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# **Waiting for a Kidney from a Deceased Donor: An Interpretative Phenomenological Analysis**

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## **Running title**

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## **Abstract**

Demand for kidneys from deceased donors far outstrips supply. Despite this, there appears to be little research that focuses solely on the experience of waiting for a kidney from a deceased donor. This study uses the qualitative methodology Interpretative Phenomenological Analysis (IPA) to explore the lives of 10 people on the transplant list, with the aims of illuminating the potential psychological challenges those on the list may face during this time, and providing information to help clinicians more fully support such people in the future. Two themes connected to the experience of waiting – adjustment to the uncertainty of waiting and thinking about receiving a kidney from a living donor – are presented here. Participants describe a sense of confusion and uncertainty around life on the list, and discuss their strategies for dealing with this. Novel complexities around the ambiguous challenge of receiving an organ from a deceased donor are revealed. It is recommended that healthcare teams provide a forum for this patient group to work through these feelings of confusion and ambiguity.

## **Keywords**

Deceased renal donor recipients; ESRD; phenomenology; renal failure; waiting list

## **Introduction**

Demand for kidneys from deceased donors far outstrips supply; around 6,000 people were on the waiting list for a kidney from a deceased donor in 2013 (NHS, 2013). In the UK, the average time spent on the waiting list is three years (NHS, 2014), whilst in the US, kidney patients can wait between five and 10 years for a new organ (LKDN, 2015). As such, we can see that this is an important period of time for health psychologists to investigate. However, there is a dearth of research focusing solely on the pre-surgery experience of waiting for a kidney transplant. The literature that does exist suggests a range of potentially psychologically distressing factors for those waiting for a kidney from a deceased donor. Several papers have found that those on the waiting list feel they do not have enough information about how it works, leading to a sense of confusion (Martin et al., 2010, Calestani et al., 2014, Weems and Patterson, 1989)

A qualitative report into life on the waiting list (Sque et al., 2010) suggests that people who are waiting for a kidney from a deceased donor are striving for normality, albeit a normality that is constrained by factors including dialysis (Sque et al., 2010). Many participants didn't think about the list; however, it came back to mind when participants faced psychological challenges such as being called as a back-up recipient for a kidney. (Sque et al., 2010).

In addition to this, quantitative research has shown that those on the waiting list for a kidney from a deceased donor are more prone to depression and anxiety than those due to receive from a living donor (Akman et al., 2007). As such, these findings

strengthen the argument that this group is worthy of further exploration.

Research that explored what it is like to wait for different organs such as livers or hearts, and found that waiting time feels like ‘purgatory’ (Brown et al., 2006) or life being ‘on hold’ (Fitzsimons et al., 2000).

Given these elements, it seems that investigating this period is worthwhile and has the potential to enable clinicians to more easily identify and therefore more fully support those on waiting list who have additional needs.

The aim of this paper is to explore what it is like to wait for a kidney from a deceased donor using the qualitative method interpretative phenomenological analysis (IPA).

## **Methods**

### *Design*

Qualitative methods are useful for researching experiential processes about which little is known (Tong et al., 2009). IPA, which allows for a nuanced explication of participants’ experiences (Smith et al., 2009), was selected as the most suitable method. IPA is a method that has roots in the philosophy of phenomenology, which is interested in exploring precisely what it is like to experience the phenomena in hand (Smith et al., 2009). IPA works with small, homogeneous samples in order to unpick the idiographic experiences of those participants in great depth (Smith et al., 2009). IPA papers aim to interpret data in a manner that is resonant and nuanced (Smith, 2011). Hence, this methodology ensures a depth of analysis which can be traced back by the reader as they consider the verbatim quotes in alignment with the researchers’

interpretations of those quotes. In this way, IPA adheres to Yardley's (2000) evaluation criteria of rigour and transparency.

### *Ethics*

This study received ethical approval from Birkbeck University of London.

### *Participants*

Ten participants were recruited from two online ESRD support groups after gaining permission from the site moderators. Inclusion criteria were that participants were native English speakers living in the UK who had been on the waiting list for a kidney for at least four months. Potential participants got in touch with the first author, were sent information sheets, and an interview was arranged. Three people who got in touch didn't go through with interviews for health reasons. All others were interviewed and included in the analysis. Informed consent was collected in person by the first author, and it was explained that all data would be anonymised before use. Demographic information is in table 1, below. Participants had been waiting between four months and two years (mean = 15.3 months).

