

## **Working to establish ‘normality’ post-transplant: A qualitative study of kidney transplant patients**

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### **Abstract**

**Objectives:** To explore patients’ perceptions and experiences of ‘normality’ and the influences on this at three time points post-transplant.

**Methods:** In-depth interviews with 25 patients at three months, one year and more than three years following kidney transplant. Patients’ accounts were compared with Sanderson et al’s typology of types of normality.

**Findings:** Post transplant, patients worked hard to re-establish normality, albeit in a ‘reset’ form. This normality was a very personal construct, shaped by a wide range of factors including age, gender and personal circumstances. Some patients encountered significant challenges in regaining normality, both at three months for those experiencing acute and distressing side effects, and later relating to the long term side effects of transplant medication and co-morbidities. However, the most dramatic threat to normality (disrupted normality) came from episodes of rejection and transplant failure.

**Conclusions:** The main forms of normality achieved varies for different conditions. Moreover despite improvements in health post-transplant and opportunities to build a new, reset normality, the participants recognised the need to pay careful attention to the spectre of future ill health and transplant failure. Transplant failure was therefore a source of disruption that was central to their illness narratives and perceived as an ever present risk

**Key words:** kidney transplantation; patient experience, normality, shifting perspectives, adherence to medication, qualitative

## **Working to establish ‘normality’ post-transplant: A qualitative study of kidney transplant patients**

### **Introduction**

In popular discourse transplant is presented as a cure. However, few studies have explored patients’ perceptions of wellness post-transplant and how these perceptions may change over time. Patient narratives are considered to offer a powerful tool for understanding biomedical reality in terms of illness experience and its social and cultural context (1-5). The specificities of kidney transplantation pose something of a problem for a narrative approach to analyzing patients’ experiences after the transplant. Were there to be a complete transition to health, then transplantation might be considered an epilogue to a previous narrative, and the object of study would be this transition to health. However, as Crowley-Matoka et al observe, it is critical that we examine the ‘versions of health offered up by biomedicine and its interventions.’ (6, 2005:831) Post transplant experience relates not only to a past of illness, but also to a present where there are side-effects to contend with, where illness may still obtrude, and to a future where there is the possibility that the transplant may fail; the illness narrative of the transplant patient is never finished, even amongst the most successful of transplant patients.

A review of the quantitative literature on quality of life post-transplant concluded that there are distinct quality of life benefits associated with kidney transplant, but that further work is required to fully understand patients’ experiences of wellness and attempts to regain normality (7). The agency of patients with chronic illness in actively adjusting to changes in their body, self and the world around them to establish a form of wellness has been documented (8). O’Neal (9) suggests that normalization can be seen as an approach to coping with chronic illness. Normalization turns the lens upon the patient and emphasises their individual efforts and agency in living with their illness. Sanderson and colleagues (10) argue that the complexity of normality has been under-explored in the literature. To address this, they draw on a study of rheumatoid arthritis patients at a single point in time to identify six types of normality: disrupted, struggling to maintain, fluctuating, resetting, returning and continuing normality. (see Table 1) Given the popular discourse around transplant, we might expect patients to reach the stage of returning normality following transplant surgery. This study provided an opportunity to explore types of normality within a different patient group (kidney transplant patients), interviewed at three time points post-transplant.

## **Methods**

Design: Semi-structured interviews were conducted with kidney transplant recipients at three time points (three months, one year and three years or more following transplant), with this selection of time points being informed by discussions with the clinical team as presenting the patient with different issues of adjustment. The first three months following the transplant often involves movement from one demanding regime (dialysis) to another, requiring considerable adjustment emotionally as well as medically, to their new status. By one year, clinic visits are typically less frequent and medication reduced. The three-year period is a time when the patient's medication and their routines for living a post-transplantation life have often re-established, and when there is generally a sense of a reduction in the immediate danger of rejection and less contact with clinical care teams.

The study was based on adults over the age of 18, with children and adolescents excluded as having distinct issues of adjustment and medication. The study only involved recipients of organ donations from the deceased as these patients face both greater risks of rejection compared with live donors, and experience different obligations and social meanings regarding their transplant (11).

