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Life on the list
An exploratory study of the life world of individuals
waiting for a kidney transplant

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Final report

Life on the list: an exploratory study of the life world of individuals waiting for a kidney transplant

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Table of Contents

	Page
Figures	iii
List of Tables	iv
List of Appendices	v
Acknowledgements	vi
Executive Summary of the Report	vii
1. Background	1
1.1 The kidney transplant list	1
1.2 Relevant research	2
2. Design and method	4
2.1 Aim	4
2.2 Overview of study design	4
2.3 Recruitment	4
2.4 Data collection	5
2.5 Interviews	5
2.6 Data analysis	6
2.7 Ethical approval	7
2.8 Project management	7
2.9 Support for participants	7
2.10 Support for researchers	8
2.11 Confidentiality and anonymity	8
3. Findings	9
3.1 Introduction	9
3.2 Sample	9
3.3 Introduction to the theory	9
3.4 Life on the kidney transplant list: seeking normality in daily life	10
3.5 Seeking normality in daily life with ESRD	12

	Page
3.6 Seeking normality in life on the kidney transplant list: dealing with waiting and hope	14
3.6.1 Maintaining hope of a transplant	14
3.6.2 Waiting as a thought process	16
3.7 Summary	17
4. Enabling and constraining factors	18
4.1 Health status	18
4.2 Social support	19
4.2.1 Support of family and friends	19
4.3 Ability to work and employer support	20
4.4 Health professional support	22
4.4.1 Information about the transplant list	22
4.4.2 Information and support for financial issues and social needs	23
4.5 Coping strategies	23
5. Conclusion	25
6. Recommendations	26
7. References	28
Appendices	30

Figure

Page

Figure 1	Life on the kidney transplant list: seeking normality	ix,11
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List of Tables

	Page
Table 1 Sample demographics	viii
Table 2 Age by no. of participants	9

List of Appendices

	Page
Appendix 1 Recruitment criteria	30
Appendix 2 Text of poster used for recruitment	33
Appendix 3 Letters of invitation	34
3.1 Letter of invitation for main recruitment method	34
3.2 Letter sent following poster enquiries to researcher	35
3.3 Letter sent following poster enquiries to transplant coordinator	36
Appendix 4 Participant information sheet	37
Appendix 5 Reply slip	39
Appendix 6 Consent form	40
Appendix 7 GP letter	42
Appendix 8 Interview topic guide	44
Appendix 9 Thank you letter	49
Appendix 10 Post interview questionnaire	50

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Executive Summary of the Report

What was the reason for the research?

Kidney transplantation is the treatment of choice for many individuals with end stage renal disease (ESRD), as transplantation is reported to offer a greater quality of life than renal dialysis. At the end of March 2008 there were 6980 people on the active transplant list for kidney or kidney and pancreas transplants. However, during the previous year a total of 1453 deceased donor kidney transplants were carried out¹, illustrating the mismatch between demand for and availability of kidneys for transplant. Whilst the Government has pledged to improve transplant services and to address the organ shortage, individuals on the kidney transplant list are currently facing an average wait of more than two years. Individuals waiting for a kidney transplant face complex challenges, which are currently poorly researched. An insight into the experience of waiting for a kidney transplant and how individuals interpret that wait could contribute to clinical knowledge and lead to improved support for these individuals. It could also raise public awareness about the issues involved in waiting for a kidney transplant, potentially encouraging donation.

What was the aim of the research?

The aim of the research was to elicit a greater understanding of what it means for potential adult recipients to wait for a kidney transplant.

Ethical approval

The study received ethical approval from the relevant NHS Research Ethics Committee (Reference no. 07/Q1701/42). Approval for the use of posters for recruitment was granted as a substantial amendment to the project. Research Governance approval was received from the relevant NHS R&D office.

Who took part in the research?

Thirty adults who had been on the active transplant list for at least three months took part in the study. Details of the sample are given in Table 1. The sample comprised 16 men and 14 women, aged between 26 and 76 years of age. Eighteen participants were on clinic based haemodialysis (HD), nine were on peritoneal dialysis (PD), one was on low clearance prior to dialysis, and two who normally used PD were temporarily on HD due to infections. Participants had been on the transplant list for varying amounts of time, the shortest time being four months and the longest nine years. While 19 participants were on the transplant list for the first time, 11 had had previous transplants. The majority of the sample was White; there was one Black and two Asian participants.

Table 1: Sample demographics

	Number	Percent %
Gender		
Male	16	53
Female	14	47
Age		
26	1	3
30-39	3	10
40-49	8	27
50-59	9	30
60-69	5	17
70-76	4	13
Ethnic group		
White	27	90
Asian	2	7
Black	1	3
Type of maintenance therapy		
Haemodialysis	18	60
Peritoneal dialysis:		
- Continuous Ambulatory Peritoneal Dialysis	4	13
- Automated Peritoneal Dialysis	5	17
Low clearance prior to dialysis	1	3
Temporarily on haemodialysis due to infection	2	7
Years on transplant list*		
< 1 year (but more than 3 months)	9	30
1-2 years	11	37
> 2 years	10	33
Number of previous transplants		
None	19	63
One	9	30
Two	2	7

* Length of time on the transplant list is reported for current wait for transplant. Some participants also had experience of waiting for a previous transplant.

How was the research carried out?

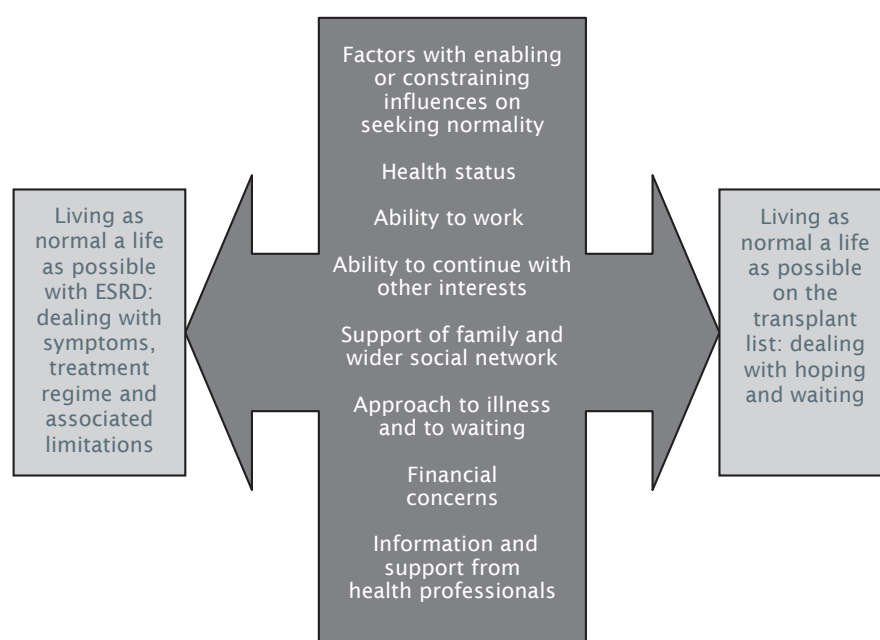
The study took place over 18 months, between November 2007 and April 2009. Participants were either purposively sampled from a collaborating renal unit to obtain a sample that reflected the range of people on the kidney transplant list, or they responded to posters advertising the study, which were displayed at the main hospital and satellite dialysis units. Participants were sent a recruitment pack of information about the study and were asked to sign a consent form before the interview. A response rate of 25% was achieved, which compares to other studies of individuals waiting for a transplant². Data were collected via a single, long interview, carried out with participants at a time and place convenient to them. The study applied the grounded theory method³, which

entailed closely examining the interview data and grouping themes or patterns in the data into larger categories that were then integrated to develop an explanation of the day to day life of participants.

What were the main findings of the study?

- Life on the kidney transplant list can be described as seeking normality (see Figure 1). In the longer term, participants described their hope for a transplant as a return to a normal life, commonly expressed in terms of the removal of the constraints of living with renal failure and its treatment. In the shorter term, there was evidence of trying to live as normal a life as possible⁴. In terms of living with ESRD, this involved dealing with symptoms, treatment and associated limitations. In terms of living on the transplant list, this involved dealing with hoping and waiting. There were a number of factors, shown in Figure 1, which had an enabling or constraining influence on seeking normality.

Figure1 LIFE ON THE KIDNEY TRANSPLANT LIST: SEEKING NORMALITY



- Waiting for a kidney transplant is lived within the context of life with ESRD. Participants described a daily life of planning, doing and recovering from their treatment and dealing with associated constraints, such as those on travel, work, diet and fluid intake, long term planning, and reduced health status. Participants were undergoing a process of negotiating⁵ these limitations into their daily lives to achieve as normal a life as possible.
- Being on the transplant list was characterised by hoping and waiting, the latter involving uncertainty and lack of control. Participants were involved in the dual processes of 'maintaining hope' and of dealing with 'waiting as a thought process'. These processes contributed to living as normal a life as possible while on the transplant list.

- Participants were undergoing a continued process of maintaining hope of a transplant. They were involved in a process of attempting to understand their own wait and of responding to challenges which they perceived to threaten their chances, and thus their hope, of a transplant.
 - To make sense of their wait, participants formed and rationalised an understanding of, and thus an expectation of, their own wait based on a perception of the average wait and of other personal attributes, such as age and the presence of antibodies, which they understood to influence that wait.
 - Challenges to hope of a transplant took a number of forms, including waiting for longer than expected, deterioration in health status, being called as a back-up recipient for a transplant, failed matches with close family members, or receiving information to indicate reduced chance of transplant, such as the presence of antibodies.
 - When such challenges to hope occurred, participants were involved in re-justifying/rationalising their wait to keep hope intact.
- Waiting for a transplant is characterised by uncertainty and lack of control. The uncertainty of being on the transplant list led some to feel they were living in limbo or living day to day, and for some others it impacted on longer term planning. Lack of control was expressed as an inability to influence the wait. In addition, some participants experienced lack of control through the need to keep telephone contact permanently available in case of a call for transplant, through restrictions on travel, through impact on longer term planning and in not being able to prepare in advance to be in hospital for an operation.
- Participants varied in how much they engaged in ‘waiting as a thought process’ that was how much they thought about being on the transplant list on a day to day basis.
 - The majority of participants reported that they did not think about being on the transplant list. Some considered this a natural process of forgetting, while others described ‘bracketing off’ their thoughts of a possible transplant. These latter participants were actively ‘containing’ their hopes of a transplant to avoid depression and to live a normal life. Certain triggers did sometimes bring thoughts of transplant to the fore, such as unexpected telephone calls, usually late at night, anniversaries of going onto the transplant list, or when hope of a transplant was challenged.
 - Some participants talked of the transplant as always being at the back of their mind, although they tried not to think about it.
 - Still other participants were thinking about the possibilities for a transplant on a regular and often very frequent basis. Some were relatively new to the transplant list and so had not undergone the process rationalisation. Others were characterised by health crises, difficulties with dialysis, inability to work and a failed transplant.

