. And like obviously n'owt happened to me so when people phoned me up "oh well. What have you been doing?" "n'owt", you know so...I don't know but...." (Int. 15, female/ Tx recipient)

One Tx recipient described how his own perceptions impacted upon his confidence and self-esteem prior to Tx:

"People have definitely got a different attitude if they see you coughing and stuff like that...I don't think they treated - I don't think they treated me much different to anybody else but I think it were more in my mind as well. I think a lot of people have been like that. I always thought that a lot of people might start thinking "Oh God. Look at him. Keep away from him" sort of thing"

(Int. 11, male/ Tx recipient)

Four participants mentioned the attitude of society and the media towards Tx. They thought that there was a mis-portrayal of facts (e.g. by the media and films suggesting that a Tx recipient will take on the characteristics of the donor), or a general lack of understanding which gave rise to feelings of anger and/or hurt (Int.'s 3, 4, 5, 7 and 13). For example, participant four stated that she felt anger towards animal rights activists. She believed they were not in a position to condemn animal research, as they had never needed the help of medical technology for their own survival. Overall, attitudes of others, as well as concern for others feelings, had an effect upon the participants' choice of confidantes and what they felt able to disclose.

(ii) Expressing to others how you feel and being heard

This sub-category divides into emotional availability and practical help and had contributions from all the participants. The greatest emotional support was from other friends with CF, as they could understand their experience, rather than non-CF friends or health professionals. In hospital, patients with CF tend to socialise and some make good friends with others on the ward, but even this can be affected by poor health status. The one person interviewed who was particularly unwell (Int. 8) commented that, even in hospital, she found it difficult to socialise because her health was so poor and that she felt jealous of others who were still relatively well. For patients who have to remain in isolation from others with CF (e.g. those with transmittable infections), there could be an increased potential for social isolation if non-CF friends drift away. One Tx candidate spoke of his lack of contact with other CF patients:

"...They keep me on a different ward so I don't really speak to anyone else...I would like to know - know them a bit better...just knowing people in the same boat as you are...you'd be able to talk to them about things quite easily I would imagine..."

(Int. 10, male/ Tx candidate)

In contrast, six people stated that they did not really want to mix with other patients with CF unless they were in hospital. This was because they wanted to distance themselves from the illness, focus on other things, and not hear about CF all the time. Furthermore, one participant commented that seeing others with CF was like looking at a mirror image of herself reflected over and over again.

Friends without CF, and family members, were seen by six participants as being supportive generally in the sense of making hospital visits, shopping, cooking, being close at hand, and "jollyng" them along. Although partners, parents, and other family members were seen as supportive, a number of participants found it difficult to discuss their deepest concerns and fears with those who were closest to them for fear of causing upset (Int.'s 2, 3, 5, 7, 10 and 12) and tried not to let their worries show. In addition, some partners and individual parents were perceived as being more able to cope with certain information than others (Int.'s 1, 2, 3, 5, 7 and 14). For example, one participant described the difficulties he had in discussing issues of life and death with his family which left him feeling unsupported:

"...and you know its all sort of emotionally tied up and its very difficult to have a dispassionate conversation about, you know, how long your going to live, with your father say. Cos you know he gets upset and I get upset and he gets upset cos. I'm upset and it all feeds on itself. And then we just finish. We all finish just, you know, not talking about the real issues and consoling each other. And you go away from that feeling fairly wretched really...Well I mean probably because of this I did actually become very, very depressed."

(Int. 12, male/ refused Tx)

Thus, expressing feelings to close relatives can be very difficult. In contrast, eight participants mentioned how easy it was to talk to the staff at the CF Unit, in particular the nurses and social worker. Most participants considered the latter vital for discussing both practical and emotional difficulties. There was a mixed response regarding professional counselling. Some felt that it would be useful at different stages in the Tx process (e.g. when complications such as cancer arose) whilst others liked to deal with problems on their own. However, a small number of people mentioned how useful some form of counselling, or group, would have been for their parents or partner (Int.'s 1, 8 and 7). These points overlap with the conceptual category "Medical management: attitude and communication style of health professionals."

(iii) Concern and care for others

Ten people contributed to the sub-category "Concern and care for others." Major concerns were for families and partners or potential partners. As already mentioned, participants were worried about them getting upset and how they were coping. In relation to this, participants tried to put on a brave face for family and friends even when feeling unhappy. For example, one participant who was having frequent thoughts about death said:

"Cos I mean, no one else knows. As far as everybody knows I have a laugh and joke all the time. But it's just some'at inside I - I do on my own really. No one else knows...I don't like to discuss it with her [partner] cos I don't like upsetting her..."
(Int. 5, male/ Tx recipient)

Four people (Int.'s 2, 3, 10 and 12) mentioned that they knew that their partners and family wanted them to have the Tx although they did not feel that this overly influenced their decision. In relation to this, three people mentioned wanting to comply with medics to keep them happy (e.g. going for Tx assessment and making the decision to have the Tx when feeling indecisive just prior to surgery). Participants also talked in a caring way about friends with CF who had died. Concern was also expressed for the families of patients who had died, including the donor family, with the knowledge that this will be difficult for their own family when it happens to them. A number of participants struggled with thoughts about the donor: that someone had to die so that they could live, with most Tx recipients expressing feelings of gratitude to the families concerned.

Four people also mentioned their concerns for their previous or present employers in that it was not fair on them if they were off sick frequently or if they could not manage a full work load. Many therefore resigned or took early retirement (Int.'s 1, 3, 12 and 14). Health status therefore influenced participants' ability to function in previous roles such as employment. It also had an impact upon friendship and self-esteem. In particular, one pre-Tx participant stated that he did not want to become involved in an intimate relationship as he did not think this was fair, given his shortened life expectancy. This was intimated by two other Tx candidates although they suggested that it was not important at the present.

Conceptual category 10: Anticipation versus disappointment

All the participants contributed to this conceptual category which is divided into two sub-categories: "Hopes and expectations for the future" and "Goals and plans." The general theme is what participants want from the future and their perceived ability to achieve their goals. Disappointment is a thread that runs through both sub-categories. The sub-categories have considerable overlap with each other and it is difficult to separate all the strands without removing context. There are close links with the conceptual category "Awareness of time" in that participants' perception of how much time they had left affected how the future was planned. It also links with conceptual category 11: "Coming to terms with life and death" (e.g. hopes and expectations shift as participants begin to accept that they cannot do everything that healthy people are capable of). It also has links with "Medical management" in that medical treatment (e.g. effect of treatment) altered hopes and plans for the future.

(i) Hopes and expectations for the future

All participants contributed to this sub-category. In this sub-category, hope was differentiated from expectation. For example, some Tx candidates and recipients were hopeful that they would receive another donor organ if theirs failed, although they did not necessarily expect to get one. Others hoped that they would live long enough to derive benefits from new technology (e.g. new anti-rejection drugs). Most Tx candidates hoped to be able to lead a normal life post-Tx but did not necessarily expect that to happen. One Tx candidate hoped that her life would return to how it was before she became ill:

"Well, I expect - I hope - that it will go back to how it was. I'll be able to just go back to that again. Be able to get out and about and just do everything again... Be able to get out again and meet people again. Just to be able to have a normal life really would be a bonus. I keep telling X [partner]we're gonna be playing football and riding bikes [laughs] and he's sweating already"

(Int. 8, female/ Tx candidate).

Surprisingly, perhaps, most of the seven pre-Tx participants (Int.'s 7, 10, 12 and 14) did not expect, or want, their life styles to change post-Tx. They merely expected it to become easier and less of a struggle. For example:

"I hope that they turn out really good and I'll be able to do more than I can do now, and hope that I can go out and walk and maybe do a bit of running, but not as exercise. I don't like exercise! Like if you have to run for the bus I won't get out of breath, start coughing when you are on the bus or like that, or like when you go from the cold to the warmth or from the warmth to the cold, start coughing and I'm looking forward to that. Looking forward to going disco night clubbing again... Just not taking your nebulisers, not having the drugs, not having to feed overnight..."

(Int. 14, female/ Tx candidate)

Another Tx candidate stated:

"I don't know. I'll have to think and try and - try not to make it change that much."

(Int. 10, male/ Tx candidate)

Participant 12 in particular, did not have great expectations of improvement and thought that it was "*false advertising*" and he had actually decided against having a Tx. Expectations of other Tx candidates also included being able to live (rather than die), to breathe, lack of a daily medical regime, to do "normal" things such as playing football, having a shower, and being able to perform an activity even if they chose not to do it. A number of participants mentioned the desire to travel. Thus, they wanted to live lives similar to many other healthy people. For those who had received a Tx, most felt that the results had met their expectations or exceeded them. None who had survived the operation regretted their decision.

Having said this, the three people who had experienced complications felt some sense of disappointment that the Tx had not matched their ideal. In retrospect, two of them felt that their expectations had been too high. One person, who had major complications in the immediate post-operative phase, had based her high expectations on someone close to her. She had seen them go through the Tx process and had expected that it would be the same for her, which was not the case. Another person (Int. 4), who had remained very well post-Tx felt that her life had been brilliant before. Increasingly good health meant that she had to work which she was finding less satisfactory, although she still commented that the Tx had exceeded her expectations. Only one person (Int. 11), who had received his Tx only 4 months previously had the expectation that he would live for a further 15 to 20 years as new technology was introduced. The other Tx recipients appeared to be less optimistic in terms of the time frame in which they operated. Although they still hoped for longevity, they did not necessarily expect it.

All except one person on the waiting list expected to receive a Tx coupled with high hopes that it would arrive in time. Conversely, some Tx recipients commented that they had hoped that a donor organ would not arrive too early as they had not felt ready for it when first put on the list (Int.'s 2, 4, 8 and 13). Interestingly, it was three of the four female Tx recipients who made this comment. For those who had received a Tx, hopes were that they would meet milestones that they had set for themselves and that they would continue to be well. Constant disappointment, however, effected how the future was planned.

(ii) Goals and plans

Eleven participants contributed to this sub-category. In this sub-category most participants, both pre and post-Tx, preferred to make small plans rather than major ones in case they became ill again. Plans and goals revolved around keeping well, getting fit for the Tx, staying alive, going on holiday, and deciding on courses and employment. Of all the 14 participants interviewed only five people were making firm career plans or had particular ambitions for the future (Int.'s 3, 12, 10, 4 and 11). Others were not sure what they wanted to do in the future, felt it was too early in the Tx process to make decisions, were not very interested in a career or job, or had career plans disrupted by ill health. Constant interruption of plans resulted in disappointment, frustration, anger and sadness, and an eventual giving up on ambitions or goals. One Tx recipient explained:

"...I was thinking then to start a family as well. That's what I was aiming for, as soon as I had my Tx you know, to go back to work. Nobody would take me on. I was a bit angry about that so. A bit narked cos that's what I was aiming for - to go back to work. I just got fed up writing letters so I don't bother now. I haven't bothered now for two years..."

(Int. 1, male/ Tx recipient)

Other disappointments centred around not being able to have children, false alarms, and disappointment in God. Hopes being raised and then dashed was mentioned by four participants (Int.'s 1, 2, 7 and 13).

Conceptual category 11: Coming to terms with life and the possibility of early death

Seven participants contributed to this category and there are no sub-categories. It contains action strategies as it deals with the process of acceptance. This conceptual category links with the previous conceptual category "Anticipation versus

disappointment" as participants began to accept that expectations had to be lowered and that they would not be able to fulfil all their plans. It also links with the conceptual category "Change in self" and "Medical management" (e.g. coming to terms with the fact that medical intervention can result in complications or can only do so much). Participants described a process of coming to terms gradually with their life as it is, the possibility of early death, and of friends dying. As one participant described: "*...it was just a case of getting over it. It was like coming to terms with it*" (Int. 7). The process seemed to involve a shift in thinking. This included taking things on board over time, the working through of emotion by talking to others, gradually facing up to reality (i.e. that they could not do what they did before or do what healthy people do), learning to accept help, changing the goal posts by making the best use of the life they had, and looking back at their lives and being appreciative of it.

For one Tx recipient, however, looking back at the good times in his life was a trigger to sadness. He recalled what he used to be able to do, became more aware of his present declining health status, and longed for more time. Some strategies used were more passive or fatalistic (Int.'s 4, 6, 7 and 12) as in "*If it happens it happens. That's life*" (Int. 6), "*That's the nature of the game anyway*" (Int. 4), or "*There is nothing I can do about it*" (Int. 12). One Tx recipient stated:

"But I sort of took the idea where, you know, well everybody has their crosses to bear and I've got this one. I'm not gonna let it get to me so."
(Int. 6, male/ Tx recipient)

Passive and active coping styles were often used together. For example, one participant who had refused to have a Tx, took early retirement from work and went part-time so that he could cope better, yet remain independent. At the same time, he also used passive coping in terms of being "*kind of resigned really*" (Int. 12). More passive coping mechanisms do not imply that the person concerned was ready to give up or was maladaptive. Rather they were struggling to come to terms with their life as it was by using a variety of strategies.

4. Differences between Tx candidates and recipients

All the conceptual categories had contributions from both Tx candidates and recipients, with Tx recipients also reporting on their pre-Tx experiences retrospectively. Hence, as many of the issues and concerns of the two groups were similar, they were combined in the model presented in Diagram 1. The main differences between Tx candidates and recipients can be seen in Table 3.

Table 3: Differences between LTx candidates and recipients

Conceptual category	Tx candidates	Tx recipients
1. Perception of health status	Less aware of health status.	More aware of health status.
2. Closeness of death	Death seems closer when first told of need for Tx, and as health deteriorates	Death seems closer when have complications and when 5 year marker approaches.
3. Awareness of time	Increases with time on Tx list. Little evidence of firm plans. Timing of Tx important - not too early or too late. Emphasis on time spent waiting.	Aim is to reach milestones. Anxiety increases as approach milestones. Make small plans and do not plan far ahead. More sense of time running out.
4. Medical management	Difficulty in making transition from CF Unit to Tx Unit, Interactions with staff in Tx Unit can be problematic. High contact with CF Unit	Depends on complications experienced. Less contact with CF Unit. Can miss that contact, but response variable.
5. Information gathering Vs blocking	Mixed response. Want more information about the Tx assessment.	If well, tend to get on with life & block negative information.
6. Weighing the odds	Emphasis on chances of getting Tx & chance of surviving surgery. Still going through decision process, sometimes right up to surgery.	Weigh odds on how long they will survive for. Weigh odds on getting a second Tx All who survived the operation did not regret decision.
7. Fighting to survive Vs giving up	Looking forward to life with Tx.	Reminders of health pre -Tx motivates participants to keep going.
8. Change in self	Changes are negative as health deteriorates. Lowered mood as health deteriorates. Sense of life on hold. Different life stage from healthy peers.	Increased confidence and self-esteem, if well. Increased physical activity. Mood can depend on health status. Some try to make up for lost time, start careers etc. Others take "early retirement."
9. Interaction with others	Potential for social isolation from healthy peers. Loss of confidence. Some reluctant to form intimate relationships.	Increased socialisation with non-CF friends. Increased confidence. More interested in the possibilities of an intimate relationship.
10. Anticipation versus disappointment	High hopes. Little change to life wanted versus larger changes anticipated.	Expectations exceeded, sense of ambivalence, or disappointment. Less hope if realise that another Tx is unlikely.
11. Coming to terms with life and the possibility of early death	Ongoing struggle. Don't believe they will ever die.	Reaching acceptance but still ongoing process. Death seems more real.

Tx recipients seemed more aware of the passage of time as they approached the fifth year after Tx, especially if they had experienced major complications. "Fighting to survive" still continued in that they wanted to beat the odds statistically and in comparison with other Tx recipients. This was exemplified by comments people made which related to others who had received a Tx around the same time as them and had since died. This sense of passing time was also more salient for the Tx candidate who seemed most ill at the time of interview and who, sadly, died a short while afterwards. The other Tx candidates were more optimistic, except for one person who had been on the waiting list for over two years. She seemed to have given up hope that she would ever get a Tx. Having said this, prior to Tx it was as if most people could not really envisage themselves dying, no matter how ill they were. Indeed, most of the Tx candidates I interviewed still expected to recover with treatment when they became ill. In contrast, Tx recipients seemed to be more aware of the possibility of their own death. This may have been due to the fact that they had been through major surgery and remembered their existence prior to getting the Tx. As they had now experienced a taste of life with healthy lungs they, understandably, feared a deterioration to their previous state of ill health, although most of them expected this to happen at some point in the future. For Tx recipients, lung complications serve as a reminder of what it is like not to be able to function: coming close to death over and over again. Indeed, this was alluded to by three participants.

For Tx candidates, lives seemed generally to slow down, or alter, once accepted onto the waiting list. Most of them did not make many plans, go on holidays or weekends away, or keep up with work or education, or found the latter difficult. Many still went out with friends if they were well enough, but waiting for the call from the Tx centre to tell them that a donor lung was available, seemed to dominate life. It was as if people could not go forward with their lives as they were always waiting for an event that might or might not happen. Indeed, most Tx candidates mentioned the waiting for the phone to ring or the bleep to go off with this becoming more salient as health deteriorated. Two participants mentioned leaving the bleep behind when they went out, not changing the bleep's batteries, or not knowing where it was. One Tx recipient was contacted by the police when was called for Tx as his bleep was switched off due to low batteries. He had been waiting 18 months for Tx and thought it was unlikely the call would come imminently (I found this surprising, initially, and wondered if this was to "tempt fate" or to try and establish some normality in their lives where they were not constantly listening for the bleep to go off). Interestingly, Int. 12, who had declined a Tx when I interviewed him, seemed to have a similar outlook to people post-Tx. Instead of placing his life on hold, he was re-planning his career within the boundaries of his health status, was making plans for the future, and

generally trying to get on with life and remain independent. He was also counting down time in a similar way to Tx recipients. Instead of counting from the date of the Tx surgery, however, he counted from when he was accepted onto the waiting list.

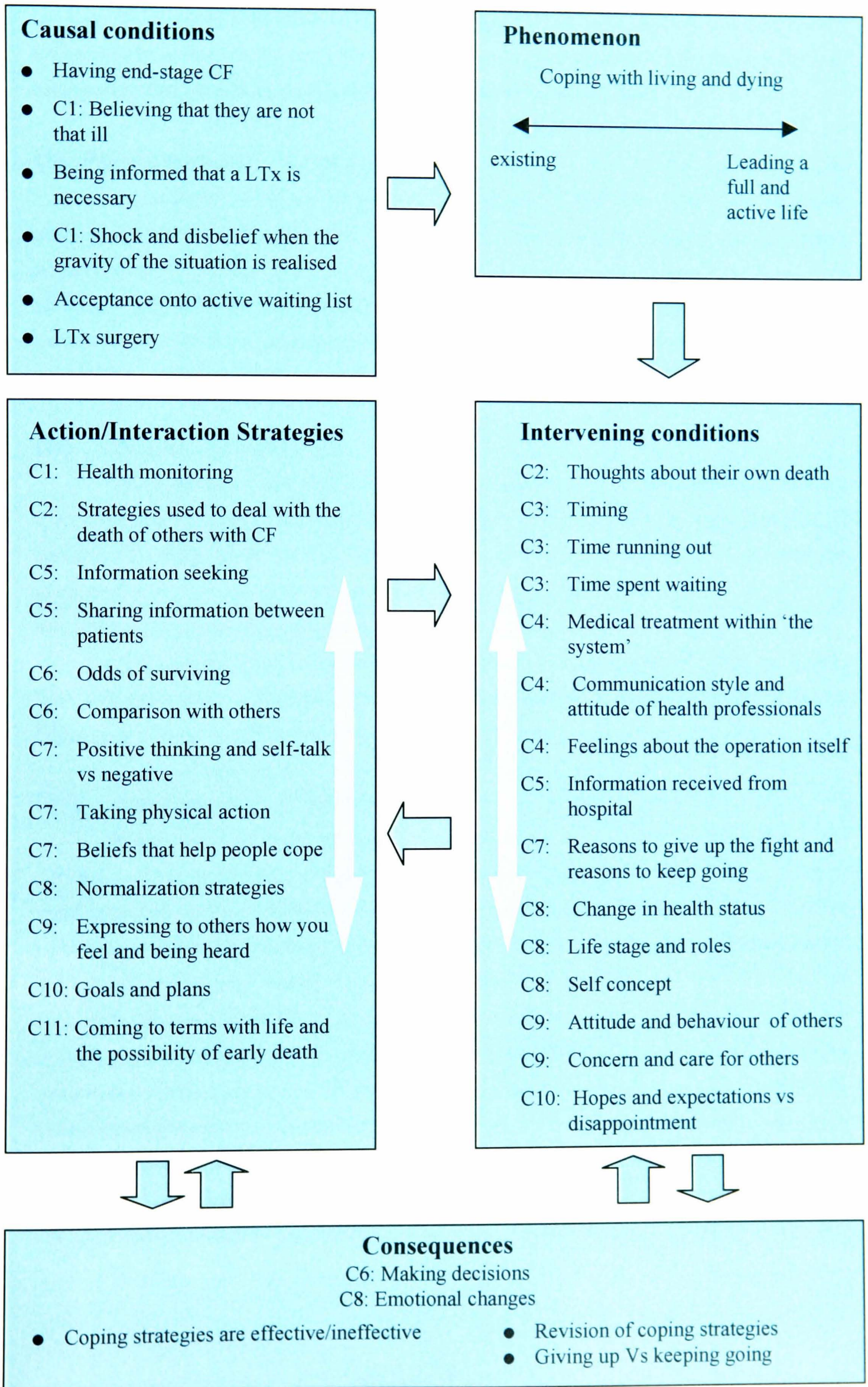
The person who had been diagnosed with CF late in life seemed to have more difficulties adjusting to her life post-Tx than the others interviewed. It seemed that she had not really come to terms with her situation in a way that most of the other Tx recipients had. She was quite pessimistic about her future, although she commented that she had always been "*a pessimist*" (Int. 2). Moreover, she had never perceived herself as someone who could cope with such difficult events and had surprised herself in this regard. Although she had speculated that adjustment to her situation may have been easier if she did not have children, one other person who was also a mother seemed to be coping better with the prospect of a foreshortened life span and was more optimistic. The latter participant had also talked about fear of death when interviewed but was handling her situation differently. She felt that she had always been a positive person, a fighter, and that she created her own energy. As regards gender, no specific differences were noticed between males and females, although more females than males had partners. Having a supportive partner also appeared to be a buffer against social isolation.