Recruitment: Participants were identified from a list provided by members of the clinical team at one large UK transplant centre treating patients from a wide geographical area, with rural and urban locations. Patients were selected to provide a mix in terms of: age, gender and length of time since their transplant. Given the sensitivity of the topic, the transplant unit staff checked the list of patients identified for inclusion to confirm that all were well enough to participate and a couple of names were removed from the list before contact was made. Participants were sent an information sheet that had been reviewed by members of the local Kidney Patient Association for acceptability and completeness. This described the purpose of the research, what would be required should they wish to be involved, including the time implications. It also provided contacts for further information and a reply slip to indicate interest in taking part. Participants were then contacted by the researcher by phone to arrange and appointment.

The length of the study period meant that it was only possible to follow up a small number of individuals at two time points. However, five participants took part in two interviews: three

months after transplant and approximately one year post transplant. Five further patients were recruited at three months and five patients at one year to achieve data saturation about post transplant experience at these time points. In order to look at long term experiences, 10 patients were interviewed three or more years post transplant

Interviews: Following participants' preference two-thirds of the interviews were conducted in their homes, a few interviews were conducted in the research teams' offices which were close to but outside the hospital and one interview was conducted at the participant's place of work at his request. Interviewers met with the research team after interviews for debriefing sessions. Some of the interviews were conducted by paired interviewers to provide additional support when a new interviewer joined the project. All interviews were digitally recorded with the participants' consent.

A topic guide for the interviews was developed in consultation with the local Kidney Patient Association and covered the following broad themes: experiences of health prior to the transplant, perceptions of current state of health, medication and side effects, support from social networks, effects of the transplant, current feelings about the transplant and the future. The final section of the topic guide focused on hobbies and interests to end with a discussion of less sensitive issues. The interviews usually lasted between one and two hours.

Analysis: Interview transcripts were entered into NVivo9. The initial coding was based on broad themes that were augmented in the analysis to take account of emerging interpretations. Types of normalization were used at this stage to further interrogate the data. Analysis involved a process of constant comparison, with particular emphasis given to deviant cases, with the aim of developing an interpretation and explanation.

Ethics: Research Ethics Committee approval was obtained from the local NHS Trust, reference number: 10/H0703/049

## **Findings**

### Characteristics of participants

The study group comprised 15 men and 10 women between the ages of 19 and 65. Twenty one of the 25 were dialysis patients prior to transplant (see Table 2). Approximately half

suffered from diabetes. Others had experienced kidney failure for different reasons including kidney disease, HIV and as a side effect of medication. Some participants had been living with ill-health (most commonly as a result of diabetes) since childhood, with one participant (Peter) estimating that he had been experiencing ill health for over 40 years.

Those interviewed more than three years post transplant, had received their transplant on average 10 years prior to the interview. Five participants (Peter, Debbie, Ali, John and Joe) had previous transplants (including two heart and lung transplants, both more than 10 years prior to their kidney transplant and three patients with previous kidney transplants). Five participants had received simultaneous pancreas–kidney (SPK) transplants (see Table 2).

### Experience prior to transplant

The interviews began with the patients retelling their pre-transplant stories, with these stories ‘setting the scene’ for a discussion of their post transplant experiences. In most cases, they had experienced a long history of ill health prior to transplant, often describing living with a consistent level of poor health, rather like ‘a flu that doesn’t go away,’ accompanied by more acute episodes of ill health and hospitalization. For example, Sophie described the ‘never ending’ tiredness she experienced pre transplant. Sara described how her life had been ‘on hold’ prior to her transplant. She and her husband had felt unable to plan for the future. She observed that she always started sentences with ‘once I’ve had the transplant,’ demonstrating a high level of expectation with regard to the transplant. Most participants were on dialysis at the time of transplant and described a wide range of health problems (many relating to their diabetes) which, combined with the dialysis regime, affected their energy levels and limited their ability to fully participate in everyday life. Even those who spoke in relatively positive terms about their experience of dialysis, observed the contrast with their post-transplant experience:

*‘On peritoneal dialysis you can’t, although you think you lead a normal life, actually when you’re thinking about it, you know, you can’t really do anything heavy.’* (Edward, 1 year post transplant)

*‘So, you know you can’t get away with having a normal life if you’re on dialysis’* (Catherine, three years+ post transplant)

Accounts of life before the transplant were typically of a disrupted state of normality (10) in which overwhelming symptoms made a normal life impossible. Only one participant, David, described his pre-transplant life as close to normal. He worked long hours in a senior post and enjoyed a busy life. David had turned down a previous offer of a transplant as he didn't feel 'ill enough' to need it.

### Three months post-transplant

The kidney transplant typically represented a major and usually sustained shift in health. At three months most participants were enjoying their first glimpses of normality. They talked about a range of aspects of normality including: work, hobbies and interests, caring for / supporting others, holidays, socialising and food and drink, and can be viewed as engaging in what Sanderson et al (10) describe as 'resetting normality' by embarking on activities (some new, some old). It was clear that they took an active role in establishing a sense of normality, with this in turn being shaped by their particular life circumstances. For example, prior to her transplant, Sara had relied on her husband and mother to look after her small children, describing how this made her feel useless. If she took her son to nursery she would need to come home and sleep for a couple of hours to recover. Post-transplant she was able to reclaim her role as wife, mother and daughter and described how she 'threw herself into lots of things' including taking the children to school and nursery, a university course, driving lessons and planning to move house. Often those who hadn't been too ill (or ill for very long) prior to transplant had quite ambitious goals. For example, Henry, whose underlying health condition made a return to work unlikely, was planning to start by doing some yoga, then to go to the gym, building up to climbing in a few months time. A couple of participants were looking forward to getting back onto the golf course and working back up to a full round. This stepped approach to resetting normality was common amongst participants at this stage.

At three months, participants were still mindful of the fragility of their health and undertook activities to maintain wellness. Some highlighted physical reminders of the operation such as discomfort walking down stairs. They described how they followed health advice such as using sunscreen and staying out of the sun due to the increased risk of skin cancer and were also making regular visits to the transplant clinic for monitoring, considering this to be a necessary part of the post-transplant regime. Discussing the clinic visits Edward commented:

*It's very important to just make sure that, that, you know, everything is working, working right. I don't ever see it as a bind or an inconvenience.'* (Edward, one year post transplant)

In particular, participants talked at length, usually in a very matter of fact way, about the side effects they were experiencing due to the high doses of immuno suppressive medication post-transplant. These included hair loss, weight gain, tremors, sickness, diarrhoea, vivid dreams, mood changes and acne. These side effects, especially physical symptoms such as acne, weight gain and hair loss, affected the resetting of normality. David described how he had found it impossible to write his daughter's birthday card because of the tremors. Women, in particular, talked about feeling self conscious about their appearance. In some cases, experience of side effects led to disrupted normality. For example, Sophie said that she wouldn't feel comfortable to leave the house until her hair started to grow back. Karen talked about her surprise in experiencing what more than one person described as 'teenage' mood swings and acne:

*'I never thought about the side effects until I started coming out in spots'* (Karen, three months post-transplant)

However, the most common response to the medication and side effects was to accept them as part of the transplant and key to recovery:

*Janet 'It [the side effects] is a small price to pay for having, what is, I suppose, my life back again, isn't it, to a normal degree'*

*Interviewer 'Is that how you would describe it then, having your life back again?'*

*Janet 'Yes and no. I think other people would describe it as that. I wouldn't because I can't remember back to not being a diabetic, because I was so young when I was diagnosed and diabetic for so long,'* (Janet, three months post- transplant)

Like Janet, other participants' view of normality was informed by their prior health and their (often distant) memory of what it meant to live a normal life. Peter, who had had a previous heart and lung transplant, explained that he hadn't been able to work for some years prior to his recent transplant and that wouldn't change. However, he could engage in some activities that hasn't been possible for years such as going out for a drink with his brothers and having a beer while watching the football at home and regarded these as important elements of his

prior normality associated with his working life as a builder. As he commented ‘every builder likes a pint, and I used to like a pint, but for four years I hadn’t had a drink’ (Peter, three months post-transplant). In resetting normality, participants were flexible about what it would mean to live a normal life. Participation in work in particular, often required supportive employers and colleagues, changes to duties, increased working from home or reduced hours.