Table 1: Demographic information

>>>>>Table here<<<<<<

### *Data Collection*

The first author, a qualitative health researcher, undertook the 10 semi-structured interviews, which took place in participants' homes, workplaces or quiet cafes. The interview schedule consisted of open-ended questions and avoided leading participants. The interviews were participant-led, thus ensuring rigour and a lack of bias. Interviews were audio recorded and transcribed verbatim. Interviews lasted between 45 and 90 minutes and were collected between October 2011 and June 2012.

### *Analysis*

Data was analysed according to the principles of IPA. Transcripts were read and analysed by searching for points of descriptive, linguistic and conceptual note. Emergent themes were clustered into tables and compared across participants. Whilst analysis was rigorous and sensitive to the context of these individual participants (Yardley, 2000), it should be noted that interpretations here are bound by the experiences and sense making of this particular sample. The qualitative nature of these findings add to our understanding of what it is like to wait for a kidney from a deceased donor in fine detail (Sandelowski, 2010).

Analysis was undertaken by the first author and audited by the second, a very experienced qualitative health researcher. Any disagreements about interpretations were discussed until an agreement was reached. Both authors were experienced with using IPA within health psychology settings. The first author is a previous living kidney donor. She kept a reflexive diary throughout the research process. However, it was not found that the experiences of the participants aligned with her own experiences, since they are quite different strands of a similar story.

## Results

### Adjusting to the uncertainty of waiting

All ten participants talked about confronting the confusion and uncertainty of waiting, and then developing coping strategies in order to adjust to this uncertainty.

#### *Confusion and uncertainty*

Several participants discussed feeling confused about how the list worked. Jenny says:

*I sort of feel like I'm waiting for a council house? That I need to get more points. But I don't know how to get more points (laughs)!*

Jenny's tone is light, but frustrated. One wonders if her frustration comes from the fact that her status on the list isn't under her control.

Michael says:

*I knew I wasn't on the list (pause) [...] you could kid yourself that that's not the case [...] Although I knew rationally that I, wasn't.*

Despite Michael's denial that he himself was confused, his use of the word 'rationally' suggests he did sometimes 'kid himself' about his list status.

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<sup>i</sup> [...] Indicates editorial elision



A sense of uncertainty accompanied the confusion for James:

*If you had the kidney, what would happen, [...] whether, I'd be worse off with it.*

James feels there is no guarantee that receiving a kidney will improve his situation.

This is an unexpected stance for a transplant list patient to take.

Finally, Wendy had a practical suggestion:

*I would like to have the occasional update to say (pause) this is the progress we're making. [...] We don't have any problem with yours except, there are a lot of people wanting the same kidneys.*

Receiving an update with a personalised element in the post would help Wendy feel more clear about her position on the list.

*Strategies for coping with waiting*

This confusion and uncertainty caused the participants to employ a range of emotion-focused coping strategies.

Jaspreet saw the list as a personal challenge:

*I could do it without going on dialysis [...] I've got probably a year, I could probably do it, I could probably do it.*

Jaspreet's repetitive language assumes a level of control over his condition. By turning the list into a challenge, it felt more like something Jaspreet could survive.

Rachel employs a 'balancing act' strategy between paying the list no mind, and yet staying on the alert for the call:

*I don't really think about it day to day. It's just if the phone goes.*

Although Rachel tells us she doesn't often think about the list, she then says she thinks about it if the phone goes – presumably a frequent occurrence. This is complex mental gymnastics.

Finally, both Elaine and Elliot employ avoidance as a coping strategy. Elaine says:

*I never think about it (pause). It's there, put it out of my mind.*

Elliot says similarly:

*I kind of don't think about it. It's not something that for me is really top of my mind.*

*Adjusting to the suspended animation of waiting*

As we have seen, participants initially felt confusion and uncertainty around the list, leading them to develop coping strategies. Eventually, their feelings about being on

the waiting list adjusted in various ways.

Jenny's initial resistance changed as time went on and her symptoms worsened:

*I think psychologically I wasn't ready for it because I, I still felt ok. [...]  
But then when I started (pause) the dialysis in the September, I was  
wrecked and shattered, I just felt awful. So when I started dialysis, I  
was like, right, I'm ready. I'm ready for this [transplant] to happen.*

In contrast, Charlotte went from expectation to cynicism:

*I packed a bag (pause) I had a phone installed upstairs, I got a mobile  
phone (pause) thinking, you know, they're gonna call me. And then you  
gradually realise (laughs), they're not gonna call you!*

Charlotte also talks about how waiting imposes a frozen passivity on her: *It is a funny  
(pause) state to be in, it is kind of like suspended animation.* The metaphor of  
suspended animation suggests that she without agency, equivalent to being dead – yet  
she can be reanimated if a kidney arrives.

