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# BMJ Open

## **“You’ve got a foreign body in there”: Renal transplantation, unexpected distress and patients’ support needs: a qualitative study**

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3 **“You’ve got a foreign body in there”**: Renal transplantation, unexpected  
4 **distress and patients’ support needs: a qualitative study**  
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8 Short title: Unexpected distress in renal transplant patients  
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## ABSTRACT

**Objective:** To explore why transplant patients experience mild-moderate distress and what support they may need.

**Design:** Qualitative study using individual in-depth interviews.

**Setting:** Four NHS Trusts in the Midlands, UK.

**Participants:** Fifteen renal transplant patients meeting the criteria for mild to moderate distress from their responses to emotion thermometers.

**Main outcome measures:** identification of the reasons for distress and support options acceptable to renal transplant patients.

**Results:** Three themes were interpreted from the data: 'I'm living with a "foreign body" inside me', 'why am I distressed?' and, 'different patients want different support'. Following their transplant, participants felt that they should be happy and content, but this was often not the case. They described a range of feelings about their transplant, such as: uncertainty about the lifespan of their new kidney, fear of transplant failure or fear of the donor having health conditions that may transfer to them. A few experienced survivors' guilt when others they had met at the dialysis unit had not received a transplant or because someone had died to enable them to receive the transplant. No longer having regular contact with the renal unit made participants feel isolated. Some participants did not initially attribute the source of their distress to their transplant. Participants' preferred support for their distress and their preferences about who should deliver it varied from peer support to seeing a psychologist.

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3 **Conclusion:** Raising the issue of post-transplant mild-to-moderate distress with  
4 patients and encouraging them to think about and plan coping strategies pre-  
5 transplant may prove beneficial for the patient and healthcare provider. Patients  
6 should be able to choose from a variety of support options.  
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## 16 **ARTICLE SUMMARY**

### 17 **Strengths and limitations of this study**

- 18 • This is the first study designed to explore the issue of mild-to-moderate  
19 distress in renal transplant patients.  
20
- 21 • The Interviews were a sub-set of data from a larger study.  
22
- 23 • To reduce bias on the basis of the services offered to liver patients multiple  
24 sites with different organisation and delivery of services were selected.  
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- 26 • The diversity of participant characteristics supports the representativeness of  
27 the findings to this patient group.  
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## INTRODUCTION

At the end of 2017, 63,162 adults were receiving renal replacement therapy in the UK<sup>1</sup>, and in the same year 3,462 transplants were performed.<sup>1</sup> Patients with end stage renal disease (ESRD) can experience distress and distress is associated with lower quality of life and greater treatment burden.<sup>2</sup> The level of emotional distress increases as the health of a patient with ESRD declines<sup>3</sup> and the prevalence of depression and anxiety in patients with ESRD is approximately four times higher than in the general adult population.<sup>4</sup> Damery et al 2019<sup>5</sup> reported that more than a third of renal dialysis patients suffer emotional distress. If suffering from mild-to-moderate distress – the unpleasant feelings or emotions that may interfere with patients' ability to cope with their kidney transplant, its physical symptoms and its treatments - patients may withdraw from treatment, be non-compliant with medication and diet<sup>6</sup> or be reluctant to engage in pre-renal replacement therapy (RRT) education and support.<sup>7</sup>

Although not a cure, for patients with ESRD, receiving a transplant provides the best chance of improving their quality of life and removing the burden of undergoing long-term dialysis treatment.<sup>8,9</sup> Nevertheless, research has shown that although receiving a transplant is the main goal for ESRD patients who are eligible for transplantation, they may continue to experience distress. For example, fear of the transplant failing can affect patient distress levels.<sup>8</sup> There is also evidence that patients may experience ongoing physical symptoms such as fatigue after receiving a transplant, and that there is substantial burden associated with taking regular immunosuppressant medication to lower the likelihood of graft rejection.<sup>10</sup> UK health

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3 policies highlight the importance of addressing the emotional and psychological  
4 needs of renal transplant patients <sup>11</sup> and the Department of Health and NHS England  
5 advocate treating mental health on an equal footing to that of physical health by  
6 incorporating it into care pathways.<sup>12</sup> Nevertheless, evidence suggests that distress,  
7 coping, and adjustment in transplant patients largely go undiagnosed or ignored and  
8 remain untreated.<sup>13</sup> Currently, there is little evidence on mild-to-moderate distress in  
9 transplant patients and further research is required in order to understand the  
10 psychological and emotional effects of a transplant.<sup>9</sup>  
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25 As an element of a larger mixed-methods study with patients and staff,<sup>14</sup> this paper  
26 reports the findings from a qualitative study with renal transplant patients. The aims  
27 were to explore why transplant patients experience distress and what support they  
28 may need.  
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## 38 **METHODS**

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41 The detailed methods for the study are in the published protocol.<sup>14</sup> In brief,  
42 participants were recruited from four National Health Service (NHS) hospitals in the  
43 West Midlands, UK. The chosen sites provided maximum diversity in patient  
44 demographics, catchment size, urban and rural locations plus the organisation of  
45 psychological support services, table 1.  
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56 **Table 1.** Summary of recruitment sites  
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Site	Size	Catchment area	On-site renal psychologist
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1	Small	Urban inner city with sizable Black, Asian and minority ethnic (BAME) population	No
2	Large	Urban inner city with sizable BAME population	Yes
3	Medium	Urban with surrounding rural districts majority white population	No
4	Large	Urban with surrounding rural districts majority white population	Yes

To be eligible for recruitment to the qualitative study, patients had to be categorised as having mild-to-moderate distress based on their responses to the distress thermometer<sup>15</sup> included in the wider study questionnaire. A researcher contacted all participants meeting the purposive sampling criteria (age, gender and ethnicity) to ask if they were willing to take part in an interview, a consent form and participant information sheet explaining the purpose of the study and what participation would involve, was sent to those expressing interest. As well as assuring patient confidentiality, the patient information sheet provided contact details for appropriate clinical staff the participants could contact if they felt distressed or upset and would like support. The following week a researcher contacted the potential participants to confirm participation and arrange an interview date and time.

Patient interviews took place between March 2016 and May 2017 and were conducted by two experienced researchers (both female and educated to masters level) employed by the University of Birmingham. Neither researcher had experience (personally or professionally) of the topic area and none of the participants knew the researchers. Interviews were either face-to-face (at a location chosen by the

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3 participant, either a quiet room at the hospital or at the patients home) or over the  
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5 telephone and lasted between 30 - 60 minutes. The interviews were in-depth and  
6  
7 semi-structured allowing the exploration of key issues without being overly  
8  
9 prescriptive about content and direction. All participants provided signed written  
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11 informed consent prior to their interview. Patient advisors, renal clinicians and the  
12  
13 current literature helped with the design of the topic guide, see box 1 for the areas  
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15 covered by the topic guide. Both researchers made field notes following each  
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17 interview. Interviews were audio-recorded and transcribed verbatim by a professional  
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19 transcribing service. Transcripts were checked against the recordings for accuracy.  
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Participants did not have the opportunity to review their interview transcript.

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|---|
| <ul style="list-style-type: none"><li>a) Experience of emotional difficulties and needs linked to their illness and/or treatment, when and for how long.</li><li>b) Language used around emotional difficulties and needs, and its meaning.</li><li>c) Whether and how emotional needs have been recognised and supported by renal staff, when and by whom.</li><li>d) What, if any, support used, when and why.</li><li>e) Likes and dislikes of support used.</li><li>f) Support would have liked/would want in future, when, and from whom.</li><li>g) Key elements would want included in an emotional support intervention</li></ul> |
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**Box 1.** Areas covered by the topic guide

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Analysis combined aspects of grounded theory<sup>16</sup> and thematic analysis.<sup>17</sup> Interviews were initially analysed inductively using the open coding and constant comparison aspects of grounded theory. The initial coding framework was developed by JJ and CG and was appropriately refined following comparison and discussion. Transcripts were coded using NVivo 11. For data that did not fit existing themes, new codes

were developed or existing ones revised until all data were coded by theme. The research team discussed the role of reflexivity and our potential influence on the data and its interpretation.

## RESULTS

Fifteen renal transplant patients aged between 30 and  $\geq 70$  years were recruited across the four sites, see tables 2 and 3.

**Table 2.** Summary of participant characteristics

		<b>N (%)</b>
<b>Gender</b>	Male	7 (47)
	Female	8 (53)
<b>Age</b>	30-39	3 (20)
	40-49	2 (13)
	50-59	4 (27)
	60-69	4 (27)
	$\geq 70$	2 (13)
<b>Ethnicity</b>	White/British	9 (60)
	Indian	4 (27)
	Caribbean	2 (13)
<b>Length of time on dialysis prior to transplant</b>	No dialysis	1 (7)
	0 – 3 years	5 (33)
	4 – 9 years	0 (0)
	$\geq 10$ years	3 (20)
	Unknown	6 (40)

**Table 3.** Individual participant characteristics

Three overarching themes were interpreted from the data. See table 4 for a summary of the themes and sub-themes:

**Table 4.** Themes and sub-themes

Theme	Sub-themes
I'm living with a "foreign body" inside me	Fear/feelings about the kidney itself
	Survivors' guilt
	Feelings of isolation
	Impacts of medication
Why am I distressed?	Initial feelings following transplant
	Association of distress to the transplant
	Coping with distress
Different patients want different types of support	Lack of information about transplants and support
	Preferred types of support and, who should deliver it

### **I'm living with a "foreign body" inside me**

#### **Fear/feelings about the kidney itself**

Living with a transplanted kidney and its associated treatments can evoke many different feelings and difficulties for patients. For many there is the fear and uncertainty of how long the transplant will last: participants talked about their transplant having a finite life and how this knowledge made them worry about what would happen in the future. Three participants had experienced a failed transplant and others understood the status of their transplant could change at any time:

*"A lot of people I knew before when I was on dialysis who had transplants, they had rejections and all sorts of things. So that's passing through your mind all the while". (M225).*