5. Overview of findings in relation to the paradigm model

As the conceptual categories described a process, the paradigm model (Strauss & Corbin, 1998) seemed to be a meaningful way to conceptualise the results further (Diagram 2). The paradigm model is a pre-determined framework which aims to show the links between categories in relation to a specific phenomenon. The phenomenon is a central set of circumstances, happenings, or events that emerged from the data and to which all the other components of the paradigm model relate. To re-cap briefly, the components consist of:

- (a) Causal conditions which lead to the development of the phenomenon.
- (b) Intervening conditions that have a bearing on the strategies people use to manage the phenomenon
- (c) Action/interaction strategies are the processes people use to respond to the phenomenon.
- (d) Consequences are the outcome of these processes mediated by the causal and intervening conditions.

Diagram 2: Results of analysis in relation to the paradigm model



As discussed in the "Method" section, assigning each conceptual category to each of the model's components would have forced the data into the model and would not have been a true reflection of the process. For this reason, most of the conceptual categories have been split so that it is the sub-categories, rather than the conceptual categories, that have been assigned to different parts of the model.

(i) Phenomenon: Coping

To reiterate, "Coping with living and dying" emerged as the core category under which every other category is subsumed and is the central phenomenon of the paradigm model. Participants' responses were in relation to existing or leading a full and active life, with the latter dependent on what leading a full and active life meant to them as individuals. Participants' responses can be conceptualised as being on a continuum.

(ii) Causal conditions

Being informed that a LTx will probably be necessary in the near future, having a Tx assessment, acceptance onto the active waiting list, waiting for a Tx donor, and having LTx surgery due to end stage CF, are the causal conditions of the central phenomenon "Coping with living and dying." For most of the participants being informed of the possibility that they would need a Tx, prior to the full Tx assessment, was, in itself, the beginning of having to face up to the seriousness of their condition. This was especially so if they did not believe that they were that ill. This gave rise to feelings of shock and disbelief when the gravity of their situation was realised.

(iii) Intervening conditions

Where participants are placed on the continuum, from existing to leading a full and active life, is dependent upon the intervening conditions. There were a large number of intervening conditions that influenced the strategies that participants used to cope. From the participants' perspective some intervening conditions appeared to have direct consequences, rather than being mediated through the action/interaction strategies. For example, "Concern and care for others" (Category 9) influenced the decisions people made regarding their future (Category 6). For those experiencing an apparently higher incidence of low mood or depression (Category 8), intervening conditions appeared to be factors that directly related to the future. Therefore, thoughts about their own death (Category 2) and a sense of time running out (Category 3) were pertinent. The closeness of death, brought home further by the death of friends with CF, gave rise to thoughts and feelings about their own mortality. Associated with this

were concerns that a donor organ would not become available in time, although hope generally was maintained that one would be.

For Tx recipients, amount of time left according to Tx statistics, was an important mitigating variable on coping. "Hopes and expectations versus disappointment" (Category 10) in regard to anticipated losses, also had an influence upon the carrying out of goals and plans. One of the main intervening conditions was the conceptual category "Medical management." (Category 4). This was especially pertinent to those in the assessment and waiting phase but was also salient to Tx recipients who had experienced complications or perceived medical inefficiency. For two of these people medical mis-management was perceived as a factor which contributed to their depression.

The most important component of medical management was the communication style and attitude of medical and nursing staff. In general, participants voiced very strong feelings about what they considered to be good and bad practice. Staff were either seen as knowledgeable, supportive and caring, or less skilled, uncaring and too busy to communicate well with their patients. Although participants acknowledged that the latter was due, in part, to staff shortages at the Tx centre many participants felt dismissed, disparaged or a nuisance. It was staff attitudes that were particularly noteworthy in making the Tx assessment and peri-operative phase tolerable or unpleasant.

Medical tests, the outcome of medical intervention, and the way in which this was dealt with by staff, also influenced people's hopes and expectation and their ability to cope. One Tx recipient, for example, had undergone radiation treatment, for post-operative complications. The treatment accidentally rendered her infertile and brought on the menopause prematurely (at aged 34). Her shock and devastation was exacerbated by the apparent cavalier and unempathic attitude of both nursing and medical staff.

One participant experienced both negative and positive staff attitudes in the same hospital: a negative experience during her first Tx assessment, but a more positive one post-operatively due to contact with different personnel. In contrast, some participants' feelings about all staff were very positive. It may be that a few individual staff were perceived in a negative light and this may have coloured some participants' views of staff in general. In contrast to the Tx centre, staff at the referring CF unit were highly regarded by the majority of participants. However, staff there knew the participants well and therefore had a different relationship with them.

The way in which information was relayed by medical staff (e.g. accurate, empathic yet maintaining hope) (Category 4), the amount of information provided, and when the information was conveyed were also considered important (Category 5).

Although it is difficult to make an informed decision if relevant and important information is unavailable, being overloaded with negative medical information may also be detrimental.

Also cogent were the participants' thoughts and feelings about the actual surgery (Category 4). In relation to this, the timing of Tx and in telling people about their illness (Category 2) was important and became influential in making decisions. "Time spent waiting" (Category 3) (e.g. for medical tests, for a donor organ) also influenced thoughts and feelings in a generally negative way.

"Change in health status" (Category 8) was also very important as to how participants coped. The majority of participants commented that their mood was very much influenced by how well they were: when feeling poorly their mood became lower and improved as their health improved. "Self concept" (Category 8), or how participants regarded themselves, was also considered an intervening condition as it impacted upon the type of coping strategies used. For example, those who viewed themselves as having inner strength felt motivated to take physical action (e.g. getting up from bed), although this could be mediated by mood state. "Life stage and roles" (Category 8) was an intervening condition that had an effect on who participants expressed feelings to, their goals and plans, and their ability to come to terms with life and the possibility of early death.

In order to mobilise strategies to keep going, participants looked for reasons to continue (Category 7). Linked to with this, was participants' concern for others (Category 9) and the "Attitude and behaviour of others" (Category 9), as this influenced whom they discussed their anxieties with. "Concern and care for others" also included caring about friends with CF who had died and concern for their family members.

To summarise, the intervening conditions influenced the action/interaction strategies that participants used to cope, and could also affect the consequences component of the model directly. The most important intervening conditions were contained within the conceptual categories "Awareness of time" and "Medical management." Another major influence was the sub-category "Thoughts about their own death." (Category 2).

(iv) Action/interaction strategies

Participants used a number of coping strategies in response to the intervening conditions. This included "Health monitoring" (Category 1), "Strategies used to manage the death of others with CF" (Category 2), "Information seeking," and "Sharing information between patients" (Category 5), "Weighing the odds,"

"Comparison with others (Category 6), "Positive thinking and self-talk versus negative," "Taking physical action," and "Beliefs that help people cope" (Category 7), "Normalisation strategies" (Category 8), "Expressing feelings to others and being heard" (Category 9), making "Goals and plans" (Category 10), and "Coming to terms with life and the possibility of early death" (Category 11).

All of these strategies appeared to be on a continuum from positive to negative and from more active to passive. For instance, positive self-talk or positive thinking (Category 7), could bolster up participants and increase motivation whereas more negative thoughts such as "*I can't be bothered*" (Int. 3) or "*How many days like these have I got left?*" (Int. 5) had the potential to spiral further down into depressed mood. In part this seemed to be due to inactivity. When ill they were unable to go out very much, were bored and had lots of time to think (e.g. about death and dying). Negative thinking was not entirely dependent on changes in health status, however. A number of people who were still able to get out and about or who still had a reasonable QoL by their standards, still mentioned having negative thoughts and/or low mood at times although this did vary across individuals.

Passive coping such as shrugging off the death of others, or not thinking about things (Category 2), appeared to be defensive as issues like death and dying may be too painful to deal with directly. Distraction techniques (e.g. music, watching football) (Category 2) can also be considered to be defensive but seem to be a useful and necessary coping mechanism.

For those who held particular beliefs (Category 7) helpful coping strategies included praying and being prayed for, Reiki healing, church involvement and taking medication (i.e. if they believed in modern medicine). Comments indicated that participants thought that these strategies either did no harm, may have helped (e.g. prevented rejection, cured lymphoma), or were detrimental as they raised hopes unrealistically. The main criterion seemed to be maintaining the belief that they would survive and that they would get a Tx in time as well as having a strong belief in self (e.g. having the will to live). Low mood or life events (e.g. friends dying, themselves becoming more ill, or needing hospital admission), could affect these beliefs and reduce hope. This, in turn, could impact further on mood and behaviour (e.g. medical compliance, willingness to eat, getting out of bed).

To combat these potential negative outcomes, participants used distraction techniques (Category 2), positive self-talk (Category 7), communication with others (Category 9) and struggled to be as active and as fit as possible within the limits of their current health status (Category 7). Common action strategies were weighing up the odds of surviving and comparing themselves with others (Category 6). "Comparison with others" involves observing similarities and differences between themselves and

others and rating themselves as having a greater chance of survival. However this falls down when a role model (i.e a Tx recipient who appeared to be fit and healthy), or someone they perceive as similar to themselves, dies. This results in a search for meaning as to why that person died so that they can try and avoid the same fate. Weighing the "Odds of surviving" included looking at statistical information on Tx survival rates over time and weighing up the chances of surviving the Tx against their present QoL. These processes potentially increased, or decreased, hope and motivation and influenced decision making. For example, the death of a previously well Tx recipient was very worrying for both Tx candidates and recipients and could impel the former to reconsider their decision.

"Health monitoring" (Category 1) was also important and seemed to be especially salient for Tx recipients, who monitored themselves for signs of rejection.

"Information-seeking versus blocking" (Category 5) varied across individuals and was an active choice. Deliberately not making use of available information appears a defensive strategy to protect oneself from negative information which could reduce hope or lower mood. Having said this, sharing information between patients (Category 5) was a strategy used by the majority of participants when they had the opportunity. This included generally those who were not "information seekers" or who preferred to distance themselves from others with CF.

The intervening conditions: "Self-concept," "Attitude and behaviour of others," and "Life stage and roles", affected "Normalisation strategies" (e.g. not telling people about their CF or struggling to keep up physically with non-CF friends, both socially and at work) and when these were used (Category 8). "Coming to terms with life and the possibility of early death" (Category 11) involves a process of acceptance. As acceptance increased, or as physical health improved, normalisation strategies appeared to be used less or were no longer needed (i.e. if Tx recipients were as physically able as their non-CF friends). However, a number of Tx recipients were still finding their situation difficult to come to terms with. For instance, one participant felt that he was resigned to his situation rather than accepting of it.

Intervening conditions such as "Time running out," "Thoughts about their own death," "Change in health status," and "Hopes and expectations versus disappointment" influenced life "Goals and plans" (Category 10). Past experience suggested that plans were often interrupted by illness. Therefore, goals tended to be small, and plans were usually made only a short time in advance in order to avoid disappointment.

(v) Consequences

Consequences are the outcome of the action/interaction strategies and the intervening conditions. This component of the model contains both sub-categories and individual elements of the different sub-categories. The sub-categories in this section of the model are: "Emotional changes" (Category 8) and "Decision making" (Category 6). Emotional changes (e.g. improved or lowered mood, anxiety, fear, anger) are a consequence of the action/interaction strategies (e.g. positive self-talk, negative thinking) resulting in raising or lowering of mood and motivation. This, in turn, affects further action/interaction strategies and impacts upon the intervening conditions. However, from the standpoint of participants some intervening conditions (e.g. Category 4: "Communication style and attitude of health professionals") seemed to have direct bearing on their emotions (Category 8) and decisions made (Category 6).

Decision making is the result of a large number of interaction strategies and intervening conditions, which may be used together. For example, the decision to have the Tx may involve the intervening conditions: "Believing that they are not that ill," "Timing," "Medical treatment within the system," "Information received from hospital," "Concern and care for others," and "Feelings about the operation itself." Action/interaction strategies may include: weighing the "Odds of surviving," "Comparison to others," "Information seeking," and "Sharing information between patients."

Other consequences of the action/interaction strategies and intervening conditions are that coping strategies are effective or ineffective. They may then be revised if they are not working (e.g. one participant struggled to keep up with her peers and tried to pursue major career plans (i.e. "Normalisation strategies") but found this too exhausting, or she had plans constantly interrupted by illness. She finally came to accept that it was not possible for her to do all that she wanted to (i.e. "Coming to terms with life and the possibility of early death"). Conversely, the patient may give up until there is a change in one of the intervening conditions, or they decide to revise their coping strategies.

However, the ultimate consequence of the action/interaction strategies and the intervening conditions is how well participants coped. The very fact that participants were able and willing to talk to me suggests that they were actually coping very well.

(iv) Summary

The paradigm model shows the links between categories in relation to the phenomenon: "Coping with living and dying." This was the central set of circumstances that emerged from the data and to which all the other components of the paradigm model relate. The

components consist of causal conditions, intervening conditions, action/interaction strategies and consequences. Causal conditions gave rise to the central phenomenon "Coping with living and dying." The intervening conditions are mitigating factors that had a bearing on the coping strategies that participants used. They are not static but are affected by the causal conditions, action/ interaction strategies, and consequences. The action/interaction strategies were the coping mechanisms participants used to respond to the phenomenon. They are influenced not only by the intervening conditions but also by the consequences. The consequences are the outcome of the action/interaction strategies mediated by the causal and intervening conditions. Therefore, there is a dynamic feedback loop in progress. Each component of the model affects another part of the model which in turn, is influenced by those changes.

Chapter four: Discussion

"Well my life has certainly changed, still is changing. I'm still not entirely sure that it's changing in a way that I'm happy with. But- well I think I've - I think I have regained, you know, some measure of control over what's going on ... Cystic Fibrosis is not the entirety of me. It's just a part and I want it to be as small a part as possible."

(Int. 12/, male/ refused Tx)

1. The aim of the research and overview of main findings

The aim of this study was to use grounded theory to explore the experiences of adult LTx candidates and recipients with CF in order to (i) identify areas of importance that may have been omitted in previous research (ii) increase understanding of the psychological processes involved in the Tx trajectory, and (iii) construct a theoretical model of the processes involved in the experience of LTx for patients with CF. This involved interviewing seven adult Tx candidates and eight adult Tx recipients with CF, with one person interviewed both before and after surgery.

I will firstly relate the findings of the present study to previous research in the area of CF and thoracic Tx and, towards the end of the discussion, identify areas that appear to have been less well researched. Secondly, in order to further explore the psychological processes involved in the Tx trajectory, I will discuss the conceptual categories that appeared to have the most important psychological implications for participants. These categories are: "Perception of health status," "Closeness of death," and "Awareness of time." These conceptual categories appeared to be at the core of participants' experiences with CF and LTx and, for some, was the dominant theme of the interview. The conceptual category, "Medical management" will also be considered, as this seemed to have a significant impact upon how participants coped. However, due to the close links between categories, it would be difficult to discuss the above without reference to the other categories identified in Diagram 1. Thirdly, I will discuss the processes involved in the experience of LTx in CF, focusing on the core category "Coping with living and dying," in relation to the paradigm model and with particular reference to models of coping in the health field.

2. Overview of results in relation to Quality of Life issues and psychopathology

(i) Quality of Life

Previous psychosocial research in the field of LTx and CF has focused mainly on QoL issues and psychopathology. Although these concepts were not addressed directly in this study, the interview questions and probes tapped some of them (e.g.

health status, mood state). Indeed, there were a number of indicators that suggested shifts in QoL and mood states over the course of the Tx trajectory. However, as the number of participants in the present study was small it would be unwise to generalise these results to other patient groups or the CF population outside of the UK. Moreover, comparing qualitative and quantitative analysis may be problematic in that different concepts are being measured in different ways.

Many QoL instruments appear to be inappropriate for use with the CF population as they are not disease specific (Gee et al., 2000; Quittner, 1998). These measures indicate that QoL improves by three to four months post-Tx (e.g. Stavem & Bjortuft et al., 2000). This is mainly in physical functioning (i.e. respiratory function, mobility, and energy levels). Less noticeable gains were made in the psychological (e.g. Lanuza & Lefaiver et al., 2000), social and emotional domains (e.g. Limbos, Chan & Kesten, 1997). In the present study, changes in QoL can be intimated by the constituents of three conceptual categories: "Change in self", "Anticipation versus disappointment," and "Perception of health status."

In the conceptual category "Change in self," participants reported generally positive changes from pre to post-Tx, mainly in the areas of physical activity and in respiratory function, a finding which is in line with previous research. However, as Limbos, Chan and Kesten (1997) suggest, this was less applicable to those who were experiencing complications. Even in those who were relatively well post-Tx, some participants remarked that they still had good and bad days.

Congleton & Hodson et al. (1996) found that QoL in adults with CF was not dissimilar to patients with minor ailments, such as varicose veins and hypothesised that patients in their sample had adjusted well to the condition. Zelter et al. (1980) also suggests that illness is not as unsettling to patients with a chronic illness as they will have developed ways of coping with it (e.g. choosing friends from their own patient group, denial and minimisation). Although Zelter et al.(1980) used an un-tested instrument, the present research appears to support their findings. It suggests that those who are ill with CF may have a different QoL base-line than the healthy population. Indeed, two participants felt that QoL was based on simple activities such as being able to get out of the house, have a drink with friends, or have a shower without becoming breathless and fatigued. Others wanted to be able to run for a bus or go to a night club. Moreover, in the conceptual category "Anticipation versus disappointment" some Tx candidates did not want many changes to their life style and one participant hoped it would not change that much.

Although it could be speculated that adults with CF have lower expectations than healthy adults, Hamlett & Murphy et al. (1996) found that the majority of adults with CF, in their sample of 75, were living independently, had partners and were

achieving their objectives in employment or education. Interestingly, a number of previous studies that used more disease-specific measures found that lung function does not always predict QoL (e.g. Weir & Freeman et al., 1991) and that similar patterns emerge regardless of gender or severity of disease (Gee & Abbott et al., from conference abstract, 2001). This would seem to be borne out, in part, by the present study. A number of Tx candidates, especially those who had only recently been accepted onto the active waiting list, suggested that they were fairly happy with their life at the present time. Indeed, in the conceptual category "Perception of health status" four of the seven pre-Tx participants did not perceive themselves as being that ill; a factor which may, in part, account for them feeling relatively content with their life. This is regardless of the fact their FEV₁ will have been 30% of predicted normal to be accepted onto the active waiting list (Conway, Littlewood & Brownlee, 2000). Believing that they were not that ill resulted in feelings of shock and disbelief when they were told that they needed a Tx. For many, this belief still held after they had been accepted onto the Tx waiting list. Underestimation of disease severity by CF patients has been noted in previous studies (e.g. Abbott et al., 1995; Strauss & Wellisch, 1981) and is thought to be a defensive coping strategy. This may also help account for the fact that previous studies have observed little change in the social, emotional, or psychological domains from pre to post-Tx.