- Maintenance and containment of hope are linked. Hope needs to be satisfactorily rationalised for thoughts of transplant to be contained. Where hope of a transplant was challenged, thoughts of a transplant were not contained.
- A number of factors contributed to living as normally as possible with ESRD and with being on the transplant list: health status, ability to work; ability to continue with other interests; support of family and wider social network; approach to illness and to waiting; lack of financial worries; information and support from health professionals. There was interplay of these factors, which fluctuated over time. The presence or absence of these factors had an enabling or constraining influence on an individual's achievement of living as normal a life as possible.
 - Health status was a key factor in living as normal a life as possible while on the transplant list. In addition to health problems related to ESRD, some participants had other health problems, experienced symptoms related to their dialysis, or suffered infections related to their illness and treatment. Several participants were experiencing such crises at time of interview. Decline in health status was a challenge to hope of a transplant. Participants recognised that deterioration in health meant possible suspension from the transplant list or possible difficulty getting onto the transplant list in the first place, and that a lengthy wait for a transplant would impact on health status.
 - Ability to continue working was a key factor in maintaining as normal a life as possible while on the transplant list. The majority of participants were working part time to be able to fit work around their treatment. Added flexibility of working patterns was considered helpful.
 - Ability to continue with other interests, such as leisure time and social activities was also important.
 - Many participants talked about the impact of their illness and of being on the transplant list on partners/spouses and other close relatives, such as parents, siblings and children, and described them as an important means of help and support. Family members were reported to help with practical tasks and to provide emotional support and encouragement for continuation of treatment and in taking a positive approach to life. A wider social network also provided important emotional support and listening.
 - The most commonly reported strategies for coping with life with ESRD and on the transplant list were: not dwelling on problems, being busy, denial of being ill, taking a positive outlook, use of humour and fatalism.
 - Lack of financial worries was important. However, several participants talked of difficulties in accessing comprehensive information about the availability of benefits and in dealing with benefit applications.
 - Information about the transplant list was a vital element in maintaining and containing hope of a transplant. There was, however, both

misunderstanding and lack of information about the transplant list and the process of allocation of organs.

- ♦ While there was understanding of the basis of matching in terms of blood group and tissue type, there was a lack of understanding of the principles of allocation beyond that. Participants had queries about the impact of factors such as age, length of wait, presence of antibodies and health status on the process of allocation. This lack of understanding led some to feel the process of allocation to be hidden.
- ♦ There was misunderstanding about issues relating to the administration of the transplant list. In particular, there was confusion over the procedure of suspension from list when travelling and concern about delays in the process of getting onto the transplant list.
- ♦ Information about the transplant list was gained mainly from health professionals, much of it from an introductory meeting when first going onto the transplant list. Participants had differing desires for information, some for instance not wanting to receive information about a reduced personal chance of a transplant.
- ♦ It was felt that information about the number of transplants conducted locally would be helpful in maintaining hope.
- ♦ Several participants mentioned lack of contact with the transplant co-ordination team. Participants commonly had not had scheduled contact with the co-ordinator beyond an initial meeting when first being put onto the transplant list, and several felt it would be useful to have additional scheduled contacts to be able to update and to air any concerns. Lack of contact led some to doubt their status as active on the transplant list.

What are the recommendations?

Information needs

- There is a lack of transparency regarding the process of allocation of organs. Personalised information should be provided for those who desire it.
- There needs to be recognition of the importance of information about the transplant list and system of allocation in dealing with hope and waiting. Information about average waiting times and the process of allocation allow people to understand their wait and to rationalise hope.
- Thought needs to be given to the impact of certain types of information on hope. For instance, giving information about low chances of a transplant or providing stories of people who have only waited a short time for a transplant become embedded into an individual's understanding and rationalisation of their wait and thus their hope. Additional emotional support may be necessary when providing such information.

- Information about local transplant activity should be offered, giving hope through knowledge that transplants are being carried out.
- Clear information should be given about the process of suspension from the transplant list when travelling.
- Some individuals need reassurance that they are still active on the transplant list, as a lack of contact with the transplant co-ordinators can lead to anxiety regarding this.
- Delays in receiving notification of being put on to the transplant list caused by the required tests can lead to turmoil and concerns about time being lost. Clear information about the process and reasons for delays should be offered at this time.
- There appears to be some misunderstanding about the transplant list which is related to individuals' perceptions of how a list works, i.e. that it is normal on lists to go on at the bottom and to work one's way up. Clarity and transparency could be increased with a move away from use of the term 'list' to an alternative term, such as a 'register'.

Support needs

- Individuals on the transplant list may require specific emotional support for the process of maintaining/rebuilding hope of a transplant in response to challenges to that hope. Loss of hope can result in insecurity, uncertainty, hopelessness, despair or depression⁶. Such challenges, which should be viewed as critical points in the waiting period include: deterioration in health status; being given information about a low percentage chance of getting a transplant; experiencing a failed match with a close family member or being called as a backup transplant recipient. Health professionals are in a position to supply information that may help to address these challenges.
- Being able to work is an important source of normality and a crucial resource in dealing with waiting for a transplant. It is important that those who wish to continue to work receive maximum support. Flexibility of treatment sessions so that work is facilitated is an important element in coping.
- Further research is needed to understand the support needs of those persons close to individuals on the transplant list.

Sources of information and support

- Information could be given, and queries and misinformation dealt with, by offering scheduled annual contact with transplant co-ordinators.
- The possibility of a support/social worker role within the renal unit should be investigated. This post would play a vital role in assessment of vulnerability and family dynamics, with the necessary provision of support. In addition, the role could provide much needed practical help for benefit applications.

- Patients new to the transplant list may benefit from written information, possibly prepared by more experienced patients, that highlights common experiences, problems and emotions.
- Participants described a lack of interaction with their peers. A buddy system could therefore provide a valuable support mechanism through a system of volunteers.

Conclusion

This is one of the first studies to examine in detail how the complexities of waiting for a kidney transplant are dealt with in daily life. As such, it is an important addition to the current body of knowledge about daily life with ESRD, and to the transplant literature.

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1. Background

1.1 The kidney transplant list

Kidney transplantation is the treatment of choice for many individuals with end stage renal disease (ESRD), as it is reported to offer a greater quality of life than long-term renal dialysis (Rebollo et al, 2000). However, the number of people registered for transplant has risen in recent years, with an 8% increase in people registered for kidney or kidney/pancreas transplant between the end March 2007 and 2008 (NHS Blood and Transplant, Transplant Activity in the UK, 2007-2008). There are currently 6,957 people (NHS Blood and Transplant figure at 22.01.2009) on the active kidney transplant list, and a further 259 registered for a kidney/pancreas transplant. This trend is set to continue due to an ageing population and increased prevalence of diabetes.

There are currently four possible routes of kidney donation in the UK. The majority of kidney donations are deceased donor kidney transplants, taking place after the donor's death. An increasing number of donations involve living donation of a kidney by a healthy donor, who is usually a relative or close friend of the recipient. Since September 2006, two additional forms of living donation are possible: paired/pooled donations involve the exchange of matched organs between incompatible donor/recipient pairs; and altruistic non-directed donation allows an individual to donate a kidney anonymously through the national allocation system.

In the year 1st April 2007 to 31st March 2008, 1,453 deceased donor kidney transplants were performed. In addition, 829 live donor adult transplants were carried out, a figure which represents 36% of all kidney transplants. Of these, four were paired donations and six were altruistic donations. (NHS Blood and Transplant, Transplant Activity in the UK, 2007-2008).

Living donation has facilitated a year on year increase in the number of transplants carried out but there is still a mismatch between demand for and availability of kidneys. Within this context, the Government has pledged to improve transplant services and address organ shortage. The National Service Framework for patients with renal disease (DH, 2004; DH, 2005) aims to establish national standards for patient care, to improve services and to increase the number of kidney transplants. The Government has more recently accepted recommendations of the Organ Donation Taskforce Organs for Transplants: A report from the Organ Donation Taskforce (DH, 2008) to try to increase donation rates through changes in the donation and transplant infrastructure and through measures to increase public awareness of the need for donation.

With donation at current levels, individuals on the kidney transplant list are facing an average waiting time of 841 days (approximately 28 months) (<http://www.uktransplant.org.uk/ukt/default.jsp>). In addition, individuals belonging to certain ethnic minority groups, tend to wait longer for transplantation due to low donation rates among these groups (Morgan et al, 2006).

Individuals waiting for a kidney transplant face complex challenges in living with their disease on a day to day basis, compounded by the uncertainty of waiting for a

transplant. These challenges are poorly researched. An insight into the experience of waiting for a kidney transplant and how individuals interpret that wait could contribute to clinical knowledge and lead to improved support for these individuals. It could also raise public awareness about the issues involved in waiting for a kidney transplant, potentially encouraging donation.

1.2 Relevant research

The renal transplant literature offers few studies that have explored how being on a transplant list is experienced by those individuals. A wait for transplantation occurs within the context of the individual's illness and treatment regime (Brown et al, 2006). The wider renal literature includes quantitative studies focused on quality of life issues (for example Griva et al, 2009) and on coping strategies (for example Gilbar et al, 2005) and some qualitative studies that explore how individuals with end stage renal failure experience their daily lives and treatment. The latter body of work, while making little mention of participants' experience of being on a transplant list, provides a context for the present study as it explicates the experience of day to day life with end stage renal failure and dialysis. The themes these studies illustrate include:

- The impact that the symptoms of renal failure and the consequences of dialysis have on the daily life of the person with kidney failure (Polaschek, 2007). For example, the studies highlight: loss of time (Polaschek, 2003) and freedom (Lindqvist, 2000); impact on social life (Lindqvist, 2000; Hagren et al, 2001); an inability to travel or take holidays (Polaschek, 2003); restrictions on diet and fluid intake (King et al, 2002) consequences for relationships (Hagren et al, 2001) and family life (King et al, 2002) and the experience of uncertainty (Polaschek, 2003; King et al 2002; Lindqvist, 2000);
- Ways that individuals cope with their illness and treatment. For example, King et al (2002) report stoicism to be the dominant coping mechanism, with other means being control seeking, denial, optimism, defeatism; Wright and Kirby (1999) found that patients used a positive outlook, looked at others as worse off than themselves, didn't think of themselves as ill, and employed humour and keeping busy;
- Studies report that people with ESRD negotiate symptoms and treatment into their everyday lives (Polaschek 2003; Polaschek, 2007), and try to live life as normally as possible (Lindqvist 2003; Lindqvist 2000; Wright and Kirby, 1999; Polaschek 2003).

While none of the above studies have a specific focus on the experience of waiting for a transplant, some do mention it: Polaschek (2003) describes respondents as coping with the uncertainty of life by hope of a transplant; Hagren et al (2001) report waiting for a transplant as a cause of suffering, although giving hope to some; children waiting for a kidney transplant has been described as living in limbo (Waters, 2008) and for whom waiting and ambiguity were central features of life. Only one of these studies (King et al, 2002) was conducted in the UK.

The wider transplant literature contains some studies (Lumby, 1997; Lowton, 2003; MacDonald, 2006) which discuss the experience of waiting for a transplant, most notably those waiting for liver transplantation. While substantially different, in that end stage liver failure is a terminal illness with no life maintaining therapy, these studies provide insight into the experience of waiting. The studies describe waiting for a transplant as characterised by ambivalence and uncertainty (Lowton, 2003); by loss of control (Lumby, 1997) and as 'life in limbo' (MacDonald, 2006). The psychological impact is acknowledged, transplant candidates being described as involved in 'emotion work' throughout their transplant journey (Lowton, 2003).