Among some patients, their fear had escalated the longer they had been with a transplant, particularly after their transplant exceeded the average lifespan. Some patients thought the longevity of a transplanted kidney was something of a lottery, which was perceived to be outside of their control and could therefore cause

1  
2  
3 distress. A few patients seemed emotionally affected by feeling they had a “foreign  
4 body” inside them (M225). One male patient talked about the possible consequences  
5 for his character of having received a female kidney. Another was anxious that his  
6 transplanted kidney might have come from someone with other health problems:  
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13 *“When I got it I started to get awful thoughts at night. ‘How did this*  
14 *person die, how old were they, did they have anything else, could*  
15 *they possibly have been HIV positive? Could there have been any*  
16 *other things that were underlying that may come forward later on?’*  
17 *and I still get those sort of thoughts at the moment”.* (M1141).  
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## 28 Survivors’ guilt

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30 Although a transplant is the gold standard treatment for ESRD, some participants  
31 mentioned feeling guilty about being distressed and some worried this may make  
32 them appear ungrateful. They felt they should be happy because they were lucky to  
33 receive a transplant: *“but you, at the same time you’ve got no reason to feel like*  
34 *that”.* (M389). This guilt and the fear of appearing ungrateful prevented some from  
35 seeking help when they needed it and stopped them from moving forward with their  
36 lives. Some participants worried about the donor, what happened to them and the  
37 family they left behind and others had survivors’ guilt because they had received  
38 their transplant before others who had been waiting longer:  
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53 *“When I had my transplant I felt, I suppose what you’d call it is like*  
54 *in a sense survivors guilt.....And because I had my transplant so*  
55 *quickly I just felt this huge amount of guilt because I thought all*  
56 *those patients that I had met at [hospital] and they’ve been on the*  
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3 *list for such a long time, and I thought ‘what’s the difference*  
4 *between me and them?’”.* (F413).  
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## 10 11 Feelings of isolation

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14 There was a perception amongst several of the participants that after receiving a  
15 transplant they were no longer part of the renal unit. They talked about feeling ‘cut-  
16 off’ and ‘abandoned’ with minimal contact. One patient explained how there had  
17 been no contact with his renal unit for several years following his transplant. Patients  
18 that had transitioned from in-centre haemodialysis (HD) seemed to feel this loss  
19 acutely - they missed the supportive relationship of staff and patients in the dialysis  
20 unit:  
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31 *“Once you’re transplanted, you don’t really have anything to do as*  
32 *such with the renal unit.....the only time I actually only ever was*  
33 *involved with the renal unit was when I was on dialysis. So that sort*  
34 *of like support was gone”.* (F726).  
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44 Some patients experienced feelings of isolation because of the lack of understanding  
45 about their disease and its treatments among family, friends and society in general.  
46 They believed only fellow transplant patients understood their feelings:  
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51 *“It helped the fact talking to a stranger about it. You know, the wife*  
52 *couldn’t understand why I was like it and that, but obviously the*  
53 *stranger could because she knew the experience of it all”.* (M369).  
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## Impacts of medication

Feeling down and finding their situation difficult to deal with was widespread amongst the participants. These feelings were often present when participants were dealing with the physical side effects of the anti-rejection medications such as, weight gain, puffy appearance and excessive hair growth. Other peoples' reactions to the physical changes were often difficult to deal with:

*“You know like the new face and excessive hair ..... and I found that I think the most difficult for me was that change and unfortunately when I went back to school I had a bit of , a bit of bullying went on, because of physically changing so much from what I was previously as well”. (F687).*

Participants explained how when they were on dialysis they felt in control of their body, their treatment and their lives but following transplant many felt they no longer had command of their body or life in general and yearned to take back control. Such as, not wanting to leave the house because of lack of bladder control. For the following patient the feeling of helplessness ended with her sabotaging her treatment:

*“So the reason my kidney failed was because I felt like I didn't have much control, so I kind of stopped taking my pills, my immunosuppressant. I stopped taking them for a while”. (F413).*

## Why am I distressed?

## Initial feelings following transplant

Following their transplant, participants did not expect to experience distress because they regarded a transplant as the best treatment option for an improved quality of life. Some patients had waited many years for the opportunity to receive the 'gift' of a transplant and had been optimistic:

*"I'm coming at it first time with an expectation that once you get a transplant and you start feeling better again, life is rosy, life can get back to normal". (M389).*

## Association of distress to the transplant

Whilst experiencing distress, many participants did not initially relate it to their transplant. The data suggest that the reasons for this were two-fold. Firstly, following a transplant there is an expectation from family, friends, clinicians and society in general that life will return to 'normal' and be 'wonderful' again. Secondly, renal staff did not forewarn the participants they might experience distress after receiving a transplant. Some only made the connection after agreeing to take part in this research study:

*"I never did link it to – there was something in your paperwork that I had. I thought I've never associated it with the kidney operation".*  
(M369).

## Coping with distress



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3 Renal disease and its lifecycle can make it hard for patients to be positive  
4 about their transplant. Several participants explained how it was difficult to  
5 cope with their emotions, to move on with their lives and how they perceived  
6 family and friends, in particular, were defining them by their health condition:  
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13 *“(Sighs) Ah, again I suppose it comes back to the fact that I don’t*  
14 *want to like, yes like I know I’ve got an illness, but I don’t want to be*  
15 *that’s who I am like. You know that’s what I’m all about sort of*  
16 *thing”.* (F726).  
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26 The majority of participants developed ways of accepting post-transplant life  
27 and found ways to cope with their distress. For some, distractions in the form  
28 of hobbies and pastimes such as gardening or reading helped them to adjust  
29 and for others it was important to maintain a positive outlook about their  
30 transplant:  
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38 *“I’ve always had this positive outlook on the transplant and that.”*  
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40 (M225).  
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## 49 **Different patients want different types of support**

50 Lack of information about transplants and support

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52 Many participants wished the renal team had explained to them the possibility  
53 of experiencing post-transplant distress and lamented the lack of information  
54 about this and the lack of available support. Many felt that “forewarned is  
55 forearmed” and were upset they missed the opportunity to plan, in advance,  
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3 coping strategies. This lack of information provision was associated with a lack  
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5 of continuity of care, and participants felt that staff regarded transplant patients  
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7 as a lower priority compared to those on dialysis:  
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11 *“Time is precious, resources are scarce, I suspect that probably it*  
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13 *never feels as though it’s a big priority”*. (M389).  
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18 Preferred types of support and, who should deliver it  
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22 There were, however, diverse views amongst the participants about the types of  
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24 support they would like to receive, and who should deliver it. For example, one  
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26 participant described how she thought talking to other patients might have provided  
27  
28 the support she sought.  
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32 *“So with other patients in your situation, so that you could liaise with*  
33  
34 *each other to see what new life is all about”*. (F494).  
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40 There were mixed views about the role of healthcare professionals (HCPs), with  
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42 some suggesting that HCPs should be more proactive in identifying distress in renal  
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44 transplant patients and directing them to appropriate sources of help and support.  
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46 Whereas others did not see this as the role of the renal team – they are there to  
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48 provide medical assistance and advice not psychological and emotional support.  
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50 Many suggested that specialist psychological services should be available as in  
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52 integral part of care for renal transplant patients:  
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57 *“I think you need psychologists as part of the renal team, a*  
58  
59 *psychologist with renal expertise”*. (F781).  
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6 However, because of the sensitive and personal nature of distress or for fear  
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8 of showing weakness there were those who were reluctant to talk about their  
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10 distress to anyone, making it difficult for HCPs to assess the support needs of  
11  
12 these patients:  
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15  
16 *“You know, it might have been something to do with medication –*  
17  
18 *I’m just guessing. But I should have told them but as I say, I mean*  
19  
20 *it’s not the sort of thing I tell people” (M369).*  
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## 23 24 25 26 **DISCUSSION**

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29 This research has highlighted the complex relationship that renal transplant patients  
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31 have with their new kidney, their surprise at the source of their distress and the  
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33 diverse opinions on the types of support they would like to help them through their  
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35 distress. Current research has shown that the prevalence of distress in renal  
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37 transplant patients is 25% and although this is lower than the 33% of dialysis  
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39 patients, it is still substantial and shows that many transplant patients experience  
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41 ongoing issues.<sup>5</sup> There is a range of reasons why despite all expectations of living  
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43 an improved life, some patients became uneasy with their transplanted kidney and  
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45 why some did not associate their distress with their transplant and/or  
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47 immunosuppressant medication.  
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56 Patients found it difficult to accept their new kidney because of a number of different  
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58 situations including: the side effects of medication, fear of transplant rejection and  
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3 feeling obliged to make the most of life because of the “gift” of a transplant. It has  
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5 been reported that although fear of rejection may be the biggest stressor  
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7 immediately after transplant, this fear subsides with time.<sup>8</sup> However, our findings do  
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9 not reflect this: the majority of our participants, regardless of time since transplant,  
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11 reported some level of emotional distress.<sup>5</sup> Emotional problems such as depression,  
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13 anxiety, stress, and concerns about body image are known indicators of poor  
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15 medication adherence.<sup>3 6</sup> and as discussed, may result in patients wishing they were  
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17 back on dialysis and in some cases sabotaging their treatment. Gill,<sup>8</sup> Suzuki<sup>18</sup> and  
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19 Fox<sup>19</sup> found that those receiving a kidney from a living donor had a vested interest in  
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21 each other’s well-being and were motivated to comply with their medication regimes  
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23 and enjoyed an improved quality of life. For those receiving a cadaver kidney,  
24  
25 thoughts about who their kidney came from were forefront in their mind and for some  
26  
27 this had a negative effect on their relationship with their kidney – making them feel  
28  
29 as though they had a “foreign body” inside them. The emotional distress patients feel  
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31 may be down to unrealistically high expectations of life post-transplant and there is a  
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33 need for these expectations to be managed by renal services.<sup>8 20 21</sup>

