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Title: Living in limbo-waiting for transplant.

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**ABSTRACT**

Lung transplant for patients with end stage cystic fibrosis (CF) in the United Kingdom is recognised as the only successful treatment for CF patients with advanced lung disease.

This study uses an exploratory approach to examine how patients with Cystic Fibrosis (CF) and their carers cope with the rigours of chronic illness and life on a transplant waiting list.

8 patients with CF, 4 awaiting transplant and 4 who had been transplanted within the previous 3 years, and 5 of their carers, were asked to recount their experiences using a semi-structured interview technique.

4 themes emerged from the interview data. Displacement, Disorder, Life in Limbo and Readjustment to wellness.

Support appears to be particularly important to patients and families, after false alarms occur, and upon return home after transplant

The small sample size precludes generalisation of the results to all patients with CF but gives an in-depth insight into the lived experience of waiting for transplant.

## *INTRODUCTION*

### *Cystic Fibrosis*

Cystic fibrosis (CF) is an inherited disorder that presently affects 7500 sufferers in the United Kingdom (Cystic Fibrosis Trust 2004). Effects include repeated respiratory infections, liver disease and pancreatic insufficiency resulting in malnutrition and altered bowel habit.

Median life expectancy is 31 years in the United Kingdom (Hodson 2000).

Pulmonary disease is the major cause of death in CF sufferers, (Hoiby and Frederiksen 2000). The disease is usually progressive in nature, characterised by periods of exacerbation of chest problems, placing increasing demands on the individual and their carers. Increased life expectancy is accompanied by increasing complexity of problems; 30% of patients over 30 years develop diabetes mellitus, (Allen 2004). For those with end stage disease, lung or liver transplants are the only options.

With waiting times for lung transplant greater than two years as a result of donor shortages, and reports of deaths in up to 40% of those currently waiting (De Meester et al. 1999, Vizza et al. 2000), it is clear that transplant has its limitations. Furthermore, the 40 people in the UK per year (McCloskey et al. 1998) who succeed in gaining a lung transplant can expect survival rates of 75% at 1 year and 45% at 3 years (Hosenpud et al. 1997). The period of waiting for transplant has been aptly described as 'playing for time' (Christian et al 1999.) The journey through these stages of selection, assessment and acceptance onto the waiting list is lengthy, arduous, and stress-filled.

### Rationale

Providing specialist nursing care to these chronically ill patients through periods of acute illness filled with periods of hope, despair and then renewed hope, can be challenging, and also offers insights into the wide ranging coping strategies which are required to live life whilst on a transplant waiting list. There is a considerable body of literature devoted to organ transplant issues, and to living with chronic conditions in general. However, there appears to be a dearth of exploratory research specifically focusing on the experience of CF sufferers, hence the rationale for this study.

## *REVIEW OF THE LITERATURE*

### *Quality of Life: coping and support*

Early literature around transplant, (lung, heart, liver), focused largely on survival outcomes alone. However, this has been augmented by a large body of literature which also focuses on quality of life pre and post transplant (Craven et al. 1990, Bussbach et al. 1994, Caine et al. 1996, Limbos et al. 1997, Tenvergert et al. 1998, Lanuza et al. 1999, Burkner et al. 2000). Lanuza and McCabe (2001) argue that lung transplantation recipients are a heterogeneous group with differences in outcomes according to gender, diagnosis and type of transplant procedure. Care provision therefore must be individualised and take account of such differences.

A further body of literature examines coping with the strains and stresses of transplant; (heart, lung, liver) in patients and carers: (Mishel and Murdaugh 1987, Saxe-Braithwaite and Chapman 1992, Benning and Smith 1994, Wainwright 1995, Collins et al. 1996, Durst et al. 2001, Lowton 2003). Recurring themes from these studies are those of uncertainty, fear of the future and a "life on hold" during the waiting period.

Support from others is recognised in the literature as significant for those who must still cope with the rigours of chronic illness whilst awaiting transplant, (Smith and Jones 2004, Lanuza and McCabe 2001, Molassiotis, et al. (1997).

Underwood (2000) suggests that people require different kinds of social support at different times, e.g. support from family and friends, or alternatively- information-giving which may help facilitate coping.

Lowton (2003) describes the experiences of post- transplant CF recipients' support of others as "emotion work". This involved selectively sharing

information with others awaiting transplant whilst being careful not to frighten them with negative narratives.