Whilst the studies listed above provide evidence of what it is like to live with ESRD, or to wait for a liver transplant there are no studies which address waiting for a kidney transplant as the primary research question.

In addition to the empirical literature, theoretical perspectives from the medical sociology literature about living with chronic illness provide a useful background to the present study. Most notably, patients' coping strategies are recognised as an attempt to maintain as much normality as possible in the face of illness (Gerhardt, 1989).

2. Design and method

2.1 Aim

To elicit a greater understanding of what it means for potential adult recipients to wait for a kidney transplant.

Objectives

1. To provide a description that contributes directly to understanding how participants experience their illness and day to day life world.
2. To provide a theoretical framework to underpin clinical knowledge and decision making.
3. To inform innovative practices so care can be targeted more effectively.
4. To provide a body of knowledge that could underpin public awareness initiatives about the effects of end stage renal disease on the lives of individuals.
5. To provide information for the development of a survey tool that could be applied to a larger population of individuals waiting for kidney transplantation to potentially provide a credible data source for national policy.

2.2 Overview of study design

A cross-sectional design applying the grounded theory method as explicated by Charmaz (2006) was used to elicit the widest view of participants' experiences and perceptions of their life world. Bryant and Charmaz (2007:608) define grounded theory as: "a method of conducting qualitative research that focuses on creating conceptual frameworks or theories through building inductive analysis from the data. Hence, the analytic categories are directly 'grounded' in the data. The method favours analysis over description, fresh categories over preconceived ideas and extant theories, and systematically focussed sequential data collection over large initial samples".

Audio-recorded, qualitative interviews were used with adults who had been on the active deceased kidney transplant list for no less than three months. Participants were recruited from a regional transplant unit using criteria to ensure a sample that reflected the range of adults on the transplant list (gender, age, type of dialysis, ethnicity, time on the transplant list, and experience of previous transplants). The study took place over 18 months, between November 2007 and April 2009.

2.3 Recruitment

Participants were recruited from a collaborating renal unit, which had approximately 200 patients on the active kidney transplant list at the start of the project. Two methods of recruitment to the study were used. The main method was via a transplant coordinator at the unit, who sent out recruitment packs on behalf of the research team. Participants were purposively sampled for inclusion in the study to obtain a sample that reflected the range of people on the transplant list. Five sampling criteria were developed by the research team over the course of the project, to include variation in the following variables: time on transplant list; type of dialysis; age; gender; ethnicity; previous transplant. These criteria, and the number of recruitment packs sent out for each set of criteria, are detailed in Appendix 1. One hundred and ten (110) recruitment packs were sent out in this manner.

As early recruitment to the study was relatively slow, posters inviting interested individuals to take part in the study (Appendix 2) were displayed at the main hospital and satellite dialysis units for the last four months of the recruitment period. An additional eight recruitment packs were sent out following enquiries from individuals who had seen the posters.

Recruitment packs sent to potential participants contained a letter of introduction to the study (Appendix 3), a participant information sheet (Appendix 4), a reply slip to indicate their willingness to join the study (Appendix 5) and a stamped, addressed envelope for return of the reply slip to the researcher. On receipt of a reply slip, the researcher (JF) telephoned or emailed the participant to arrange a mutually convenient time for the interview. At this point, the researcher discussed the need for the participant to have support following the interview and potential participants had the opportunity to ask any questions.

As Appendix 1 shows, recruitment packs sent out by the transplant co-ordinator were usually sent out in batches of 10 or 20. The final batch of 20 recruitment packs achieved three more positive responses than required for the sample. Therefore the participants indicated in the final three reply slips received by the researcher were contacted by phone so that the researcher could explain the situation and thank them for their interest.

The sample is described in the Findings.

2.4 Data collection

Data collection used prospective, semi-structured, audio-recorded interviews that offered participants the opportunity to give accounts of their understanding of events and experiences. Provision had been made for an interpreter to be used where required, although this was not needed as all participants spoke English.

2.5 Interviews

All interviews were conducted face to face. Participants were also offered, but did not take up, the option of a telephone interview. Twenty-nine of the interviews took place in the participant's home, and one was conducted in a private office at the University. The majority (16) of the interviews lasted between one and two hours; eight were less than an hour in length and six (with agreement of the participant to continue) were over two hours long. In eight cases a second person was present for all or some of the interview, at the invitation of the participant.

Prior to the start of the interview, participants were reminded about the purpose of the research. The interviewer explained that interviews of this nature could be emotive and tiring and discussed participant's avenues of support once the interview was complete. Participants were told that they could stop the interview at any point and could withdraw from the study without giving a reason. Participants were given the opportunity to ask any questions they had about the study. Written consent (Appendix 6) was obtained from participants before the interview commenced. Participants were given a copy of

the signed consent form to keep. Participants were asked for consent to inform their GP of their participation in the study and this was received in all cases. Participants' GPs were informed of their patient's participation and were sent information about the study (see Appendix 7).

The interview was conducted using a topic guide (Appendix 8). Participants were asked to talk about:

- their diagnosis of kidney failure
- their dialysis and other treatments
- any symptoms they experienced
- the impact of kidney disease on their life
- their experience of being on the transplant list including: getting on to the list; any impact of being on the list on their life; their experience of waiting; their feelings about being on the transplant list; any experience of being called as a transplant reserve; feelings about the need to be permanently contactable by the hospital
- any previous transplants
- how they coped with kidney failure, dialysis and being on the transplant list
- their views of information, care and support received
- their understanding of how the transplant list works
- their understanding of and feelings about their own wait
- their hopes for life after transplant
- their views on a system of presumed consent

At the end of the interview, the researcher arranged a time to telephone the participant (usually the next day) to check that they were okay following the interview and to answer any further questions about the study (one participant stated that this was not necessary). The researcher subsequently sourced and reported back on local provision of benefits advice for one participant. Participants were all offered and accepted a summary of the study findings.

Participants were sent a thank you letter (Appendix 9) and a post interview evaluation questionnaire (Appendix 10) a few days after the interview. The purpose of the latter was to inform the researchers about the acceptability of the interview experience and the impact of the interviews on participants. These responses were not intended to be part of the study results. Twenty-five questionnaires were returned to the Principal Investigator (MS). Responses, which were generally positive, were discussed with the researcher conducting the interviews.

2.6 Data analysis

The study applied the grounded theory method as formulated by Charmaz (2006). Data analysis was ongoing throughout the study, employing the constant comparative method. Each audio-recording was transcribed verbatim and the transcript checked for accuracy against the recording. Audio-recordings were listened to and transcripts read several times and concepts or ideas were labelled through line-by-line coding. The first five transcripts were analysed separately by three members of the research team and

then discussed until coding and key themes were agreed. Coding of the complete data set was reviewed by two of the co-investigators and any discrepancy discussed and agreed. The interview transcripts were imported into the qualitative software package, ATLAS.ti, for security and coding purposes. Concepts were clustered together to form themes. Each interview transcript was analysed as an individual unit and then subjected to inter-case analysis. The identified themes were collapsed to form larger categories that explained the life world of participants and met the aim and objectives of the study.

Categories and their associated themes were arranged around the central aim of the research: 'to understand what it means for potential adult recipients to wait for a kidney transplant', to form an analytical version of their story. An integrated version of their story was written using illustrative interview excerpts to provide a holistic, cogent view of the data, to explicate arguments, gain theoretical completeness and make links with appropriate literature. A core variable or unifying theme that explained participants' psychosocial concerns and behaviour was identified following further intense deliberation and scrutiny of the data. A theory grounded in participants' experiences and behaviour, described in the findings section, was developed using this core variable.

2.7 Ethical approval

The study received ethical approval from the relevant NHS Research Ethics Committee (Reference no 07/Q1701/42). Approval for the use of posters was granted as a substantial amendment to the project. Research Governance approval was received from the relevant NHS R&D office.

2.8 Project management

The emotive nature of the research and the ethical debates about interviewing vulnerable groups were appreciated (Sque, 2000). The research team as a whole had considerable experience of conducting qualitative interviews on sensitive issues. Weekly meetings took place between the Principal Investigator (MS) and the Research Fellow conducting the study (JF). Monthly management meetings involving other co-investigators (TLS and JAH) also took place.

An Advisory Group met twice during the life of the project. The Group's purpose was to advise the researchers on the development and implementation of the project. Members were chosen to ensure that the project was carried out sensitively, was appropriate, and had scientific rigour. Membership of the Advisory Group comprised the research team at the University of Southampton; the link clinical team; a service user representative; who was invited to comment on the sensitivity and responsiveness of the project, and a Professor of Public Health, University of Southampton, who had an interest in chronic kidney disease.

2.9 Support for participants

As noted above, the researcher ensured, prior to the start of the interview, that the participant would have a source of support following the interview. It is noteworthy that the majority of participants stated at this point that they did not find discussion

of their illness to be upsetting and thus did not expect to find the interview difficult or problematic. Should any issues have been raised during the interview that threatened the safety of the participant, the researcher would have discussed referral to an appropriate professional with them. A sheet with sources of information and support about renal failure, the transplant list and benefits was compiled and offered to participants at the end of the interview and was accepted by all.

2.10 Support for researchers

Support for the researcher was provided in the form of debriefing sessions by the Principal Investigator and co-investigators. The University of Southampton's Lone Research Policy was implemented to ensure the safety of the researcher when at an interview.

2.11 Confidentiality and anonymity

Audio-recordings and transcripts were kept in a secure environment. All identifiable information was removed from the interview transcripts. All data are to be retained in a secure environment for 15 years and then destroyed, in accordance with University of Southampton policy.

3. Findings

3.1 Introduction

The findings will start with a description of the sample. This will be followed by an exposition of the ground theory that explains participants' experiences and perceptions of waiting for a kidney transplant. Exemplars drawn from the interview transcripts, which most represent participants' experiences, will be given as evidence to support data interpretation. P will be used to identify the participant and INT the Interviewer.

3.2 Sample

Interviews were conducted with 16 men and 14 women. Their ages ranged from 26 years to 76 years (Table 2.).

Table 2. Age by no. of participants

Age	No. of participants
26	1
30-39	1
40-49	8
50-59	9
60-69	5
70-76	4

There was a good variety of maintenance therapy type: 18 participants were on clinic based haemodialysis (HD), nine were on peritoneal dialysis (PD), with four of these using CAPD and five using APD, one participant was on low clearance prior to dialysis, and two who normally used PD were temporarily on HD due to infections in their catheters.

Nineteen participants were on the transplant list for the first time, nine had had one previous transplant and two participants had had two transplants.

Nine participants had been on the transplant list for less than a year, 11 for between one and two years and 10 for more than two years. The longest current wait for transplant was 9 years.

The majority of the sample was White; there was 1 Black and 2 Asian participants.