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43 Some of our participants did not explicitly link their distress to their transplant or the  
44  
45 immunosuppressive medication. To our knowledge, there is no discussion of this  
46  
47 aspect of distress and renal transplantation in the current literature. The reason for  
48  
49 this lack of association may be that patients naively perceive that by having a  
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51 transplant their quality of life will improve quickly and they will return to a normal  
52  
53 life.<sup>22</sup> Given that patients receive little, if any, information about post-transplant  
54  
55 distress from HCPs<sup>3</sup> this is not surprising. Consequently, patients are often ill-  
56  
57 prepared and feel helpless when trying to cope with their distress.<sup>23</sup> Evidence has  
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2  
3 shown that improving coping skills,<sup>24</sup> education before and after transplantation,<sup>25</sup>  
4 and active information seeking by patients can have a beneficial effect on patients'  
5 medical and psychological problems.<sup>8 20 26</sup> The National Institute for Health and  
6 Clinical Excellence (NICE) advocate keeping patients informed at all stages of  
7 treatment and encourage the promotion of self-care and self-management skills.<sup>27</sup>  
8 However, HCPs can find it difficult to recognise distress or anxiety in patients and  
9 are unsure at which point in the disease trajectory to discuss this with their  
10 patients.<sup>28</sup> When a patient is informed, it empowers them to take control of their  
11 condition and having control can itself lower the chances of distress.<sup>6</sup> It is therefore  
12 important that HCPs provide and share information and discuss all possible  
13 outcomes and coping strategies at the appropriate time in the treatment pathway.<sup>3 21</sup>  
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Not all renal transplant patients will experience distress and not all of those who do will want to receive support. This research has shown that some patients do not wish to talk about their feelings for fear of appearing ungrateful or weak, making it difficult for HCPs to understand, assess and procure appropriate support.<sup>28</sup> Even when patients do want to talk about their feelings, there is “no one size fits all” solution to the provision of support.<sup>29</sup> Different patients have different emotional needs indicating that any support offered to patients should be individualised in order to meet this variance of need.<sup>30</sup>

A limitation of this study is that the interview data analysed for this research is a subset of a larger set of data. Although the 15 in-depth interviews provided sufficient

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2  
3 data to answer the research questions, it is important for future research to explore  
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5 these areas with a more diverse and carefully stratified sample.  
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## 10 11 **CONCLUSIONS** 12

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14 Our research has highlighted a number of points: firstly, it is important to talk to  
15  
16 patients and their families pre-transplant about the possibility of experiencing mild-to-  
17  
18 moderate post-transplant distress. Secondly, patients should be encouraged to think  
19  
20 about potential coping strategies and finally, transplant patients with mild-to-  
21  
22 moderate distress should be able to choose from a variety of support options: peer  
23  
24 support; HCPs with augmented skills in detecting and managing distress; access to  
25  
26 psychology services.  
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53 interpretation of data, methodology, validation, writing (original draft); GC: formal  
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55 analysis, validation, writing (critical review and editing); SD, & KA: interpretation of  
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3 data, writing (critical review and editing), JN & JB: Conceptualisation, validation,  
4  
5 writing (critical review and editing). All authors have approved the final version.  
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21 Social Care.  
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34  
35 **Ethical approval:** The Coventry and Warwickshire Research Ethics Committee  
36  
37 granted approval for this and the wider study in October 2015 [Ref 15/WM/0288].  
38  
39 The Research Governance office at each of the participating hospital trusts also  
40  
41 gave approval for the study.  
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48 **Data availability:** The research data is confidential. Participants did not give consent  
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50 to share their data and the ethical requirements of the study do not allow us to share  
51  
52 the study data.  
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## 58 REFERENCES

59  
60

1. UK Renal Registry 21st Annual Report - data to 31/12/2017. Bristol, UK, 2019.
2. Soni RK. Health-related quality of life outcomes in chronic kidney disease. *Curr Opin Nephrol Hypertens*;19(2):153-60. doi: <https://doi.org/10.1097/MNH.0b013e328335f939>
3. Schell JO, Patel UD, Steinhauser KE, et al. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *American journal of kidney diseases : the official journal of the National Kidney Foundation* 2012;59(4):495-503. doi: <https://doi.org/10.1053/j.ajkd.2011.11.023> [published Online First: 01/04]
4. Murtagh FEM, Addington-Hall J, Higginson IJ. The Prevalence of Symptoms in End-Stage Renal Disease: A Systematic Review. *Advances in Chronic Kidney Disease* 2007;14(1):82-99. doi: <https://doi.org/10.1053/j.ackd.2006.10.001>
5. Damery S, Brown C, Sein K, et al. The prevalence of mild-to-moderate distress in patients with end-stage renal disease: results from a patient survey using the emotion thermometers in four hospital Trusts in the West Midlands, UK. *BMJ open* 2019;9(5):e027982. doi: <https://doi.org/10.1136/bmjopen-2018-027982>
6. Cukor D, Rosenthal DS, Jindal RM, et al. Depression is an important contributor to low medication adherence in hemodialyzed patients and transplant recipients. *Kidney Int* 2009;75(11):1223-29. doi: <https://doi.org/10.1038/ki.2009.51>
7. Combes G, Allen K, Sein K. Evaluation of case study sites for home therapies for people with chronic kidney disease Birmingham: University of Birmingham: West Midlands Central Health Innovation and Education Cluster; 2013 [Available from: <http://www.birmingham.ac.uk/research/activity/mds/projects/WMC-HIEC/publications.aspx> accessed May 19.
8. Gill P. Stressors and coping mechanisms in live-related renal transplantation. *J Clin Nurs* 2012;21(11-12):1622-31. doi: <https://doi.org/10.1111/j.1365-2702.2012.04085.x>
9. Kohlsdorf M. Coping Strategies Adopted by Patients With Chronic Kidney Disease in Preparation for Transplant. *Psychol Comm health* 2015;4(1):27-38. doi: <https://doi.org/10.5964/pch.v4i1.103> [published Online First: 2015-03-31]
10. Cukor D, Newville H, Jindal R. Depression and immunosuppressive medication adherence in kidney transplant patients. *General hospital psychiatry* 2008;30(4):386-7. doi: <https://doi.org/10.1016/j.genhosppsy.2007.12.003> [published Online First: 2008/07/01]
11. Department of Health, The National Service Framework for Renal Services Part 2: Chronic kidney disease, acute renal failure and end of life care. London: Department of Health 2005.
12. Department of Health, Closing the gap: priorities for essential change in mental health. London: Department of Health 2014
13. Spencer BW, Chilcot J, Farrington K. Still sad after successful renal transplantation: are we failing to recognise depression? An audit of depression screening in renal graft recipients. *Nephron Clinical practice* 2011;117(2):c106-12. doi: <https://doi.org/10.1159/000319657> [published Online First: 2010/08/10]
14. Taylor F, Taylor C, Baharani J, et al. Integrating emotional and psychological support into the end-stage renal disease pathway: a protocol for mixed methods research to identify patients' lower-level support needs and how these can most effectively be addressed. *BMC nephrology* 2016;17(1):111. doi: <https://doi.org/10.1186/s12882-016-0327-2> [published Online First: 2016/08/04]
15. Mitchell AJ, Baker-Glenn EA, Granger L, et al. Can the Distress Thermometer be improved by additional mood domains? Part I. Initial validation of the Emotion Thermometers tool. *Psycho-Oncology* 2010;19(2):125-33. doi: <https://doi.org/10.1002/pon.1523>
16. K C, L B. Qualitative interviewing and grounded theory analysis. In: Gubrium JF, Holstein AB, McKinney KD, eds. *The SAGE Handbook of interview research: The Complexity of the Craft*. California, USA: Sage publications 2012.
17. Braun V, Clarke V. *Successful Qualitative Research: a practical guide for beginners*. Thousand Oaks, CA: Sage 2013:174-179.



- 1  
2  
3 18. Suzuki A, Kenmochi T, Maruyama M, et al. Changes in quality of life in deceased versus living-  
4 donor kidney transplantations. *Transplant Proc* 2012;44(1):287-9. doi:  
5 <https://doi.org/10.1016/j.transproceed.2011.11.056> [published Online First: 2012/02/09]  
6  
7 19. Fox RC. Through the lenses of biology and sociology: Organ replacement. In: Williams SJ, Birke L,  
8 Bendelow GA, eds. *Debating Biology: Sociological reflection on health, medicine and society*.  
9 London: Routledge 2003.
- 10 20. Chilcot J, Spencer BWJ, Maple H, et al. Depression and Kidney Transplantation. *Transplantation*  
11 2014;97(7):717-21. doi: <https://doi.org/10.1097/01.TP.0000438212.72960.ae>  
12  
13 21. Pinter J, Hanson CS, Craig JC, et al. 'I feel stronger and younger all the time' —perspectives of  
14 elderly kidney transplant recipients: thematic synthesis of qualitative research. *Nephrol Dial*  
15 *Transplant* 2016;31(9):1531-40. doi: <https://doi.org/10.1093/ndt/gfv463>  
16  
17 22. Boaz A, Morgan M. Working to establish 'normality' post-transplant: a qualitative study of kidney  
18 transplant patients. *Chronic illness* 2014;10(4):247-58. doi:  
19 <https://doi.org/10.1177/1742395313504789> [published Online First: 2013/09/28]  
20  
21 23. Cormier NR, Gallo-Cruz SR, Beard RL. Navigating the new, transplanted self: how recipients  
22 manage the cognitive risks of organ transplantation. *Sociology of health & illness* 2017;39(8):1496-  
23 513. doi: <https://doi.org/10.1111/1467-9566.12610> [published Online First: 2017/10/11]  
24  
25 24. Been-Dahmen JMJ, Beck DK, Peeters MAC, et al. Evaluating the feasibility of a nurse-led self-  
26 management support intervention for kidney transplant recipients: a pilot study. *BMC nephrology*  
27 2019;20(1):143. doi: <https://doi.org/10.1186/s12882-019-1300-7> [published Online First:  
28 2019/04/29]  
29  
30 25. Curcani M, Tan M. the factors affecting the quality of life of patients who have undergone  
31 kidney transplants *Pakistan Journal of Medicine* 2012;27(5):1092-97.  
32  
33 26. Muehrer RJ, Becker BN. Life after transplantation: new transitions in quality of life and  
34 psychological distress. *Semin Dial* 2005;18(2):124-31. doi: <https://doi.org/10.1111/j.1525-139X.2005.18214.x> [published Online First: 2005/03/18]  
35  
36 27. National Institute for Health and Clinical Excellence, CG138 Patient experience in NHS services:  
37 improving the experience of care for people using adult NHS services Manchester: National Institute  
38 for Health and Clinical Excellence 2012 [Available from: <http://guidance.nice.org.uk/cg138> accessed  
39 July 2019].  
40  
41 28. Damery S, Sein K, Combes G. The prevalence, experience and management of mild to moderate  
42 distress in patients with end stage renal disease: results from a multi-centre, mixed methods  
43 research study: NIHR CLAHRC-WM, University of Birmingham, 2019.  
44  
45 29. Been-Dahmen JMJ, Grijpma JW, Ista E, et al. Self-management challenges and support needs  
46 among kidney transplant recipients: A qualitative study. *Journal of advanced nursing*  
47 2018;74(10):2393-405. doi: <https://doi.org/10.1111/jan.13730> [published Online First: 2018/06/06]  
48  
49 30. Grijpma JW, Tielen M, van Staa AL, et al. Kidney transplant patients' attitudes towards self-  
50 management support: A Q-methodological study. *Patient Educ Couns* 2016;99(5):836-43. doi:  
51 <https://doi.org/10.1016/j.pec.2015.11.018> [published Online First: 2015/12/20]  
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## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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# BMJ Open