The notion that coping changes over time has been well established in the literature, Lazarus and Folkman (1984). Lepore et al. (1991) have demonstrated that in the context of chronic stress, social support also shifts over time: hence the need to measure coping and social support longitudinally. However, Lepore (1997) suggests that chronic stressors, by their very nature may be uncontrollable and therefore resistant to change or coping efforts. Furthermore, eliciting social support may be difficult for people suffering from chronic illness. For example, those on a transplant waiting list may be confined to their homes and dependent on oxygen. This results in a reduction in meeting people under usual social circumstances: at work, in pubs, meeting neighbours in the street.

### *Coping and denial*

A study by Abbot et al (1995) found that patients with cystic fibrosis perceived themselves to be in better health than their attending physician. Abbot contends that this may be an adaptive way of coping with CF.

That is, although denial, is normally regarded as a negative way of coping, it can be a positive coping strategy in some chronic illnesses (Abbot et al (1996), a finding which was supported by Lazarus (2000). Furthermore, Lazarus and Folkman (1984) contend that that the choice of coping strategy will usually vary with the adaptational significance and requirements of each threat and its status as a disease, which will change over time. Thus in chronic illness, people may cope differently at different stages of the disease, and use a variety of coping strategies simultaneously

### Summary

Issues of quality of life and coping strategies such as support and denial have been examined in the literature review, with these findings in mind, this study seeks to examine the specific experience of cystic fibrosis sufferers in relation to the issues identified.

### Aim of the study

**To examine the lived experience of patients with cystic fibrosis, and their carers, of coping with the rigours of chronic illness whilst waiting for lung transplant.**

### METHODS

#### Design

A descriptive, exploratory approach was adopted. While the study intended to discover the lived experience of patient and carer, this was in relationship to specific phenomena – coping and support. The findings from the literature review were used to inform data collection and analysis. It was not appropriate therefore to adopt a strict phenomenological design, (although elements of this informed the methodology )

#### Sample

Eight patients with cystic fibrosis, (five male, three female) and five carers (one male, four female) took part in the study, (See tables 1 and 2). The sample number of 13 is consistent with qualitative approaches. There is no intention to generalise from qualitative studies, as there is in quantitative. The key driver in sample size determination in qualitative research is that of the need to determine a large enough sample to achieve data saturation. This was difficult to achieve in this population.

At the time of carrying out this research there were only 4 patients waiting for lung transplant in the CF centre. Post- transplant patients were therefore included to gain perspectives pre and post- transplant. Of those who had been transplanted, only 4 fitted the inclusion criteria of having been transplanted in the past 3 years. Asking patients to recall events further in their past may have given rise to recall bias. The nature of this group means that patient numbers are always small. It is rare for more than 1 patient per year to be transplanted. In addition, pre transplant patients at the end-stage of their disease may be too ill to participate in research projects.

### Tools

Data was collected by semi- structured interview. This was designed to allow patients a degree of freedom in recounting their experiences of waiting for transplant, whilst addressing issues which emerged from the literature review.

### Ethical considerations

Ethical approval for the study was sought from the appropriate Local Research Ethics Committee. Ethical standards in relation to maintaining confidentiality and anonymity were adhered to throughout the study.

### Procedure

Each subject was interviewed once. Interviews lasted between 25 and 65 minutes. Interviews were structured around the 4 stages of transplant: discussion, referral, acceptance on the waiting list and post transplant. Open questions were used.

Interviews were audio taped, and took place either in hospital, in the patient's room in the ward, or at the patient/carers home. Where two people from the

same household were being interviewed, these were done separately to gain individual perceptions rather than a shared view.

### Data analysis

Content analysis using broad coding/indexing categories was employed.

The data from the audio tapes was transcribed verbatim. Patterns, keywords and phrases were transcribed onto cards. The file cards were then sorted into piles representing headings. It was envisaged that “a priori” issues such as coping and support would be evident, however “in vivo codes” also emerged from the raw data.

Thirty eight headings were formulated from recurring, significant keywords and phrases. These were then reduced into eleven sub-themes, and finally into four themes (see fig 1).

### Credibility, fittingness and confirmability

All informants were previous known to the researcher and appeared to take a relaxed approach to the interview.

An Independent nurse researcher was asked to carry out analysis on the raw data and field notes. Findings were in largely in concordance with the principal investigator and there was agreement regarding the emergent themes.