3.3 Introduction to the theory

Living with end stage renal disease (ESRD) imposes specific restrictions on day to day living. From the requirement of undergoing renal dialysis via peritoneal dialysis (requiring up to four cycles per day or overnight dialysis) or haemodialysis (usually

undertaken 3-4 times a week) to the less obvious requirement for personal adaptation to, and negotiation with, a disease process that has only one potentially long lasting treatment i.e. a kidney transplant. How individuals live with the necessity of maintaining a health status that will facilitate kidney transplantation, along with fulfilling the 'normal' requirements of daily living is explicated in the following sections. The patient with ESRD is on a trajectory that juxtaposes the desire to live as normal a life as possible (Polaschek, 2003; Lindqvist et al, 2000) with the many difficulties associated with chronic illnesses (Wright and Kirby 1999). Added to these difficulties are those imposed by being on an active waiting list for kidney transplantation, which offers the promise of leaving the life with ESRD behind.

This findings section sought to explicate the life world of individuals who live with ESRD, and who are on an active waiting list for kidney transplantation. The data produced categories which conceptualised participants' experiences and described their commonly constructed realities of waiting for a transplant. Participants' behaviours were explained through a process of 'seeking normality' which pervaded the categories and formed the core variable of their experiences. Categories were integrated around the main theme of the research, 'life on the kidney transplant list' and the core variable 'seeking normality' to provide a conceptual model of their life on the transplant list (Figure 1).

3.4 Life on the kidney transplant list: seeking normality in daily life

Participants' behaviours while living on the transplant list can be explained as a process of seeking normality. First, participants described their longer term hopes for life after transplantation as a return to normal life:

INT: We were just talking about what your hopes were, you know, how you'd see life with the ... with that transplant?

P: Back to normal. I could drink as much fluid, I can eat whatever I like, I can work full time, I can get more money, I could hopefully become self-employed again, go and do something else, and have a better quality life.

Interview 15

Second, in the shorter term, there was evidence that participants were seeking to live as normal a life as possible while on the transplant list. While this process has been previously documented in terms of living with the illness and its treatment (Lindqvist et al 2000), the present study also recognises that participants were seeking normality in dealing with their wait for a transplant:

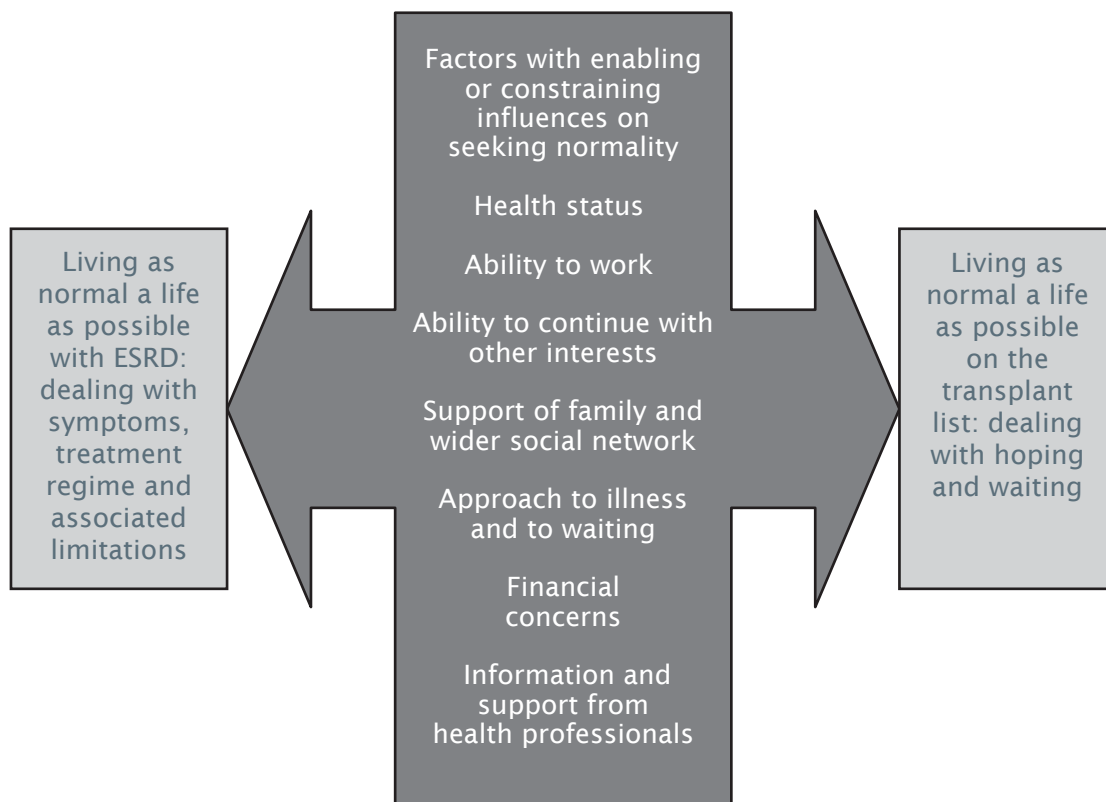
P: You can never portray how strongly or how much you want a transplant. But waiting is waiting, as [partner] said, there's nothing we can do to influence the transplant, beyond being ready for one when it happens. You know, making sure you keep, I keep as well as I can, as fit as I can. Beyond

that there's nothing I can do. I'm not in control, we're not in control of it, so what else can you do? Just carry on as normally as possible, do what you can

Interview 29

There were thus two strands to seeking normality in daily life on the transplant list: participants were dealing with the demands of the symptoms and treatment of their illness and also with the uncertainties of being on a transplant list. Dealing with the former has been described as a process of negotiation (Polaschek, 2007) of the treatment regime and the associated limitations into life and the present study confirms this. Dealing with the latter involved the two processes of 'maintaining hope of a transplant' and 'waiting as a thought process'. It is these processes that contributed to the normality of life while on the transplant list. These processes form the basis of the model presented in Figure 1 and are described below.

Figure 1. LIFE ON THE KIDNEY TRANSPLANT LIST: SEEKING NORMALITY



The data also showed that there were a number of factors that appeared to be important in achieving this normality. The presence or absence of these factors for an individual enabled or constrained/helped or hindered achievement of normality both in terms of living with the illness and in terms of waiting. These factors included health status, social support, health professional support and coping strategies. These are presented in Figure 1. The manner in which they could contribute to the normality of life in either a positive or negative manner is described in the section 'enabling and constraining factors' below.

3.5 Seeking normality in daily life with ESRD

Analysis indicated that day to day living with ESRD was governed by dealing with symptoms, treatment, and the resulting restrictions on life. There was a process of negotiation (Polaschek, 2007) of these factors to live as normal a life as possible.

Participants were more or less well with their ESRD and a number were negotiating crises in their general health or the health of their dialysis mode at the time of the interview. The impact of health status on daily life is discussed in more detail later, in section 4.1

A dominant theme in the interviews was of planning, doing and recovering from dialysis. Participants described how they dealt with dialysis on a daily basis. A number of participants, both those using PD and HD, spoke of how dialysis had been incorporated either to become a normal part of their lives, or as fitting their lives around the dialysis. This participant using APD explains:

“No. No, it’s just like - it’s just like living a normal life, apart from you, you know, you, you just plug yourself in at night and away you go.”

Interview 17

However, for other participants dialysis had a much greater impact on the normality of day to day life. This was particularly the case for those who experienced a variation in their wellness in relation to their dialysis routine (Polaschek, 2003), since, for these participants, symptoms of dialysis, such as tiredness and headaches, spilled into life outside the actual dialysis session. This participant explains:

“If we get the dialysis wrong on a Monday afternoon, it will be Wednesday morning before I’m recovering from it and then of course we’ve got dialysis again Wednesday afternoon. So it does tend to dominate life in its entirety”

Interview 8

As Polaschek (2007) has noted, even those for whom dialysis was acceptable were still undergoing a process of negotiation to fit dialysis into life. Participants in this study using CAPD described how they would juggle their dialysis sessions, or sometimes miss out a fluid change, if they wished to go out for the day. Participants who used APD spoke of how they juggled the start and finish times of their nightly sessions according to their plans for the day. Clearly there is a lack of flexibility for those using HD, but some participants described trying to use the time productively or of thinking of their dialysis sessions as part time work.

The dialysis routine also imposed other limitations on participants, such as on travelling. A number of people, both those using PD and HD, had travelled whilst on dialysis. However, for the majority, travelling was problematic. Participants using HD were limited, both in visiting relatives and friends and in holidaying, by the effort to organise alternative sessions, and by feelings of insecurity in dialysing at a different

unit. Several participants explained that loss of holiday time to dialysis made them feel that it was not worth going. While some participants using PD were happy to travel and take their equipment with them, others similarly described feelings of insecurity and the effort of organisation. In addition, they did not wish to impose their dialysis on family and friends they might be visiting.

In addition to dialysis, participants commonly had dietary and fluid restrictions which had an impact on the normality of life and needed to be negotiated into daily living. In this study, 20 participants had fluid restrictions at the time of interview and nine did not. One participant did not mention fluid restriction as being an issue. Twelve participants said they had got used to their restriction and had found ways to cope with it. Eight said they found their restriction hard to deal with; three of these reported that they did adhere to their restriction, whereas four said that they didn't. For the majority of those with fluid restrictions, social drinking was problematic, as this participant explains:

P: What social life? I can't...I go out occasionally with my sister, and we go to bingo. And, I have one drink, because of the restriction. And, that's annoying. Or, if I go out for, for a lunch, you know, for a dinner or something, and you go to a restaurant, they don't do small servings, of drink.

INT: No.

P: And you say, I'll have a half a cup of tea. They look at you...or, I'll have a small glass of lemonade...You know, and...lets face it, that's stopped me going out and doing...you know I go out for coffee with me mates, or a cup of tea, you know, I hate coffee. I go out with my mates, and I...you know, they say, "oh, do you want to stop in and we'll have a coffee at so-and-so". "No, it's all right thanks". I mean I could go and sit with them, but...that's not the point is it?...You know, yeah. That's stopped me socialising that way, because they all expect you to have a drink in your hand.

Interview 18

Similarly with dietary restrictions, while eating at home was a challenge, there was the added impact of the social aspect of eating to deal with. This participant explains about eating with friends:

"And sometimes you go to someone's house and they've done you this food, and you feel so awful that I think, Oh, I don't want to seem like a pain in the neck, you know. And yet I did start at one time, and say, "Look I'll bring my own food". "No, no, no, we'll do it." So I've got friends that were double boiling their vegetables and stuff like that and I used to feel so guilty, you know. Cos they're there doing this meal, and then they've got to worry about what they've got to do for me, you know. So when I go now, I say, "No, I'll have anything". Well, well, there's certain

foods I must, must not have, but, but I'll, I'll, for the once, I'll say, "Yep. No. Don't worry, don't worry. I'll have the same as everybody" and, you know, but I'll only have little portions of it, or whatever. You know, so it tends to make it difficult when you're visiting friends and stuff like that, you know."

Interview 12

The majority of participants experienced symptoms related to renal failure which impacted on their ability to live their normal life. The most common of symptoms was tiredness, which restricted participants in undertaking activities which were normal for them, such as daily household tasks and leisure activities. This participant explains:

"You do get tired, you know. Cos you haven't got the, the energy of a normal person. I just find I can't sort of do things round the home like I used to. Takes more time to do things."