## **“You’ve got a foreign body in there”: Renal transplantation, unexpected mild-to-moderate distress and patients’ support needs: a qualitative study**

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Date Submitted by the Author:	13-Dec-2019
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Keywords:	Renal transplantation < NEPHROLOGY, Anxiety disorders < PSYCHIATRY, QUALITATIVE RESEARCH

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3 **“You’ve got a foreign body in there”:** Renal transplantation, unexpected mild-  
4 **to-moderate distress and patients’ support needs: a qualitative study**  
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8 Short title: Unexpected distress in renal transplant patients  
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11 Janet Jones\*<sup>1</sup>, Sarah Damery<sup>1</sup>, Kerry Allen<sup>2</sup>, Johann Nicholas<sup>3^</sup>, Jyoti Baharani<sup>4</sup>, and  
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## ABSTRACT

**Objective:** To explore why transplant patients experience unexpected mild-to-moderate distress and what support they may need.

**Design:** Qualitative study using individual in-depth interviews.

**Setting:** Four NHS Trusts in the Midlands, UK.

**Participants:** Fifteen renal transplant patients meeting the criteria for mild to moderate distress from their responses to emotion thermometers.

**Main outcome measures:** identification of the reasons for distress and support options acceptable to renal transplant patients.

**Results:** Three themes were interpreted from the data: 'I'm living with a "foreign body" inside me', 'why am I distressed?' and, 'different patients want different support'. Following their transplant, participants felt that they should be happy and content, but this was often not the case. They described a range of feelings about their transplant, such as: uncertainty about the lifespan of their new kidney, fear of transplant failure or fear of the donor having health conditions that may transfer to them. A few experienced survivors' guilt when others they had met at the dialysis unit had not received a transplant or because someone had died to enable them to receive the transplant. No longer having regular contact with the renal unit made participants feel isolated. Some participants did not initially attribute the source of their distress to their transplant. Participants' preferred support for their distress and their preferences about who should deliver it varied from peer support to seeing a psychologist.

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3 **Conclusion:** Raising the issue of post-transplant mild-to-moderate distress with  
4 patients and encouraging them to think about and plan coping strategies pre-  
5 transplant may prove beneficial for the patient and healthcare provider. Patients  
6 should be able to choose from a variety of support options.  
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## 16 **ARTICLE SUMMARY**

### 17 **Strengths and limitations of this study**

- 18 • This is the first study designed to explore the issue of unexpected mild-to-  
19 moderate distress in renal transplant patients.  
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- 21 • The Interviews were a sub-set of data from a larger study.  
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- 23 • To reduce bias on the basis of the services offered to renal patients multiple  
24 sites with different organisation and delivery of services were selected.  
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- 26 • Participants were diverse thus the findings are representative of the wider  
27 group of renal transplant patients.  
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## INTRODUCTION

At the end of 2017, 63,162 adults were receiving renal replacement therapy in the UK<sup>1</sup>, and in the same year 3,462 transplants were performed.<sup>1</sup> Patients with end stage renal disease (ESRD) can experience distress and distress is associated with lower quality of life and greater treatment burden.<sup>2</sup> The level of emotional distress increases as the health of a patient with ESRD declines<sup>3</sup> and the prevalence of depression and anxiety in patients with ESRD is approximately four times higher than in the general adult population.<sup>4</sup> Damery et al 2019<sup>5</sup> reported that more than a third of renal dialysis patients suffer emotional distress. If suffering from mild-to-moderate distress – the unpleasant feelings or emotions that may interfere with patients' ability to cope with their kidney transplant, its physical symptoms and its treatments - patients may withdraw from treatment, be non-compliant with medication and diet<sup>6</sup> or be reluctant to engage in pre-renal replacement therapy (RRT) education and support.<sup>7</sup>

Although not a cure, for patients with ESRD, receiving a transplant provides the best chance of improving their quality of life and removing the burden of undergoing long-term dialysis treatment.<sup>8,9</sup> Nevertheless, research has shown that although receiving a transplant is the main goal for ESRD patients who are eligible for transplantation, they may continue to experience distress. For example, fear of the transplant failing can affect patient distress levels.<sup>8</sup> There is also evidence that patients may experience ongoing physical symptoms such as fatigue after receiving a transplant, and that there is substantial burden associated with taking regular immunosuppressant medication to lower the likelihood of graft rejection.<sup>10</sup> UK health

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3 policies highlight the importance of addressing the emotional and psychological  
4 needs of renal transplant patients <sup>11</sup> and the Department of Health and NHS England  
5 advocate treating mental health on an equal footing to that of physical health by  
6 incorporating it into care pathways.<sup>12</sup> Nevertheless, evidence suggests that distress,  
7 coping, and adjustment in transplant patients largely go undiagnosed or ignored and  
8 remain untreated.<sup>13</sup> Currently, there is little evidence on mild-to-moderate distress in  
9 transplant patients and further research is required in order to understand the  
10 psychological and emotional effects of a transplant.<sup>9 14 15</sup>

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25 As an element of a larger mixed-methods study with patients and staff,<sup>16</sup> this paper  
26 reports the findings from a qualitative study with renal transplant patients. The aims  
27 were to explore why transplant patients experience distress and what support they  
28 may need.  
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## 38 **METHODS**

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41 The detailed methods for the study are in the published protocol.<sup>16</sup> In brief,  
42 participants were recruited from four National Health Service (NHS) hospitals in the  
43 West Midlands, UK. The chosen sites provided maximum diversity in patient  
44 demographics, catchment size, urban and rural locations plus the organisation of  
45 psychological support services and were categorised according to the size of the  
46 catchment area. Table 1.  
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**Table 1.** Summary of recruitment sites

Site	Size	Catchment area	On-site renal psychologist
1	Small	Urban inner city with sizable Black, Asian and minority ethnic (BAME) population	No
2	Large	Urban inner city with sizable BAME population	Yes
3	Medium	Urban with surrounding rural districts majority white population	No
4	Large	Urban with surrounding rural districts majority white population	Yes

To be eligible for recruitment to the qualitative study, patients had to be categorised as having mild-to-moderate distress based on their responses to the distress thermometer<sup>17</sup> included in the wider study questionnaire. Participants indicated on the questionnaire whether or not they would be willing to take part in an interview and provided their preferred contact details. A consent form and participant information sheet explaining the purpose of the interview study and what participation would involve were sent to those expressing interest. The following week those meeting the purposive sampling criteria (age, gender and ethnicity) were contacted by a researcher (FT) to confirm participation and arrange a date and time for the interview. If participants had changed their mind they were able to withdraw from this part of the wider study. As well as assuring patient confidentiality, the patient information sheet provided contact details of appropriate clinical staff the participants could contact if they felt distressed or upset and would like support. Contacting the participants to answer their questions, to arrange the interview and to

1  
2  
3 remind them a few days beforehand helped to build up a rapport with each  
4  
5 participant prior to their interview.  
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10  
11 Patient interviews took place between March 2016 and May 2017 and were  
12  
13 conducted by two experienced qualitative researchers (FT, EK) (both identifying as  
14  
15 female and educated to masters level) employed by the University of Birmingham.  
16  
17 Neither researcher had experience (personally or professionally) of the topic area  
18  
19 and none of the participants knew the researchers. Interviews were either face-to-  
20  
21 face (at a location chosen by the participant, either a quiet room at the hospital or at  
22  
23 the patients home) or over the telephone and lasted between 30 - 60 minutes. The  
24  
25 interviews were in-depth and semi-structured allowing the exploration of key issues  
26  
27 without being overly prescriptive about content and direction. All participants  
28  
29 provided signed written informed consent prior to their interview. Patient advisors,  
30  
31 renal clinicians and the current literature helped with the design of the topic guide,  
32  
33 see box 1 for the areas covered by the topic guide. Prior to the start of the interview  
34  
35 participants were advised to let the researcher know if they needed to take a break  
36  
37 during the interview or if they no longer wished to carry on. At the end of each  
38  
39 interview participants were asked if they had any further comments on the topics  
40  
41 covered or whether there were any important areas they felt had not been discussed.  
42  
43 Both researchers made field notes following each interview. Interviews were audio-  
44  
45 recorded and transcribed verbatim by a professional transcribing service. Transcripts  
46  
47 were checked against the recordings for accuracy. Participants did not have the  
48  
49 opportunity to review their interview transcript.  
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- a) Experience of emotional difficulties and needs linked to their illness and/or treatment, when and for how long.
- b) Language used around emotional difficulties and needs, and its meaning.
- c) Whether and how emotional needs have been recognised and supported by renal staff, when and by whom.
- d) What, if any, support used, when and why.
- e) Likes and dislikes of support used.
- f) Support would have liked/would want in future, when, and from whom.
- g) Key elements would want included in an emotional support intervention

**Box 1.** Areas covered by the topic guide

Analysis combined aspects of grounded theory<sup>18</sup> and thematic analysis.<sup>19</sup> Interviews were initially analysed inductively using the open coding and constant comparison aspects of grounded theory. The initial coding framework was developed by JJ and CG and was appropriately refined following comparison and discussion. Transcripts were coded using NVivo 11. For data that did not fit existing themes, new codes were developed or existing ones revised until all data were coded by theme. The research team discussed the role of reflexivity and our potential influence on the data and its interpretation.<sup>20 21</sup>

**Patient and public involvement**

The patient and public involvement group of the NIHR CLAHRC West Midlands long-term conditions theme and a renal patient advisory group provided advice on the design of the study, the data collection tools and the selection of outcomes. All participants received a summary of the study findings.