In contrast, retrospective accounts by Tx recipients of their lives just prior to Tx, suggest that they had a more realistic perception of their health status. Indeed, two Tx recipients stated that they had "*really needed it*" (Int.'s 4 and 15) when the donor organ became available. One Tx candidate whom I interviewed shortly before she died, said that she was just existing. Another participant who had been interviewed before and after Tx and commented, at second interview, that she had not been able to leave her chair just before her Tx and that her mood had been quite low. At the first interview she stated that she felt fine and had never been depressed. No doubt the psychological, social and emotional aspects of a QoL measure will not have altered much from pre- to post-Tx if the measures had been completed at the first interview, whereas there may have been large shifts if it was administered just prior to Tx. Perhaps there is a metaphorical line which patients cross, with perception of health status moving closer to actual physical health status as breathing becomes more difficult, and as physical activity and social interaction become severely limited. Alternatively, the positive change in physical health post-Tx may have altered their perception of health status pre-Tx. Unfortunately, none of the QoL studies provide this type of information and most of them are cross sectional in design.

In the CFQoL questionnaire (Gee & Abbott et al., 2000) administered to ten participants in the present study, there appears to be a general trend towards

improvement from pre- to post-Tx in all but one of the sections of the questionnaire (i.e. future concerns). The most notable positive change was "physical functioning", followed by "social functioning" and "treatment and chest symptoms." Having said this, in the pre-Tx group only two mean scores fell below 50 (indicating an area of difficulty). These were "career concerns" and "interpersonal relationships." Of course, the number of participants is very small and only the means and ranges have been calculated, but there appears to be some similarities and differences between these scores and other QoL research (i.e. large improvements in physical functioning, improvement in social functioning respectively). One striking difference between the scores of Tx candidates and recipients was in "Concerns for the future." Here, there were large differences between the means in the opposite direction: Tx recipients seem to have greater concerns about the future than Tx candidates. Moreover, the trends observed in the questionnaire mirrored many of the responses given by participants at interview. Indeed, concerns for the future emerged as being more pertinent for Tx recipients than Tx candidates. This concept is discussed more fully under the conceptual category "Awareness of time" (see section 3).

(ii) Psychopathology

Studies have looked for evidence of psychopathology in both the CF population and in Tx patients. Studies looking at the CF population report mixed results although the more recent studies find that patients with CF function adequately, both socially and emotionally, and that severity of illness does not equate with psychological distress (Sensky, 1990 cited in Aspin, 1991). However, Mador and Smith (1988) suggest that adolescents with CF may adapt socially but not necessarily psychologically. They identified a number of psychosocial concerns about the limitations of their disease, their potentially fore-shortened future, feelings of inadequacy, isolation, and anger towards themselves and medical staff. Indeed, feelings of anger, isolation, low self-esteem, fear of the future, and a sense of unfairness about having CF, were not uncommon concerns in the present participants (conceptual categories "Medical management," "Change in self," "Emotional changes" and "Awareness of time"). Mediating factors proposed by Mador and Smith (1988) are gender, health status, age, and family dynamics and support (e.g. withdrawal by father and over involvement by mothers). Indeed, the latter type of family dynamic was alluded to by some participants in the conceptual category: "Change in self: life stage and roles."

Although Mador and Smith (*ibid*) cite illness severity as an intervening variable in psychological adaptation, studies suggest that illness severity does not equate with degree of emotional disturbance (e.g. Cowen et al., 1984). However, Grassi & Rosli et al. (1996) did find positive correlations between anxiety, depression and physical

distress in bone marrow patients. In the present study, Tx candidates reported lower mood when their health decreased markedly or when they experienced complications post-Tx. This suggests that negative changes in health status affected mood and influenced thoughts about the future in this group.

CF sufferers reportedly cope well socially although their social group tends to be others with CF (Shepherd et al., 1990). Indeed, most of the participants I interviewed had friends with CF as they felt that they understood one another better, but they also had non-CF friends. Seven of the 14 participants did not mix much with others who had CF, unless they were in hospital. Instead, they preferred to socialise with friends and family away from the CF "scene" so that they had less reminders of their illness, although this has the potential to result in social isolation if non-CF friends start drifting away.

Reportedly, depression and anxiety are common in those waiting for HTx surgery (Manzetti et al., 1997). Improvements have been noted post-Tx (e.g. Freeman et al., 1995) with gains in QoL and low depression scores maintained over a five year period (Fisher et al., 1995). Similar findings are reported in LTx patients with CF (LeHeuzy et al., 2000). However, Dew et al. (1996) found that clinical depression was higher in HTx recipients than in the general population. In medical patients depression and anxiety are not uncommon problems and prevalence exceeds that of the general population (Katon & Sullivan, 1990). Moreover, Derogatis & Morrow et al. (1983) found that 47% of cancer patients could be classified as having a psychiatric disorder and that this was more likely to occur when patients were aware of their diagnosis and if they considered treatment as palliative rather than curative (Alexander, Dinesh & Vidyasagar, 1993). It is also acknowledged that depression often remains undiagnosed in the medical arena (Brody & Larson, 1992; Magruder-Habid & Zung et al., 1989), as depressive symptoms (e.g. weight loss, poor sleep, energy loss) may be attributed to the physical illness. Given the nature of CF it would not be surprising if similar oversights were common. This may be especially pertinent for patients who are concerned about being accepted onto the Tx waiting list as this may influence disclosure. Having said this, it may not be wise to psychopathologise someone who already has a multi-system disease and who is facing a Tx.

In the present study, psychopathology was not addressed directly, but some of the interview questions, and probes tapped these areas (e.g. "How are you feeling in yourself at the moment?", "How did that make you feel?"). Indeed, periods of depression, low mood or sadness were disclosed by many of the participants. In the conceptual category "Change in self" (sub-categories, "Emotional changes" and "Change in health status") nine participants acknowledged feeling very down at different time points. Low mood was more likely to occur when unwell, when bored

and ruminating, when the reality of their future became more salient (e.g. if lung function decreased), or when bad news was imparted (e.g. needing a Tx. organ rejection, malignancy). Depression and sadness also seemed to be associated with thoughts of a fore-shortened or uncertain future, lack of emotional support, thwarted life plans, and anticipated losses (e.g. career, having children).

In the conceptual category "Fighting to survive versus giving up," as physical activity decreased and the medical regime increased there was increased boredom, resulting in increased potential for negative thinking. In order to "keep going" participants tried to combat negative mood states. Strategies used included thinking of reasons to stay alive, thinking positively and giving themselves positive self-talk, doing something physical (e.g. getting out of bed), distraction (e.g. computers, music), and maintaining beliefs (e.g. in God, prayer, the universe, themselves).

Feelings of social isolation from their healthy peer group was also evident, with some participants describing feelings of hurt, loss of confidence and low self-esteem (see also conceptual category "Interaction with others"). Anxiety was more covert but seemed to concern death, dying, declining health status, organ rejection and infection and therefore links with the conceptual category "Awareness of time" (see section 3). However, in the conceptual category, "Expressing to others how you feel and being heard," some participants did not feel that professional counselling would be useful as they preferred to deal with things alone. Others thought that it would be useful for them and their families and/ or partner at different time points in the Tx trajectory. However, it rarely seemed to be offered.

It is not possible to form firm conclusions about psychopathology in the present study as no specific measures were taken. However, in contrast to quantitative methodology, qualitative data can give a better indication as to the cause of depression in certain groups. It can also suggest how well coping strategies are working which, in turn, may aid clinicians in the targeting of interventions, and enhance coping strategies that are already in use. Due to the nature of CF, LTx, and the uncertain future, it would perhaps, be surprising if there was a low incidence of depression and anxiety in this patient group. Indeed, two Tx candidates and two recipients stated that they had been diagnosed with clinical depression, whilst others acknowledged periods of very low mood but saw themselves as generally positive.

(iii) The LTx trajectory

Psychosocial research into LTx has also focused on patients' experiences within the LTx trajectory. Worby and Smith (1997) proposed seven stages within this trajectory, each stage requiring different psychosocial tasks. Although the LTx trajectory is proposed as a psychosocial model, it appears to be medically based rather

than being patient-centred. It is also North American so that some of the processes outlined may not be applicable in the UK (e.g. Stage Three: patient considers whether or not to move to city where the Tx centre is). To re-iterate briefly: In Stage One the Tx is proposed, the patient finds out information about what is involved in the Tx procedure and considers whether he or she will have one. In Stage Two, Worby suggests that participants are referred to the Tx team for assessment and begin lifestyle changes if necessary (e.g. stopping smoking, alcohol reduction). Stage Three is the wait for Tx. Worby suggests that the psychosocial tasks of this stage include staying alive, avoiding infection, maintaining hope, dealing with anxiety and depression, keeping up social and family relationships, and coping with envy and jealousy of those who get a Tx before them. Stage Four involves the call for Tx (including false calls) the surgery and immediate post-operative care. The psychosocial tasks described in this stage include the patient's memory of the call, coping with ICU, intubation, delirium and concern about acute rejection and fear of leaving the hospital. The psychosocial tasks at Stage Five are identified as patients recuperating from surgery at different rates, awareness of differences between the Tx and CF teams, identity modification, and awkwardness with others who do not know how to treat the patient. Stage Six includes returning to the CF unit as an outpatient, dealing with close relations who may find it difficult to come to terms with the patient when well, re-evaluation of intimate relationships, looking towards education and employment, enjoyment in living a fuller life than before, and dealing with obstacles and complications. Stage Seven is the stage of irreversible decline and death occurring in half of Tx recipients between two to five years post-Tx (Worby, 1998).

Worby (*ibid*) proposes seven psychosocial stages in the LTx trajectory. However, rather than going through a stage process *per se*, the participants in the present study seemed to move backwards and forwards along a continuum: from perceived wellness to bouts of illness, to declining health, improving health and then back to decline, intercepted by periods of varying health states. Taking movement along this continuum into account, the stage model can therefore be viewed from a different psychological perspective. The Tx trajectory, as proposed by Worby, has been altered and expanded, by incorporating the present analysis.

1. Telling: Is this real? Am I that ill?

Initially participants described feelings of SHOCK AND DISBELIEF when the gravity of the situation was realised, and as DEATH MOVED CLOSER. A number of participants felt anger with the medical staff or were self-blaming. Many participants PERCEIVED THAT THEY WERE NOT THAT ILL. Their knowledge about CF appeared variable, with limited knowledge of LTx or the criteria for LTx. Even if they

had previously anticipated needing a Tx it was generally felt to be too soon, or participants had expected to need one when they were older. Feelings about Tx tended to be very ambivalent, and remained this way for some time after notification of the need for Tx, if not until the Tx operation itself. Prior to assessment, some participants talked to others who had already experienced a Tx assessment but they were usually given very little information about assessment from the referring CF unit. Therefore, for a number of participants, the decision to have a Tx was not well thought out at this stage.

2. Assessing: Will I be accepted on to the Tx list ? Do I want to be?

This stage was marked by ANXIETY, ANGER, and AMBIVALENCE about the Tx and assessment procedure. There was anxiety regarding the Tx assessment, and dissatisfaction with medical and nursing staff at the Tx centre, especially in terms of communication and staff attitudes. Some felt angry that they were not made to feel "special" and "cared for." There was also realisation that the Tx team, and ward organisation, was different to that of the CF unit, but some participants had difficulty in accepting this. After acceptance onto the waiting list, if not before, a decision to have a Tx was made as options seemed limited, but participants tended to remain ambivalent. Many felt that they did not need a Tx and went along to the Tx assessment to please the medical staff and/ or relatives, or to confirm that they were not that ill. Many, but not all, described their Tx assessment as an unpleasant experience. The conceptual category "Medical management" suggests that the main influencing factors were: "Medical treatment within the system" and "Communication style and attitude of health professionals." Participants had to cope with unfamiliar surroundings and, sometimes, brusque staff and spend time waiting for tests to be done. They then had an anxious wait to find out if they were accepted onto the Tx waiting list.

3. Waiting: Do I really need it now?

In Stage Three participants commonly described feelings of AMBIVALENCE, FEAR, ANXIETY, EXCITEMENT and ANTICIPATION when they were on the waiting list. Ambivalence was more marked if they felt relatively well. Apart from the actual fear of having the surgery *per se* (i.e. surviving the operation, being cut open), anxiety stemmed, in part, from the ANTICIPATED LOSS OF THEIR OWN LUNGS, as well as the DESIRE TO EXTEND THEIR TIME by keeping their own lungs for as long as possible. Another concern was that if they died soon after surgery, they could have survived for longer with their own lungs. Therefore, the TIMING OF TX was important: not too early and not too late. Excitement and anticipation were also

expressed, especially as the Tx became more imperative. Fear of having a Tx too early was replaced by fear of running out of time before a Tx became available. Having said this, many of the participants (either Tx candidates or Tx recipients talking retrospectively) DID NOT BELIEVE THAT THEY COULD DIE, and all but one Tx candidate believed that a Tx would arrive in time. In addition, there was POTENTIAL FOR LOSS OF SOCIAL CONTACT WITH NON CF FRIENDS as they become more unwell so that many participants became more reliant on their friends with CF, maintaining communication by telephone if not in person.

There was also INCREASING DEPENDENCE on others and a need for practical, as well as emotional, support. PARTNERS BECAME WORRIED about how their relationship would change post-Tx, so participants tried to provide reassurance. BOREDOM, NEGATIVE THINKING and LOW MOOD had potential to increase when unwell. The psychosocial tasks outlined by Worby (1998) were also pertinent to the participants interviewed (e.g. maintaining hope, avoiding depression and anxiety). In the conceptual category "Fighting to survive versus giving up" participants outlined strategies they used to maintain hope and ward off depression and anxiety. Sometimes the strategies were unsuccessful and they wanted to give up.

This stage is not static and appears to have "STAGES WITHIN STAGES" in that participants described periods of becoming more unwell, being admitted to hospital, improving after a few weeks, maintaining relative health, and becoming unwell again, although health gradually deteriorated overall. Participants also described how they tried to maintain physical fitness, avoid people with infections, cut down on alcohol and generally tried to stay well enough for Tx to occur (knowing that if they got an infection or became too ill, they would become ineligible for surgery). Some managed to keep up with employment even if part-time, whilst others were unable to work. Most Tx candidates did not express feelings of jealousy or envy if a friend received a Tx before them, unless they felt that they were becoming desperate for a Tx themselves. This may be because a number of participants were quite ambivalent about the surgery initially, wanted the most time out of their own lungs, or did not feel ill enough to need a Tx. They were therefore reluctant to rush into surgery. This may be exemplified by the fact that bleeps (used to contact a patient when a donor is available) were not uncommonly left behind, batteries were allowed to run down and not replaced quickly and the bleeps turned off, or they did not know where the bleep was. Although suggesting AMBIVALENCE about having the actual surgery, it may also have been a way for participants to NORMALISE their lives or helped to REDUCE THE ANXIETY of "being called."

4. Will I get a Tx in time?

For some, health deteriorated markedly, especially if the wait for Tx was long. Many Tx recipients stated that they knew they really needed one when the call came, or that they were getting desperate. Descriptions of their lives just before Tx sounded like that of dying people, although there was always the hope that a Tx would arrive. As only 40% of patients who need a LTx will actually receive one (Conway et al., 2000), the majority of patients on the waiting list will not get the call (Stage Five).

5. Being called: Will this really go ahead? What should I be thinking?

The main feelings described were AMBIVALENCE, FEAR and EXCITEMENT when the call for Tx came. Participants then described the wait in hospital, and getting ready for surgery, whilst medical staff decide if the Tx could go ahead.

6. Dealing with the aftermath of false calls: Will I get another chance?

Profound DISAPPOINTMENT or RELIEF were felt if they received a false call (i.e. the Tx was unable to go ahead). This seemed especially poignant if they actually got to the Tx centre (rather than having surgery cancelled whilst still at home). Participants described being concerned that their opportunity for a Tx had gone and needed reassurance from medical staff. Others, who did not feel ready for a Tx when the call came, described great relief when it was cancelled.

7. Surgery: Will I survive?

After the operation, participants talked about the post-operative physical PAIN. However, they were also reluctant to complain of pain too much, especially if nursing staff were felt to be less than sympathetic. FEAR OF DEATH immediately after surgery, and fear of leaving the hospital environment to cope at home was also highlighted. All had very individual concerns depending on experience/complications. Participants had mixed feelings about their care at the Tx centre. Some had vivid memories of the Intensive Care Unit (ICU) where some experienced frightening hallucinations, feared going to sleep in case they did not wake up again, not being able to talk for weeks due to a tracheostomy, and difficulties in communication with staff which resulted in anger and frustration for the participant.

Although I did not interview anyone in the three months following their surgery, retrospective reporting by participants suggested that they did recuperate at

different speeds. Some experienced major complications post-Tx whilst others had a smooth recovery. Most participants became aware of differences between the Tx and the CF team much earlier in the Tx trajectory than suggested in Worby's (1998) stage model, usually during the assessment phase (Stage Two). For those who survived the operation and initial post-operative period, the next stage involves three to four months of recuperation.

8. Going home: Can I manage? What now?

After participants arrived home they could begin to PLAN FOR THE PRESENT AND THE FUTURE (e.g. employment, continuing education where it had been interrupted). However, these tend to be small plans. RELATIONSHIPS WITH OTHERS IMPROVED OR CHANGED (e.g. separations, regaining social contacts and forging new ones), although most of the Tx recipients did not feel that people treated them differently than before surgery. This may be because most participants perceived that their non-CF friends had usually treated them the same as everybody else (see conceptual category: "Attitude and behaviour of others"). However, prior to Tx a two-way process between Tx candidates and non-CF friends was evident. Social contacts decreased as friends drifted away, but many participants did not wish to see their non-CF friends when they were ill, as they did not wish to be viewed as different.

In addition, many people had known the participants when they were relatively well, before they were considered for Tx surgery. Therefore, it was not that difficult for them to regain their "well" identity and re-establish some of the social contacts that had dropped off before Tx, as well as form new ones. Hence, contrary to the literature, most participants did not seem to have to undergo a huge process of identity modification after their Tx. However, this information may be better elicited by interview with family and partners.

During Stage Eight CONFIDENCE AND SELF ESTEEM INCREASED. Tx recipients were also planning holidays (often the first in years), INCREASING INDEPENDENCE and ACTIVITY, and going out more. Adjusting to reality, included realisation that expectations pre-Tx may have been too high. A few appeared to be at a later life stage, both before and after Tx, than their chronological age would suggest. Prior to Tx, participants were becoming more dependent on others due to ill health, or they feared this happening rather than becoming more independent as would be the norm in this age range. Many were physically less fit than older adults. After surgery, medical/ drug complications or fatigue inhibited certain activities or life roles (e.g. having an early menopause, inability to have children, considered unsuitable for in-vitro fertilisation (IVF), difficulty in keeping up physically with both young and older adults, more vigorous activities restricted due to ill health). Some were looking back at

their lives with happiness or regret, a feature more akin to the end of life stage "Integrity versus Despair" (Erikson, 1963). Smith (1986), in describing his life with CF, states: "The maturing of disease and frame of mind exact their toll. I call it growing old early. It seems some symptoms now are much like old age. I have gone through the sadness of physical disabilities...I walk slowly, have to sit down a lot, take a nap every day...Most of all I am facing the end of life. College was my working years before it ended abruptly. Now is my retirement..." (p. 138).

EMPLOYMENT AND EDUCATION ALSO REMAINED AN AREA OF DIFFICULTY for four Tx recipients. It seemed as if they too had taken early retirement as the description of their lives reminded me of an older age group (e.g. in activities, limited future planning as unsure how much time left, in expectations for the future). In contrast, the other four Tx recipients were RE-COMMENCING THEIR EDUCATION, CAREER, OR BUSINESS, HAD ACTIVE SOCIAL LIVES and were moving forward generally with their lives and planning ahead. In general, Tx recipients appeared to have a strong awareness of time left, even if they were well when interviewed. The exceptions to this were those who were interviewed shortly after surgery.

9. Reaching Tx milestones: How long have I got left?

As Tx recipients approached the five year Tx marker (Note: post-Tx survival rate at the participating hospital is 60% at five years. UK figures give a survival rate of 30% at three years post-Tx), FEAR of chronic rejection increased. Most Tx recipients only MADE LIMITED PLANS. ANXIETY OR PRE-OCCUPATION ABOUT TIME RUNNING OUT was more salient. They were also looking back as well as looking forward, whilst at the same time were trying to enjoy life. CAREERS AND EMPLOYMENT REMAINED A PROBLEM for half the recipients. Two of the Tx recipients I interviewed had decreasing lung function, had experienced malignancies, and were having similar symptoms to CF. They were aware of their declining health status and were finding this difficult to cope with. The initial unrealistic perceptions of health status, seen in a number of Tx candidates, seems to be replaced by realistic appraisal of the situation. Therefore, DEATH SEEMED MORE OF A REALITY than before with less defensive denial of symptoms bringing with it the POTENTIAL FOR DEPRESSION AND ANXIETY, sadness, and anger. Participants were still struggling to come to terms with life and the possibility of early death at this stage.