Interview 17

In line with other studies of life with ESRD (Polaschek, 2007; Lindqvist, 2000), this study has shown that the symptoms, treatment and associated limitations of ESRD have a large impact on life, and that participants were involved in a process of negotiation to live 'as normal a life as possible' within these limitations.

3.6 Seeking normality in life on the kidney transplant list: dealing with waiting and hope

Participants were also involved in living as normal a life as possible while on the transplant list. This involved dealing with hope and with waiting, and participants were engaged in the processes of 'maintaining hope of a transplant' and of 'waiting as a thought process'.

3.6.1 Maintaining hope of a transplant

Participants were undergoing a continual process of maintaining hope of a transplant. They were involved in a process of attempting to understand their own wait and of responding to challenges which they perceived to threaten their chances, and thus their hope, of a transplant.

To make sense of their wait, participants formed and rationalised an expectation of their own wait time. This understanding and expectation was based on their perception of the average wait, their understanding of the system of allocation of organs, and on other personal attributes, such as age and the presence of antibodies, which they perceived would influence that wait time.

A few also indicated factors such as luck in their rationalisation of their wait:

"I just thought, you know, I would be one of the lucky ones who would be called within a very short space of time so I just waited for that to happen, waiting for that to happen, I'm going to get a kidney, I'm going to be lucky."

Interview 8

There were a number of different challenges to hope of receiving a transplant. Length of time on the transplant list could emerge as a challenge hope, when a transplant did not happen within the person's expected time:

"I know I've been on there quite a long time, which is why I always think well maybe I'm not going to get a kidney."

Interview 23

Challenges to hope could also arise in terms of the individual's chances of getting a transplant match. A number of participants were aware that they had antibodies which would make matching a kidney more difficult:

"So the more antibodies you've got, your matchability goes down. So mine's gone down quite a bit. I inherited quite a few um, antibodies from the transplanted kidney, from the donor. So, so, that gentleman had certain antibodies that I didn't have, but I've now got. And it's the same with the blood. There's antibodies in that blood that I didn't have, that I now have. So, so all of those antibodies stop me having a transplant... Not stop me, but the more I've got of 'em the less chance I have of getting a match."

Interview 15

Similarly, a couple of participants described having had failed matches with close family members, which was of concern to them in relation to their potential 'matchability'.

Being called for a transplant which was then not received could raise and then dash hope. Deterioration in health status was a challenge to hope and is discussed in detail in 4.1

It should be noted that, in addition to challenges, participants could experience boost to hope of a transplant, through the possibility of a live donation.

When challenges to hope occurred participants were involved in a process of re-justifying their wait and thus maintaining their hope. This participant, who had been waiting for her second transplant for 14 months when she was interviewed, explains how this might happen at several points in time:

"I sat and I thought, 'well, I'd had a phone call this time, last time I was on it', sort of thing and then you sit and think to yourself 'well, you are a little bit older now, your antibodies are a little more active so it's going to take longer' and, and you, you do, you have these conversations with yourself to sort of, justify why you haven't heard anything."

Interview 2

The process of justifying and maintaining hope could be problematic, some participants having unanswered questions about their wait for transplant:

“I've got an extremely good blood type, anybody can give me a kidney. How come then I haven't even had a whisper, you know?”

Interview 8

Important factors in this process of maintaining hope were information about the transplant list, the system of allocation of organs and transplant waiting times. Another important factor was the coping strategies that participants were able to employ. These varying factors are discussed in the section below on enabling and constraining factors (see section 4).

3.6.2 Waiting as a thought process

Waiting for a transplant was described by participants as characterised by uncertainty and lack of control. Some participants described how the uncertainty of being on the transplant list made them feel that they were living in limbo or living day to day. Others described how the uncertainty impacted on longer term planning:

“I feel I can't plan anything, you know, sort of (my husband) will say, “oh, are you getting excited about whatever?” and I'll be like “yeah” but I never take it for granted, you know what I mean?”

Interview 7

Lack of control was expressed in terms of: an inability to influence the wait; through the need to be constantly available for a transplant, which practically meant ensuring telephone contact at all times plus restrictions on distance travelled away from their renal unit; and through not being able to prepare one's home in advance of being in hospital for an operation.

In dealing with waiting for a transplant, participants clearly varied in how much they engaged in 'waiting as a thought process', that is, how much they thought about being on the transplant list on a day to day basis. The majority of participants reported that they did not think about being on the transplant list, being able to put aside such thoughts and get on with life. These participants were involved in a process of 'bracketing off' or 'containing' their hope of a transplant. This participant explains:

“It's at the back of your mind, well the back of my mind, lost somewhere deep in the filing cabinet.”

Interview 27

Bracketing off of thoughts of future ill health and possible lung transplant has been reported in adults with cystic fibrosis (Lowton, 2003). Such bracketing off has previously been identified as a means to minimise the effects of the illness on the person's identity (Bury, 1991), and as a construction of normal life (Brindle, 2000). Here, the purpose of this containment was to be able to live as normal a life as possible. These participants felt it important to achieve this 'containment' to manage the uncertainty of their wait:

INT: You are not feeling that you are waiting for something?

P: No, no. I think if you, obviously I can't speak for everybody, but personally I think if you felt like that then you would never do anything, and it would, it's like even though practically when you look at things, we are living in limbo waiting for something to happen, which may or may not happen and it could happen in 10 minutes, it could happen in 10 years, if you, if you lived your life thinking that, you wouldn't do anything, you couldn't do anything and you couldn't function.

Interview 2

For this group who did actively bracket off, there were certain events which might bring thoughts of transplant to mind. For example, participants described how when they received unexpected telephone calls, usually late at night, that their first thought would be of a possible transplant.

Maintenance and containment of hope were linked, in that participants needed to have rationalised their wait to bracket off thoughts of a transplant. Where hope of a transplant was challenged, then thoughts were not bracketed off. In addition, this process of containing hope took time, participants describing how they had thought about the transplant much more frequently when they were first on the transplant list.

A number of the factors identified in the model in Figure 1 as having enabling or constraining influences were important to this containment of hope. These were factors which contributed to feelings of a normal life, like the ability to continue to work, which is discussed in detail later.

While the majority of participants were containing their hope of a transplant, other participants were thinking about the transplant on a regular and often very frequent basis. This participant, for instance, explains:

"I am always hoping maybe today and tomorrow."

Interview 1

A number of these participants who did not bracket off thoughts of a transplant had been on the transplant list for a relatively short time and so were unlikely to have formed an initial rationalisation of their wait. Others in the group were characterised by such challenges to hope identified earlier: health crises, inability to work, and difficulties with dialysis. There were also a couple of participants who had experienced traumatic failed transplants.

3.7 Summary

There appeared to be two sides to seeking normality in daily life while on the transplant list. Participants waiting for a kidney transplant needed to deal with the symptoms, treatment and limitations of ESRD but also deal with the uncertainties of being on a transplant list. They deal with the former by negotiation of these factors into daily life and with the latter by processes of maintaining and containing hope.

4. Enabling and constraining factors

As illustrated in Figure 1, there were certain factors that were important in dealing with ESRD and life on the transplant list, and the presence or absence of these factors appeared to support or hinder the achievement of normality in life on the transplant list.

4.1 Health status

A key factor in the stability of daily life was health status. Status of health is important on a number of levels and can impinge on both living with ESRD and living on the transplant list.

It is no surprise that fluctuation in status of health has an impact on living with ESRD. Participants faced the possibility of deterioration in health status in relation to their ESRD and to other co-morbidities. A number of participants were experiencing crises in health at the time of the interview and resultant restrictions and uncertainty that brought. Participants also reported incidents of infections, such as peritonitis and other acquired infections over their time on dialysis. This participant explains her perception of the possible fluctuation in health status:

P: You just go through a bit of a traumatic time, and then sort of, you know, you get back up there again.

INT: So when everything's going well, you're feeling all right?

P: Yeah. Yeah. When you say you forget it as well, you are still...I just appreciate now that anything can go wrong, just like that. So, you can't take anything for granted really.

Interview 17

In addition, it has been shown that participants were more or less well in relation to their dialysis, some participants reporting symptoms which impacted on their life.

While deterioration in health clearly impacts on the normality of daily living, there were also implications for the wait for a transplant, with deterioration in health being a potential threat to chances of a transplant.

Some participants were aware of the importance of maintaining their general health to be fit enough to receive a transplant, should one become available. Some reported continued 'work', for example with diet, fluid restriction and physical fitness, to try and maximise their health and thus their chances of being fit for a transplant:

P: I have to make sure that every time I do have a blood test and everything else like that the conditions are good. So it's something else to think about, you know.

Int: Yeah, that all your results are...

P: Yeah that all the results are good”

Interview 9

There was also recognition of being able to wait for a transplant in one’s current health state:

“I know, eventually I’ll get one, but for now, as long as I don’t deteriorate, you know, if my health doesn’t become any worse, for now, then I think I can cope with it.”

Interview 19

Participants also spoke of health status in relation to being able to continue their preferred type of dialysis. There was recognition that living with ESRD and thus waiting for a transplant might be more difficult if forced to use a less preferred dialysis mode:

“Saying that, I mean, I love this form of dialysis. My biggest fear is having to stop this type of dialysis...that’s why I, I hope a kidney comes along sooner.”

Interview 17

In addition, participants perceived that an extended time waiting for a transplant might have an impact on their health status and thus their fitness to receive a transplant:

“If I get the kidney transplant at a young age maybe matching er easily. After I’m getting old, not proper matching and then very difficult to match the, the functioning and everything, you know.”

Interview 1

A couple of participants had, because of health status, previously experienced suspension from the transplant list, and a number had had difficulties getting on to transplant list in the first place. This was experienced as frustrating and also accentuated the vulnerability of their situation. It is suggested that staying healthy was to some extent the motivation for compliance with dialysis. In addition, frequent problems with dialysis and difficulties with resultant symptoms could make the wait for transplant more difficult.

4.2 Social support

Participants indicated that social support was an important factor in maintaining normality in life while on the transplant list. Support could be received (or not) from family members and a wider social network.

4.2.1 Support of family and friends

Participants indicated the importance of the support of family and friends in coping with their life with ESRD and on the transplant list. Many participants described their main support as being their spouse or partner, but sometimes from other family members such as parents and siblings, as well as friends. There was evidence in the data of support and lack of support from family members for all aspects of life on the transplant list.

In terms of living with ESRD and its treatment this support took a number of forms. Participants described a variety of support with practical issues, including help with the dialysis routine. Participants on PD for instance described how family members would help them to set up and clear their equipment, while participants undertaking HD described how family members or friends would drive them to and from dialysis. Both practical and emotional support was provided in relation to diet and fluid restrictions. Family members were involved in encouraging participants to maintain these restrictions and helping with practical issues of cooking suitable food.

Emotional support was also received from family and friends, both in terms of living with illness and living with the uncertainty of the transplant list:

INT: So what sorts of things would you say help you cope with all of this?

P: (Name of partner), she's, she's ultimately how I get through it.

Interview 29

Participants described the importance of having people to talk to, someone to 'sound off' to. Participants also mentioned the importance of support from friends in visiting and enquiring when they were not well. Social support was also important in general coping, with family members encouraging the participants to take a positive attitude to life on the transplant list.