For those patients who had had a simultaneous kidney and pancreas transplant, the end of the diabetes dietary and treatment regime was a particularly positive aspect of resetting normality. For example, Joseph described how he continued to test his blood each day and was constantly surprised by the consistent blood sugar reading. He also took considerable pleasure in going out for a meal and having a glass of wine and whatever he liked from the menu.

Most patients consistently described their health status in positive terms. However these are not accounts of the reestablishment of an objective state of wellness, but rather reflected their desire to regain control over their health when and where they can. As Joseph observed:

*‘At the moment you know I feel I can take on the world, but erm, actually the reality of it is probably i’ll be knackered by the time dinner comes around.’* (Joseph, three months post transplant)

Not everyone was experiencing improved health three months post transplant. A small group of patients were focusing on ‘keeping going’ and were trying to come to terms with the transplant not being a cure. Their lives were on hold and their prior state of disrupted normality continued as they waited to see if the transplant would stabilise. An extreme example was David who had been diagnosed with diabetes brought on by the transplant and the transplant itself was not doing well. He was experiencing a loss of normality as his condition prior to transplant had not interfered with his ability to pursue a normal life, while at three months, he had had three bouts of rejection, six biopsies and an additional angioplasty procedure.

*‘I knew what I had been given was a chance and then it all started to fall around me, gradually, very quickly. And it took that away, that euphoric feeling of ‘wow, i’ve got a chance now.’... And it’s a much, much slower climb back up, than it is to come back down. It*



*is like a freefall down and then God you've really got to dig deep to get back to where you believe it's worth it.* (David, three months)

### One year post transplant

A small group of patients continued to experience a disrupted sense of normality one year post transplant. For David, the promise of the transplant had slipped away by 12 months and he was back on dialysis at 12 months. Two other participants had kept their kidney transplant, but lost the pancreas. Others while retaining their transplant were experiencing on-going health problems that sometimes acted as a barrier to their attempts to re-establish normality. Alan explained that he was still taking a lot of anti-rejection drugs to support the transplant. While he felt better than when he was on dialysis and was managing to get to work, he still felt very tired. He had negotiated reduced hours and some home working with his employer. His wife was taking a greater share of domestic responsibilities. His account was one of continued disrupted normality, while he continued to wait for the transplant to stabilize.

Janet, who had been doing well at three months had experienced 8 episodes of rejection by 12 months. Her pancreatic transplant had failed and she was still attending the clinic every week. She commented on how different this was from her expectations at transplant:

*'You're basically told you have the operation, six months later your back at work and all is rosy.'* (Janet, follow up interview at one year).

Janet had moved from attempts at resetting normality at three months, to a disrupted normality. She was getting used to being a diabetic again and worried about the likelihood of the kidney failing and needing to start dialysis. Her new partner, who was present at the second interview, felt that she had gone 'too far' in her pursuit of normality following the transplant. He observed that she '*came home and acted normal...she was normal in her eyes.*' Janet also commented that the health professionals had implied that she was, in part, responsible for the failure of her transplant. She felt she hadn't been given sufficient guidance about the type of normality she could establish post-transplant. Normal was a complicated idea for Janet as she had been ill since childhood and commented at three months that she couldn't remember what it meant to be well and normal. Her response had been to '*go with the flow, sort of quite relaxed about a lot of things.*' Furthermore, At 33, Janet was younger than many other participants and had experienced a lot of changes at home

around the time of her transplant, with a relationship ending and meeting a new partner. She explained how she liked to go out and have fun with friends, describing how to mark a special occasion she had ended up in a night club with a cannula in her arm. While other participants mentioned occasionally forgetting to take their medicines, only Janet admitted to reducing some of her medication without consulting her doctors because it was making her feel sick.