10. Dying all over again

Although I did not interview anyone who was at this stage it could be hypothesised that as a patient goes into irreversible decline, they have to face, once

again, the process of dying. However, this time there is less hope, or no hope, as the chance of getting another Tx is usually very slim (and often not available). Perhaps it would be at this stage that LTx patients are more likely to correspond to the last few stages of Kübler-Ross' (1970) model on dying (i.e. when they are *really* dying) (Kübler-Ross' (1970) stage model of dying is discussed more fully in sections 3 and 4).

(iv) Summary

To summarise, previous literature on LTx has generally focused on QoL issues and psychopathology. In addition, there is a proposed LTx trajectory that Tx patients follow although it appears to be more medical in orientation than psychosocial and the processes outlined are very scanty (Worby, 1998). The present study has made a contribution to this stage model although further detailed examination of this process is recommended.

3. Conceptual category: Perception of health status

One of the research aims was to increase understanding of the psychological processes involved in the Tx trajectory. As previously mentioned, the conceptual category, "Perception of health status," (mediated by "Medical management"), was the first step in the LTx trajectory and had psychological implications as to how participants coped with the pre-Tx stage. It has been mentioned that participants described feelings of shock and disbelief when told that they needed a Tx as they did not believe that they were that ill. Indeed, Strauss and Wellisch (1981) found that patients with CF rated themselves as being significantly healthier than their doctors did, with many of the sample rating themselves as healthier than other people with CF. Therefore, for most of the participants, this news was the first realisation of the gravity of their situation and it brought death much closer.

Research into other types of organ Tx and major thoracic surgery show similarities between these patients' experiences and those of LTx patients. Abram (1965) found that patients facing open heart surgery experienced a strong fear of death which was dealt with by denial, high anxiety or resignation. In renal patients waiting for Tx, Kempf (1966) observed high levels of denial of the gravity of their condition in response to high anxiety. Bruce and Beard (1969) used psychiatric interview to elicit the concerns of 14 adult kidney Tx patients. Like the patients in Kempf's study, Bruce and Beard found that 79% of their participants used denial as a defence against the fear of death when first diagnosed. However, these studies are 30 to 40 years old when medical technology was not as advanced as it is now. It is therefore possible that this could have resulted in increased use of denial as a way of coping.

Kastenbaum (2000) defines denial as "the rejection of, or an inability to accept, a significant facet of reality" (p. 90). This did not seem to be the case in the present sample. On the contrary, here the participants were more than aware of the precariousness of their existence and, rather than deny it *per se*, they were dealing with it in the best way possible in order to maintain psychological health. Denial is usually temporary and soon passes being replaced by the more adaptive strategies of avoidance and control. These tactics include: selective attention, compartmentalising, self-deception, and resistance, all tactics used to reduce anxiety in themselves and others. Kastenbaum (*ibid*) uses the term "normative denial" (p. 90) for these strategies.

Some of the strategies outlined by Kastenbaum (*ibid*) were evident in the present participants (e.g. avoidance, self-deception). One participant, for example, wanted to train horses after her Tx (yet contact with horses made her CF worse). Some patients did not believe that they could die. In contrast, the majority of participants tended to make small, realistic, plans (see conceptual category: "Anticipation versus disappointment" and "Awareness of time"). In the conceptual category "Information gathering versus blocking," participants who did not actively seek out information acknowledged that they preferred to "*compartmentalise*" (Int. 6) their CF, focus on other things, and not talk about it. One participant commented that he had wanted to hear the minimum amount of information about Tx and no more. Another would not watch certain media items on the television as he found it too upsetting. A few would not read the CF or Tx literature that came from the hospital, and one Tx recipient remarked that he generally took little notice of doctors. On the other hand, the latter participant could also relate survival statistics and only made limited plans for the future. Therefore, his denial appeared to be only partial. This seemed to be a type of "selective attention" in that participants did not attend to information that they did not want to know about, but remained aware of their situation.

Indeed, the contents of the conceptual category: "Information gathering versus blocking" suggests that participants actively disengaged from the information gathering process if they did not wish to hear it, whilst others coped better by finding out as much as possible about their condition and prognosis. This blocking out of information or "selective attention" is part of the process of "normative denial" described by Kastenbaum (2000, p. 90) and is used in order to help contain anxiety. This suggests that no matter what information is provided to patients before a Tx is proposed, it will still come as a shock when this is finally confirmed.

Glaser and Strauss (1965) suggest that denial manifests itself in various behaviours such as: comparing ones self to others with the same illness but who are not as healthy; believing that one is exceptional and will live whereas others with the same

illness have died; by strenuous activity; unwillingness to discuss the illness, ask questions, or demonstrate an inability to hear what the doctor is communicating, and by making large (and perhaps unrealistic) plans for the future. The participants I interviewed demonstrated some of these strategies to varying degrees. In the conceptual category "Weighing the odds" participants compared themselves to others with CF who were worse off. They also looked for differences between themselves and other patients who had died. Two Tx recipients appeared to be trying to convince themselves that they were different, or special, and that they would continue to survive where others had not. For example, they remarked upon how long they had lived, and that they were the last survivors of a cohort that had received a Tx around the same time as them.

Findings in the oncology literature suggest that cancer patients go through a similar process to LTx patients when they are first given bad news about their illness. Although participants in the present study could anticipate improved health with Tx, it seems that there are some similarities between the two patient groups. Rutherford and Foxley (1995) summarise the pattern of transition that occurs when someone is first faced with a terminal illness. They describe a process beginning with numbness and denial, minimisation (including disbelief, anxiety and anger), and depression. Even when individuals have suspicions that something is seriously wrong, it is suggested that having this validated results in feelings of shock and numbness. This, as previously mentioned, was a common response by the participants I interviewed even if they were already aware of the implications of having CF. Indeed, one of the Tx candidates described not only the shock she felt when she was told that she needed a Tx but also the numbness she experienced, so that she did not even remember the drive home from the hospital. Perhaps the common denominator between cancer patients and those needing a LTx is trauma. Indeed, research into people's responses to traumatic events suggest that people develop the illusion that reality is more positive than is actually the case (Taylor, 1983).

Rutherford and Foxley (1995) suggest that denial and minimisation are coping strategies which prevent "emotional disintegration" (p. 112), but that marked deterioration in health may mean that defensive strategies begin to fail. As mentioned, the Tx candidates in the present study tended to minimise their illness, comparing themselves to others with CF who they thought were worse off than themselves (see conceptual category 6: "Comparison with others"), or they recalled a time when they had done this. Some did not believe that they could die, even when facing imminent death, whilst others described times when they knew that they were seriously ill and did not think that they would survive. Thus, as Rutherford and Foxley (*ibid*) suggest,

minimisation of illness symptoms cannot always hold up in the face of contrary evidence.

Certainly, the Tx candidates gave the impression of being more "up beat" and more optimistic than the majority of Tx recipients, which was unexpected. It seemed that the majority of Tx recipients were no longer minimising their difficulties although, when recalling their response when told of the need for a Tx, minimisation was evident. Indeed, minimisation of illness symptoms has been noted before in CF patients (Abbott, Dodd & Webb, 1995). However, there are concerns that minimisation has potential to cause difficulties for adherence in treatment or when treatment decisions need to be made. No consensus appears to have been reached in the literature on if, and when, denial should be replaced by realism. In a recent study, Chapman and Bilton (2001) found that CF patients had a less than clear understanding of CF and its implications for treatment and health. They speculate as to whether providing patients with more information will increase adherence but suggest that this may be at the expense of psychological health.

Minimisation may be a defensive strategy used by some individuals to maintain hope and optimism and help preserve a sense of normality. It seemed to remain intact for most, even when close to death or when inundated with a plethora of factual medical information (e.g. patients on the Tx list who had been provided with facts and figures by the hospital at Tx assessment still believed that they were too well for Tx). Importantly, however, avoidance, denial, and minimisation have been deemed to be beneficial in the CF population (Aspin, 1991).

Overall, it was the Tx recipients that appeared to have a more realistic perception of their health status. It could be speculated that this may be because they had come close to death previously. One Tx recipient, for example, described the process as "*like dying all over again*" (Int. 5). With defensive denial, or minimisation no longer in place, there seemed to be an increased potential for depression and anxiety in Tx recipients, especially as time passed. This seemed to be because they were more aware that they could die, as they had come close before and that if they rejected their donor lungs, the chances of getting another LTx would be slim. Having said this, Tx recipients seemed to find this concept difficult to acknowledge as they were trying to maintain hope (see conceptual category: "Anticipation versus disappointment"). Low mood and depression also appeared to reduce participants desire to comply with their medical regime as it diminished their desire to fight to survive (see conceptual category: "Fighting to survive versus giving up").

To summarise, "Perception of health status" usually involved a period of time in which the participant did not really believe that they were that ill, with this resulting in shock and disbelief when told of the need for Tx. It bears similarities to the

oncology literature and research on other types of Tx surgery and seems to be a useful coping mechanism, protecting Tx candidates from death anxiety although had implications for how they felt about the surgery (see section 4). It also suggests that being told news of a life threatening nature elicits a similar response in many patients, no matter what the cause of the illness.

4. Conceptual categories: Closeness of death and Awareness of time

"Closeness of death" and "Awareness of time" seemed to be the most important psychological variables in determining how participants coped with being on the Tx trajectory. As there are close links between them it would seem artificial to discuss them separately.

The initial fear engendered by being told of the need for a Tx seemed to be pervasive throughout the Tx process, although being stronger at certain time points (e.g. if health deteriorated markedly, when friends with CF died, when called for Tx, in the immediate post-operative period, when complications or rejection occurred and as time passed post-Tx). Although there were differences in responses between LTx candidates and recipients the general themes were similar. For Tx candidates, timing of the Tx appeared to be most pertinent with concerns that they should not get the Tx too early or too late. Time running out became more relevant as time passed on the waiting list and as health deteriorated. For Tx recipients, there appeared to be more of a sense of time running out, or more awareness of time, especially as Tx milestones were reached (e.g. when approaching five years post-Tx). Indeed, similar concerns have been observed in renal Tx recipients. Kempf (1966) noted periods of severe depression and feelings of uncertainty concerning life expectancy and continued fear of premature death.

In adult renal patients, Bruce and Beard (1969) found that denial was followed by feelings of dejection, depression, hopelessness, sadness, and difficulty in communicating their fears to significant others. Resentment and envy of others with good health was acknowledged by five patients in Bruce and Beard's study (*ibid*). Those with good emotional support from one other person seemed to adjust better. These findings, although over three decades old, bear striking similarities to the findings reported in the conceptual categories: "Change in self," and "Interaction with others." Like the findings reported by Bruce and Beard (*ibid*), participants in the present study also had difficulty in expressing how they felt to loved ones for fear of upsetting them. Those with good emotional support appeared to have less potential for social isolation. Interestingly, it was the females in the present study who were more likely to have a supportive partner. Some participants also talked about their

intolerance for healthy people who complained about their health, finding this irritating, whilst at the same time feeling envy as they wished to be healthy too (see conceptual category, "Weighing the odds: comparison with others").

A qualitative study (Haberman & Bush et al., 1993), using content analysis of an open-ended questionnaire, examined the QoL of 125 long term adult survivors of bone marrow Tx (mean time since Tx was 10 years). Although the pre-operative preparation, method of Tx and prognosis is very different (e.g. bone marrow Tx is preceded by total body irradiation and chemotherapy, no open surgery is required, cure is possible), the emergent themes show some similarities between this patient group and the present participants. Haberman & Bush et al. (*ibid*) noted some themes that are also relevant to the findings of the present study. Difficulties observed for bone marrow recipients involved coping with physical problems, recovery not always being smooth, continuation of illness symptoms, difficulties in resuming employment or education, having a new perspective on life and on time (e.g. live more in the present), and concerns about future complications or a lack of concern.

The LTx recipients I interviewed had variable recovery with some experiencing major complications and continued symptoms of CF (see conceptual category, "Change in self: change in health status"). In the sub-category "Life stage and roles," half the Tx recipients were experiencing difficulties in returning to work. This was because they had been unable to find work, were worried about losing benefits, decided to make the most of the time they had left, or had a career interrupted by illness. Some, therefore seemed to take a kind of early retirement. Coupled with continued health difficulties and poor stamina due to breathing problems, some Tx recipients therefore appeared to be at a later life stage than their chronological age would suggest. In the conceptual category "Change in self," participants also described how they looked at life differently: that they considered it to be more precious or they didn't want to waste their chance. They also lived life in the present as they were concerned about future complications and tended to make small plans (see conceptual categories "Awareness of time" and "Anticipation versus disappointment").

The coping mechanisms used by the bone marrow recipients were both cognitive and behavioural and are very similar to the coping strategies used by participants in the present study (e.g. keeping positive, ignoring difficulties, praying, helping other patients, fighting illness, trying to stay active). They also resemble the cognitive coping strategies used by terminal cancer patients (Haberman et al., 1993).

One type of coping mechanism is anger as this can protect against more difficult to manage feelings. Rutherford and Foxley (1995) suggest that anger may be displaced onto the medical profession. Feelings of anger towards the medical profession, and others were applicable to four participants in the present study. One Tx recipient, for

example, was angry with the medical profession for perceived poor care (see conceptual category: "Medical management"), and also angry with CF, God and the unfairness of life. Thus, anger may be experienced at various stages in the Tx trajectory and, as mentioned, may be a defence against feelings that may be more difficult to manage, such as despair. Interestingly, three of the people who articulated angry feelings had all experienced clinical depression at some stage during the Tx trajectory.

Rutherford and Foxley (1995) suggest that the fourth stage in the transition process is acceptance of reality or letting go of the past. Kübler-Ross (1970) describes this stage as being devoid of feeling when dying patients often wish to be left alone and are disinterested in the outside world. In the conceptual category: "Coming to terms with life and the possibility of early death" a number of participants describe the process of acceptance and how this is mitigated by time. For the participants who are in the LTx trajectory, however, Kübler-Ross' (*ibid*) description does not quite match. This may be because most of the participants were further away from death than were the patients that Kübler-Ross interviewed. Most participants (i.e. all except one) were not dying in the sense of being on their "death bed." Instead, death seemed to hang over them like the sword of Damocles, and their response seemed to be more about death anxiety. Interestingly, and contrary to the participants' responses in the present study, Dougherty and Kimberly et al. (1986) found that terminal cancer patients had lower death anxiety, as measured by the death anxiety scale, than controls. In contrast, Tross and Holland (1999) outline concerns of survivors of cancer. Many of these are similar to the worries of the Tx recipients. They include fear of deterioration, continued and increasing fear of death, vulnerability, anxiety and depression, employment worries, and concerns regarding an uncertain future.

In the conceptual category "Coming to terms with life and the possibility of early death," acceptance in the Tx population (especially Tx recipients) seemed to pertain more to coming to terms with the fact that they could not do what their healthy peers did. Acceptance also involved acknowledging that they needed practical help, that they would not achieve their life's ambition, and that the Tx was not all that they thought it would be. Having said this, none who survived regretted the decision to have it. However, acceptance that they would probably die prematurely still seemed some way off. Kastenbaum (2000) suggests that responses to dying are affected by physical health: when physical resources are depleted and people cannot keep going any longer, he suggests that there is a shift from the previous stages to one of acceptance. Perhaps this level of acceptance is only seen close to death, especially in those who keep fighting to live. Rutherford and Foxley (1995), outline three stages that appear to have manifested themselves quite subtly in the present participants.

These are: testing out a new way of being in life, search for meaning, and bringing meaning back into life. In "Change in self," a number of participants carried out a search for meaning which included trying to reach understanding of their present state of health, and life review. Part of "Coming to terms with life and the possibility of early death" included trying to make the most of the time they had within the boundaries of their health. However, these did not appear to be stages but rather activities that were undertaken at different time points within the Tx trajectory.

The stages of dying that Kübler-Ross (1970) suggests are similar to that of Rutherford and Foxley: denial, anger, bargaining, depression and acceptance. However, arguably dying is not necessarily a sequential process and every stage may not be experienced. Moreover, this five-stage process has never been verified by Kübler-Ross or any other researchers. The stage explanation also tended to neglect the context of the patient's life (e.g. a patient may be justifiably angry if there is medical mismanagement), and the five stages were assumed to be incontrovertible (Kastenbaum, 2000). In contrast to Kübler-Ross' stage model, Glaser and Strauss (1965) proposed that the patient's response of being told of the news of a terminal illness is firstly acute depression, followed by denial or acceptance but that the patient's response can shift in either direction or stop in one place. They also suggest that a doctor's harsh disclosure to the patient of their condition can result in increased denial and more severe depression. In the present study, Tx recipients did not seem to go through all the stages as described by Kübler-Ross. Participants aimed to reach milestones but only one participant articulated any form of bargaining. Consequently, she became involved with religion but then felt betrayed when her condition did not improve (see conceptual category: "Fighting to survive versus giving up"). This bargaining was prior to her being recommended for Tx and was not therefore part of the Tx trajectory. Acceptance still appeared to be an ongoing process in all the participants.

In their seminal work "Awareness of dying," Glaser and Strauss (1965) observed and reported upon the interactions of dying hospital patients, their families, and staff, using grounded theory. Although this work was conducted in a hospital setting, was North American, and not focused on the CF or Tx population, the authors describe a number of processes used by dying patients which are applicable to the present study. They state that patients demonstrated acceptance by active preparation (e.g. putting affairs in order, life review, through religion), and passive preparation (e.g. calm resignation). These behaviours are exemplified in the conceptual categories "Coming to terms with life and the possibility of early death" and "Change in self" (e.g. looking back on life and stating that they had a good one, being resigned to the situation). Although one participant in the present study organised her own funeral

payment plan, it is uncertain if the other participants who made wills and were thinking about organising their funerals would have done so without encouragement from a hospital social worker. Their comments to me suggested that this was not something that they had wanted to think about and it seemed to bring home to them, once again, the closeness of death (see conceptual category: "Closeness of death").

Glaser and Strauss (*ibid*) also proposed that younger patients seemed more likely to fight death and tried to beat their illness, by attempting to lead as full a life as possible. Although participants were not always able to lead a full as life as possible, as described by Glaser and Strauss (*ibid*), many saw themselves as fighters and as having inner strength (see conceptual category "Change in self: self concept"). In "Fighting to survive versus giving up" participants described strategies they used to help keep them going (e.g. thinking positively, remembering when they had overcome illness in the past, and believing in themselves or God). Tx candidates also used distraction techniques to remain positive, including taking physical action. This is often seen as a form of denial although it appears to be an adaptive coping mechanism. However, the death of other patients with CF can have a negative effect upon the ability to sustain adaptive coping mechanisms. Craven, Bright and Dear (1990) and Smolin and Aguiar (1996) comment upon the effect of other patients dying and note that the death of a LTx recipient is especially difficult "because the post transplant patient embodies the hopes and dreams of those awaiting transplantation" (Smolin & Aguiar, 1996, p. 298). Indeed, in the conceptual category, "Strategies used to deal with the death of others with CF" this was also relevant to the participants in the present study. However, most of the research concerning LTx patients seems to have underplayed the issues of death, dying and time awareness, especially as they pertain to LTx recipients. This may be because quantitative research has not tapped into these fears in any depth, or researchers have not followed the Tx trajectory over a long enough time period.

Overall, it appears that many of the participants' responses in relation to death and dying follow a similar trajectory to that of other patients with serious illnesses whose outcome is uncertain, and who will probably have a premature death. The stages outlined by Rutherford and Foxley (1995) bear more similarities to participants on the Tx trajectory than does Kübler-Ross' five-stage model although the two are similar. However, it would be wrong to suggest that participants go through the process in a set way, that there are no other psychological processes involved, or even that they go through every stage. Although feelings of shock, disbelief, and denial, do seem to be the first step on the Tx trajectory the other psychological processes appear to shift throughout and are influenced by a number of factors. For example, medical management (which is an intervening condition in the paradigm model) can impact upon the process of acceptance (an action strategy). Feelings of shock may also return

at different time points on the trajectory depending on circumstance. For example, one participant described feeling more shocked about the side-effects of treatment (e.g. infertility, early menopause) than she was about the Tx. Another patient was more shocked to discover that he had developed a malignancy post-Tx as he immediately saw this as an immediate death sentence. Thus, the Tx process contrasts the oncology literature (i.e. most end-stage oncology patients are trying to sustain life generally whereas Tx candidates are hoping to start a new one). Perhaps Tx candidates who are becoming dangerously ill, and Tx recipients who are experiencing complications, are more akin to oncology patients: both are fighting to stay alive and well for as long as possible whilst death draws closer.