### **Thinking about receiving a kidney from a deceased donor**

In addition to adjusting to being on the waiting list, participants had to prepare for  
the possibility of receiving a kidney from a deceased donor. As with the previous  
theme, this meant that participants had to adjust their cognitions and find coping  
strategies for this possibility. Seven participants discussed this.

*Complex presentation of comfort with deceased donor donation*

Several participants gave a presentation of being at ease with the idea of receiving a kidney from a deceased donor, although this may have belied more mixed feelings.

Jaspreet says:

*Being [...] a logical, science-based person, [...] I see it as (pause) and some people at work have said it's akin to (pause) a spare part for a car.*

Jaspreet employs a machine narrative for the donor, calling them 'it' and likening their kidney to a car part. However, he prefaces his take on this situation with a rationalisation of who he is, and backs this up by saying that others agree with him. It feels as though Jaspreet is justifying his stance of being ok with using a deceased donor.

This feeling of internal conflict is deepened by Jenny:

*I probably will be quite selfish about it and just be like well (pause) that's good (pause) for me. Cos I don't know the person that's gonna pass away. That sounds horrible.*

Jenny is critical of her expected ease around receiving a kidney. Unlike Jaspreet, Jenny sees the donor as a person, and uses the softer terminology of 'passing away'. The emotions here are not straight forward.

Elaine responds in another way:

*I always used to give blood. Anybody can have anything of mine that's salvageable (pause)[...] I think a lot of deceased families get comfort [...] from the fact that some good has come from their loss.*

Elaine talks about her own actions as a blood donor, and the benefits of donation to the grieving family. It could be that this is a neat way to avoid thinking about the arguably emotionally complex fact of receiving the organ of a recently killed person in order to sustain one's own life.

*Awareness of potential emotional difficulties around receiving a kidney*

Despite these presentations of being at ease, there was awareness for one participant that receiving a kidney may not be as easy she hoped.

Rachel was the only participant who had already had a kidney from a deceased donor, which had since failed:

*I can remember waking up from my transplant, and thinking yay! It's happened. [...] And then I thought (pause) oo, I've got somebody's (pause) body part in me.*

Rachel's initial joy swiftly becomes an unexpected, embodied sense of feeling unsettled. Her use of the term 'body part' conjures up images of Frankenstein's monster. Rachel doesn't use metaphors about recycling or spare car parts. The 'body

part' is something that was once 'somebody's' and is now inside her.

This experience means that Rachel's attitude has changed:

*I know somebody's got to die. [...] I shock people, cos they're saying  
have you got a transplant yet, [...] I say well somebody's got to die  
(pause) for me to have a transplant [...] somebody's got to actually  
(pause) to die.*

Rachel repeats 'somebody's got to die' three times. Although Rachel says she now knows the reality of the situation, her repetition of this blunt phrase, plus the fact that she is using it to shock others, suggests that she is still trying to make sense of it.

Whereas others avoided talking about their potential deceased donors in humanising ways, Rachel is bludgeoning us with this fact. One could speculate that the lengthy time those on the transplant list must wait could feed into concerns about who the donor may be and what may happen to them, increasing the need to use avoidant coping, such as that demonstrated by Elaine and Elliot earlier.

## **Discussion**

### **Adjusting to the uncertainty of waiting**

Existing work in this area has found uncertainty to be of concern to those on the waiting list for organs (NHS, 2013, Calestani et al., 2014, Weems and Patterson, 1989, Martin et al., 2006). Just as James, Jenny and Wendy describe, patients waiting for a liver transplant (Moran et al., 2009) found that a lack of contact from the team

left them feeling forgotten. Some of these liver patients also questioned whether they truly wished to be on the list (Moran et al., 2009), mirroring James's experience and demonstrating the depths of uncertainty some list members feel.

Both James and Jenny felt frustration as a result of their confusion. It could be posited that this is because they have no ability to control the situation (Lefcourt, 2014, Rotter, 1966). This interpretation is deepened when we consider the coping strategies used by the participants. Many of these strategies (reframing the situation, adopting a mental balancing act and acceptance) are emotion-focused rather than problem-focused (Folkman and Lazarus, 1985). This fits in with existing literature, which suggests that emotion-focused coping is best employed in situations where stressors are uncontrollable (Folkman and Lazarus, 1985, Nicholls et al., 2012). The waiting list seems to be an exemplar of an uncontrollable stressor, since not only are the participants unable to control their place on it, they also struggle to understand what that place is.