## RESULTS

Fifteen renal transplant patients aged between 30 and  $\geq 70$  years were recruited across the four sites, see tables 2 and 3.

**Table 2.** Summary of participant characteristics

		<b>N (%)</b>
<b>Gender</b>	Male	7 (47)
	Female	8 (53)
<b>Age</b>	30-39	3 (20)
	40-49	2 (13)
	50-59	4 (27)
	60-69	4 (27)
	$\geq 70$	2 (13)
<b>Ethnicity</b>	White	9 (60)
	Indian	4 (27)
	Caribbean	2 (13)
<b>Length of time on dialysis prior to transplant</b>	No dialysis	1 (7)
	0 – 3 years	5 (33)
	4 – 9 years	0 (0)
	$\geq 10$ years	3 (20)
	Unknown	6 (40)

**Table 3.** Individual participant characteristics

<b>ID</b>	<b>Age</b>	<b>Time on dialysis prior to transplant</b>
P129	40-49	No dialysis
P267	60-69	Not stated
P384	50-59	16 ½ years
P413	30-39	Not stated
P494	50-59	11 years
P687	30-39	Not stated
P726	50-59	10 years
P781	$\geq 70$	11 months
P197	40-49	1 year

P225	≤70	3 years
P369	60-69	Not stated
P389	50-59	3 years
P401	30-39	Not stated
P1028	60-69	6 months
P1141	60-69	Not stated

Three overarching themes were interpreted from the data. See table 4 for a summary of the themes and sub-themes:

**Table 4.** Themes and sub-themes

Theme	Sub-themes
I'm living with a "foreign body" inside me	Fear/feelings about the kidney itself
	Survivors' guilt
	Feelings of isolation
	Impacts of medication
Why am I distressed?	Expectations of living with a transplant
	Coping with distress
	Lack of information about transplants and support
Different patients want different types of support	

### **I'm living with a "foreign body" inside me**

Fear/feelings about the kidney itself

Living with a transplanted kidney and its associated treatments can evoke many different feelings and difficulties for patients. For many there is the fear and uncertainty of how long the transplant will last: participants talked about their transplant having a finite life and how this knowledge made them worry about what would happen in the future. Three participants had experienced a failed transplant and others understood the status of their transplant could change at any time:

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2  
3           *“A lot of people I knew before when I was on dialysis who had*  
4           *transplants, they had rejections and all sorts of things. So that’s*  
5           *passing through your mind all the while”.* (P225).  
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13       Among some patients, their fear had escalated the longer they had been with a  
14       transplant, particularly after their transplant exceeded the average lifespan. Some  
15       patients thought the longevity of a transplanted kidney was something of a lottery,  
16       which was perceived to be outside of their control and could therefore cause  
17       distress. A few patients seemed emotionally affected by feeling they had a “foreign  
18       body” inside them (M225). One male patient talked about the possible consequences  
19       for his character of having received a female kidney. Another was anxious that his  
20       transplanted kidney might have come from someone with other health problems:  
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32           *“When I got it I started to get awful thoughts at night. ‘How did this*  
33           *person die, how old were they, did they have anything else, could*  
34           *they possibly have been HIV positive? Could there have been any*  
35           *other things that were underlying that may come forward later on?’*  
36           *and I still get those sort of thoughts at the moment”.* (P1141).  
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#### 48       Survivors’ guilt

49  
50       Although a transplant is the gold standard treatment for ESRD, some participants  
51       mentioned feeling guilty about being distressed and some worried this may make  
52       them appear ungrateful. They felt they should be happy because they were lucky to  
53       receive a transplant: *“but you, at the same time you’ve got no reason to feel like*  
54       *that”.* (M389). This guilt and the fear of appearing ungrateful prevented some from  
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3 seeking help when they needed it and stopped them from moving forward with their  
4  
5 lives. Some participants worried about the donor, what happened to them and the  
6  
7 family they left behind and others had survivors' guilt because they had received  
8  
9 their transplant before others who had been waiting longer:  
10  
11

12  
13 *"When I had my transplant I felt, I suppose what you'd call it is like*  
14  
15 *in a sense survivors guilt.....And because I had my transplant so*  
16  
17 *quickly I just felt this huge amount of guilt because I thought all*  
18  
19 *those patients that I had met at [hospital] and they've been on the*  
20  
21 *list for such a long time, and I thought 'what's the difference*  
22  
23 *between me and them?'"*. (P413).  
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### 30 Feelings of isolation

31  
32  
33 There was a perception amongst several of the participants that after receiving a  
34  
35 transplant they were no longer part of the renal unit. They talked about feeling 'cut-  
36  
37 off' and 'abandoned' with minimal contact. One patient explained how there had  
38  
39 been no contact with his renal unit for several years following his transplant. Patients  
40  
41 that had transitioned from in-centre haemodialysis (HD) seemed to feel this loss  
42  
43 acutely - they missed the supportive relationship of staff and patients in the dialysis  
44  
45 unit:  
46  
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48

49  
50 *"Once you're transplanted, you don't really have anything to do as*  
51  
52 *such with the renal unit.....the only time I actually only ever was*  
53  
54 *involved with the renal unit was when I was on dialysis. So that sort*  
55  
56 *of like support was gone"*. (P726).  
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3 Some patients experienced feelings of isolation because of the lack of understanding  
4 about their disease and its treatments among family, friends and society in general.  
5

6  
7 They believed only fellow transplant patients understood their feelings:  
8

9  
10 *“It helped the fact talking to a stranger about it. You know, the wife*  
11 *couldn’t understand why I was like it and that, but obviously the*  
12 *stranger could because she knew the experience of it all”*. (P369).  
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### 18 19 20 21 Impacts of medication

22  
23 Feeling down and finding their situation difficult to deal with was widespread  
24 amongst the participants. These feelings were often present when participants were  
25 dealing with the physical side effects of the anti-rejection medications such as,  
26 weight gain, puffy appearance and excessive hair growth. Other peoples’ reactions  
27 to the physical changes were often difficult to deal with:  
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35  
36 *“You know like the new face and excessive hair ..... and I found*  
37 *that I think the most difficult for me was that change and*  
38 *unfortunately when I went back to school I had a bit of , a bit of*  
39 *bullying went on, because of physically changing so much from*  
40 *what I was previously as well”*. (P687).  
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51 Participants explained how when they were on dialysis they felt in control of their  
52 body, their treatment and their lives but following transplant many felt they no longer  
53 had command of their body or life in general and yearned to take back control. Such  
54 as, not wanting to leave the house because of lack of bladder control. For the  
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3 following patient the feeling of helplessness ended with her sabotaging her  
4  
5 treatment:  
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8 *“So the reason my kidney failed was because I felt like I didn’t have*  
9 *much control, so I kind of stopped taking my pills, my*  
10 *immunosuppressant. I stopped taking them for a while”.* (P413).  
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### 19 **Why am I distressed?**

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21  
22 Expectations of living with a transplant  
23

24  
25 Following their transplant, participants did not expect to experience distress because  
26 they regarded a transplant as the best treatment option for an improved quality of  
27 life. Some patients had waited many years for the opportunity to receive the ‘gift’ of a  
28 transplant and had been optimistic:  
29  
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31  
32

33  
34 *“I’m coming at it first time with an expectation that once you get a*  
35 *transplant and you start feeling better again, life is rosy, life can get*  
36 *back to normal”.* (P389).  
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45  
46 Whilst experiencing distress, many participants did not initially relate it to their  
47 transplant. The data suggest that the reasons for this were two-fold. Firstly, following  
48 a transplant there is an expectation from family, friends, clinicians and society in  
49 general that life will return to ‘normal’ and be ‘wonderful’ again.  
50  
51  
52  
53

54  
55 *“I never did link it to – there was something in your paperwork that I*  
56 *had. I thought I’ve never associated it with the kidney operation”.*  
57  
58  
59 (P369).  
60

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6 Secondly, renal staff did not forewarn the participants they might experience  
7  
8 distress after receiving a transplant. Some only made the connection after  
9  
10 agreeing to take part in this research study:  
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15

16 *But being in the hospital and then having all sorts of side effects*  
17 *which is effecting me emotionally now. And that things could have*  
18 *been told to me before, you know, I would have prepped myself up.*  
19 *Some of those things could have been addressed before. It could*  
20 *have been helpful to have been told beforehand. (P129).*  
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### 31 Coping with distress