Glaser and Strauss (1965) make some reference to younger terminally ill patients wanting to make the most of the time they have left as a way of fighting illness. In some Tx candidates this is seen in their ambivalence to having a Tx too early in the Tx process so that their time is extended. They also talked about "*living life to the full*" (Int. 14) and of them and their families living life "*more immediately*" (Int. 13). Although time is mentioned in the literature, little attention appears to have been paid to patients' concerns about time running out, rather than death and dying *per se*. Yet, in the present study, time was of central importance for many. Kastenbaum (2000) describes a model of time anxiety in which dying people have to deal with the anticipation of not enough time. He states: "The better we understand the role of time anxiety in our lives - and the more adept we become in reducing this anxiety - the better we will be able to assist the dying person who now has an indisputable reason for being concerned about squeezing a lot of life in a little time" (p. 233).

This may be especially pertinent when young. It could be speculated that older adults look back to what was, and what could have been, with a sense that things are unfinished. Younger people, on the other hand, may look back to what was, but also look forward to what they anticipated they would have had, and with a sense of things not even started. Indeed, this was alluded to by Tx recipients, whereas the Tx candidates were still maintaining hope that they would be able to lead a "*normal life*" (Int. 3). In the conceptual category: "Anticipation versus disappointment," for example, a number of recipients discussed what they would have liked to have achieved in life but sensed that time was running out, or that circumstances or illness had prevented these things being achieved (e.g. having children, having grandchildren, marriage, travel, owning their own house, career).

To summarise, issues of death, dying, time awareness, and anxiety, seem to have been paid little regard in the Tx literature, or only alluded to indirectly. The oncology literature offers more insight into the psychological processes of dying patients, but not all of this is applicable to the Tx patient. Even in the oncology

literature, death and dying, as oppose to time, is the central focus. Yet, although closely related, they are different concepts. For LTx recipients, surgery can mean a new lease of life yet they are aware that time is still limited, this becoming more pertinent with the passage of time.

Moreover, not all aspects of the stage models proposed by Kübler-Ross (1970) or Rutherford and Foxley (1995) seemed to apply to the participants I interviewed (unless this was because these concepts were just not articulated although they may have been present). Although oncology patients may go into remission, this seems different from the new lease of life anticipated by most LTx candidates. In addition, the wait for a donor organ means that the experience of LTx patients is different in several respects to that of oncology patients (except when a Tx is involved such as in bone marrow Tx). LTx patients have to go through the process of dying twice: as their health deteriorates in the wait for a donor organ, and when the Tx eventually fails. Previous experience of dying does not appear to make it easier. In fact, it seems to make the dying process, and the thought of time running out again, more frightening. Perhaps this also makes acceptance much more difficult the second time round. LTx patients therefore seem to follow a different trajectory than oncology patients, as discussed in the following section.

5. Conceptual category four: Medical management

As mentioned at the beginning of this chapter "Medical management" was an important variable in participants' experience in the Tx trajectory, as it seemed to play a large part in their sense of psychological well-being, and feelings of safety. This conceptual category contained three sub-categories: "Medical treatment within the system," "Communication style and attitude of health professionals," and "Feelings about the operation itself." The main concerns surrounding "the system" seemed to stem mainly from the assessment phase of the Tx process. One complaint was that patients with CF were in a ward with patients who had other respiratory or cardiac conditions, were often much older than themselves, complained frequently and were quite demanding of the nurses' attentions. One Tx candidate was unhappy that he had not been welcomed onto the ward by staff when he arrived for Tx assessment, that no bed was available to him for hours after arrival, that no-one told him what was happening, and that he had to wait in a small room with another patient with CF who had Cepacia (note: patients with Cepacia are usually isolated from other patients with CF for fear of cross-infection). Moreover, patients with CF were not seen as different, or special, whereas the participants felt that their needs were different (e.g. being more susceptible to infection). This may be because they were used to a unit which was

devoted to CF care with nurses who were specialists in CF whom they knew and trusted, and who listened to them.

Other studies report patient dissatisfaction with some aspects of hospital care, including feeling devalued, loss of power and dehumanisation (Rogers, Karlson & Addington-Hall, 2000). Interestingly, one study examined the stress of hospitalised patients with AIDS in two units: a specialist AIDS unit and an integrated unit. The major stressors across both units were loss of independence, the drug regime, and separation from significant others. However, those on the integrated unit were also concerned about ambiguities in their care, feeling abandoned, impersonal treatment, and perceived discrimination (Van Servellen, Lewis & Leake, 1997). Some of the latter examples are similar to the complaints of the participants I interviewed as regards the CF unit versus the Tx centre. Having said this, not all participants observed this differentiation, or had a more positive experience when admitted for surgery than when they had their assessment.

Although not explicitly stated, an underlying thread seemed to be the lack of control participants experienced once the Tx process commenced (e.g. waiting for unpleasant tests to be done without knowing what was happening, waiting for medics to decide whether or not they were eligible for a Tx). Lack of control continued throughout the wait for Tx and during the peri-operative phase (e.g. waiting for the nursing staff to answer their buzzer, obtaining adequate pain relief). The lack of control which is experienced by hospital patients is well documented (e.g. Taylor, 1979). In a qualitative study examining the experiences of patients undergoing stoma surgery for cancer (Clayden, Madill & Fielding, in press), it was found that lowered personal control was central to patients' experience once they entered the hospital system. Facets of lowered control included uncertainty about the future, unpleasant medical procedures, and symptoms of illness. These concerns are also applicable to LTx patients, even though patients with CF are used to being in the medical system. It has been noted previously that when an individual enters the hospital system and becomes "a patient" they are often required to give up power and control to others. This change in role can be demoralising, and is thought to predispose towards depression (Schain, 1980). The experience of the participants I interviewed varied both across individuals and from the Tx centre to the CF unit. Some patients had both good and bad experiences at different time points. Others had only had positive experiences. This was especially so in relation to the CF unit. In the main, positive or negative experiences depended upon the interactions and attitude of hospital staff. Indeed, "Communication style and attitude of health professionals" was emphasised as important by many participants.

Part of doctor-patient communication involves creating good relationships, this being essential for good medical care (Ong & de Haes et al., 1995). Some researchers look upon the relationship as a social one, requiring humour, politeness, interest in the patient, friendliness, honesty, helpfulness, and a non-judgmental attitude (e.g. Roter, Hall & Katz, 1987). Others see it as a therapeutic relationship in which conveying empathy is paramount, with the patient and doctor having a more egalitarian relationship (Irwin, McClelland & Love, 1989, cited in Ong & de Haes et al., 1995). Indeed, a combination of good social skills, empathy, and a caring attitude were emphasised by participants in the present study. Also seen as important were medical staff not being disparaging or arrogant, and giving participants credit for knowledge about their own condition. This was mentioned in relation to junior doctors especially, and suggests a desire for a more equal relationship with medics involving mutual respect.

Research looking at doctor-patient communication has focused, in particular, on the way in which bad news is relayed to patients. Conveying bad news to patients is a difficult task, made more problematic by the fact that many doctors are not adequately trained to do this although this is changing, with many medical schools now teaching communication skills (Bennett & Alison, 1996). Bennett and Alison (*ibid*) provide some guidelines for how bad news should be conveyed and emphasise that doctors need training in this area. The present participants were satisfied generally by the way in which they were told that they needed a Tx. A number commented that it was difficult information to impart no matter how conveyed, or that it could be done better, but were not sure how. Some would have liked to have had a relative with them whilst others felt that, if this had been suggested, they would have become more alarmed.

Although Bennett and Alison (*ibid*) focused on Doctors giving a cancer diagnosis, the same principles apply to any patient receiving bad news. Their recommendations include: preparing for the interview, establishing whether the patient would like a relative with them, allowing privacy and enough time, giving accurate information in an understandable way, checking patient's understanding frequently, pacing of information, avoiding defensiveness (e.g. if the patient becomes angry), identifying concerns for the future, not providing false optimism but not removing all hope. Some participants gave vivid descriptions of their experience. This ranged from patients being told of the need for a Tx in such a way it was as if the doctor was asking them if they wanted a paracetamol, to the doctor conveying empathy and giving them space to cry.

In the third sub-category, "Feelings about the operation itself" participants described a mixture of feelings about the actual Tx surgery ranging from excitement and ambivalence to terror. Studies on pre-operative anxiety demonstrate that moderate

fear results in information seeking behaviour and grounding in reality, and is associated with less distress post-operatively (Janis, 1958). Other studies suggest that pre-operative information can aid recovery (e.g. Johnston, 1980) by reducing stress and increasing feelings of control (Anderson, 1987). However, it is not known which elements of the information exchange are most helpful: the actual information received, or the caring components conveyed in the telling (Van Der Molen, 1999). In this study it appears that both elements were considered important (e.g. one participant described the caring, concerned attitude of a Tx co-ordinator who provided her with information and was interested in her personally).

Ogden (1996) describes three types of information that are useful to help recovery post-operatively: facts about the actual procedure and after care; information about how the person might feel (psychologically and physically); and useful coping mechanisms. It is suggested that information can help patients mentally rehearse how they will cope, interpret bodily sensations more accurately (Johnston, 1996), and therefore be better prepared. Participants in the present study appeared to have been provided with a plethora of factual information about the surgery, after care, and expected outcome of LTx. However, it is less certain how much emphasis was placed on feelings or on coping mechanisms (e.g. how the Tx centre would be different from the CF unit and how this might affect them, feelings in relation to the wait for Tx, the actual surgery and post-operatively).

To summarise, the conceptual category "Medical management" contained three sub-categories the most important of which was "Communication style and attitude of health professionals," although all interact with each other. The importance of a good relationship between the patient and health professionals cannot be over emphasised. It can contribute to, or detract from, the well-being of the patient and may play a part in adherence to treatment (Ley, 1988) and recovery. Participant responses supports other research concerning doctor-patient communication, the importance of information giving and the manner in which this is conveyed. Information giving should not only include factual information, but also material about anticipated thoughts, feelings and physical sensations, and how patients might cope with these.

6. Core category: Coping with living and dying

(i) Coping with living and dying in direct relation to the paradigm model

Coping with living and dying is the core category under which all the conceptual categories are subsumed (see Diagram 1). It is also the central phenomenon of the paradigm model (see Diagram 2). The paradigm model has been used to conceptualise the data and make explicit the processes involved in the experience of the

participants. It therefore addresses one of the aims of the research: to construct a theoretical model of the processes involved in the experience of LTx for patients with CF.

Participants had to cope with the death of others with CF, thoughts about their own death, and the process of dying as their health deteriorated. In addition, they had to live with the knowledge of a fore-shortened, unpredictable life-span, and try to continue their lives whilst waiting for Tx. The coping strategies utilised by participants are contained within the action/ interaction strategies of the paradigm model, whilst the influences on coping are contained within the intervening conditions. All the processes were aimed at managing the central phenomenon. Below is an example of how one participant coped with an unpleasant symptom of end-stage CF, how this experience is incorporated into the paradigm model, and how the components of the model can influence each other.

Intervening condition: Increased coughing (Cat. 8: "Change in health status").

RESULTS IN:

Intervening condition: Other people respond negatively to him when he coughs (Cat. 9: "Attitude and behaviour of others").

RESULTS IN:

Action/interaction strategy: Compares self to healthy peers (Cat. 6: "Comparison with others").

RESULTS IN:

Action/interaction strategy : Perception that other people do not like him (Cat. 7: "Positive versus negative thinking and self-talk").

RESULTS IN:

Action/interaction strategy : Withdrawal from non-CF friends and acquaintances (Cat. 8: "Normalisation strategies").

RESULTS IN:

Consequences: Lowered mood, decrease in self-esteem, decreased confidence (Cat. 8: "Emotional changes").

RESULTS IN:

Intervening condition: Views self negatively (Cat. 8: "Self concept").

This example describes a number of maladaptive coping strategies (i.e. negative thinking, negative self-other comparison, and social withdrawal). To extend this further, as one of the intervening conditions changed (i.e. the participant had Tx surgery) so did his coping strategies. Following Tx, he no longer coughed and was relatively healthy in comparison to his peer group. As his self-esteem and confidence grew so his self concept altered to one that was more positive. Interaction with others also increased. In this example, one intervening condition affected another intervening condition. Following Tx surgery (Cat. 4: "Medical treatment within the system" and "Feelings about the operation itself"), health improved (Cat. 8: "Change in health status"). As coughing decreased, the attitude of others was perceived as more positive (Cat. 9: "Attitude and behaviour of others"). He therefore moved in a positive direction along the continuum, from "existing" to "leading a full and active life." The model is therefore dynamic and will shift and change continuously.

Coping strategies used to manage the central phenomenon are mediated by the intervening conditions. Intervening conditions may be perceived as potential stressors depending on how the situation is appraised, and has important consequences for psychological well-being (Beck & Rush et al., 1979). For example, the sub-category: time running out (C3: intervening condition), resulted in participants thinking that there was no point in planning too far ahead as they could become ill or die. Concern about this happening therefore influenced the goals and plans participants made (e.g. only making short term plans, living life more immediately, deciding not to work) (C10: action strategy). Change in health status (C8) and thoughts about their own death (C2), which are intervening conditions, influenced positive versus negative thinking and self talk (C7: action strategy), the consequence of which was emotional changes (either positive or negative) (C8). This, in turn, influenced the decision (C6) whether to give up or to keep going and therefore influenced behaviour (e.g. C7: taking physical action). If the coping strategy was ineffective (e.g. negative thinking resulted in depression) it may be revised over time so that other more adaptive methods of coping could come into play (e.g. C7: thinking positively: taking physical action: C9: expressing to others how you feel and being heard). In addition, the consequences

can impact upon the intervening conditions (e.g. depression can lower hopes and expectations for the future or alter the reasons to give up the fight or keep going).

These examples show how cognitive appraisal of the meaning or significance of an event (Lazarus, 1982), which can be identified by the thoughts people have, are followed by an emotional reaction and behavioural change. Indeed, this sequence is embodied within the basics of Beck's cognitive model of depression (Beck & Rush et al., 1979). Beck proposes that changing thought content affects mood and behaviour. This certainly seemed to be true for the participants in the present study. The most common example given as to how they kept motivated was "thinking positively." When asked how they did this, participants identified a number of forms of cognitive control (e.g. focusing on the positive aspects of a situation rather than the negative). Participants also remembered when they had coped with something similar in the past, used positive affirmation, suppressed negative thoughts, concentrated on something else. Therefore, although a conscious cognitive process (i.e. it was something participants consciously made an effort to do) it was also an effective coping strategy.

The paradigm model allows a clearer delineation of the coping strategies that participants use, and how these are mediated by other action/ interaction strategies and intervening conditions. Many of the intervening conditions consist of factors that are not wholly within the control of the participants (e.g. time spent waiting, change in health status), whereas the action/ interaction strategies and consequences are more controllable. This suggests that action/ interaction strategies would be more amenable to modification. Control over the intervening conditions is more indirect: via the action/ interaction strategies and consequences (as outlined above), and consists of a number of outside influences which would be more difficult to shift (i.e. C9: Attitude and behaviour of others). Indeed, lack of control can result in feelings of helplessness, anxiety and depression (Schwarzer & Fuchs, 1996). Having said this, although it may not be possible to control the intervening conditions *per se*, it may be possible to change the person's appraisal of them, as suggested by Beck et al. (1979). As the paradigm model can help identify possible influences on behaviour, cognitions and affect, it can therefore help clinicians identify where to target client interventions and resources, and at which level.

(ii) Coping strategies identified by previous research

Coping strategies used by LTx patients described by Smolin and Aguir (1996) and Bright, Craven & Kelly (1990) included the use of black humour and gaining support from other patients. Similar responses were noted in the present study within the sub-category: "Strategies used to manage the death of others." The present study also supports the work of Muirhead et al. (1992) whose HTx candidates used humour.

staying positive, belief in God, and distraction, as coping mechanisms. In a Scottish study, Kaba & Shanley (1997) described the coping mechanisms used by HTx recipients. Their study sample were found to use more passive coping strategies (e.g. watching television, belief in luck, waiting for problems to disappear) than the American normative sample. Some participants in the present study were quite fatalistic on one level (i.e. making comments such as "*that's the name of the game*" (Int. 4), or that there was nothing they could do about it (i.e. dying) which could be seen as passive appraisal. However, they also used other coping strategies (such as positive self-talk) with, apparently, good effect.

Another study which examined the relationship between types of coping and psychological distress, provides more insight into adaptive versus maladaptive coping mechanisms and the consequences of each (Zabalegui, 1999). The author describes five types of coping strategy used by terminal cancer patients undergoing chemotherapy: "seeking and using social support (e.g. information seeking, seeking emotional help); behavioural escape-avoidance (e.g. risk taking behaviour, smoking, alcohol consumption, taking stress out on others); cognitive escape avoidance (e.g. wishful thinking, wishing problems would all go away); distancing (e.g. minimising significance of the stressor, not thinking about it, keeping objectivity); focusing on the positive (e.g. positive re-framing, changing as a person in a positive way, re-evaluating what is important in life)" (Dunkel-Schetter & Feinstein et al, 1992, cited in Zabalegui, 1999, p. 1512). Zabalegui (1999) found that lower levels of psychological distress were associated with more positive thinking and distancing. This was especially noticeable if patients sought more social support. More distress was observed in those who used escape-avoidance strategies (cognitive or behavioural).

In the present study, participants used a number of adaptive coping mechanisms as reported in Zabalegui's study. In the conceptual category: "Fighting to survive versus giving up" it was notable that a common cognitive strategy was positive thinking. However, negative thinking was also a risk, especially if health deteriorated. Other methods of positive re-framing used by participants are exemplified in the conceptual category: "Change in self." This included: re-evaluating life as to what was really important (e.g. friends and family), becoming more "*laid back*" (Int. 7), seeing life as precious, and looking back on life and being appreciative of it. In addition, the sub-category; "Taking physical action" involved distraction, or distancing activities (e.g. watching football, computers, listening to music) in order not to think about their situation. Both positive thinking and distraction helped to counteract negative mood states.

The notion of distancing as a positive coping strategy seems to be at odds with the suggestions by Kaba & Shanley (1997). They propose that some of these activities

(e.g watching television) are passive appraisal coping responses and increase psychological distress. However, the participants in this study found benefits in using a number of different coping mechanisms and, perhaps, different coping strategies are beneficial at different times. Another positive coping strategy identified by Zabalegui (1999) was the seeking of social support. In the conceptual category: "Interaction with others" (sub-category: "Expressing to others how you feel and being heard"), participants often found it difficult to discuss their feelings with close family/partners for fear of upsetting them. Most support came from other patients with CF. This seems to be in line with Kaba & Shanley's (1997) study. They found that HTx recipients scored slightly lower than a normative American sample on gaining social support and that there was potential to lose social contacts pre-Tx as illness increased. Indeed, in the conceptual category "Change in self" (sub-category: "Normalisation strategies") participants began to isolate themselves from their healthy peer group or found themselves being isolated as health deteriorated (see conceptual category: "Interaction with others").

However, potential for social isolation from healthy peers does not appear to be restricted to those whose health is deteriorating. Some of the participants in the present study discussed how they coped with their illness when they were younger, before they were accepted onto the Tx list. Some tried to hide their illness and maintain a normal image (see Conceptual category: "Change in self: normalisation strategies"), whilst others were more open. In a qualitative study, Admi (1995) found that adolescents and young adults with CF were more likely to tell someone about their illness if that person also had a health problem, that they minimised the seriousness of their condition, rarely discussing their fears or life expectancy, but that keeping oneself physically isolated from healthy peers was rare. The other person asking questions about their illness was seen as being interested and eager to listen. However, like the participants in Admi's study whose disclosure was dependent on timing and mood, those in the present study stated that they did not often want to talk about CF. In particular, some did not like to talk about their fears of death as this was felt to be too depressing. In the present study this was more applicable to the male participants. Indeed, Strauss and Wellisch (1981) found that only 25% of males with CF in their sample talked about death, whereas 66% of the women did. In line with this, Cowen et al. (1984) found that age was an important variable in social adjustment for patients with CF, with social concerns increasing over the age of 23. They suggest that this is due to increasing anxiety about death as they age, making them wary of initiating relationships as they don't know how long they will survive, concern about upsetting others if bonds are formed, and uncertainty about disclosure of illness. Indeed, these concerns were mentioned by three participants in the pre-Tx group in regard to forming

relationships (conceptual category: "Interaction with others"), although tended to be shrugged off as not being important at the present time.