After twelve months other people described their lives as less dominated by medication and hospital visits and often talked about their recovery in terms of their improved 'energy' levels. At one year, they were more actively engaged in aspects of everyday life: working, shopping, cooking, cleaning, supporting others and caring for children, and had either taken or were planning holidays and were able to resume previous hobbies and pursue new interests. Karen had moved house and embarked on an ambitious DIY project, before returning to work just before her second interview at 12 months. She commented how she hadn't realised how ill she was until after the transplant when she began to feel so much better. Joseph's description of his ability to help around the house echoed the comments of other participants:

*'I had a bit of a mad purge last weekend. I cut the front lawn, the back lawn, did the hoovering and painted the garage door all in one day...I was a bit tired at the end of it, but yes I'm really pleased that I can do that sort of thing, which, before the transplant I was really limited. I just couldn't do anything. Even walking up stairs was an effort, it really was.'* (Joseph, 12 months follow up interview)

Participants like Peter who had been ill for longer periods talked about less ambitious goals, but nonetheless sought to reset normality by, for example, going out for a drink or going for a walk. Sue described an arresting image of her path to recovery, signalling the distance she felt she had travelled towards a state of health and normality in which she could take the dog for a walk without having to take constant breaks:

*'But it's interesting, having started to walk the dog again after the transplant, we've got a cycle track at the bottom of the road down here, and we used to walk down the cycle track and then there's a big field. And when I started taking the dog down there after the transplant, it's very interesting, the dog used to stop at all the places I used to sit down, So it was like, and I'd walk and think, 'oh I used to sit down there, I used to sit down there.'* I

*mean I don't sit down at all now. That's an interesting sort of measure you can see.'* (Sue, one year follow up interview)

However, participants were mindful that the normality they were establishing post transplant did not constitute a return to full health. As Sue observed:

*'People think when you've had the transplant, it's finished. You know, you've had the transplant and now you're better, you're perfect. And, you know, the fact that you've discovered that actually that isn't, that isn't the case, that you can never say, 'I am well, I am now a perfectly fit person,' because you're not.'* (Sue, 1 year post-transplant)

### Three years or more post-transplant

At three years or more post-transplant most people required far fewer clinic visits and usually received care at their local hospital rather than the transplant centre. Aisha described how, 17 years post-transplant, she takes just 4 tablets a day and visits the clinic once every four months. Medication continued to be described as a necessary evil. Catherine had recently complained to her husband that she was 'fed up' with all the medication. However, she stressed that one negative comment in eight years 'wasn't bad' and that the medicines were part of her lifestyle and something she was used to.

*'It is always in the back of your mind that it [the transplant] will fail, at times. And I think if anything that makes you more inclined to comply with your treatment, comply with your medication because at the end of the day if, you know, if you do the utmost that you can and you take your medicine and you go to your follow up appointments, then there's hopefully less chance of it failing in the long run.'* (Catherine, three years + post transplant)

Many of the three years and over group were working. Some participants, especially men, placed particular emphasis on the importance of work for their sense of normality. Ken commented:

*'It gives me a relatively normal way of life...I go to work and everything else.'* (Ken, three years+ post transplant)

Others discussed positive experiences of leading a more normal life post-transplant that were not defined by work. These included being able to play an active role in their families and looking after themselves, freedom from the burden of regular dialysis, volunteering, pursuing

interests and going on holiday. Catherine explained how her transplant had allowed her and her husband to have the family they wanted.