4.3 Ability to work and employer support

A small number of participants continued to work full time; the majority were working part time; three were on sick leave at the time of the interview. ESRD had had an impact on work for the majority of participants in that they had reduced working hours to fit in dialysis or to allow for recuperation;

The ability to continue to work was of key importance to participants in that it maintained their feeling of being a normal person. It was a key factor both in dealing with life with ESRD and in waiting for a transplant. It was important in bracketing off thoughts of a transplant. This participant explains:

"That's another reason for keeping my job, is it's very important to have as normal a life as possible...Because if, if, if say you didn't have any other distractions, whether it be family, work, hobbies, if all you had was being ill and the light at the end of the tunnel and that's all you concentrated on, it would, I am sure it would drive you nuts, it would make you depressed and it would make life drag and it would be, it would make life a nightmare. And life can be very difficult enough anyway, [laughs] having to deal with this, without making it worse for yourself...so the, the more normal a life you can, you can lead and the less you think about, on a daily basis, about, sort of having, that the, the transplant may happen at any time, then I think it makes life a lot easier, it makes you a much happier person, I think, because you then

feel like, not that we all want to be led by sheep, act like sheep, but it makes you feel like more, more normal, more like everybody else in the world because, like I say, you are, you are working and you are doing the same things that everybody else is doing, even though you are waiting for a transplant.”

Interview 2

A key aspect in being able to continue to work was a degree of flexibility, to be able to fit in both treatment and work. Many had had to reduce their working hours to achieve this flexibility. Flexibility within one’s employment was also very valuable:

“And, it’s a flexible sort of company I work for, so I tend to do some work in the evenings, possibly, or out of normal hours anyway, so, my boss is very flexible in letting me do whatever I need to do. So quite often I, I have to go down to the hospital so I take a morning off and go down and do that or if I need to get blood taken or anything like that. Or, if I got delayed because of dialysis I’d just turn up to work late, and it’s not really a problem, so I’m very fortunate that I happen to have a job like that.”

Interview 13

Conversely, lack of flexibility made working more difficult. This was expressed in terms of lack of flexibility in working hours and lack of flexibility of the employer in finding a suitable place to carry out CAPD. This man explains:

“I don’t know, perhaps in the future I might be able to go part time or something. I would prefer it if I could, just that when I do wake up and feel rubbish I feel ‘Oh I haven’t got to go to work now’. Or if my time was more flexible I suppose.”

Interview 29

A number of those who were not working had experienced difficulties in finding a job:

“I have been for a couple of interviews sort of for like part time work. The trouble is as soon as you tell them you’ve got kidney failure or you’re on kidney dialysis, it’s “Oh well, that doesn’t bother us” but you never hear, so, you know, it’s [pause] I would love to go back to work, but then I’ve got to try and find a job that will go around me dialysis as well. I mean there are some places where you can do, do it at work, but, you know, you’ve got to find a place where they’ve, they’ve got the facilities for it so, no, so it’s quite hard to get, for you to get a job”.

Interview 5

4.4 Health professional support

It has been stated that information from health professionals was an important factor in maintenance of hope. The level of care and information giving were important factors for achieving normality while on the transplant list. Participants had requirements for three main types of information: information about kidney disease, information about having a transplant and information about the transplant list. It is the last of these which is addressed here.

4.4.1 Information about the transplant list

Participants needed information about the way the transplant list worked to rationalise their own wait. Participants generally understood the basis of matching in terms of blood group and tissue type; but there were many misconceptions/lack of understanding about kidney allocation, beyond that. Participants had queries about the impact on the process of allocation of kidneys of the age of the recipient, the length of time on list, and how ill you were. Those who had been told that the presence of antibodies was limiting their chance of a transplant had questions about whether these antibodies could be influenced and whether they were permanent. Lack of such information could make understanding one's own wait problematic, as this participant illustrates:

“Because I am very common apparently on blood and tissue, I, you know, I can't imagine why it's taking so long.”

Interview 4

A number of participants expressed concern about the transparency of the transplant list, feeling that the allocation process was hidden, and again, this could make rationalisation of their own wait problematic. This participant explains:

“I always feel they don't want to tell me very much to be honest, the Transplant people, because my one question is “where am I on the List?” And that's the one thing they can't tell me. The answer is always “It's not a question of moving up the list, it's a question of a match”. Well I think that's an easy answer for them to give, because it means that I cannot possibly come back to them and say “It must be my turn”, because it's not about turns, or that's what they say. But at the same time, I simply don't believe that I would come before a teenager, say a teenager with all their life ahead of them.”

Interview 22

Most information about the transplant list was received from health professionals and, in fact, very little information was sought elsewhere. Information might have been imparted at different points in the participant's illness trajectory. In addition, participants had received information in different forms. It was common for stories of both long and short transplant waiting times to be recounted by participants in talking of their own wait time. Such stories had been gleaned both from health professionals and other patients.

4.4.2 Information and support for financial issues and social needs

A number of participants noted a lack of support for financial issues and social needs. There was a lack of information and support in dealing with benefits and several participants had found completing the required paper work to be particularly difficult when feeling unwell:

“I mean benefits are rubbish and trying to get them is like a nightmare, it’s so difficult because there’s so many forms to fill in, it’s like a mini booklet and then there are so many forms and things you have to get and you have to get this signed from that person and this, and when you are incapacitated and not feeling well, it’s so difficult to do those things. It needs somebody to say “right, Ok, I’ll do it and take it over”. You need an Advocate really to help you. There is nobody really to help, it’s very difficult.”

Interview 23

In addition there was a lack of social worker/counsellor support for dealing with related issues:

INT: Did you have any support when you were feeling down? Did you, did you have anywhere you could go?

P: No. And that’s what I’m saying, there should be some, I know they’ve got the help line, but run by patients and what have you, but sometimes it’s not as good as perhaps, not a psychiatrist, but a social worker, or someone on those lines. Does that make sense what I’m saying?

INT: Yes, definitely.

P: Because where they’re trained in those areas (pause) you would be able to sort it out, wouldn’t you?

Interview 10

4.5 Coping strategies

A number of different coping styles were identified as being important to participants in achieving this. Taking a positive approach was a key style for coping with being on the transplant list:

“It’s difficult to um, to cope. That’s a concern, but obviously I have to remain positive, yes. I can’t do much about it, but at the same time I have to go over it by remaining positive. To be grateful of what I am getting now because it’s sustaining me and um maybe even if I get the transplant, it may not

work, after all. So yes, I have to be positive. Yes. And I think that's what keeps me going."

Interview 24

Many of the participants noted that there were others worse off than themselves:

A couple of participants described a fatalistic approach which helped them in maintenance of their hope:

I believe that. If I'm, when it's my turn I'll be here and it'll all (pause), you know, so (pause) I've got to believe that really, I think"

Interview 7

A number of participants also mentioned the need for humour as an approach to the whole of their illness situation:

"My pal says, "At least you can laugh about it". I said, "Look, (name), if I didn't laugh"...I said, I'd run away". I said, "because it's the only way I cope."

Interview 14

5. Conclusion

The medical sociology literature has highlighted the importance for patients with chronic illness of negotiating as much normality as possible in their lives (Gerhardt, 1989) . This study has been shown that patients on the kidney transplant list are seeking normality on a number of levels: in the shorter term there are dual aspects relating first to treatment and second to being on a transplant list; and in the longer term in hope of a transplant to leave living with ESRD behind and return to normal.

This study confirms others (Lindqvist, 2000; Polaschek, 2007) which show that people living with ESRD are involved in a process of negotiation to live as normal a life as possible within the limitations of their illness and its treatment. This study adds to this work by showing that participants on the transplant list undergo processes of 'maintaining hope' and 'containing hope' to live life as normally as possible while waiting for a transplant. The study has shown that there are a number of factors, the presence or absence of which can enable or constrain these processes of seeking normality.

6. Recommendations

Information needs

- There is a lack of transparency regarding the process of allocation of organs. Personalised information should be provided for those who desire it.
- There needs to be recognition of the importance of information about the transplant list and system of allocation in dealing with hope and waiting. Information about average waiting times and the process of allocation allow people to understand their wait and to rationalise hope.
- Thought needs to be given to the impact of certain types of information on hope. For instance, giving information about low chances of a transplant or providing stories of people who have only waited a short time for a transplant become embedded into an individual's understanding and rationalisation of their wait and thus their hope. Additional emotional support may be necessary when providing such information.
- Information about local transplant activity should be offered, giving hope through knowledge that transplants are being carried out.
- Clear information should be given about the process of suspension from the transplant list when travelling.
- Some individuals need reassurance that they are still active on the transplant list, as a lack of contact with transplant co-ordinators can lead to anxiety regarding this.
- Delays in receiving notification of being accepted onto the transplant list can contribute to a fear that time is being lost. Clear information about the process and reasons for delays should be offered at this time.
- There appears to be some misunderstanding about the transplant list, which is related to individuals' perceptions of how a list works, i.e. that it is normal on lists to go on at the bottom and to work one's way up. Clarity and transparency could be increased with a move away from use of the term 'list' to an alternative term, such as a 'register'.

Support needs

- Individuals on the transplant list may require specific emotional support in maintaining/rebuilding hope of a transplant in response to challenges to that hope. Loss of hope can result in insecurity, uncertainty, hopelessness, despair or depression⁶. Such challenges, which should be viewed as critical points in the waiting period, include: deterioration in health status; being given information about a low percentage chance of getting a transplant; experiencing a failed match with a close family member or being called as a back up transplant

recipient. Health professionals are in a position to supply information and emotional support, which may help to address these challenges.

- Being able to work is an important source of normality and a crucial resource in dealing with waiting for a transplant. It is important that those who wish to continue to work receive maximum support. Flexibility of treatment sessions so that work is facilitated is an important element in coping.
- Further research is needed to understand the support needs of those persons close to individuals on the transplant list and who share their day to day life with them.

Sources of information and support

- Information could be given, and queries and misinformation dealt with, by offering scheduled annual contact with transplant co-ordinators.
- The possibility of a support/social worker role within the renal unit should be investigated. This post would play a vital role in assessment of vulnerability and family dynamics, with the necessary provision of support. In addition, the role could provide much needed practical help for benefit applications.
- Patients new to the transplant list may benefit from written information, possibly prepared by more experienced patients, that highlights common experiences, problems and emotions.
- Participants described a lack of interaction with their peers. A buddy system could therefore provide a valuable support mechanism through a system of volunteers.

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Appendix 1

Recruitment criteria

- The aim of recruitment was to achieve a sample which reflected the range of adults on the transplant list in terms of a number of sample characteristics, which were believed to impact on the individual experience: age, gender, type of dialysis, ethnic group, time on the transplant list, and experience of previous transplant.
- To achieve this, recruitment packs were sent according to certain criteria developed by the research team.
- The research team devised 5 criteria over the course of the project. Each criterion was devised having reviewed the characteristics of the sample already achieved.
- The 5 criteria are detailed in the table below, showing the requirements for each sample characteristic and the number of recruitment packs sent out. For instance, the second column of the table shows that with Criteria 1 the transplant co-ordinator was asked to send packs to people who were aged between 18 and 70; 3 being men and 2 women; 3 on HD and 2 on PD; to both white and non-white individuals; and with varying time on the transplant list. 20 packs were sent within these criteria.
- The criteria were used sequentially and might be used more than once, i.e. Criteria 1 was used to send out the first 20 packs and the sample was reviewed; Criteria 2 was used to send out the next 30 packs and the sample was reviewed; Criteria 3 the next 20 packs and so on.
- Criteria 5 was different from the others in that it was to be used sequentially from 5a to 5e; i.e. if the characteristics in 5a could not be met then move to 5b and so on.