One form of social support seeking is the eliciting of information. Participants in the present study found that "Sharing information between patients" (C5) not only increased their knowledge of the Tx process but was also emotionally supportive. Interestingly, this contrasts with Strauss and Wellisch's (1981) study in which other patients with CF were considered the least valuable information source. Information seeking has already been discussed in relation to the conceptual category: "Medical management" (see Section 6). However, Van Der Molen (1999) suggests that information seeking is also seen as a coping strategy in patients with cancer. Gaining information is a form of "cognitive control" (Van Der Molen, 1999, p. 239) in that information is needed to make decisions, to appraise situations, and to evaluate potential harm. Information seeking is part of problem focused coping and can help control difficult emotions (emotion focused coping). Emotion focused coping strategies include denial and attribution of blame (Van Der Molen, 1999). Most of the strategies used by the present participants seem to have involved problem focused coping (e.g, facing problems, learning from experience, distraction, positive thinking), although some emotion focused coping strategies was also observed in a few participants who articulated anger (i.e. towards the medical profession, God, the CF Trust).

(iii) Models of coping with illness

In the present study, "Coping with living and dying" was identified as the central phenomenon of the paradigm model. As one of the research aims was to construct a theoretical model of the processes involved in the experience of LTx for patients with CF, I have examined coping models that are already in use in the health field which can help explain, and support, the present findings. I am therefore going to discuss three in relation to the results of the analysis. These are the most well known of the health coping models and also seem very accessible for clinical practice. These are the models of: a) Levanthal, Meyer, and Nerenz (1980; Ogden, 1996); b) Lazarus and Folkman (1984); Folkman and Lazarus (1988); c) Moos & Schaefer (1984; Ogden, 1996).

(a) Levanthal's self-regulatory model of illness behaviour

Levanthal's self-regulatory model of illness behaviour (1980) is a problem-solving model based on the notion of people as self-regulators, so that when they encounter a problem they constantly try and re-establish normality. The model focuses

on three main areas which are interactive: 1) Interpretation of illness symptoms or diagnosis involves a search for meaning resulting in emotional change; 2) Identification of coping strategies. These are divided into approach coping (e.g. taking action, gaining emotional support), and avoidance coping (e.g. denial, minimisation); 3) The third stage involves appraising, and revision of, the coping strategies used.

Findings from the present study suggest that participants did try to establish a sense of normality and expressed the desire to be able to lead a "normal" life. Participants also made attributions as to reasons their health began to deteriorate (e.g. going on holiday against the doctor's advice, relationship breakdown, poor medical care). Participants' coping strategies included both approach and avoidance. However, most of the sub-categories in the action/ interaction strategy component of the paradigm model are approach strategies (e.g. positive thinking and self-talk (C7), information seeking behaviour (C5), taking physical action (C7)). Avoidance strategies were observed more in the early stage of the Tx trajectory. Responses suggested that participants appraised their coping mechanisms and altered them if they were deemed to be ineffective. For example, three participants altered their spiritual beliefs over time and in response to their health state. However, Leventhal's model cannot explain certain behaviours (e.g. consistent use of maladaptive coping strategies that do not return the person to a state of equilibrium, self-destructive behaviour, or non-compliance). Moreover, it would seem that it is the individual's perception of normality that is important in self-regulation, and that this may shift over time, especially in a chronic illness such as CF.

(b) Lazarus and Folkman's (1984) model of how people cope with stressors

Similarly, Lazarus and Folkman (1984) and Folkman and Lazarus (1988) emphasise two types of coping which bear similarities to that described by Levanthal et al. (1980). These are: problem focused coping and emotion focused coping. This has already been discussed briefly in section 7 (ii) in relation to the work of Van Der Molen (1999). It was also used as the framework for Zabalegui's (1999) study on coping in cancer patients.

Lazarus and Folkman (1984) propose that if a situation is appraised as being manageable then problem focused coping is usually chosen. If it less manageable, as in the case of end-stage CF or terminal illness, then emotion focused coping is often used. Both aim to minimise stress: problem focused coping by controlling the stressor (e.g. by actively seeking information: C5) and emotion focused coping by controlling the emotional response engendered (e.g. by minimising their illness: C1). Participants seemed to use both emotion focused and problem focused coping together. For

example, some used emotion focused coping to deal with the death of others (C2: Closeness of death) (e.g. they were dismissive, did not think about it, or used humour) whilst, at the same time, they used problem-focused coping (e.g. saying good-bye in order to reach some form of closure). The model does not imply that one form of coping is better than another, but that different types of coping strategies may be affective at different times. However, it seems difficult to partial out emotion focused coping from problem focused coping, especially if both are being used together. For example, is distancing ones self from the illness (e.g. by watching football or playing computer games: C7) problem focused coping, emotion focused coping or both?. It deals with the problem of negative thinking (about the illness/Tx) but it also changes the emotional response. The division between coping strategies may therefore be more blurred than the model suggests.

In the stage models of death and dying, described in section four of this chapter, an initial typical response to bad news is an emotional one: shock, disbelief, numbness, denial, followed by anger, and depression (e.g. Kübler- Ross, 1970). Re-gaining meaning in life, fighting the illness, and making the most of time left come later in the dying trajectory and are problem focused strategies. In support of this is a study which evaluated patients' experiences of stoma surgery for cancer. It was found that emotion focused coping was evident in the initial post-operative phase, but that problem focused coping (e.g. seeking help) was used more at three month follow up (Clayden, Madill & Fielding, in press). This is also in line with the present research as regards being told of the need for Tx. However, it is uncertain if emotion focused coping was in use in the immediate post-operative phase as participants were not interviewed in this time period. Those interviewed at four months seemed to be using mainly problem focused coping (e.g. planning career, education, re-gaining social contacts, compliance with medication).

(c) Moos and Schaffer's (1984) Crisis theory

In contrast to the models cited above, Moos and Schaffer (1984) describe a model in which illness is seen as a crisis due to changes in identity, circumstances, role, social interaction, and future prospects. In the present study, the turning point seemed to emanate initially from the sudden closeness of death and the lack of time left. Deteriorating health resulting in changes to their role (e.g. as employee), and change in social interactions (e.g. less able to socialise due to ill health) added to the crisis over time.

Moos and Schaffer (1984) describe three mechanisms which make up the coping process: cognitive appraisal, adaptive tasks, and coping skills. Cognitive appraisal involves an individual's perception as to how serious their condition is and

what the outcome will be. The adaptive tasks describe conditions that the person needs to cope with (e.g. pain, the hospital, treatment, emotions, change in self, hospital staff, social and family relationships, unpredictable future). These conditions are similar to the intervening conditions in the paradigm model developed in the present study (e.g. medical treatment within the system, communication style and attitude of health professionals, surgery) that impact upon the coping strategies that participants used. The coping skills are similar to those identified by Lazarus and Folkman (1984), Folkman and Lazarus (1988) and Leventhal et al. (1980). Moos and Schaffer (1984) propose that a person who is faced with illness has three tasks that are illness specific and four general tasks. The illness tasks are: coping with pain and illness symptoms, being in hospital, and interaction with health workers. The general tasks are: maintaining emotional equilibrium, maintaining a positive self image, maintaining relationships, and preparing for future uncertainties. The illness tasks are exemplified in the conceptual category "Medical management" (e.g. coping with the medical regime and decreasing lung function, coping with differences between the CF unit and the Tx centre, interacting with staff in the Tx centre). The general tasks can be incorporated into the central phenomenon of the paradigm model in the present study: "Coping with living and dying" involves living with a terminal illness and an uncertain future. The way that people manage these core tasks is by use of coping strategies. These processes are contained within the action/ interaction strategy component of the paradigm model, mediated by the intervening conditions. Moos and Schaffer's (1984) model and the paradigm model therefore appear to be very similar offering confirmation of some of the findings of the present study.

7. Summary

The aim of the present research was to explore the experiences of adult LTx candidates with CF. The focus was on the psychological mechanisms involved in the LTx trajectory, in order to construct a theoretical model of these processes. In addition, I proposed to identify areas of research that may have been omitted by previous studies. The theoretical model was structured upon the paradigm model (Strauss & Corbin, 1998) as this seemed to be a useful way to conceptualise the data. The most significant psychological variable identified was "Coping with living and dying." This was identified as the central phenomenon in the paradigm model. The other sub-categories were either causal conditions, intervening conditions, action/ interaction strategies, or consequences which were aimed at managing the phenomenon, or a consequence of them.

The most important findings to emerge were as follows: "Coping with living and dying" was the central theme of participant's experience, in response to

having end-stage CF and needing a LTx. The conceptual category "Perception of health status" was the first step on the Tx trajectory. Two of its sub-categories: "Believing that they are not that ill" and "Shock and disbelief when the gravity of the situation is realised" were identified as being causal conditions in "Coping with living and dying." These responses were the first in a chain of events on the Tx trajectory and the first realisation that death was close. The way that participants coped with this was mitigated by the intervening conditions, especially "Medical management," "Thoughts about their own death," and "Awareness of time." Coping mechanisms were considered adaptive or maladaptive depending on the consequences and were revised accordingly. Coping strategies include appraisal-focused coping, incorporating cognitive mechanisms, emotion-focused coping, and problem-focused coping. The most common coping strategies were positive thinking and self-talk, physical action (e.g. distraction), and comparison with others. Defensive denial and minimisation were also common appraisal-focused coping responses. However, the term "denial" is often over used and does not adequately explain the experience of participants as most were realistic about the final outcome of CF and LTx.

One of the consequences of the action/interaction strategies was emotional change. Pre-Tx, the most notable effect was one of ambivalence. Post-Tx, it was initially anticipation. Later in the Tx trajectory, fear of what the future might bring seemed to occupy some Tx recipients so that there was an increased sense of time awareness and potential for depression if medical complications developed. Indeed, "Time running out" and pre-occupation with time left seemed particularly salient to many post-Tx participants, especially as Tx milestones approached. Timing was of more consequence pre-Tx, in order to extend life. Awareness of time is an important issue in coping with terminal illness which appears to have been overlooked in the research literature in favour of a focus on death and dying.

There are many similarities between the findings here and research on cancer patients and those with other terminal illnesses. This is not only in regard to the type of stressors experienced, but also to how people cope with those stressors. This is exemplified by the three health models of coping examined in the former section. The crisis theory described by Moos and Schaffer (1984) is particularly pertinent.

8. Limitations of the study

(i) Shortcomings of the present research

The aim of this study was to use grounded theory to explore the experiences of adults with CF who were in the LTx trajectory. I conducted fifteen interviews with LTx candidates and recipients, although it was only possible to follow one participant through from pre to post-Tx. Much of the past research on LTx patients has been

cross-sectional in design due to the low number of LTx's being performed, and the death of patients before a Tx becomes available. This was also applicable to the present study. Although it would have been enlightening to follow more participants through the LTx experience this was not possible. Instead, Tx recipients gave retrospective accounts of their experiences pre-Tx. Retrospective accounts can be problematic in that time and experience can distort memories. Therefore, this is not an ideal way of data gathering. Having said this, it appeared that Tx recipients could recall in vivid detail certain aspects of the Tx experience and in general, their retrospective accounts were very similar to those in the pre-Tx group.

Participants were drawn from one CF unit in the local area although not everybody was attending the same Tx centre. Although I would expect some differences between CF units and Tx centres across the UK, I would not expect differences to be vast due to similarities in medical care. This research cannot, however, be generalised outside of the UK due to differences between health care systems.

In order to situate the sample, participants completed the CFQoL questionnaire (Gee et al., 2000) which is a recently developed measure of QoL and one of the few applicable to the CF population. Unfortunately, not all participants were able to complete the questionnaire due to time constraints, or they had only just completed one for the participating hospital and did not want to fill out another form. Only ten questionnaires were therefore available for analysis. Inspection of the means suggested that participants' responses mirrored their interview responses. This provides further credibility to the findings of the analysis.

However, triangulation of data would have increased credibility further (e.g. by interviewing partners, staff). This was not possible within the time and space constraints of this study but it is interesting that the findings of the analysis bear many similarities with the experiences of LTx candidates in the USA, as described by Craven, Bright and Dear (1990) and Smolin and Aguiar (1996).

In retrospect, I would also have used another measuring instrument in order to identify depression and anxiety. This would have been interesting in comparison to the content of the interviews and QoL questionnaire. However, most of the interviews were very long, and participants were already being asked to complete one measuring instrument so additional information was not gathered.

One of my concerns was that the emergent themes would mirror the interview questions. Although this was inevitable for a few of the sub-categories (i.e. "Hopes and expectations for the future" and "Attitude and behaviour of others) these are in the minority. In general, the interview format was only loosely adhered to as the majority of participants were very spontaneous and needed little encouragement to talk about

their experiences. Ideally, a more extended pilot study would have been beneficial, from participants both pre- and post-Tx, in order to refine the interview schedule further and to develop my interview style. However, this was not possible due to the limited number of potential participants, especially those in the pre-Tx group.

Strauss and Corbin (1998) recommend that data gathering and analysis be done hand in hand for reasons of theoretical sampling and to follow up interesting themes. Although this would have been ideal it was not possible. Participants were ill and their future was uncertain. It was therefore necessary to gather the data when they were well enough. In addition, the time taken to transcribe each interview would have made the research process very slow, if not impossible. Having said this, interesting leads could be followed up (e.g. with regard to beliefs) as memos were written after each interview.

In addition, it would have been illuminating to take the model back to a few participants to gain their comments and criticisms. However, it was decided not to do this. As the analysis was an over view of all the participants' experiences, it would not necessarily coincide exactly with the views of one or two participants. Moreover, as the analysis centred upon death and dying, taking this back to participants could have been potentially distressing for them.

(ii) Limitations of the paradigm model

The paradigm model as described by Strauss and Corbin (1998) is a way of structuring data around a central phenomenon. I found this method particularly useful in the present study as it enabled the process of participants' experiences to be described coherently. However, at first I found it difficult to decide where each sub-category should be placed within the components of the model. This was because some sub-categories contained both intervening conditions and action/ interaction strategies. In addition, the action/ interaction strategies were a consequence of the intervening conditions. One of the consequences was also an action strategy (e.g making decisions). "Emotional changes," which have been included under consequences, could also be considered an intervening condition as emotions impact upon the way that people cope. "Believing that they are not that ill" and "Shock and disbelief when the gravity of the situation is realised" have been included under causal conditions as these concepts had an influence upon the phenomenon, "Coping with living and dying." However, they could also be considered intervening conditions, influencing the coping strategies that participants used (e.g. affecting "Coming to terms with life and the possibility of early death"). A decision therefore needed to be made as to where the sub-category fitted best. In the final analysis, researchers must make decisions as to where meaning units fit best conceptually which can be especially

difficult if there is overlap between categories. However, being "forced" to delineate sub-categories in this way was, in some ways, artificial and limiting. I was also reluctant to force the model onto the data and feel that this has been avoided as far as possible.

Indeed, Glaser (1992) has criticised the concept of the paradigm model as being over prescriptive and complex, suggesting that there are other ways that structure and process can be incorporated into a model. He states: "to use this model out of hand will merely give the appearance of making the analyst think systematically about data ... In actuality it teaches the analyst to force a full conceptual description on data with no questions about whether the links are relevant to any emerging theory that really explains how the participants process their main concerns" (Glaser, 1992, p. 63). In the present study the data appeared to fit the paradigm model well, barring the difficulties outlined in the former paragraph, and was found to be a useful tool for the structuring of participants' experiences. Moreover, the categories emerged before it was decided how the model would be structured, rather than the analysis being undertaken with the paradigm model in mind. In addition, the paradigm model may be especially useful for clinical practice as it enables clinicians to focus their interventions whilst taking social context and environment into account (e.g. the causal and intervening conditions provide context. The action/ interaction strategies indicate processes used to cope with the phenomenon, "Coping with living and dying," and can suggest which strategies may need to be enhanced or altered).

(iii) Evaluation of qualitative research

Due to the recent growth in qualitative methodology in psychology, Elliott, Fischer and Rennie (1999) have published guidelines for its evaluation. They suggest that the guidelines are proposed in order to sanction qualitative research, to encourage more scientific evaluation of qualitative research, and for reasons of quality control. I have therefore used these guidelines to review the present study.

1. *"Owning one's perspective"*

In Chapter Two (Section Two) I have described my personal orientation and how this influenced the analysis. As my interaction with participants was central to information gathering I have also written in the first person.

2. *"Situating the sample"*

In Chapter Two (Section Six) I have described the sample demographically and also reported the results of the CF QoL questionnaire. The findings in this study can therefore be contrasted with the questionnaire means.

3. "*Grounding in examples*"

In the Methodology Section (Chapter Two; Section Eight) I have provided verbatim quotes in order to illustrate how the analysis was conducted.

4. "*Providing credibility checks*"

In the Methodology (Chapter 2: Section Nine) I have described the two methods which were used to increase credibility. Credibility checks (matching quotes with conceptual categories) were provided by another clinical psychology trainee. The CF QoL questionnaire was also compared with the content of the analysis. Use of supervision is also deliberated.

5. "*Coherence*"

Categories have been organised into two frameworks. In Chapter Three (Diagrams 1 and 2), Diagram 1 clarifies how the conceptual categories link. In Diagram 2, the sub-categories are integrated into the paradigm model, depicting structure and process. Moreover, the analysis centres around one core category/ one central phenomenon.

6. "*Accomplishing general versus specific tasks*"

The research is specific to adult LTx candidates and recipients with CF in the UK population. As far as was possible, in each group of participants there was an even spread of gender and age. This is described more fully in the Methodology Section. Limitations of the study are discussed in the current chapter (Section Nine)

7. "*Resonating with readers.*"

In the Results and Discussion Section of this thesis (Chapters Three and Four) I have tried to convey the experiences of participants accurately and bring their experiences to life. In order to do this, and to enhance the credibility of my findings, I have used verbatim quotes from the interviews.

9. Suggestions for future research

During the literature search for this project, no published qualitative accounts of the experience of patients undergoing LTx were found. In addition, few quantitative psychosocial studies appear to have followed up LTx recipients for any length of time. These areas therefore require further examination.

The present research has identified a number of areas that warrant further investigation and which seem to have been overlooked in previous studies. First, research is required on how the timing of Tx surgery affects patients. Many

participants were very concerned that they would get a Tx too early and, although they had agreed to a Tx, tended to remain indecisive until health deteriorated markedly. Secondly, post-Tx patients need to be followed up for longer periods of time, and over time. This study indicates that Tx recipients may be more vulnerable psychologically as the five year Tx milestone is reached. Indeed, time anxiety in itself, and the clinical implications of this, need to be better understood. Thirdly, the Tx trajectory needs further investigation. Although the findings of the present research have added to it, research that focuses specifically on this area would be beneficial. In order to do this patients need to be followed prospectively, although this would be difficult to achieve. Fourthly, participants' responses suggested that some of them found the Tx assessment difficult and that they had problems in adapting to the environment of the Tx centre. Little research appears to have focused on the way that Tx centres are organised and run, how they compare to CF units, and the effect that this can have on the well-being of the patient. It would be interesting to compare the differences between the Tx centre and CF unit in more detail, including interactions of staff and patients, and to elicit patients' views so that any difficulties could be addressed. Finally, qualitative studies looking at the coping of partners and families and staff and the interactions of this with patients' coping patterns would be illuminating and add further depth to the research initiated in the present study.

10. Clinical implications

The paradigm model, developed from the analysis of data collected in the present study, can help clinicians target possible areas of difficulty for patients. It can also provide insight into how patients may respond under certain conditions, the type of coping strategies used, and suggest ways in which coping skills can be enhanced or made more adaptive. For example, if it is established by careful enquiry that a patient's contact with non-CF friends has decreased, this may alert clinicians to possible difficulties and suggest intervention strategies. Anticipating difficulties in the transition from the CF unit to the Tx centre can guide health professionals as to appropriate information to impart. Awareness of the difficulties that patients may have in discussing their feelings about Tx with significant others, and the possible consequences of this, may suggest to clinicians that emotional support may need to be gained elsewhere, or that families and partners need to be included more in the Tx process.

Moreover, health professionals need to be alert to the fact that death anxiety can increase over time, especially coming up to five years post-Tx, and yet contact with health professionals, and other CF patients, will have decreased. Initially this can feel strange for some Tx recipients as the CF unit has been such a big part of their lives for

so long. This can also make it difficult for them to mobilise support when needed, especially if they feel unable to talk to significant others. Indeed, as participants expressed reluctance to relate their deepest fears to close family, partners, or friends this can mean that they may be left alone to deal with their own fears. People around them believe that they should be embracing their "second chance at life" not realising, or understanding, the anxiety and fear that is not able to be expressed. Thus, health professionals need to be alert to these factors and make time available to give support during clinics for these very important issues.

For patients in whom depression could be confused with the symptoms of physical illness (e.g. fatigue), by both the patient and the doctor, it is suggested that careful screening be undertaken according to DSM IV criteria. Guidelines differentiating between physical illness and depression include sleep difficulties not attributable to pain, persistent low mood, hopelessness, guilt, low self-esteem, desire to die, poor symptom control and excessive and unusual complaints of pain or other symptoms (Billings, 1995; Lynch, 1995). Although depression can be considered a normal response to terminal illness (Kübler-Ross, 1970), it is recommended that anti-depressant medication be prescribed, if in doubt, in order to help improve QoL (Billings, 1995; Lynch, 1995).