One source of disruption for this group were the long term side effects of the post transplant medication, with minor episodes of ill health sometimes quickly becoming serious threats to their health requiring hospitalization. They also sometimes needed additional medication and occasionally surgery to treat a range of conditions linked with their transplant including osteoporosis, cancer, diabetes and neuropathy. While some described a single episode of disruption others listed a number of episodes of poor health. These episodes were described in terms linked to disrupted normality rather than fluctuating normality. Each acted as a reminder of the potentially limited life of the transplant:

*'I was ill 18 months ago and I had to go into [the hospital] because I had a really bad infection and naturally then I thought, 'Oh is this it?' (Rose, 3+ years post transplant)*

While their accounts demonstrated resilience and positivity, episodes of ill-health often came as a serious blow, that disrupted their normality albeit temporarily. Sanderson et al (10) observed that disrupted normality presents the biggest challenge for patients in terms of their personal identity and self worth. For example, Sally who had recently had kidney cancer talked about the impact this had had on her psychologically, and described feeling very low and worried about her own mortality:

*'And having had cancer in the last 15 months, that's also an enormous shock to the psyche. And I've got to get my boy to university.'* (Sally, 3+ years post transplant)

For transplant patients the psychological challenge presented by episodes of ill health was reinforced by the on-going fear of transplant failure that was shared by all participants in the study.

*'I think about my kidney failing all of the time... I don't think it goes away'* (Teri, female, 3+ years post transplant)

With the spectre of transplant failure and thus the need for further dialysis and another transplant, most patients were cautious about embarking upon treatment options (such as reductions in steroids) that might jeopardise the kidney. The patients' prior experience of dialysis shaped their feelings about needing to return to dialysis in the future:

*'It's all part of the same story. If I were to talk about my transplant, I would almost certainly talk about dialysis'* (Joe, male, 3+ years post transplant)

## **Discussion**

In a study of pre transplant experience, Sque et al (15) found that patients sought to live as 'normal a life' as possible while they waited for a transplant, although this was constrained by symptoms and treatment and the uncertainty of when a transplant might be available. , Transplantation is often considered to hold the promise of a return to good health (3), or at least of relief from the constraints of living with renal failure. However, our study of patients post transplant showed how notions of normality vary, with participants typically representing just two of Sandersons et al's 'types of normality,' (reset and disrupted normality) neither of which involved a return to a previous symptom free state of normality. Participants worked towards and were prepared to accept a new form or 'reset' normality that was aligned with their capacities post-transplant. with this normality forming a very personal construct that was shaped by their age, gender and life circumstances.

Achieving reset normality and experiences of disruption varied over time post transplant. Three months post transplant most patients saw a glimpse of normality and began to take cautious steps towards it. At one year they were bolder in their attempts to reset normality, pursuing work, hobbies and holidays. In the three year plus group most were living with a form of reset normality that made room for their illness, medication and treatments. However, three types of disruption emerged from the data. For some, particularly women, short term side effects post transplant (such as weight gain, hair loss and acne) made it particularly difficult to start pursue a more normal life at three months. In the three year plus group, long term side effects, (such as cancer) and co-morbidities disrupted the normality they had re-established post transplant. However, the biggest source of disruption came from episodes of rejection and transplant failure (experienced in both the three months and one year groups). Not only is dialysis part of the past experience of many patients, it is also conceived of as a threat to future normality. These findings are consistent with an Australian study in which transplant patients placed an extremely high value on retaining their transplant, tolerating side effects and appearing to rank transplant survival higher than life itself (14) and emphasises how illness narratives vary for different chronic conditions.

The absence of examples of returning and continuing types of normality reflects a difference in the nature of kidney transplant and of rheumatoid arthritis as chronic conditions, where the latter can be associated with quite mild symptoms with some potential for a return to full health. The absence of struggling and fluctuating normality may also be linked to the resilience of this set of patients and their experiences of both ill health and of self management. As Sanderson et al note (10), the typologies of normality represent different moral positions. Whereas disrupted normality presented the greatest challenge to self worth and identity, our study participants had the capacity, experience and resilience to cope. Those offered a chance to reset normality demonstrated powerful agency in rebuilding their normality and protecting their health. The role of the patient in actively pursuing a 'normal life' seems critical to the post-transplant experience.