Variables	Recruitment criteria			
	Criteria 1	Criteria 2	Criteria 3	Criteria 4
Age groups	18-29 30-39 40-49 50-59 60-70	18-39	Any	Any
Gender	3 men, 2 women	5 male, 5 female	10 male, 10 female	10 male, 10 female
Type of dialysis	3 people on HD 2 people on PD	at least 5 people on HD	10 people on HD 10 people on PD	10 people on HD 10 people on PD
Ethnic groups	White/ Non-white	White and Non-white	White and Non-white	White and Non-white
Experience of transplant list	1 person on the transplant list (Tx) less than 1 year; 1 person on Tx list 1-3 years 1 person on Tx list 3-6 years 1 person suspended from Tx list 1 person suspended from Tx list and then returned to Tx list	At least 5 people who have spent less than 2.5 years, but not less than three months, on the Tx list; If possible, those who have not had a previous transplant	at least 10 people who have been less than 2.5 years, but not less than three months, on the Tx list If possible, at least 10 people who have not had a previous transplant	15 people who have been on the Tx list for more than 2.5 years; 5 people who have been on the Tx list less than 2.5 years, but not less than three months If possible, at least 10 who have not had a previous transplant
Number of packs sent for each criteria	20	30	20	20
Total packs sent	90			

HD = Haemodialysis; PD = Peritoneal dialysis; Tx list = Transplant list

Recruitment criteria (continued)

Variables	Recruitment criteria				
	Criteria 5a	Criteria 5b	Criteria 5c	Criteria 5d	Criteria 5e
		If not possible then:	If not possible then:	once 5a to 5c dealt with then the remainder to:	if it is not possible to send out to pre dialysis patients, as in 5d, then more 61-70 year olds as in 5c.
Age	any individuals aged under 40 (and who have been at least 3 months on the list) who have not yet been approached	10 people aged over 70 of whom:	5 people aged 61-70 of whom:	a range of ages	
Gender		5 men, 5 women	3 men, 2 women	half age group men and half age group women	
Type of dialysis		5 HD 5 PD	all on PD	Pre-dialysis	
Ethnic group		Any	Any		
Experience of transplant list		5 people less than 18 months on the Tx list (but more than three) and 5 people more than 18 months on Tx the list; People who have not had a previous transplant	2 people less than 18 months on the Tx list (but more than three) 3 people more than 18 months on the Tx list; People who have not had a previous transplant	half of group less than 18 months (but more than three) and half more than 18 months on the list	
Number of packs sent					20

Appendix 2

Text of poster used for recruitment

Are you on the kidney transplant waiting list? Volunteers wanted for research project

A team of researchers at the School of Nursing and Midwifery, University of Southampton are carrying out a study to understand what life is like for individuals who are waiting for a kidney transplant.

We would like to talk to you about your experiences of waiting for a kidney transplant. This would involve an interview, at your home or by telephone, which would take a maximum of two hours.

The study has been approved by the Isle of Wight, Portsmouth and South East Hampshire Research Ethics Committee (ref: 07/Q1701\42).

If you would be willing to talk to us and should like to know more about the study, please contact the researcher, Jane Frankland, or (name co-ordinator), recipient transplant coordinator:

Jane Frankland
tel: 023 80598229
email: j.l.frankland@soton.ac.uk

(Name Co-ordinator)
tel:
email:

Version 1.0 30.04.08

Appendix 3

Letters of invitation

3.1 Letter of invitation for main recruitment method

(Produced on hospital headed paper)

Study No: IOW, Portsmouth & SE Hampshire REC reference number: 07/Q1701/42

Study Title: Life on the list: An exploratory study of the life world of individuals waiting for a kidney transplant

Dear (Name)

I am writing to you on behalf of a team of independent researchers based at the University of Southampton, to invite you to take part in a research project. The researchers have been funded by the British Renal Society to carry out a study exploring the experiences of individuals who are waiting for a kidney transplant.

The aims of the research are detailed in the enclosed participant information sheet. I would be grateful if you would read this information before deciding whether you would be willing to take part in this research. The participant information sheet also outlines what your role in the research would be if you agree to participate.

If you are willing to take part in this study please could you fill in and return the enclosed reply slip in the stamped addressed envelope enclosed, within the next 7 days. On receiving your response, Dr Jane Frankland, the Research Fellow for the project, will then telephone you to discuss the project and make any necessary arrangements.

Jane will be happy to discuss any questions you might have, before you make up your mind. Her contact details are given at the top of the participant information sheet.

Thank you for taking the time to read this letter.

Kind regards

Clinical link transplant coordinator

Appendix 3

3.2 Letter sent following poster enquiries to researcher

(produced on university headed paper)

Ref: Letter of invitation 2

Study No: IOW, Portsmouth & SE Hampshire REC reference number: 07Q1701/42

Study Title: Life on the list: An exploratory study of the life world of individuals waiting for a kidney transplant

Dear (Name)

Thank you for your interest in taking part in the above research study. I enclose a participant information sheet, which details the aims of the study and what your role in the research would be if you agree to participate. I should be grateful if you would read this information before finally deciding whether you would be willing to take part in the research.

If you are willing to take part in this study please could you fill in and return the enclosed reply slip in the stamped addressed envelope provided, within the next 7 days. On receiving your response, I will contact you to make any necessary arrangements.

I will be happy to discuss any questions you might have, before you finally make up your mind. My contact details are given at the top of the participant information sheet.

Thank you for taking the time to read this letter.

Kind regards

Jane Frankland
Research Fellow

Appendix 3

3.3 Letter sent following poster enquiries to transplant coordinator

(produced on university headed paper)

Ref: Letter of invitation 3

Study No: IOW, Portsmouth & SE Hampshire REC reference number: 07Q1701/42

Study Title: Life on the list: An exploratory study of the life world of individuals waiting for a kidney transplant

Dear (Name)

Thank you for your interest in taking part in the above research study, which is being undertaken by a team of independent researchers based at the University of Southampton. I enclose, on behalf of the researchers, a participant information sheet which details the aims of the study and what your role in the research would be if you agree to participate. I should be grateful if you would read this information before finally deciding whether you would be willing to take part in the research.

If you are willing to take part in the study, please fill in and return the enclosed reply slip in the stamped addressed envelope enclosed, within the next 7 days. On receiving your response, Dr Jane Frankland, the Research Fellow for the project, will telephone you to discuss the project and make any necessary arrangements.

Jane will be happy to discuss any questions you might have, before you make up your mind. Her contact details are given at the top of the participant information sheet.

Thank you for taking the time to read this letter.

Kind regards

Recipient Transplant Coordinator

Appendix 4

Participant information sheet

(produced on University headed paper)

Dr. Magi Sque

Principal Investigator
School of Health Sciences
University of Southampton
Southampton, SO17 1BJ.

Direct line: 02380 597970
E-mail: mrs@soton.ac.uk

Dr Jane Frankland

Research Fellow
School of Health Sciences
University of Southampton
Southampton, SO17 1BJ.

Direct line: 023 8059 8229
E-mail: J.L.Frankland@soton.ac.uk

Study Title: Life on the list: An exploratory study of the life world of individuals waiting for a kidney transplant

Study No: IOW, Portsmouth & SE Hampshire REC reference number 07/Q1701/42

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Please take time to decide whether or not you want to take part.

What are the aims of the study?

The study aims to provide a greater understanding of what life is like for individuals who are waiting for a kidney transplant.

Specifically the study aims to:

- explore the impact on day to day and home life of waiting for a kidney transplant.
- explore the impact and nature of relationships and support systems in relation to waiting for a kidney transplant.
- explore specific areas of need such as might be encountered when adjusting to treatment regimens or being suspended, temporarily, from the active transplant list.

What would happen to me if I take part in the study?

We are asking you to share your experiences and any issues related to waiting for a kidney transplant. This would be done through an interview with a researcher. The interview would be carried out at a time and place which is convenient to you and the researcher, and may be face-to-face or via the telephone (whatever you prefer). The interview would be conducted using an Interview Guide. The interview would be audio-recorded to provide an accurate record of the experiences you share with us. After the interview the audio-recording would be listened to and the information on it transcribed by a research secretary. The transcription of the interview will then be analysed by the researchers.

The interview is expected to last no longer than two hours. Interviews of this kind can sometimes be emotive and you may feel tired afterwards. The researcher is trained to support you, but we would recommend that following the interview you have someone who can be with you, or someone who you can talk to after the researcher leaves. The researcher will also have the contact details of support networks available to you at the time of the interview. This leaflet will be left with you after the interview.

Would my taking part in this study be kept confidential?

Anything you say would be treated as confidential. All information collected would be kept in the strictest confidence and would be secured against unauthorised access. Your name is not recorded anywhere within the study and no individual would be identifiable from the published results. You would be completely free to withdraw from an interview or the study at any time, without giving reasons. Audio-recordings would be retained for 15 years in accordance with University regulations and then destroyed. In view of this we need your consent to these arrangements. The researcher would explain the study before starting the interview and you would have the opportunity to ask questions. You will then be asked to sign a Consent Form agreeing to participate in the study and for the interview material to be used for research purposes under the stated conditions. This Information Sheet is for you to keep. You would also be given a copy of the signed Consent Form.

After the interview

You will receive a thank you letter from the Research Team with contact details, which you can use at any time to discuss any issue raised in the interview or progress of the research. Whatever your decision is regarding participation in this research study, it will have no impact on the care or treatment provided to you by the health care professionals.

Contact for Further Information

The Researcher, Jane Frankland, can be contacted by any of the methods shown over the page, should you need to discuss anything or have any further questions at any time. If you wish to gain an independent view about being involved in research the contact below may be of use to you.

Contact details of local NHS R&D Office

Thank you for taking the time to read this information.