The causal conditions that led to the phenomenon: "Coping with living and dying" included shock and disbelief when told of the need for a Tx. This was even when participants were aware of the ultimate outcome of CF. This suggests that having awareness of a shortened life does not alleviate the feeling of devastation as health deteriorates. Although some were aware that they would need a Tx one day, it was still a shock that it was happening now, and to them. Perhaps information regarding Tx needs to be introduced much earlier, and made more explicit so that the process of realisation is a more gradual one.

Believing that they are not that ill is also a causal phenomenon as it placed participants further along the continuum, in their minds, towards leading a full and active life. This in itself appeared to be a useful defensive coping strategy that was maintained for some time after they were told that a Tx would be required, and allowed them to keep a sense of normality. Whilst beneficial at one level, it also meant that participants were reluctant to have a Tx too early, and this worry about timing caused quite a lot of distress. Therefore, timing of Tx, and what this would mean for the patient, also needs to be addressed early on.

The intervening conditions that were most pertinent in influencing coping strategies was the conceptual category "Medical management" and the sub-categories "Thoughts about their own death," and "Time running out" (conceptual category "Closeness of death"). "Communication style and attitude of health professionals"

and "Medical treatment within "the system" were especially relevant to the way that participants felt about their medical care. Whilst many were happy with this aspect of their care, there were a significant number of participants who were less than complimentary about the Tx centre. This suggests that many health professionals need to look at their practice and communication style with patients. Time spent with patients, a professional yet caring manner, a sense of humour, taking time to do things, making them feel welcome on the ward, and being empathic were all seen as important.

Part of the difficulty appeared to be the difference between the CF unit where participants felt safe and comfortable, and the Tx centre where the set up was different, possibly higher paced in some respects, where they did not know the staff and where they have less personal control. Staff in the Tx centre can help patients regain a sense of autonomy by a number of strategies, for example, allowing patients to decide when they will have their blood taken and by whom. Although there would be organisational issues to address, it is not out of the bounds of possibility that this could be done. Information as to the differences between the two hospital set-ups may also need to be discussed with patients prior to Tx assessment. A useful tool may be a video tour of the Tx centre, and ICU, including interviews with staff and LTx patients with CF who are "on site." Information also needs to include how it might affect them psychologically, how it might feel to be on a Tx unit (both for assessment and surgery), aspects of it that they might find frustrating, or frightening, as well as other kinds of factual information.

Ways of conveying "bad news" have already been discussed (under "Medical management"). Most participants were fairly happy with the way that they were told about needing a Tx or were unsure how it could be improved. However, previous research suggests that medical staff need training in this area although it is often included in current medical training (e.g. Bennett & Alison, 1996).

"Thoughts about their own death," "Dealing with the death of others with CF," "Timing" of Tx, and "Time running out," had major implications for the psychological well-being of participants. Fears were also heightened for some participants in the initial post-operative phase (i.e. in ICU), when leaving ICU (if they had been there a while), and when leaving the safety of the hospital to go home after surgery. Tx candidates and recipients found that staff at the CF unit and other patients with CF were good forms of emotional support but a few felt that staff needed to ask the right questions for them to be able to express their emotion. The implications of this for staff is that they need to be aware of the major anxieties of LTx patients and when these concerns may arise throughout the Tx trajectory. They also need to be cognisant of the fact that patients may need to be "drawn out" and that they may put on a brave face for others in order not to worry them, or because they wish to be seen as a "fighter" or

"coper." Availability of a professional counsellor or clinical psychologist may also be beneficial and help reduce the emotional burden on staff.

In summary, the findings of the present study have helped highlight areas of importance for LTx patients with CF, at different stages in the Tx trajectory, the way in which patients cope, and the outcome of their coping mechanisms. It also suggests where professionals can intervene when patients are experiencing difficulties, and times at which they may be particularly vulnerable. Although LTx is a very difficult process to go through, none of the Tx recipients interviewed regretted their decision to have a Tx, even if they had been beset by complications. Most saw themselves as positive people who were coping as well as they could with a difficult situation.

11. Conclusion

The present study has contributed to the understanding of the experiences of adults with CF who are in the LTx trajectory. Most of the previous research in the area has focused on psychopathology and QoL using quantitative methodology. In contrast, this study is qualitative in design using grounded theory which is a systematic and rigorous method of analysis. One core category: "Coping with living and dying" emerged from the data analysis which subsumed all the other conceptual categories. However, the conceptual categories do not link together in a hierarchical fashion. Rather, "Coping with living and dying" is the back drop to the whole of the participants' experiences. The dynamic aspects of the participants' experiences have been conceptualised within the paradigm model which identifies both structure and process. Coping was not focused on explicitly in the interview schedule, except via prompts (e.g. how did you deal with that? what did you do?) and therefore arose unexpectedly.

In addition, "Closeness of death" and "Awareness of time" also emerged spontaneously and were central themes in the participants' experience. The concept of time, as opposed to dying *per se*, seemed of particular significance and a source of distress. This research has also contributed to, and extended upon, the Tx trajectory outlined by Worby and Smith (1997) and Worby (1998). It has highlighted areas for future research, and outlined the clinical implications of findings.

"The secret of a man's being is having something to live for"

(Doestoevsky)

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Appendix 1

Ethical approval

ST JAMES'S UNIVERSITY HOSPITAL

REGIONAL NEONATAL INTENSIVE CARE UNIT

Secretary Ext 65382
Our Ref: PRFD/JK

5 November 1999

Dr A J A Duff
Clinical Child Psychologist
Dept of Clinical & Health Psychology
Ashley Wing Extension
St James's University Hospital

CONSULTANTS

Dr P R F Dear
Dr S J Newell
Dr S J Thomas

Dear Alistair

Re: Experiences of young adults with cystic fibrosis, pre and post-lung transplantation: a qualitative study

Thank you for sending me the protocol and patient information sheets for this study. I am happy for you to proceed as planned without the need for a formal submission to the ethics committee. I think that the patient information sheet is quite good and I understand that you will be in a position to provide psychological support to any subjects who become distressed by their involvement in the project.

Yours sincerely



DR P R F DEAR MD FRCP
Consultant and Senior Lecturer in Neonatal Medicine

Appendix 2

Participant information sheet

DOCTOR OF CLINICAL PSYCHOLOGY COURSE

From the School of Medicine
Division of Psychiatry and Behavioural Sciences
in Relation to Medicine



15 Hyde Terrace
Leeds LS2 9LT UK

Fax 0113 243 3719
Telephone 0113 233 2742/2732
Direct line 0113 233 + extension nu

INFORMATION FOR RESEARCH PARTICIPANTS

Researcher: Janet McCarthy
Address: Division of Psychiatry and Behavioural Sciences
in relation to Medicine and School of Psychology
University of Leeds.
15, Hyde Terrace
Leeds, LS2 9JT

Telephone: C/o Carol Sloman (Department Secretary)
0113 233 2732/ 2742

Dear

You will recently have received a letter from Dr. Conway about some research that I am undertaking at Seacroft Hospital in the field of transplantation. Although Dr. Conway gave you some brief information, this sheet gives you a bit more detail about the project so that you can decide if you would like to participate.

I am a Psychologist in clinical training at the University of Leeds. As part of my training I am carrying out a research project looking at the experiences of people with Cystic fibrosis who have had a lung transplant or who are waiting for one.

This research is subject to ethical guidelines set out by the British Psychological Society. These guidelines include principles such as obtaining your informed consent before research starts, notifying you of your right to withdraw, and protection of your anonymity. This sheet will hopefully provide you with enough information about the study to allow you to make an informed decision about participation. However, if you have any questions or would like to discuss anything, please do not hesitate to contact me.

I am approaching you as a potential research participant as you have undergone a transplant or are on the waiting list for one. I am interested in your experiences of transplantation, and how it has affected your life. This would entail interviewing you, somewhere you feel comfortable. I would anticipate the interview lasting for about an hour. However, as long as you are happy, the interview could last much longer.



If the length of time of the interview would be a problem for you, it may be possible to carry it over two sessions. The interview will be conducted sensitively and I hope that you will feel comfortable talking about your transplant with me.

I will need to audio-tape the interview in order to study the information you give me. The tape will be typed up into a transcript to help me do this. However, you will remain anonymous as I will change any identifying names or places that are mentioned. The tapes and transcripts will be kept in a secure place and given a code number to maintain your anonymity. I might want to use extracts from the transcript in a report of the research. These reports could include presentations at academic conferences and articles in academic journals. However, again, no-one would be able to identify you from these extracts and at no point will your identity be divulged. Your decision to participate, or not to participate, in this study will not effect your medical care in any way.

Over leaf is a consent form. This gives your consent to participate in the research. You are free to withdraw your consent AT ANY TIME. Just because you have signed the consent form, does not mean you can't change your mind. It also does not commit you to any thing you do not wish to do. Thank you for considering to take part. I will be contacting you again by telephone. I hope this is all right with you.

Yours sincerely

Janet McCarthy
Psychologist in Clinical Training

Contact phone numbers

Contact phone numbers

Following our talk there may be some issues that were raised that you may have found distressing. If you would like to talk to anyone about the issues raised then the people listed below are more than happy to be contacted.

Dr. Steve Conway - Consultant physician, Seacroft Hospital (You will already have his phone number)

Dr. Christine Etherington - Clinical Specialist. Christine can be contacted at the CFU, Seacroft Hospital or, if out of hours, on her mobile phone which is **0802 591611**.

Dr. Alistair Duff - Clinical Psychologist. Phone **0113 233 2732/ 2742** (c/o Psychology Department Secretary, Carol Sloman, Mondays and Fridays 9.00 to 5.00pm. From Tuesday to Thursday, 9.00 to 5.00pm. Alistair can be contacted at the Psychology Department, St. James's Hospital. The phone number of the department is **0113 2065897**.

Appendix 4

Consent form

**LUNG TRANSPLANTATION IN ADULTS WITH CYSTIC
FIBROSIS: A QUALITATIVE ANALYSIS.**

Thank you very much for agreeing to take part in my research. The purpose of this form is to make sure that you are happy to take part, and that you know what is involved.

1. Have you had the opportunity to ask questions and discuss the study?
(Remember, you can ring me to discuss the study if you wish).

YES NO

2. Do you understand that you are free to end the interview at any time?

YES NO

3. Do you understand that you are free to choose not to answer a question,
without having to give a reason why?

YES NO

4. Do you agree to take part in this study?

YES NO

5. Do you agree to the interview being audio-taped?

YES NO

6. Do you grant permission for extracts from the interview to be used in reports of
the research on the understanding that your anonymity will be maintained?

YES NO

Name (in Block capitals) _____

Signature _____

Date _____

Appendix 5

Transcriber's confidentiality statement

Agreement of Confidentiality

I agree to keep all the information on this tape private and confidential. The tape will be heard by myself and the researchers (J. McCarthy, A. Duff and A. Madill) and no others. The tape will be kept secure at all times (e.g. not left in the car).

Signature 

Date 13 / 1 / 00

Appendix 6

Cover letter to participants from the Consultant
Physician

Please reply to Seacroft Hospital, York Road, LEEDS LS14 6UH

Regional Adult Cystic

Direct line: 0113 2063252

Fibrosis Unit

Lead Clinician - DR. S.P. CONWAY

Fax: 0113 2063540

Consultant - DR. D. PECKHAM

Clinical Assistant - DR. C. ETHERINGTON

Telephone enquiries please contact

Mrs J. Hirst ext 62105 /63252

Our Ref: SPC/JH

Date: 15th November 1999

Dear [PATIENT'S NAME]

I am writing to let you know about some work that we are planning to do in the field of transplantation which we all feel is very valuable. We are combining with Dr. Alistair Duff, who works as a Clinical Psychologist in the Paediatric and Adult Cystic Fibrosis Units, and one of his team, Janet McCarthy, in this work.

Although alot of units across the world have looked at the effect of lung transplant on simple things such as shortness of breath before and after transplant, feeling of general wellbeing before and after, exercise capacity etc etc, there are no studies that have looked at deeper psychological adjustments whilst on the waiting list and following transplant. We are hoping to do this over a 1-2 year study, the first year of which Janet McCarthy will interview patients who have had a transplant and those who are still waiting. The interviews will be in a semi-structured way which means that she will open with a question, but then allow you very much to lead the discussion. She will of course be prepared to come and see you at home or wherever it is most convenient for you.

I am sure that this is a very important piece of work and will help us very much to treat patients on the waiting list and patients after surgery in a more productive and understanding way.

I must emphasise to you however that you under absolutely no obligation and under absolutely no pressure to take part in this study. If you don't want to take part in it you just have to refuse and you don't have to give a reason, and it will not in any way affect the way that we look after you or the medical care that you receive. I have however given Janet a list of names and telephone numbers so that she will be able to get in touch with you and talk to you and see whether you are interested in taking part in this study.

I hope that this is OK, and if for any reason you do not want to have a phone call just give myself, Alison or Janet a ring on 0113 2063513 or 0113 2062105 and we will tell Janet McCarthy and Alistair not to telephone you.

Many thanks for your help as always and kindest regards.

Kindest regards

Yours sincerely

DR. S.P. CONWAY

Consultant Paediatrician and Lead Clinician in CF Services
St. James's and Seacroft Hospitals, Leeds

c.c. Janet McCarthy, University of Leeds, Division of
Psychiatry and Behavioural Sciences in Relation to
Medicine, 15 Hyde Terrace, LS2 9LT

Dr. A. Duff, Clinical Psychologist, Paediatric CF Unit,
St. James's Hospital ✓

Cystic Fibrosis Quality of Life Questionnaire

Final version of the CFQoL

The Cystic Fibrosis Quality of Life Questionnaire.

The following questionnaire is designed to find out how CF affects your life. Read each statement, and then indicate which response is closest to how you feel, by ticking (✓) one of the boxes after each statement. Please try to answer ALL the questions, as honestly as you can.

SECTION ONE:

How often, over the last two weeks, do you feel that your CF has affected the following aspects of your physical functioning/mobility?

1. Because of my CF, During the last two weeks, I have had difficulty doing heavy physical jobs. For example, digging, moving furniture, washing the car, vacuuming etc.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
2. During the last two weeks, my CF has prevented me from getting out of the house to run errands. For example, paying bills, posting a letter, doing light shopping etc.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
3. Because of my CF, over the last two weeks, it has been difficult for me to do light tasks around the house. For example, preparing a light snack, washing up, picking up the mail etc.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
4. Over the last two weeks, getting around the house has been difficult because of my CF.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
5. For the last two weeks, CF has made it difficult to move from my bed or my chair.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
6. Despite CF, over the last two weeks I have got around and done what I like.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
7. During the last two weeks, there are places that I would like to have gone but didn't because of my CF.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
8. My CF has limited the type of sports and exercise I have been able to do over the last two weeks.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
9. During the last two weeks, my CF has made me feel lacking in energy.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
10. Over the last two weeks, I have found that my physical functioning and mobility have affected my quality of life by making life less enjoyable.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never

SECTION TWO:

Over the past two weeks, has CF affected your social life in any of the following ways?

11. When I have been out socialising, over the last two weeks, I have behaved more cautiously than I would like to because of my CF.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
12. Because of my CF, during the last two weeks, I have tended to avoid visiting friends.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
13. For the last two weeks, I have avoided going out and socialising because of my CF.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
14. I find that the way in which CF affects my socialising interferes with my overall enjoyment of life.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never

SECTION THREE:

The following questions ask you about symptom and treatment aspects of your CF. How have the following factors affected you over the last two weeks?

15. Over the last two weeks, I have found my treatments (ie physio, enzymes etc) very time consuming.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
16. During the last two weeks, my treatments have interfered with other things that I have wanted to do.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
17. Over the last two weeks, I have found that my treatments have interfered with my enjoyment of life.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
18. I have found my breathlessness troublesome, during the last two weeks.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
19. Over the last two weeks, I have found my coughing troublesome.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
20. I have found my coughing embarrassing over the last two weeks.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
21. For me, over the past two weeks, breathlessness / coughing have made life less enjoyable.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never

SECTION FOUR:

Over the past two weeks, I have found that my CF has made me feel:

22. Resentful:

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
23. Angry:

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
24. Embarrassed:

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
25. Irritable:

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never
26. So fed up that nothing can cheer me up:

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All of the time	most of the time	good bit of the time	sometimes	occasionally	never

Appendix 8

Format of pilot interview

Pilot Interview

Interviews will be conducted using a semi-structured format. This allows the researcher to cover consistent areas of interest with participants while giving the flexibility of following the topical progression relevant to participants' own understanding. I have outlined two interview formats, one for pre Tx and one for post Tx, with different patients in each group.

Pre Tx Interview questions

1. Just to launch us off, perhaps it would be a good idea if you could tell me a bit about yourself and your background.

2. How are you feeling in yourself at the moment?

(How would you describe your physical health and mood in general?)

3. How would you describe your life now?

(How do you spend your day?

How do you anticipate your life changing after the Tx?)

4. How would you describe yourself as a person ?

5. How would other people describe you, do you think?

(e.g. wife/children/parents/friends/medics).

(Prompt: What about intimate relationships. Have they changed at all since you've been on the waiting list? How have they changed / not changed?).

6. Could you tell me about your experiences of waiting for a Tx?

(Did you anticipate that you might need a Tx one day?.

Have you had any false calls?

How did you cope with that?/ How do you think you'd cope with that?

What's helping you most in this waiting period?

What's most difficult?)

7. When you think about the Tx itself, what sort of thoughts run through your head?

(Some people have described having unusual worries and beliefs about transplantation. Do you have any worries and concerns about it?)

Can you tell me about them?

Do you have the chance to talk about your worries with someone, who is not on the Tx team?

Would this be helpful? (In what way?)

8. Could you tell me about your feelings about Tx?

How did you come to be told about the need for a transplant?

Could you describe what took place to me?

How do you feel about the way you were told?

In what way could it have been done better?

Looking back, do you remember what ran through your head at that time?

If you could use one word to describe that initial feeling, what would it be?

What/ who helped you deal with the news?

Was there anything in particular that helped or made things more difficult?

What would be helpful to you at this time?)

9. How do you see the future?

(When you think about the future, what are your expectations?

The speed of CF research is moving pretty fast, but maybe not as fast as we would like. How do you feel about that?).

10. Now that we've had the chance to talk, is there any thing else that you'd like to ask me about the research?

11. Thank you for your time and effort etc.

Post Tx Interview Questions

1. Just to launch us off, perhaps it would be a good idea if you told me a bit about yourself and your background.

2. How are you feeling in yourself at the moment?

(How would you describe your mood and physical health in general?)

3. How would you describe yourself as a person ?

4. How would other people describe you, do you think?

(e.g. wife/children/parents/friends/medics).

(How would have they described you before your Tx?

What about intimate relationships. In what way have they changed/ not changed?)

5. Could you tell me what it was like when waiting for a Tx?

(Did you anticipate that you might need a Tx one day?.

Did you get any false alarms?

How did you cope with that?

How did you cope generally?

What about the final call, when you knew it was really happening?

What was your recuperation like? (e.g. fast/slow).

What were your main feelings when you were being discharged from hospital?

Was there anything in particular that helped or made things more difficult?).

6. How would you describe your life now?

Has your life changed since the Tx?

In what way?

Are there areas in your life you thought would change but haven't?

Did your expectation of change match the reality?)

7. When you think about the Tx itself, what sort of thoughts run through your head?

(How did you come to be told about the need for a transplant? Could you describe what took place to me?

Looking back, do you remember what ran through your head when you were told?

How do you feel about the way you were told?

In what way could it have been done better?

If you could use one word to describe that initial feeling, what would it be?

Some people have described having unusual worries and beliefs about the transplant itself. Did you have any worries and concerns about it?

Could you tell me about them?

What/ who helped you deal with the news?

Did you/ do you have the chance to talk about your worries with someone, who was not on the Tx team?

Would this have been helpful?

In what way?

Do you remember the sort of things you thought about when you were waiting for Tx?

What do you think about now?

8. Could you tell me about your feelings about the Tx?

(What was the worst bit about the waiting process? Were there any good aspects to the waiting?

What were they?

What would have been helpful to you at this time?

How would you have described yourself and your life when you were on the waiting list?

How would you have described your mood in general during that period?

Do you remember your thoughts immediately after surgery, when you woke up?

How do you feel about it all now?

9. How do you see the future?

(When you think about the future, what are your expectations?

What would you like to do with your life in the future?

Is that different from what you thought you'd want?

Do you feel you've changed at all?

In what way?