Member checking was undertaken with one subject reviewing the principal investigator’s analysis of his transcript. This was found to be in accordance with findings.

Reflexivity; the continuous process of reflection on the researcher’s own values, preconceptions and behaviour (Parahoo 1997) was attempted through self awareness and critical reflection on the preconceptions of the phenomenon under study.

## RESULTS AND DISCUSSION

Four main themes emerged from the interview data: Displacement, Disorder, Life in limbo and Adjustment to wellness. These themes correspond with the phases in the transplant process of Referral, Assessment, Acceptance onto the waiting list and Post –Transplant (see fig 1). All 4 themes are characterised by a common feeling of uncertainty. Each main theme has one or more sub theme attached to it (See fig 1).

### Displacement

This refers to the view that patients have of themselves as being "fine", of, getting on with their lives in their own normal way. The introduction of discussions regarding referral for transplant displaces this status quo of "normal life". Patients, and to some extent carers, whilst considering that transplant may be something that will be required in the future, are not usually prepared for the conversation when it is raised. This is often despite being given cues from health professionals indicating a deteriorating picture over time:

*" I was shocked that he had even thought, how dare they say I was as bad, that I have only got so long to live or something like that" (Patient 7)*

*I don't think my health is, it is no' dropping down, it's me getting lazy"(Patient 4)*

*"I was angry, I thought it was too soon" (Patient 2)*

Displacement of this altered perception of well-being being leads to reactions of surprise, anger, and downward comparison of self to their peer group.

*"I had seen other people in the clinic and they looked more poorly than I did" (Patient 5)*

*"I was comparing myself to other CFs, I am no better but about the same"*

(Patient 1)

Two patients who had been transplanted 3 years ago and 1 year ago respectively, appeared in hindsight more able to reflect on this theme

*"You don't see how poorly you are because you are so used to being poorly"*

(Patient 5)

Carers expressed feelings of relief and joy as opposed to shock and anger, when transplant was mentioned, suggesting that they may have more ready for the news than their charges. However this was tempered by comments such as

*"you wouldn't have thought he was as far down the line as that" (Carer 2)*

and *"It's a funny thing, she was so ill, and yet I never thought of her as an invalid" (Carer 5)*

### Disorder

This refers to the disordered nature of emotions that subjects felt through the second stage of the transplant process; attendance at the transplant centre for assessment. Patients and families stay for four days during which time the patient is subjected to a variety of tests, and introduced to the transplant team. On the fourth day, all information is reviewed and a decision made to accept or reject the patient for active transplant. There is huge uncertainty experienced at this stage by both patients and their carers coupled with extreme highs and lows of emotions.

*"It was an exciting feeling, it was like, God, I'm going on the transplant list, I'm going to be normal like everyone else" (Patient 5)*

*"There is fear, what the hell is going to happen, you didn't ken what to do-uncertainty" (Patient 7)*

*"We were both pleased but frightened, and then it was like waiting for a time bomb to go off"(Carer 4)*

**Support: (sub theme fig 1)**

The nature of the support that patients talked about most was emotional support; the concept of "being there"

*Just being there, someone to talk to about everything" (Patient 7)*

*"They were there as a crutch for me" (Patient 3)*

Carers usually discussed support in the same terms- that of emotional support, and some recognised reciprocity between themselves and their loved ones.

*"We both more or less helped each other along" (Carer 1)*

*"We helped each other, there is a bond there". (Carer 5)*

One patient, who had been turned down first time around, emphasised the importance of support:

*" I had decided that I wasn't going for one (transplant) because of the hassle I was getting at home,...the second time round I was ready because I had 100% support, I mean I had no support from anybody the first time, but the second time I had John's support, I mean, that is all I needed was support." (Patient 5)*

Another form of support, which was recognised as helpful by patients and carers, was that of peer support: speaking to someone who had benefited from transplant.

*"One way we were helped out (speaking to a transplantee) I got all my questions answered" (Patient 4)*

*"One of my mates had a heart/lung transplant and I used to call him in for a cup of tea and I got to know different things" (Carer 1)*

*"The big thing for me was meeting Jill (name changed) someone that had been through it so well, and could tell me that it wasn't going to be any worse than anything I'd already been through" (Patient 8)*

### Life in Limbo

This third emergent theme- "life in limbo"- follows acceptance onto the active transplant list and refers to the period of waiting until "the beeper goes off" and transplant takes place, or alternatively, death occurs. When carrying out a member check, the patient summed up "life in limbo" commenting:

*"If I was a video recorder, I'd be on pause at the moment. I'm not really living, I'm just getting by"(Patient 3)*

From this phase-life in limbo- five sub categories emerged; two of these which appeared to be of major significance to patients and carers will be discussed; "buying time" and "missing the boat".