## **Conclusions**

This paper provides insights into how patients experience life after transplantation and the importance they place on achieving normality. However application of Sanderson et al's typology to our group of transplant patients indicated that the main forms of normality achieved can vary for different conditions, with the absence among this group of post-transplant patients of what they identified as continuing, struggling and fluctuating normality. Instead post-transplant, participants in this study worked hard to re-establish a new form of 'reset' normality. This was a very personal construct, shaped by age, gender and a range of other situational factors.

While the transplant usually brought opportunities to build a new normality, Thorne et al and Patterson's concept of 'illness in the background' (12, 13) helped to explain the ways in which participants lived their lives as fully as possible while paying careful attention to the spectre of future ill health and transplant failure. They therefore did not lose sight of the importance of disease management and emphasised adherence to medication, attending clinic appointments, and generally looking after their health. Patients experienced different threats to normality at the three time points, with the most dramatic threat to normality coming from episodes of rejection and transplant failure.

Transplant failure was thus both a real source of disruption and perceived as an ever present risk, with the high value placed on transplant survival and how this influenced their

adherence and acceptance of side effects of medications forming a core feature of participants' illness narratives.

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Table 1: Types of normality

| <b>Types of normality</b>       |   |
|---------------------------------|---|
| <b>Disrupted normality</b>      | Symptoms are overwhelming and normal life is considered to be impossible  |
| <b>Resetting normality</b>      | Reconceptualising normal life to include the illness, symptoms and a changed body and self  |
| <b>Struggling for normality</b> | Emphasis on the struggle to maintain a normal life, despite severity of symptoms and underlying disruption. Seeking to present a normal life to others whatever to cost |
| <b>Fluctuating normality</b>    | Fluctuating and uncontrolled disease activity, (characterised in Arthritis by severe and frequent flares of inflammation), preventing normal life for its duration      |
| <b>Returning to normality</b>   | Normal life is reinstated and symptom free  |
| <b>Continuing normality</b>     | Normal life is unchallenged and symptoms are mild and manageable<br><br>Sanderson et al 2011  |

Table 2: Sample characteristics

| <b>Pseudonym</b> | <b>Time of interview post transplant</b> | <b>Gender</b> | <b>Age</b> | <b>Dialysis</b> |
|------------------|--|---------------|------------|-----------------|
| Karen**          | Three months + one year                  | Female        | 41         | Yes             |
| Janet**          | Three three months + one year            | Female        | 33         | No              |
| Joseph**         | three months + one year                  | Male          | 48         | No              |
| David            | three months + one year                  | Male          | 40         | Yes             |
| Sue**            | three months + one year                  | Female        | 47         | No              |
| Henry            | three months                             | Male          | 42         | Yes             |
| Sophie           | three months                             | Female        | 52         | No              |
| Peter*           | three months                             | Male          | 58         | Yes             |
| John*            | three months                             | Male          | 47         | Yes             |
| Kofi             | three months                             | Male          | 55         | Yes             |
| Alan             | one year                                 | Male          | 47         | Yes             |
| Sara**           | one year                                 | Female        | 29         | Yes             |
| Carl             | one year                                 | Male          | 53         | Yes             |
| Debbie*          | one year                                 | Female        | 42         | Yes             |
| Edward           | one year                                 | Male          | 54         | Yes             |
| Geoff            | 25 years                                 | Male          | 65         | Yes             |
| Sally            | Eight years                              | Female        | 50         | Yes             |
| Rose             | Nine years                               | Female        | 59         | Yes             |
| Catherine        | Eight years                              | Female        | 40         | Yes             |
| Teri             | three years                              | Female        | 19         | Yes             |
| Ken              | 12 years                                 | Male          | 52         | Yes             |
| Jack             | 24 years                                 | Male          | 60         | Yes             |
| Joe*             | eight years                              | Male          | 44         | Yes             |
| Ali*             | seven years                              | Male          | 47         | Yes             |
| Steven           | eight years                              | Male          | 51         | Yes             |

\*denotes previous transplant operations

\*\*denotes simultaneous pancreas–kidney transplant