32  
33 Renal disease and its lifecycle can make it hard for patients to be positive  
34 about their transplant. Several participants explained how it was difficult to  
35 cope with their emotions, to move on with their lives and how they perceived  
36 family and friends, in particular, were defining them by their health condition:  
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43 *“(Sighs) Ah, again I suppose it comes back to the fact that I don’t*  
44 *want to like, yes like I know I’ve got an illness, but I don’t want to be*  
45 *that’s who I am like. You know that’s what I’m all about sort of*  
46 *thing”. (P726).*  
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56 The majority of participants developed ways of accepting post-transplant life  
57 and found ways to cope with their distress. For some, distractions in the form  
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2  
3 of hobbies and pastimes such as gardening or reading helped them to adjust  
4  
5 and for others it was important to maintain a positive outlook about their  
6  
7 transplant:  
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9

10 *"I've always had this positive outlook on the transplant and that."*  
11  
12 (P225).  
13  
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### 19 Lack of information about transplants and support

20  
21 Many participants wished the renal team had explained to them the possibility  
22  
23 of experiencing post-transplant distress and lamented the lack of information  
24  
25 about this and the lack of available support. Many felt that "forewarned is  
26  
27 forearmed" and were upset they missed the opportunity to plan, in advance,  
28  
29 coping strategies. This lack of information provision was associated with a lack  
30  
31 of continuity of care, and participants felt that staff regarded transplant patients  
32  
33 as a lower priority compared to those on dialysis:  
34  
35  
36  
37

38 *"Time is precious, resources are scarce, I suspect that probably it*  
39  
40 *never feels as though it's a big priority".* (P389).  
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### 47 **Different patients want different types of support**

48  
49 There were, however, diverse views amongst the participants about the types of  
50  
51 support they would like to receive, and who should deliver it. For example, one  
52  
53 participant described how she thought talking to other patients might have provided  
54  
55 the support she sought.  
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3           *“So with other patients in your situation, so that you could liaise with*  
4  
5           *each other to see what new life is all about”*. (P494).  
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10  
11       There were mixed views about the role of healthcare professionals (HCPs), with  
12  
13       some suggesting that HCPs should be more proactive in identifying distress in renal  
14  
15       transplant patients and directing them to appropriate sources of help and support.  
16  
17       Whereas others did not see this as the role of the renal team – they are there to  
18  
19       provide medical assistance and advice not psychological and emotional support.  
20  
21       Many suggested that specialist psychological services should be available as in  
22  
23       integral part of care for renal transplant patients:  
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28           *“I think you need psychologists as part of the renal team, a*  
29  
30           *psychologist with renal expertise”*. (P781).  
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36  
37       However, because of the sensitive and personal nature of distress or for fear  
38  
39       of showing weakness there were those who were reluctant to talk about their  
40  
41       distress to anyone, making it difficult for HCPs to assess the support needs of  
42  
43       these patients:  
44  
45

46           *“You know, it might have been something to do with medication –*  
47  
48           *I’m just guessing. But I should have told them but as I say, I mean*  
49  
50           *it’s not the sort of thing I tell people”* (P369).  
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## 56       **DISCUSSION**

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3 This research has highlighted the complex relationship that renal transplant patients  
4 have with their new kidney, their largely unanticipated experience of their distress  
5 and the diverse opinions on the types of support they would like to help them through  
6 their distress. Current research has shown that the prevalence of distress in renal  
7 transplant patients is 25% and although this is lower than the 33% of dialysis  
8 patients, it is still substantial and shows that many transplant patients experience  
9 ongoing issues.<sup>5</sup> There is a range of reasons why despite all expectations of living  
10 an improved life, some patients became uneasy with their transplanted kidney and  
11 why some did not associate their distress with their transplant and/or  
12 immunosuppressant medication.  
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30 Patients found it difficult to accept their new kidney because of a number of different  
31 situations including: the side effects of medication, fear of transplant rejection and  
32 feeling obliged to make the most of life because of the “gift” of a transplant.<sup>22-25</sup> It  
33 has been reported that concern about potential lifespan of the transplanted kidney  
34 may be the biggest stressor immediately after transplant, this fear subsides with  
35 time.<sup>8</sup> However, our findings do not reflect this: the majority of our participants,  
36 regardless of time since transplant, reported some level of emotional distress.<sup>5</sup>  
37 Emotional problems such as depression, anxiety, stress, and concerns about body  
38 image are known indicators of poor medication adherence.<sup>3 6</sup> and as discussed, may  
39 result in patients wishing they were back on dialysis and in some cases sabotaging  
40 their treatment. Gill,<sup>8</sup> Suzuki<sup>26</sup> and Fox<sup>27</sup> found that those receiving a kidney from a  
41 living donor had a vested interest in each other’s well-being and were motivated to  
42 comply with their medication regimes and enjoyed an improved quality of life. For  
43 those receiving a cadaver kidney, thoughts about who their kidney came from were  
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3 forefront in their mind and for some this had a negative effect on their relationship  
4 with their kidney – making them feel as though they had a “foreign body” inside  
5 them. The emotional distress patients feel may be down to unrealistically high  
6 expectations of life post-transplant and there is a need for these expectations to be  
7 managed by renal services.<sup>8 23 28</sup>

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18 The majority of participants did not expect to experience distress after a transplant.  
19 This may be that patients naively perceive that by having a transplant their quality of  
20 life will improve quickly and they will return to a normal life.<sup>29</sup> Consequently, patients  
21 are often ill-prepared and feel helpless when trying to cope with their distress.<sup>30</sup>  
22 Evidence has shown that improving coping skills,<sup>31</sup> education before and after  
23 transplantation,<sup>32</sup> and active information seeking by patients can have a beneficial  
24 effect on patients’ medical and psychological problems.<sup>8 23 33</sup> The National Institute  
25 for Health and Care Excellence (NICE) advocate keeping patients informed at all  
26 stages of treatment and encourage the promotion of self-care and self-management  
27 skills.<sup>34</sup> However, HCPs can find it difficult to recognise distress or anxiety in patients  
28 and are unsure at which point in the disease trajectory to discuss this with their  
29 patients.<sup>35</sup> When a patient is informed, it empowers them to take control of their  
30 condition and having control can itself lower the chances of distress.<sup>6</sup> It is therefore  
31 important that HCPs provide and share information and discuss all possible  
32 outcomes and coping strategies at the appropriate time in the treatment pathway.<sup>3 28</sup>

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3 Not all renal transplant patients will experience distress and not all of those who do  
4 will want to receive support. This research has shown that some patients do not wish  
5 to talk about their feelings for fear of appearing ungrateful or weak, making it difficult  
6 for HCPs to understand, assess and procure appropriate support.<sup>35</sup> Even when  
7 patients do want to talk about their feelings, there is “no one size fits all” solution to  
8 the provision of support.<sup>36</sup> Different patients have different emotional needs  
9 indicating that any support offered to patients should be individualised in order to  
10 meet this variance of need.<sup>37</sup>  
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25 There were no discernible differences in the depth of data and the length of interview  
26 between those conducted face-to-face and those conducted over the telephone. A  
27 limitation of this study is that the interview data analysed for this research is a sub-  
28 set of a larger set of data. Although the 15 in-depth interviews provided sufficient  
29 data to answer the research questions, it is important for future research to explore  
30 these areas with a more diverse and carefully stratified sample.  
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## 43 CONCLUSIONS

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45 Our research has highlighted a number of points: firstly, it is important to talk to  
46 patients and their families pre-transplant about the possibility of experiencing mild-to-  
47 moderate post-transplant distress. Secondly, patients should be encouraged to think  
48 about potential coping strategies and finally, transplant patients with mild-to-  
49 moderate distress should be able to choose from a variety of support options: peer  
50 support; HCPs with augmented skills in detecting and managing distress; access to  
51 psychology services.  
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11  
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13  
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15  
16 time to talk to us.  
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23 **Author Contributors:** JJ: Conceptualisation (for this sub-study), formal analysis,  
24  
25 interpretation of data, methodology, validation, writing (original draft); GC: formal  
26  
27 analysis, validation, writing (critical review and editing); SD, & KA: interpretation of  
28  
29 data, writing (critical review and editing), JN & JB: Conceptualisation, validation,  
30  
31 writing (critical review and editing). All authors have approved the final version.  
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46  
47 the author(s) and not necessarily those of the NIHR or the Department of Health and  
48  
49 Social Care.  
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56 **Competing interests:** -None  
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3 **Ethical approval:** The Coventry and Warwickshire Research Ethics Committee  
4 granted approval for this and the wider study in October 2015 [Ref 15/WM/0288].  
5  
6 The Research Governance office at each of the participating hospital trusts also  
7  
8 gave approval for the study.  
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16 **Data availability:** The research data is confidential. Participants did not give consent  
17 to share their data and the ethical requirements of the study do not allow us to share  
18 the study data.  
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### REFERENCES

1. UK Renal Registry 21st Annual Report - data to 31/12/2017. Bristol, UK, 2019.
2. Soni RK. Health-related quality of life outcomes in chronic kidney disease. *Curr Opin Nephrol Hypertens*;19(2):153-60. doi: <https://doi.org/10.1097/MNH.0b013e328335f939>
3. Schell JO, Patel UD, Steinhauser KE, et al. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *American journal of kidney diseases : the official journal of the National Kidney Foundation* 2012;59(4):495-503. doi: <https://doi.org/10.1053/j.ajkd.2011.11.023> [published Online First: 01/04]
4. Murtagh FEM, Addington-Hall J, Higginson IJ. The Prevalence of Symptoms in End-Stage Renal Disease: A Systematic Review. *Advances in Chronic Kidney Disease* 2007;14(1):82-99. doi: <https://doi.org/10.1053/j.ackd.2006.10.001>
5. Damery S, Brown C, Sein K, et al. The prevalence of mild-to-moderate distress in patients with end-stage renal disease: results from a patient survey using the emotion thermometers in four hospital Trusts in the West Midlands, UK. *BMJ open* 2019;9(5):e027982. doi: <https://doi.org/10.1136/bmjopen-2018-027982>
6. Cukor D, Rosenthal DS, Jindal RM, et al. Depression is an important contributor to low medication adherence in hemodialyzed patients and transplant recipients. *Kidney Int* 2009;75(11):1223-29. doi: <https://doi.org/10.1038/ki.2009.51>
7. Combes G, Allen K, Sein K. Evaluation of case study sites for home therapies for people with chronic kidney disease Birmingham: University of Birmingham: West Midlands Central Health Innovation and Education Cluster; 2013 [Available from: <http://www.birmingham.ac.uk/research/activity/mds/projects/WMC-HIEC/publications.aspx> accessed May 19.
8. Gill P. Stressors and coping mechanisms in live-related renal transplantation. *J Clin Nurs* 2012;21(11-12):1622-31. doi: <https://doi.org/10.1111/j.1365-2702.2012.04085.x>
9. Kohlsdorf M. Coping Strategies Adopted by Patients With Chronic Kidney Disease in Preparation for Transplant. *Psychol Comm health* 2015;4(1):27-38. doi: <https://doi.org/10.5964/pch.v4i1.103> [published Online First: 2015-03-31]