### Buying time

Patients' attempts to try and keep well, to avoid the next infection, to maximise treatments, despite failing health and in the hope that "the beeper will go off" has been labelled "buying time". Patients and carers take action to optimise what little health is left, by being vigilant for early signs of further deterioration, or by keeping people away who may be at risk of causing infection.

*"Not a lot of visitors came, it was a risk of infection,... my main job was to try for as little deterioration as possible"*

*"We picked the biscuits that had the most calories in them, I would try and find things that really appealed" (Carer 5)*

*I concentrate on my weight, I am eating better" (Patient 3)*

Carers sometimes had to take on the role of "enforcer" or resort to "bullying" in order to achieve adherence to treatment and therefore buy more time.

*"He was more pushy than me, I was "oh I can't be bothered. He was " get up on that bench!" (Patient 5)*

"We bullied him a lot, you just had to keep him going and not give up" (Carer 3)

### Missing the boat

False alarms are not uncommon in the transplant process. By the time the state of the donor lungs is known, the waiting recipient may be ready and prepared for theatre. Finding that the donor lungs are unsuitable causes great disappointment and stress, and engenders further uncertainty as to when, and if, another donor may be found.

" The bottom dropped out of his world, he was so sure he was going the second time" (Carer 3)

" It felt as if someone had ripped the insides out of me" (Patient 6)

" ...and he (transplant co-ordinator) said "you are not going to get your transplant", and I thought that was a final thing and he said "your time will come", and I thought, oh it's not the end, oh it's not the end then." (Carer 5)

It would appear that there is continued need for contact during the life in limbo phase, particularly from the transplant centre. Patients and carers want to be reassured that they have not been forgotten during the wait:

"They could phone us now and again to let us know how far I am on the list" (Patients 1,2)

"I started with every fortnight (telephoning), every 10 days and I am saying yes I am still here....but I realised yes, to keep phoning and I think it helped her to know that I was in touch" (Carer 5)

This was tempered against the need to not be a bother, or not be too pushy:

" I think that over the 18 months we only heard from them twice... I suppose maybe there could have been a bit more of that, but I mean they are busy" (Carer 3)

### Re-adjustment to wellness.

This theme is specific to those patients who were post-transplant. Whilst their experiences were different in terms of outcomes, this theme was common to them all.

Initial reaction by patients was of satisfaction with their new life, however it becomes apparent, that there are difficulties of adjustment, which perhaps had not been considered pre-transplant. Life was not completely normal as dreamt about before transplant, but continued to be full of stresses and strains, which were different to those incurred previously.

The final sub-theme "*guilt versus gratitude*" describes the ways patients and carers justify their continued struggle to adjust to this new life.

*" You couldn't imagine ever a down side (before) so it was a bit of a surprise when I started feeling like that and then I felt guilty about feeling that way, I know I shouldn't be feeling guilty, I should be grateful. It is adjusting to normal life. That has probably been more difficult than anything". (Patient 8)*

*"I am always trying to prove to people, especially my donor family their lungs haven't gone to waste, that I'm really looking after them....I get depressions so low that if it wasn't for the fact that I had someone else's lungs inside me I could quite easily do myself in."(Patient 5)*

#### *Coping and Support: Implications for Practice*

Findings suggest that most of this group of patients perceive themselves to be healthier than does their attending physician at the time of referral for transplant. This is consistent with Abbot et al.'s (1996) study. As the literature suggests, denial or healthy avoidance can be seen as an effective coping strategy in the context of chronic illness (Lazarus 2000), providing it is not at a cost to treatment (Abbot et al. 1996).

Lowton's (2003) study also found that CF patients engaged in comparing themselves to others in the clinic, in order to ascertain whether they were suitable candidates for surgery.

What are the implications of these findings for practice? If - as these findings and the literature suggest, - avoidance is a healthy coping mechanism in chronic illness then taking this away from patients may do more harm than good in the long term. What may be more important is that health professionals recognise that patient's perception of their illness may be different from theirs, and, instead of being surprised at the reaction of patients during the transplant discussion, be aware that this reaction is perhaps not an unusual one.

