

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

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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 out, 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 %
<b>Gender</b>		
Male	16	53
Female	14	47
<b>Age</b>		
26	1	3
30-39	3	10
40-49	8	27
50-59	9	30
60-69	5	17
70-76	4	13
<b>Ethnic group</b>		
White	27	90
Asian	2	7
Black	1	3
<b>Type of maintenance therapy</b>		
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
<b>Years on transplant list*</b>		
< 1 year (but more than 3 months)	9	30
1-2 years	11	37
> 2 years	10	33
<b>Number of previous transplants</b>		
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 transplant<sup>2</sup>. 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 method<sup>3</sup>, 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 possible<sup>4</sup>. 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.

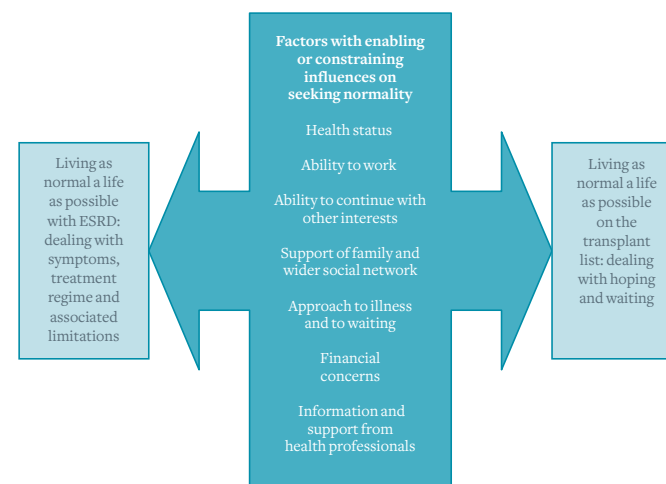


Figure 1 - Life on the Transplant List: Seeking Normality

- 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 negotiating<sup>5</sup> 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 of 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 depression<sup>6</sup>. 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.

## References

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