10. Cukor D, Newville H, Jindal R. Depression and immunosuppressive medication adherence in kidney transplant patients. *General hospital psychiatry* 2008;30(4):386-7. doi: <https://doi.org/10.1016/j.genhosppsych.2007.12.003> [published Online First: 2008/07/01]
11. Department of Health, The National Service Framework for Renal Services Part 2: Chronic kidney disease, acute renal failure and end of life care. London: Department of Health 2005.
12. Department of Health, Closing the gap: priorities for essential change in mental health. London: Department of Health 2014
13. Spencer BW, Chilcot J, Farrington K. Still sad after successful renal transplantation: are we failing to recognise depression? An audit of depression screening in renal graft recipients. *Nephron Clinical practice* 2011;117(2):c106-12. doi: <https://doi.org/10.1159/000319657> [published Online First: 2010/08/10]
14. Almgren M. The meaning of being in uncertainty after heart transplantation - an unrevealed source to distress. *European Journal of Cardiovascular Nursing* 2017;16(2):167-75. doi: 10.1177/1474515116648240
15. Mauthner OE. Heart transplants: Identity disruption, bodily integrity and interconnectedness. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine* 2014;19(6):578-95. doi: 10.1177/1363459314560067
16. Taylor F, Taylor C, Baharani J, et al. Integrating emotional and psychological support into the end-stage renal disease pathway: a protocol for mixed methods research to identify patients' lower-level support needs and how these can most effectively be addressed. *BMC nephrology* 2016;17(1):111. doi: <https://doi.org/10.1186/s12882-016-0327-2> [published Online First: 2016/08/04]
17. Mitchell AJ, Baker-Glenn EA, Granger L, et al. Can the Distress Thermometer be improved by additional mood domains? Part I. Initial validation of the Emotion Thermometers tool. *Psycho-Oncology* 2010;19(2):125-33. doi: <https://doi.org/10.1002/pon.1523>
18. K C, L B. Qualitative interviewing and grounded theory analysis. In: Gubrium JF, Holstein AB, McKinney KD, eds. *The SAGE Handbook of interview research: The Complexity of the Craft*. California, USA: Sage publications 2012.
19. Braun V, Clarke V. *Successful Qualitative Research: a practical guide for beginners*. Thousand Oaks, CA: Sage 2013:174-179.
20. Alley S, Jackson SF, Shakya YB. Reflexivity: A Methodological Tool in the Knowledge Translation Process? *Health Promotion Practice* 2015;16(3):426-31. doi: 10.1177/1524839914568344
21. Berger R. Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research* 2015;15(2):219-34. doi: 10.1177/1468794112468475
22. Achille MA, Ouellette A, Fournier S, et al. Impact of Transplant-Related Stressors and Feelings of Indebtedness on Psychosocial Adjustment Following Kidney Transplantation. *Journal of Clinical Psychology in Medical Settings* 2004;11(1):63-73. doi: 10.1023/B:JOCS.0000016271.10786.ee
23. Chilcot J, Spencer BWJ, Maple H, et al. Depression and Kidney Transplantation. *Transplantation* 2014;97(7):717-21. doi: <https://doi.org/10.1097/01.TP.0000438212.72960.ae>
24. Shemesh Y, Peles-Bortz A, Peled Y, et al. Feelings of indebtedness and guilt toward donor and immunosuppressive medication adherence among heart transplant (HTx) patients, as assessed in a cross-sectional study with the Basel Assessment of Adherence to Immunosuppressive Medications Scale (BAASIS). *Clinical Transplantation* 2017;31(10):e13053. doi: 10.1111/ctr.13053
25. Poole J, Ward J, Deluca E, et al. Grief and loss for patients before and after heart transplant. *Heart & lung : the journal of critical care* 2016;45(3):193. doi: 10.1016/j.hrtlng.2016.01.006
26. Suzuki A, Kenmochi T, Maruyama M, et al. Changes in quality of life in deceased versus living-donor kidney transplantations. *Transplant Proc* 2012;44(1):287-9. doi: <https://doi.org/10.1016/j.transproceed.2011.11.056> [published Online First: 2012/02/09]
27. Fox RC. Through the lenses of biology and sociology: Organ replacement. In: Williams SJ, Birke L, Bendelow GA, eds. *Debating Biology: Sociological reflection on health, medicine and society*. London: Routledge 2003.

- 1  
2  
3 28. Pinter J, Hanson CS, Craig JC, et al. 'I feel stronger and younger all the time'—perspectives of  
4 elderly kidney transplant recipients: thematic synthesis of qualitative research. *Nephrol Dial*  
5 *Transplant* 2016;31(9):1531-40. doi: <https://doi.org/10.1093/ndt/gfv463>  
6  
7 29. Boaz A, Morgan M. Working to establish 'normality' post-transplant: a qualitative study of kidney  
8 transplant patients. *Chronic illness* 2014;10(4):247-58. doi:  
9 <https://doi.org/10.1177/1742395313504789> [published Online First: 2013/09/28]  
10  
11 30. Cormier NR, Gallo-Cruz SR, Beard RL. Navigating the new, transplanted self: how recipients  
12 manage the cognitive risks of organ transplantation. *Sociology of health & illness* 2017;39(8):1496-  
13 513. doi: <https://doi.org/10.1111/1467-9566.12610> [published Online First: 2017/10/11]  
14  
15 31. Been-Dahmen JMJ, Beck DK, Peeters MAC, et al. Evaluating the feasibility of a nurse-led self-  
16 management support intervention for kidney transplant recipients: a pilot study. *BMC nephrology*  
17 2019;20(1):143. doi: <https://doi.org/10.1186/s12882-019-1300-7> [published Online First:  
18 2019/04/29]  
19  
20 32. Curcani M, Tan M. the factors affecting the quality of life of patients who have undergone  
21 kidney transplants *Pakistan Journal of Medicine* 2012;27(5):1092-97.  
22  
23 33. Muehrer RJ, Becker BN. Life after transplantation: new transitions in quality of life and  
24 psychological distress. *Semin Dial* 2005;18(2):124-31. doi: [https://doi.org/10.1111/j.1525-](https://doi.org/10.1111/j.1525-139X.2005.18214.x)  
25 [139X.2005.18214.x](https://doi.org/10.1111/j.1525-139X.2005.18214.x) [published Online First: 2005/03/18]  
26  
27 34. National Institute for Health and Clinical Excellence, CG138 Patient experience in NHS services:  
28 improving the experience of care for people using adult NHS services Manchester: National Institute  
29 for Health and Clinical Excellence 2012 [Available from: <http://guidance.nice.org.uk/cg138> accessed  
30 July 2019].  
31  
32 35. Damery S, Sein K, Combes G. The prevalence, experience and management of mild to moderate  
33 distress in patients with end stage renal disease: results from a multi-centre, mixed methods  
34 research study: NIHR CLAHRC-WM, University of Birmingham, 2019.  
35  
36 36. Been-Dahmen JMJ, Grijpma JW, Ista E, et al. Self-management challenges and support needs  
37 among kidney transplant recipients: A qualitative study. *Journal of advanced nursing*  
38 2018;74(10):2393-405. doi: <https://doi.org/10.1111/jan.13730> [published Online First: 2018/06/06]  
39  
40 37. Grijpma JW, Tielen M, van Staa AL, et al. Kidney transplant patients' attitudes towards self-  
41 management support: A Q-methodological study. *Patient Educ Couns* 2016;99(5):836-43. doi:  
42 <https://doi.org/10.1016/j.pec.2015.11.018> [published Online First: 2015/12/20]  
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## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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# BMJ Open

## **“You’ve got a foreign body in there”: Renal transplantation, unexpected mild-to-moderate distress and patients’ support needs: a qualitative study**

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Article Type:	Original research
Date Submitted by the Author:	20-Jan-2020
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<b>Primary Subject Heading</b>:	Renal medicine
Secondary Subject Heading:	Qualitative research
Keywords:	Renal transplantation < NEPHROLOGY, Anxiety disorders < PSYCHIATRY, QUALITATIVE RESEARCH

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3 **“You’ve got a foreign body in there”**: Renal transplantation, unexpected mild-  
4 **to-moderate distress and patients’ support needs: a qualitative study**  
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8 Short title: Unexpected distress in renal transplant patients  
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11 Janet Jones\*<sup>1</sup>, Sarah Damery<sup>1</sup>, Kerry Allen<sup>2</sup>, Johann Nicholas<sup>3^</sup>, Jyoti Baharani<sup>4</sup>, and  
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## ABSTRACT

**Objective:** To explore why transplant patients experience unexpected mild-to moderate distress and what support they may need.

**Design:** Qualitative study using individual in-depth interviews.

**Setting:** Four NHS Trusts in the Midlands, UK.

**Participants:** Fifteen renal transplant patients meeting the criteria for mild to moderate distress from their responses to emotion thermometers.

**Main outcome measures:** identification of the reasons for distress and support options acceptable to renal transplant patients.