Patients and carers would like more contact at more regular intervals from their transplant centre as they feel isolated and want to know they are not forgotten. This finding was communicated to the transplant centre.

Subjects viewed emotional support as of particular importance; however, practical support became increasingly important with disease progression. This has implications for health care providers in what they can offer in terms of both types of support. With regard to emotional support, professionals should be aware of the need to allow both patients and carers the opportunity to vent emotions, especially if they do not feel able to do so in front of each other. Practical support should be offered in terms of nursing care, and practical home help to ease the burden on carers. Additional emotional and practical support should be offered following episodes of false alarms, which patients found both emotionally draining, and caused deterioration in physical health in some cases.

Difficulties adjusting post transplant are documented in the literature (Mishel and Murdaugh 1987). Findings are similar in this study, which found that families' expectations of life after transplant were not as they had imagined

pre transplant. These findings have important implications for future management of this group of patients, suggesting that this group require as much emotional support after transplant as they did before. In addition, practical support in terms of benefits help, and back to work courses may have an important effect on building self-esteem.

#### LIMITATIONS OF THE STUDY

In this study, the overall sample size of patients and carers was small, While generalisability is not sought, it may be that data saturation was not achieved.

The literature suggests that coping changes over time. This study has reflected only one snapshot in time: more complete information would be obtained by conducting a prospective longitudinal study to investigate individual experiences at different stages of the journey through transplant.

Prior knowledge of the subjects has both advantages and disadvantages from a research stance. The advantage is that perhaps subjects have been more open in their retelling of stories, thus providing greater richness of data. The disadvantage of having prior knowledge leads one to unconsciously form opinions of people and how they will behave. A challenge to validity arises from the researcher being a member of staff at the referring centre: patients may therefore have felt inhibited about being critical of this service.

Lastly, there may have been some recall bias in those patients who were post-transplant. Asking them to recall their experiences when they were awaiting transplant, may have been unrealistic, as memories and perceptions change over time and the results therefore should be viewed with some caution. The results of this study may not be transferable to other groups but go some way to explore the experiences of this particular group.

## CONCLUSION

This study has described the lived experience of patients with CF and their carers, of the transplant process through referral, assessment, waiting, and for some, life after transplant.

The professionals involved in caring for these patients believe they have some insight into these people's lives. The researcher would argue that what health professionals see is the tip of the iceberg. This small study could serve as a platform for developing future inquiries, for example larger, prospective studies, exploring experiences as individuals with CF move through their journey. Further research of this nature has the potential to afford greater insight into the difficulties patients and their families' face, and their needs for support, as this may then help us to meet those needs sensitively and appropriately.