Looking back, and forwards, would you have made the same decision, to have the Tx?

The speed of CF research is moving pretty fast, but maybe not as fast as we would like. How do you feel about that?).

10. What's helped you most over this time/ What's been most difficult?

11. Now that we've had the chance to talk, is there any thing else that you'd like to ask me about the research?

12. Thank you for your time and effort etc.

Final interview schedule

Final Interview Schedule (adapt for post-Tx participants appropriately)

- 1. How are you feeling in yourself at the moment?**
(Prompt: How are your blows? What treatment are you on now?)
- 2. How long have you been diagnosed with CF?**
- 3. How long have you been on the waiting list?**
- 4. Just to put me in the picture a bit, could you tell me a bit about yourself such as where you were brought up, your living situation now and a bit about your family and friends.**
- 5. If you had to describe yourself, say to a new pen pal. what would you say** (Prompt: How would your best friend describe you / your personality?).
- 6. Would other people describe you in the same way** (Prompt: How do other people see you? e.g. mood, personality).
- 7. How do other people treat you at the moment? Could you give me some examples?**
- 8. How do you think you'll feel about having less contact with the CF Unit and the CF team after your Tx?**
- 9. Can you tell me what its like to be waiting for a Tx?** (Prompt: Have you had any false calls? What was the hardest bit about it? How did you handle that?)
- 10. In your minds eye, what do you expect to happen at Tx?**
- 11. Do you remember when you were told that you would be needing a Tx? Could you describe to me what took place?** (Prompt: How did you react? I wonder what sort of thoughts ran through your mind at the time).
- 12. Looking back, is there any way that the telling could have been handled differently/ better.** (Prompt: In what way?).
- 13. Have you been offered any sort of counselling?** (Prompt: Would that be helpful to you? In what way?).
- 14. How did you come to the decision to have the Tx?** (Prompt: I'm wondering what sort of thoughts ran through your mind).

15. What, or whom, has helped you through this process most?

(Prompt: How? What did they do?).

16. What is your life like at the moment? (Prompt: What's a typical day like?)

Are you working or doing any courses? Have you done that sort of thing in the past?).

17. In what way do you expect your life to change after Tx, if at all?

18. What are your thoughts about the possibility of having someone else's lungs inside your body?

19. How do you see your future?

20. The speed of CF research is moving pretty fast although not as fast as we would like. How do you feel about that?

21. Is there any thing that you would like to tell me that you think is important that I haven't asked about? Is there anything further you'd like to ask me?

Post transplant Interview schedule 2.

1. How are you feeling in yourself at the moment?

(Prompt: Do you still have to do your blows? What are they like at the moment?

What treatment are you on now? If not so well, how are they dealing with this?).

2. How long have you been diagnosed with CF and how long since the Tx?

3. How long were you on the waiting list for?

4. Just to put me in the picture a bit, could you tell me a bit about yourself such as where you were brought up, your living situation now and a bit about your family and friends.

5. If you had to describe yourself, say to a new pen pal. what would you say (Prompt: How would your best friend describe you / your personality?).

- 6. Would other people describe you in the same way** (Prompt: How do other people see you? e.g. mood, personality).
- 7. How would you, and other people, have described you when you were on the waiting list?** (e.g. mood, personality).
- 8. Do you feel different in yourself since having the Tx?**
- 9. Has the Tx effected other people and their attitudes towards you?** (Prompt: In what way? Could you give me some examples?).
- 10. How did it feel having less contact with the CF Unit and the CF team after your Tx?** (Prompt: How has it affected you?).
- 11. Can you tell me what it was like when waiting for Tx?** (Prompt: Did you have any false calls? How did you handle that?).
- 12. What was the hardest thing about the wait?** (Prompt: How did you cope with that?).
- 13. In your minds eye what had you expected to happen at Tx? Was it like you expected?**
- 12. Do you remember when you were told that you would be needing a Tx? Could you describe to me what took place?** (Prompt: How did you react? I wonder what sort of thoughts ran through your mind at the time).
- 13. Looking back, is there any way that the telling could have been handled differently/ better.** (Prompt: In what way?).
- 14. Were you offered any sort of counselling?** (Prompt: Would that have been helpful to you? In what way?).
- 15. How did you come to the decision to have the Tx? I'm wondering what sort of thoughts ran through your mind?**
- 16. What, or whom, has helped you through this process most?** (Prompt: How? What did they do?).
- 17. Could you describe your life now?** (Prompt: Is it very different from your life before Tx? In what way? What's a typical day like for you now? Are you working or doing any courses at the moment? Have you done that in the past? I'm wondering what stops you from doing that now?).

18. Looking back, has your life changed/ not changed in the way you thought it would? (Prompt: I'm wondering if your expectations matched the reality. In what way did having the Tx live up to your expectations or not? Is life better or worse than you thought it would be or pretty much the same? In hind sight would you make the same decision again? (i.e. to have a Tx).

19. What are your thoughts about having someone else's lungs inside your body?

20. How do you see your future? (Prompt: How are you dealing with not being as well as you were shortly after Tx? (should this be the case).

21. The speed of CF research is moving pretty fast although not as fast as we would like. How do you feel about that?

22. Is there any thing that you would like to tell me that you think is important that I haven't asked about? Is there anything further you'd like to ask me?

Appendix 10

Example of a memo

Memo 2 9/3/00 Int 4.

Link with theme of "Coping Strategies"

Coping - acceptance of fate

- fighting

- defenses { denial
repression of emotion
humour

rationalization

avoidance

Minimization.

Coping is very broad & can be active or passive (eg repressing it or not thinking about something). Need to understand more how people put a stop to negative thoughts. Some use distraction, but so far people

seem to say they "just don't think about it" - How? How to thought stop/suith off or do they re-frame positively (eg downward comparison). Compare to cancer victims or people undergoing

other major surgery or with chronic/deathly illnesses. Compare to say how people deal with depression or therapy for depression.

How do they cope if get depressed (→ catastrophic thinking, black & white thinking etc). Do they use similar strategies as ~~that~~ ~~for~~ when dealing with ~~people~~ & with CF? Compare lung Tx for other reasons. / age groups. What happens when people don't cope? Do they

die? Can I see people who don't cope as well. What about people without much family support or support of friends. Those who don't bond with the CF lot - do they use other coping strategies what? Are they different in other ways too?
for - downward comparison - others worse off - ? literature on cancer pts / other illnesses/surgery. (eg a breast)

line 850 - 868

Theme Pride Proud to be alive, having made it to age 33 + 5 yrs post Tx. Compares self to statistics (mentioned often) & to others he knows now & knew at school. Mentions sister also (? link to genes her - strong genes as in survival against all odds/ized gene of CF). Possible feelings of being different from others with CF ("I will survive"). Different as in positive & up & about - "wouldn't stay in the - downward comparison

— (against the sick role)

links with rebelliousness (seen as a true trait) & positive thinking
 (Positive thinking means not thinking about what could happen. Keeping goals - sees himself as a fighter, a beater of the odds - see line 878.
 "Even when I was really poorly, before my Tx, I wouldn't stay in the ward I?" (line 861/862)

Theme

Rebelliousness reminds me of adolescence, of going against the rules, the expected norms (I wanted to feel different). Rebel implies

adventurous, unconventional, someone who will stand up against authority for what they believe. Looking down on others who conform to being in the sick role/give in to their CF. Feels himself stronger, better than them. In dictionary - rebel = non-conformist, defy (his illness?) resistance fighter. Rebelliousness = defiant, disobedient, ungovernable, difficult, incorrigible, resistant, mutinous, recalcitrant, obstinate.

See also line 237 - 254 - Maintaining feelings of self worth, rebellious role in life

Appendix 11

Validation exercise

Check of category meanings: 21. 05. 01

C1. Perception of health status:

Thinking they are not that ill
Shock and disbelief when the gravity of their situation is realised
Health monitoring

C2. Closeness of death:

Thoughts about their own death
Strategies used to deal with the death of others with CF

C 3. Awareness of time:

Timing
Time running out
Time spent waiting

C4. Medical management:

Medical treatment within "the system"
Communication style and attitude of health professionals
Feelings about the operation itself

C5. Information gathering Versus blocking:

Information received from hospital
Information seeking
Sharing information between patients

C6. Weighing the odds:

Comparison with others
Odds of surviving
Making decisions

C7. Fighting to survive Versus giving up:

Reasons to give up the fight and reasons to keep going
Positive thinking and self-talk versus negative
Taking physical action
Beliefs that help people cope

C8. Change in self:

Change in health status
Self concept
Normalisation strategies
Emotional changes
Life stage and roles

C9. Interaction with others:

Attitude and behaviour of others
Expressing to others how you feel and being heard
Concern and care for others

C 10. Anticipation Versus disappointment:

Hopes and expectations
Goals and plans

C 11. Coming to terms with life and the possibility of early death

Quotes used for reliability check

1. Blows [test of lung function] had been down ever so slightly (Int 4).
 2. I had actually been like extremely stable in terms of lung function for a long time, in excess of 10 years, but actually with a rather, at a lower level than I had thought (Int 12)
 3. Yeah, oh yeah, I remember it really well. That's the one thing I won't ever forget cos when he mentioned it I just couldn't believe it. I just thought - there's no way that I'm that poorly (Int 11).
-
1. I think seeing quite a few of my friends die in here and then you think well certain things are just not important at all. You know its just sort of living your life and being happy and stuff and doing what you want to do. co life is quite short at first, so... (Int 7)
 2. ..it's just the thought of being zipped up in a black bag and put in a box. I just don't like that idea at all... (Int 14)
 3. It's like it's really difficult...living with CF is like you're on a plane that's about to crash constantly and its like, it is just like that...It's like being in a war zone. I can only describe it as that. Constantly aware that at any moment you're going to live or die (Int 13)
-
1. I think in one way I've had more years than I should (Int 1)
 2. I don't know. If I got a call I would be pleased but I can wait or at least I think I can wait (Int 9/15).
 3. I was sort of more thinking ' I hope they don't call me up too quickly.' (Int 2)
-
1. The second time it wasn't as bad because they didn't need as much blood and stuff because they already had my tissue type and stuff, but the first time, 3 days it were awful cos they could have done it like in 2 days. i just wanted to go home (Int 9/15).
 2. ...a mixture of sort of being very scared and being very excited. It was just about 50/ 50 you know... being sort of you know, half shitting yourself and half thinking "Yeah, this is what I really want. Its cos, it was just so exciting. The adrenaline is really going and your in the ambulance and your going "oh, oh, what am I supposed to be thinking about now? (Int 6).
 3. .. I think the minute you arrive that somebody - the minute you arrive - somebody should come and talk to you about what's goner happen, what's going on.

1. Yeah there was one lad whose had it done and I've spoke to him how's he got on and what he had to do and this, that and the other. But otherwise, no, I haven't really talked about it at all (Int 14).

2. And then Dr. X showed them me, this Dr. had shown me all the different patches which he said was good, which is a lot, and Dr. X showed me and it was all bad. So it was the complete opposite of what he'd said. So basically he said "all of this is the whole of the lungs. It's completely destroyed. It's all damaged. And basically I think you should look at having a transplant... (Int 13).

3. I think the main thing _ I think they should definitely bring out some sort of booklet or some'at to tell you about more what's goner happen when you have a Tx. Definitely to do with transplants anyway... (Int 11).

1. Well its very hard to pin anyone down on that one. the only hard and fast statistic that I can get, like comparative stats, is that once your lung function falls below 30% then its... then the survival chances at 2 years are 50% (Int 12).

2. Always known since Tx became a reality... deep down I always knew that was going to be my - well, it's the only option. You either take it or you die. End of story. If I wanted to live, that's the route I have to go down - deep down I knew that was what I had to do (Int 4)

3. I do get some comfort out of thinking that someone else in the world is worse off than me (Int 8).

1. Just tell my mind it's some'at else to fight (Int 5).

2. I was just... I was just wasn't going to give up. There's no way. I think - I think its... it helped that I had everyone around me...and my family have been brilliant, all my friends have been brilliant...and I just felt that I had - I had so much to live for that I wasn't going to give up (Int 6).

3. I mean I don't think about it that often. There's no point in thinking about it all the time... I just try and do other things really. Try and focus on other things (Int 10).

1. Oh, I mean a lot of people used to say when they first had it they could feel how light it was to breathe straight away, but I didn't find that really. I found- I still found - cos of the scar - it goes across, it felt tight. So it were getting used to it really. But I think once I had the Tx it felt like I felt right like alive and warm and all - you know, cos before I used to just feel right cold all the time (Int 11).

2. I've always been fairly independent even when I'm really struggling (Int 4).

3. I think by nature I'm not a depressive person. I think I am quite a positive... I wouldn't describe myself as a depressive person but I do have bouts of depression (Int. 13).

1. You can tell your family some things but even your husband you don't want to tell. you feel as though you can't tell them everything because you don't want to upset them too much (Int 2).

2. I mean my boss always said " Look, as soon as you've had your Tx you can come back. Come back (Int 3).

3. Cos I mean no one else knows. As far as everybody know I have a laugh and joke all the time. But it's just some'at inside I --I do on my own really. No one else knows (Int 5).

1. I didn't really have any expectations. I just - it was more a sort of long term thinking like "oh well, after I have it done then perhaps a year afterwards I'll be able to do all the normal things that I've talked about before, going on holiday and what have you...I think the expectations were on a long term basis you know. I'll be able to live, hopefully a longer life (Int 6).

2. ..and I hope that maybe I can go out for a walk and maybe do a bit of running,, and just not taking nebulizers, not having drugs, not having feeds over night...I'd like to go travelling a bit more. And I hope to go, I'd love to go to walk the wall of China... (Int 14).

3. Well it's not going to be the future I thought I was going to have 5 years ago, but I don't think it's going to be bad. I think things are going to be okay. You know, I've sort of rearranged my career path if you like and you know I've got something - well I've got some plans now I'm tolerably happy with...(Int 12)

1. Well, I came here as I was feeling really bad...so nothing really happened. It was just a case of getting over it. It was like coming to terms with it (Int 7).

2. Quality of life is just being on this planet really. that's enough quality of life for me. Just being here (Int 5).

3. and so I'm at the stage now where I've just finally during the summer started to accept that I'm not going to have a full life as in how I wanted it to be after my Tx. It isn't (Int 13).

Appendix 12

Table 4: showing which participants contributed to which sub-categories

Table showing which participants contributed to which categories (Note: contributions of five or more instants to a category are denoted by the symbol xx)

Category	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
C1. Thinking that they are not that ill	x	xx	x	xx				xx	x	x		xx			
Shock and disbelief when the gravity of the situation is realised		xx	x	x	x	x		x	x		x	xx	x	x	
Health monitoring	x		x	x	x	x	x	x			x	x		x	
C2. Strategies used to deal with the death of others	x		xx	x	x	x	xx	x			x	x	x	x	x
Thoughts about their own death	x		xx	xx	xx	x	x	x			x		xx	xx	
C3. Timing	x	xx		x	x	x	x	xx	x	x		xx	xx	x	
Time running out	x	x	x	x	x			x			x	x	x		
Time spent waiting	x	x	xx	x	x		xx	x	xx	x	x	x	x	x	x
C4. Medical treatment within 'the system'	x		x	xx	x	x	xx	x	x		x	x	xx	x	x
Communication style and attitude of health professionals			x		x	x	xx	x	xx			x	xx	xx	x
Feelings about the operation itself	x	xx	x			x						xx	x	x	xx
C5. Information received from hospital	xx	x	x		x		x	x	x		x	x	xx	x	x
Information seeking		x	x		x	xx	x					xx	x	x	x
Sharing information between patients		x	x	x	x	xx	x			x	x		x	x	x

Category	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
C6. Comparison with others	x		x	xx	x	x	xx	x	x		x		xx	x	x
Odds of surviving	xx	x	x	x			x	x	x		x	xx	x		x
Making decisions	x	x			x	x						x	x	x	x
C7. Reasons to give up the fight and reasons to keep going	xx		x	x	xx	x	x	x				x	x		
Positive thinking and self-talk Vs negative	x	x	x	xx	x	x	xx	x	x		x	x	x		x
Taking physical action				x		xx				x	x	x	x		
Beliefs that help people cope				xx	xx	x	x	x			x	x	xx		
C8. Change in health status	x	x	x	x	x	x	x	x			x	x	x	x	x
Self concept		x	x	xx		x	x	x	x	x		x		x	x
Normalisation strategies	x		x		x		xx	x	x			x	xx	x	
Emotional changes	x	x	x		x		x	x			x	x	x	x	x
Life stage and role	xx	xx	x	x	xx	x	x	x	x		x	xx	xx	x	
C9. Attitude and behaviour of others	x	x	xx	x	x		xx	x	x		x		xx		x
Expressing to others how you feel and being heard	x	xx	x	x	xx	x	xx	x	x	x	x	xx	xx	x	x
Concern and care for others	x	xx	xx	x	xx		xx			x		x	x	x	
C10. Hopes and expectations for the future	x	x	xx	x	x	x	x	x	x	x	x	x	x	x	x
Goals and plans	x	x	x	x		xx	x			x	x	x	xx		x
C11. Coming to terms with life and the possibility of early death		x		x	xx	x	x					x	xx		

Appendix 13

Example of a section of interview transcript

543 P: It's, say you're having a mil of drug, they break that mil up in to seven
544 syringes and fill them with water. And then - no there's six syringes and on the
545 seventh syringe they nearly give you the full dose.

546 I: Alright.

547 P: Or they put half of the dose in them other syringes and then another big
548 half. And the rest of your body has got used to it. And then it's like you've had
549 the full dose but slowly so your body knows how to cope. And sort of I don't
550 know if it's built up antibodies, but built up a control of it. And they do it all the
551 time now. Every time I have a drug they do that before.

552 I: Right.

553 P: Just in case. But always the ones they know I'm ^{safe} safe with (cough). So ^{dangerous as} So
554 coromicine (drug) were nerve racking really. I went in to the anaesthetic room ^{Safety}
555 and she said right we're gonna start, and I were on the heart monitors, ^{- nerve}
556 everything. And the anaesthetist had to stop just in case they need her. She ^{racking}
557 said if she starts going funny they were just gonna ventilate me straight away so ^{Special care}
558 that I wouldn't panic and make it worse. ^{extra care needed}

559 I: Yeah.

560 P: And it went alright. My heart didn't change at all and I mean I slept most
561 of it. I think when you're nervous you try and sleep though don't you and get ^{copied with}
562 away from it. But my mum and dad said they were sat there biting their ^{anxiety}
563 fingernails. But that went alright. And they did it on the 1st of October. And N ^{- Parental support}
564 (co-ordinator's name) rang me that afternoon. I were out, but he rang and spoke
565 to my dad and said "Right her bleeper is in the post. She's on the list". And it ^{"on the list"}
566 were oh thank god for that. ^{relief}

567 I: So a relief?

568 P: And then I didn't have an alcoholic drink, they said you can't be drunk
569 when you go.

normalisation

570 I: That's true.

571 P: So I didn't have an alcoholic drink all Christmas. All that Christmas, and
572 for that year. And then I started having maybe half a lager but feeling guilty. And
573 then the Christmas after I got shingles. So I had to come off the list. It was like a
574 dangerous infection.

guilt
(external)

danger vs safety
- Coff (10A)

575 I: Yes.

576 P: And I got so drunk. And I said to N (co-ordinator's name) I right enjoyed it
577 being able to drink. He said "You can anyway just don't be silly". 'Cos I didn't
578 live at all. I didn't go out hardly. I carried my bleeper like this all the time.

alcohol/
Drinking (normal)
- life vs fear of
death

579 I: What stopped you from sort of going out and?

580 P: I was just worried that my bleeper wouldn't work. 'Cos with us being in
581 this area I used to go to B (place) all the time which is over the hill, it's not far.

- fear (of
missing call)
vs
forgetting
bleeper

582 But no mobile phone will work there. Even if it's on the BT connection they don't
583 work because it's in such a deep valley. And there's a big stone - I don't know
584 what stone it is - but there's stone round and I thought my bleeper won't work

normalisation
vs
?

585 there. So I didn't do there anymore with my friends and - I didn't - I used to go
586 swimming all the time - not just to swim 'cos I'm rubbish, but being in water it's
587 easier to breathe and it's more relaxing. And I stopped doing that 'cos I didn't give

- need to structure
monitoring

588 my bleeper to the life guard in case I forgot it. So I daren't not be with it. And
589 then after that second Christmas I though phew, what's the point in .. if I'm not

washed
time

590 gonna get a transplant and some'at is gonna happen, I'm wasting my time. So I
591 enjoy myself all the time. And it sounds silly but the amount of times I've gone
592 out of the house, got where I'm going and thought where is my bleeper. Oh it's

(fear)
- ambulance
10 1+

health
status

life