Further to this, it is noteworthy that Elaine and Elliot use avoidant coping to deal with their uncertainty. It has previously been shown that avoidant coping is related to poorer health outcomes in heart disease patients (Eisenberg et al., 2012). However, the participants in this study did not seem to be experiencing heightened distress as a result of using this coping style. Participants in another qualitative study (Sque et al., 2010) discussed deliberately putting the list out of their minds as a way to manage their hopes, suggesting that the waiting list may be unique in terms of relevant coping strategies.

It is clear many waiting list patients feel confused. Therefore, it seems prudent for healthcare teams to be as transparent as possible with patients about waiting times, bearing in mind that these patients may be unable to take the information in at first. Regular updates, as Wendy suggested, may be needed to remind patients of how the system works, a finding also reflected in existing qualitative literature (Sque et al., 2010).

### **Thinking about receiving a kidney from a deceased donor**

The in-depth design of this study allowed for novel findings around the psychological complexity of receiving a kidney from a deceased donor.

Previous research has demonstrated that receiving a kidney from a living donor can be psychologically complex (Spiers et al., 2015). However, one might speculate that receiving a kidney from a deceased donor would be less challenging. Indeed, participants in several qualitative studies have expressed a preference for deceased donors so that they do not have to inconvenience loved ones (de Groot et al., 2012, Gill and Lowes, 2014, Pradel, 2003). Consequently, our finding that it can be challenging for renal patients to accept kidneys from deceased is important.

Our finding can be compared to the experiences of heart transplant patients (Shildrick et al., 2009), who are told on the one hand that their donors are selfless givers, and on the other hand that the organ they are receiving is akin to a spare part for a car. The metaphor of the body as a machine is one that Jaspreet uses. Sanner (2003) suggests that seeing the body in this way aids psychological adjustment to receiving a kidney



(Sanner, 2001, Sanner, 2003). However, Sanner states that it is hard for anyone to fully buy into this construct.

Svenaesus (2010) uses Heideggerian phenomenology to draw our attention to the different narratives we have around the body and inherently, therefore, for the organs within it that are exchanged in transplantation. He makes the point that potential transplant recipients are encouraged to use the narrative of the gift of life. Donors are presented as generous givers. However, the underlying and contradictory narrative seems to be one that positions organs as a shared resource rather than a gift (Svenaesus, 2010). Svenaesus uses the example of opt-out systems as an example of the way in which we see organs as a resource. The expectation behind these systems is that organs are a resource to be used for the benefit of society, rather than something solely belonging to the person in whose body they reside. This phenomenological perspective may help explain why several of the participants presented such complex emotions around the tricky phenomena of receiving a kidney from a deceased donor.

Based on the findings of this study, and in line with existing research (Calestani et al., 2014), it is recommended that waiting list patients be given more clarity around how the list works and their continued status on it; and that clinicians offer talking therapies to waiting list and transplant patients so that they have space to work through any issues arising from receiving a kidney from a deceased donor.

#### *Limitations and future research*

A potential limitation of this study is that, given that two of the participants had not yet started dialysis, whilst the others were on different dialysis types, the homogeneity

principle of IPA (Smith et al., 2009) may have been contravened. However, convergences in terms of participant experience and emergent themes was strong, so it was felt that participants could be treated as a homogeneous group despite differences. It may also be considered that the ability to compare somewhat more divergent cases in terms of dialysis brought an unexpected strength to the analysis, demonstrating the flexible nature of qualitative inquiry, wherein no one rule fits all.

Future researchers might speak to ESRD patients who have received deceased donor kidneys to find out how they have made sense of this phenomena.

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Table 1: Demographic information for participants

<b>Name</b>	<b>Age</b>	<b>Dialysis type</b>	<b>Time on list</b>	<b>Illness?</b>	<b>Previous tx?<sup>a</sup></b>
Miranda	20s	Overnight PD	7 months	Alport's	No
Jenny	20s	Overnight PD	2 years	PKD	No
Rachel	50s	Overnight PD	10 months		Yes (deceased)
Wendy	50s	CAPD	18 months	PKD	No
Michael	40s	CAPD	4 months	PKD	Yes (living)
Jaspreet	40s	Haemo (home)	2 years	PKD	No
James	60s	Haemo (home)	2 years	PKD	No
Elaine	50s	Haemo (hosp)	2 years	PKD	No
Charlotte	50s	None	1 year	PKD	No
Elliot	30s	None	6 months	IgA nephropathy	No

<sup>a</sup>TX = transplant