Dr. Magi Sque

Dr Jane Frankland

Appendix 5

Reply slip

Study No: IOW, Portsmouth & SE Hampshire REC reference number: 07/Q1701/42

Study Title: Life on the list: An exploratory study of the life world of individuals waiting for a kidney transplant

I am willing to talk to Jane Frankland about my experiences in a face-to-face/
telephone interview* ***please delete as necessary**

Your Name (Please print): _____

Signature _____

Your telephone contact no: _____

or

E-mail address: _____

Preferred contact method e. g. Telephone or E-mail: _____

Best time to contact you: _____

Appendix 6

Consent Form

Study Title: Life on the list: An exploratory study of the life world of individuals waiting for a kidney transplant

Study No: IOW, Portsmouth & SE Hampshire REC reference number: 07/Q1701/42

Principal Investigator: Dr. Magi Sque,
Senior Lecturer, School of Health Sciences
University of Southampton, Highfield, Southampton, SO17 1BJ

Researcher: Dr Jane Frankland
Research Fellow, School of Health Sciences
University of Southampton, Highfield, Southampton, SO17 1BJ
Direct line: 023 8059 8229

Please initial box

1. I confirm that I have read and understood the Information Sheet version 10th July, 2007 for the above study and have had the opportunity to ask questions.
Yes

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
Yes

3. I agree to direct quotes being used in any presentation of the research (verbal presentation or paper publication).
Yes No

4. I agree that the audio recording and transcription of my interview can be used for the purposes of: teaching emerging research students and secondary analysis.
Yes

5. I agree to take part in the above study.
Yes

6. I am happy for Jane Frankland to inform my GP that I am taking part in the above named study?

Yes

No

Name of GP

Address of GP

Name of Participant

Date and signature

Name of Researcher

Date and signature

1 Copy to participant

1 Copy to researcher

Appendix 7

GP Letter

Participant Information Sheet

Dr. Magi Sque

Principal Investigator
School of Health Sciences
University of Southampton
Southampton, SO17 1BJ.
Direct line: 02380 597970
E-mail: mrs@soton.ac.uk

Dr. Jane Frankland

Research Fellow
School of Health Sciences
University of Southampton
Southampton, SO17 1BJ.
Direct line: 023 8059 8229
E-mail: J.L.Frankland@soton.ac.uk

Study Title: Life on the list: An exploratory study of the life world of individuals waiting for a kidney transplant

Study No: IOW, Portsmouth & SE Hampshire REC reference number: 07/Q1701/42

Dear Dr. (GP Name)

Your patient, (name) has been invited and has agreed to take part in the above research study. They have consented to us informing you of their decision. In order for you to understand why the research is being done and what it would involve, we would like to ask you to read the following information which has been provided to your patient and refers to them.

What are the aims of the study?

The study aims to provide a greater understanding of what life is like for individuals who are waiting for a kidney transplant.

Specifically the study aims to:

- To explore the impact on day to day and home life of waiting for a kidney transplant.
- To explore the impact and nature of relationships and support systems in relation to waiting for a kidney transplant
- To explore specific areas of need such as might be encountered when adjusting to treatment regimens or being suspended, temporarily, from the active transplant list.

What would happen to me if I take part in the study?

We are asking you to share your experiences and any issues related to waiting for a kidney transplant. This would be done through an interview with a researcher. The interview would be carried out at a time and place, which is convenient to you and the researcher and may be face-to-face or via the telephone (whatever you prefer). The interview would be conducted using an Interview Guide. The interview would be audio-recorded to provide an accurate record of the experiences you share with us. After the interview the audio-recording would be listened to and the information on it transcribed by a research secretary. The transcription of the interview will then be analysed by the researchers.

The interview is expected to last no longer than two hours. Interviews of this kind can sometimes be emotive and you may feel tired afterwards. The researcher is trained to support you, but we would recommend that following the interview you have someone who can be with you or someone who you can talk to after the researcher leaves. The researcher will also have the contact details of support networks available to you at the time of the interview. This leaflet will be left with you after the interview.

Would my taking part in this study be kept confidential?

Anything you say would be treated as confidential. All information collected would be kept in the strictest confidence and would be secured against unauthorised access. Your name is not recorded anywhere within the study and no individual would be identifiable from the published results. You would be completely free to withdraw from an interview or the study at any time, without giving reasons. Audio-recordings would be retained for 15 years in accordance with University regulations and then destroyed. In view of this we need your consent to these arrangements. The researcher would explain the study before starting the interview and you would have the opportunity to ask questions. You will then be asked to sign a Consent Form agreeing to participate in the study and for the interview material to be used for research purposes under the stated conditions. This Information Sheet is for you to keep. You would also be given a copy of the signed Consent Form.

After the interview

You will receive a thank you letter from the Research Team with contact details, which you can use at any time to discuss any issue raised in the interview or progress of the research. Whatever your decision is regarding participation in this research study, it will have no impact on the care or treatment provided to you by the health care professionals.

Contact for Further Information

The Researcher, [Name] can be contacted by any of the methods shown over the page should you need to discuss anything or have any further questions at any time. If you wish to gain an independent view about being involved in research then either of the contacts below may be of use to you.

Contact details of local NHS R&D Office

Thank you for taking the time to read this information.

Dr. Magi Sque

Dr. Jane Frankland

Appendix 8

Interview topic guide

Introduction

- Thank you
- Summary of research.
- Format of interview

- Emotive and tiring

- Support

- Stop at any time;
- Withdraw at any time, without reason
- Wouldn't impact on care
- Confidential to research team

- Will record if happy
- Also write things down

- Any questions?

- Consent form

Diagnosis of disease	
Before start talking about being on the transplant list, should like to get a background to your kidney disease	
<i>What's it like and how does it make you feel?</i>	
<i>Could you tell me about your kidney disease from the start?</i>	
Age	Then and now
When first aware	Signs and symptoms
When/where sought help	Who? What? When? Where? How?
Diagnosis	How came to be diagnosed?
	What doctors said was cause?
	How felt when told?
Previous transplant	Offered kidney; how felt
How life changed with transplant and how it changed when transplant failed	Transplant; how felt
	Off dialysis; how felt
	When/why failed; how felt
	Back on dialysis; how felt
Kidney disease now	
<i>Could you tell me about your kidney disease now?</i>	
Dialysis	At what point dialysis?
	What was it like going onto dialysis? How find dialysis now? How feel about it?
	History of type of dialysis: what types had? How found each? Where go? Time travel? Why chose HD/PD; explored other as option? Any problems with dialysis? How cope with dialysis routine?
Treatment	What treatment now? Medication, (for? How much?) diet, (certain things shouldn't eat?) fluid, epo? How find them/feel about them? How manage them? Why do that? Tell hospital?
Symptoms	What symptoms now? How cope with them? Fatigue? Depression? Aches and pains? Sleep problems? Energy? Any support for depression?
What like living with renal failure?	How feel? How cope with it?
Does being on the waiting list affect your life in any way?	Life in general/day-to-day life? Anything can't do?
	Daily living; work; relationships; family life; other roles; social life; finances; insurance?
	What have been the main issues for you?

Information, care and support	
<i>Could we think about the care you have received FOR KIDNEY DISEASE ?</i>	
How found care?	How has your care been, would you say?
How found support?	Where get social support from? E.g. other kidney agencies
How have you found info from health professionals?	About kidney disease About the transplant list Hospital; GP; consultant; surgeon; transplant team?
Other sources of information?	Charities Internet
Unfulfilled needs	Anything like/need to know more about?
	Feel you can ask if have query/problem? Who, when, where?
Experience of being on the transplant list	
<i>Thank you for that; could we now talk about your experience of the waiting list?</i>	
Getting on the list	
History on the list	How long been on? How far into disease?
	Ever suspended? Illness/holidays
	Ever possible that someone you know might donate to you?
	Ever any possibility of a kidney in that time?
	Ever called in with possibility of a kidney which then didn't happen for some reason?
<i>Think back to when first went on the list and about the process of getting on.</i>	
How/when was possibility raised?	By who? Remember what they told you about it?
	Remember how felt?
	Why did you decide to go on list? Reason for wanting a transplant?
	Was it the right time for you? Would you have been happy with it earlier/would it have been better later?
	What think about process of getting on list?
	Given enough information at the time?

Being on the list	
Does being on the waiting list affect your life in any way?	Life in general/day-to-day life? Anything can't do?
	Daily living; work; relationships; family life; other roles; social life; finances; insurance?
What is typical day like?	
Work	When gave up? How fit in with dialysis?
Any issues/problems that you think have been to do with being on the list?	What have been the main issues for you?
Depression	Ever feel depressed? Any support?
Information, care and support	
<i>Could we think about the care you have received ABOUT BEING ON THE TRANSPLANT LIST ?</i>	
How found care?	How has your care been, would you say?
How found support?	Where get social support from? E.g. other kidney agencies
How have you found info from health professionals?	About kidney disease About the transplant list Hospital; GP; consultant; surgeon; transplant team?
Other sources of information?	Charities Internet
Unfulfilled needs	Anything like/need to know more about?
	Feel you can ask if have query/problem? Who, when, where?
Feelings about being on the list	
<i>Can you tell me what it's like being on the kidney waiting list?</i>	
Waiting	How describe being on the list? Does it change over time? How do you find the waiting? How make you feel?
Concerns?	Any concerns/worries about being on the list?
Coping mechanisms	Anything that helps you cope with waiting/cope with how you feel?
Uncertainty	How feel about fact of not knowing when it might happen? About uncertainty of when?
Phone standby	How feel about having to have phone on all the time? Find that difficult? How make you feel? Did it take time to get used to e.g. jump when phone rings? Does this change over time?
Being offered a kidney	Give any thought to actually being offered a kidney? What thought about it? How think might feel? Worries/concerns?

Life after transplant See it as before kidney disease or different to that? Healthy, normal, still patient but different?	Reason for wanting a transplant? What are hopes for life after transplant? How do you see your life after your transplant? Any concerns about it?
How the list works	
<i>Like to talk about how the transplant waiting list works and how you feel about that.</i>	
How the waiting list works? Do people understand how the list works? If not, where does the confusion come from?	What do you know about how the waiting list works? average wait; allocation system; need to match Where got information from? Has it been explained to you enough?
How feel about system?	Straightforward/easy to understand?
Length of wait	How feel about how long waited/might wait? Why think waited (so long)? How found waiting so long?
Any other comments/ feelings about way list works?	
View of presumed consent?	
Transition	Paediatric to adult services
Anything else you would like to tell me about waiting for a transplant?	

ENDING THE INTERVIEW

- Offer summary
- Offer sheet of information
- Can call tomorrow to check feel okay about the interview and things we've talked about
- Send thank you and form to complete which asks you about the interview and how you found it.

What do now?

Appendix 9

Thank you letter

(produced on University headed paper)

Date

Dear (Name)

Re: Life on the list: An exploratory study of the life world of individuals waiting for a kidney transplant

Just a note to say a personal thank you for sharing your experiences with me, and for so generously giving up your time.

The Research Team would be grateful for some feedback on your impression of the interview and how it may have affected you [please see enclosed Post Interview Questionnaire]. We appreciate a number of difficult issues were raised and it would be helpful to know your feelings about what it was like to take part in the interview.

Please could you return the questionnaire with your comments to Dr. Sque. I have enclosed a stamped, addressed envelope for your reply.

I would like to take this opportunity to thank you, once again, for all your help.

With kind regards

Dr Jane Frankland
Research Fellow

Appendix 10

Post Interview Questionnaire

1. Did you feel that you were able to cope with the length of the interview?

- Yes, quite easily
Only just
No

2. Did you find talking to Jane Frankland in the interview helpful?

- Yes, very helpful
Yes, a little
No

3. Did you feel the interview caused you distress?

- Yes, a lot
A little
No

4. Did you feel that Jane Frankland was understanding during the interview?

- Yes, very understanding
Yes, a little
No

5. Did you find it easy to talk to Jane Frankland during the interview?

- Yes, very easy
Difficult at times
Extremely difficult

If you have any other comments please write below.

Thank you for completing the questionnaire

Notes

Notes

Notes

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