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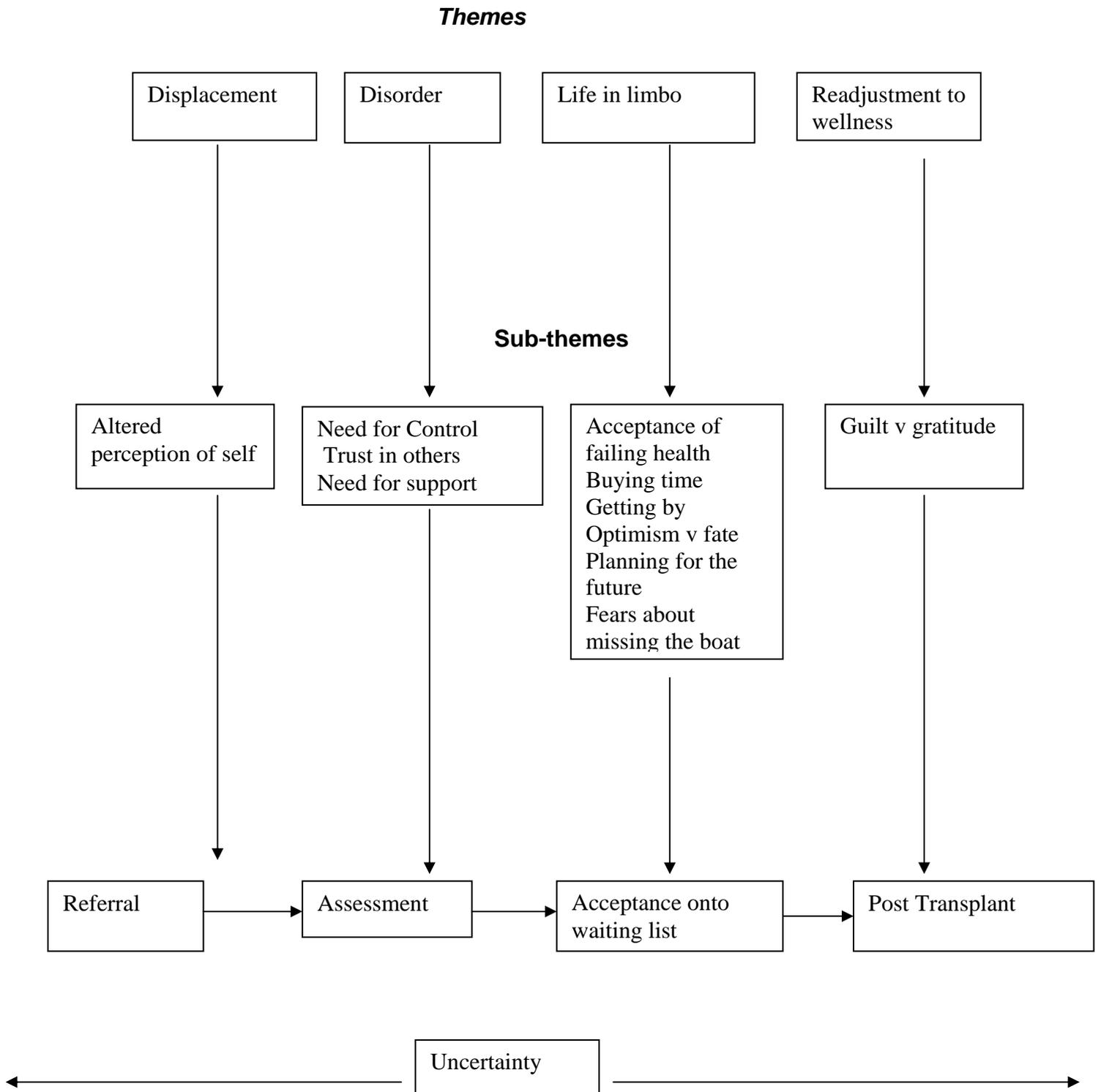
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**Table 1: Characteristics of patients**

<b>Patient No.</b>	<b>Age</b>	<b>Status Pre/ Post-transplant</b>	<b>Sex</b>	<b>%FEV1</b>	<b>Body Mass Index (BMI)</b>	<b>Months on active list (A/L) Months post-transplant/(P/T)</b>
1	21	pre	M	21%	16	<b>10 A/L</b>
2	22	pre	M	14%	17.9	<b>17 A/L</b>
3	40	pre	M	20%	23.1	<b>40 A/L</b>
4	19	pre	M	16%	16.2	<b>2 A/L</b>
5	35	post	F	80%	21.4	34 P/T
6	26	post	F	118%	22.9	18 P/T
7	28	post	M	71%	30.3	3 P/T
8	40	post	F	104%	22.3	14 P/T

**Table 2: Characteristics of carers**

<b>Carer</b>	<b>age</b>	<b>sex</b>	<b>Status in relation to CF Patient</b>
1	38	M	Partner of Pt. 5
2	64	F	Mother of Pt.2
3	60	F	Mother of Pt. 8
4	50	F	Mother of Pt. 7
5	72	F	Mother of Pt. 3



**Fig 1: A Conceptual model of the lived experience of transplantation.**

**Table 3: Summary of recommendations/Key points**

<ul style="list-style-type: none"> <li>• Raise awareness among health professionals caring for people with CF of the ways in which illness perception may be altered in this group.</li> </ul>
<ul style="list-style-type: none"> <li>• Recognise that avoidance and denial can be an adaptive coping strategy.</li> </ul>
<ul style="list-style-type: none"> <li>• Take forward to the transplant centre the finding that waiting list patients would like more telephone contact, on a more regular basis.</li> </ul>
<ul style="list-style-type: none"> <li>• Be aware of the emotional and physical impact of "false alarms" to patients and carers and offer support accordingly.</li> </ul>
<ul style="list-style-type: none"> <li>• Raise awareness that most families have difficulty in re-adjusting to life after transplant and offer more practical and emotional support to families following transplant</li> </ul>