**Results:** Three themes were interpreted from the data: 'I'm living with a "foreign body" inside me', 'why am I distressed?' and, 'different patients want different support'. Following their transplant, participants felt that they should be happy and content, but this was often not the case. They described a range of feelings about their transplant, such as: uncertainty about the lifespan of their new kidney, fear of transplant failure or fear of the donor having health conditions that may transfer to them. A few experienced survivors' guilt when others they had met at the dialysis unit had not received a transplant or because someone had died to enable them to receive the transplant. No longer having regular contact with the renal unit made participants feel isolated. Some participants did not initially attribute the source of their distress to their transplant. Participants' preferred support for their distress and their preferences about who should deliver it varied from peer support to seeing a psychologist.

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3 **Conclusion:** Raising the issue of post-transplant mild-to-moderate distress with  
4 patients and encouraging them to think about and plan coping strategies pre-  
5 transplant may prove beneficial for the patient and healthcare provider. Patients  
6 should be able to choose from a variety of support options.  
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## 16 **ARTICLE SUMMARY**

### 17 **Strengths and limitations of this study**

- 18 • This is the first study designed to explore the issue of unexpected mild-to-  
19 moderate distress in renal transplant patients.  
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- 21 • The Interviews were a sub-set of data from a larger study.  
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- 23 • To reduce bias on the basis of the services offered to renal patients multiple  
24 sites with different organisation and delivery of services were selected.  
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- 26 • Participants were diverse thus the findings are more representative of the  
27 wider group of renal transplant patients.  
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## INTRODUCTION

At the end of 2017, 63,162 adults were receiving renal replacement therapy in the UK<sup>1</sup>, and in the same year 3,462 transplants were performed.<sup>1</sup> Patients with end stage renal disease (ESRD) can experience distress and distress is associated with lower quality of life and greater treatment burden.<sup>2</sup> The level of emotional distress increases as the health of a patient with ESRD declines<sup>3</sup> and the prevalence of depression and anxiety in patients with ESRD is approximately four times higher than in the general adult population.<sup>4</sup> Damery et al 2019<sup>5</sup> reported that more than a third of renal dialysis patients suffer emotional distress. If suffering from mild-to-moderate distress – the unpleasant feelings or emotions that may interfere with patients' ability to cope with their kidney transplant, its physical symptoms and its treatments - patients may withdraw from treatment, be non-compliant with medication and diet<sup>6</sup> or be reluctant to engage in pre-renal replacement therapy (RRT) education and support.<sup>7</sup>

Although not a cure, for patients with ESRD, receiving a transplant provides the best chance of improving their quality of life and removing the burden of undergoing long-term dialysis treatment.<sup>8,9</sup> Nevertheless, research has shown that although receiving a transplant is the main goal for ESRD patients who are eligible for transplantation, they may continue to experience distress. For example, fear of the transplant failing can affect patient distress levels.<sup>8</sup> There is also evidence that patients may experience ongoing physical symptoms such as fatigue after receiving a transplant, and that there is substantial burden associated with taking regular immunosuppressant medication to lower the likelihood of graft rejection.<sup>10</sup> UK health

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3 policies highlight the importance of addressing the emotional and psychological  
4 needs of renal transplant patients <sup>11</sup> and the Department of Health and NHS England  
5 advocate treating mental health on an equal footing to that of physical health by  
6 incorporating it into care pathways.<sup>12</sup> Nevertheless, evidence suggests that distress,  
7 coping, and adjustment in transplant patients largely go undiagnosed or ignored and  
8 remain untreated.<sup>13</sup> Currently, there is little evidence on mild-to-moderate distress in  
9 transplant patients and further research is required in order to understand the  
10 psychological and emotional effects of a transplant.<sup>9 14 15</sup>

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25 As an element of a larger mixed-methods study with patients and staff,<sup>16</sup> this paper  
26 reports the findings from a qualitative study with renal transplant patients. The aims  
27 were to explore why transplant patients experience distress and what support they  
28 may need.  
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## 38 **METHODS**

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41 The detailed methods for the study are in the published protocol.<sup>16</sup> In brief,  
42 participants were recruited from four National Health Service (NHS) hospitals in the  
43 West Midlands, UK. The chosen sites provided maximum diversity in patient  
44 demographics, catchment size, urban and rural locations plus the organisation of  
45 psychological support services and were categorised according to the size of the  
46 catchment area. Table 1.  
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**Table 1.** Summary of recruitment sites

Site	Size	Catchment area	On-site renal psychologist
1	Small	Urban inner city with sizable Black, Asian and minority ethnic (BAME) population	No
2	Large	Urban inner city with sizable BAME population	Yes
3	Medium	Urban with surrounding rural districts majority white population	No
4	Large	Urban with surrounding rural districts majority white population	Yes

To be eligible for recruitment to the qualitative study, patients had to be categorised as having mild-to-moderate distress based on their responses to the distress thermometer<sup>17</sup> included in the wider study questionnaire. Participants indicated on the questionnaire whether or not they would be willing to take part in an interview and provided their preferred contact details. A consent form and participant information sheet explaining the purpose of the interview study and what participation would involve were sent to those expressing interest. The following week those meeting the purposive sampling criteria (age, sex and ethnicity) were contacted by a researcher (FT) to confirm participation and arrange a date and time for the interview. If participants had changed their mind they were able to withdraw from this part of the wider study. As well as assuring patient confidentiality, the patient information sheet provided contact details of appropriate clinical staff the participants could contact if they felt distressed or upset and would like support. Contacting the participants to answer their questions, to arrange the interview and to

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2  
3 remind them a few days beforehand helped to build up a rapport with each  
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5 participant prior to their interview.  
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11 Patient interviews took place between March 2016 and May 2017 and were  
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13 conducted by two experienced qualitative researchers (FT, EK) (both identifying as  
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15 female and educated to masters level) employed by the University of Birmingham.  
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17 Neither researcher had experience (personally or professionally) of the topic area  
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19 and none of the participants knew the researchers. Interviews were either face-to-  
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21 face (at a location chosen by the participant, either a quiet room at the hospital or at  
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23 the patients home) or over the telephone and lasted between 30 - 60 minutes. The  
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25 interviews were in-depth and semi-structured allowing the exploration of key issues  
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27 without being overly prescriptive about content and direction. All participants  
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29 provided signed written informed consent prior to their interview. Patient advisors,  
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31 renal clinicians and the current literature helped with the design of the topic guide,  
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33 see box 1 for the areas covered by the topic guide. Prior to the start of the interview  
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35 participants were advised to let the researcher know if they needed to take a break  
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37 during the interview or if they no longer wished to carry on. Although included in the  
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39 participant information sheet participants were reminded that taking part in an  
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41 interview would not impact on the care they receive. At the end of each interview  
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43 participants were asked if they had any further comments on the topics covered or  
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45 whether there were any important areas they felt had not been discussed. Both  
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47 researchers made field notes following each interview. Interviews were audio-  
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49 recorded and transcribed verbatim by a professional transcribing service. Transcripts  
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51 were checked against the recordings for accuracy. Participants did not have the  
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53 opportunity to review their interview transcript.  
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- a) Experience of emotional difficulties and needs linked to their illness and/or treatment, when and for how long.
- b) Language used around emotional difficulties and needs, and its meaning.
- c) Whether and how emotional needs have been recognised and supported by renal staff, when and by whom.
- d) What, if any, support used, when and why.
- e) Likes and dislikes of support used.
- f) Support would have liked/would want in future, when, and from whom.
- g) Key elements would want included in an emotional support intervention

**Box 1.** Areas covered by the topic guide

Analysis combined aspects of grounded theory<sup>18</sup> and thematic analysis.<sup>19</sup> Interviews were initially analysed inductively using the open coding and constant comparison aspects of grounded theory. The initial coding framework was developed by JJ and CG and was appropriately refined following comparison and discussion. Transcripts were coded using NVivo 11. For data that did not fit existing themes, new codes were developed or existing ones revised until all data were coded by theme.

Following the completion of data collection the research team met and agreed that in order to understand participants' experiences and to help inform future practice a generic pragmatic hybrid approach to analysis was appropriate<sup>20 21</sup>. The research team also discussed the role of reflexivity and how our personal views and experiences may influence our interpretation of the data.<sup>22 23</sup>

**Patient and public involvement**

The patient and public involvement group of the NIHR CLAHRC West Midlands long-term conditions theme and a renal patient advisory group provided advice on the design of the study, the data collection tools and the selection of outcomes. All participants received a summary of the study findings.

## RESULTS

Fifteen renal transplant patients aged between 30 and  $\geq 70$  years were recruited across the four sites, see tables 2 and 3.

**Table 2.** Summary of participant characteristics

		<b>N (%)</b>
<b>Sex (participant self-identified)</b>	Male	7 (47)
	Female	8 (53)
<b>Age</b>	30-39	3 (20)
	40-49	2 (13)
	50-59	4 (27)
	60-69	4 (27)
	$\geq 70$	2 (13)
<b>*Ethnicity (participant self-identified)</b>	White	9 (60)
	Indian	4 (27)
	Caribbean	2 (13)
<b>Length of time on dialysis prior to transplant</b>	No dialysis	1 (7)
	0 – 3 years	5 (33)
	4 – 9 years	0 (0)
	$\geq 10$ years	3 (20)
	Unknown	6 (40)

\*According to the Office of National Statistics ethnicity groupings 2015

**Table 3.** Individual participant characteristics

<b>ID</b>	<b>Age</b>	<b>Time on dialysis prior to transplant</b>
P129	40-49	No dialysis
P267	60-69	Not stated

P384	50-59	16 ½ years
P413	30-39	Not stated
P494	50-59	11 years
P687	30-39	Not stated
P726	50-59	10 years
P781	≥70	11 months
P197	40-49	1 year
P225	≤70	3 years
P369	60-69	Not stated
P389	50-59	3 years
P401	30-39	Not stated
P1028	60-69	6 months
P1141	60-69	Not stated

Three overarching themes were interpreted from the data. See table 4 for a summary of the themes and sub-themes:

**Table 4.** Themes and sub-themes

Theme	Sub-themes
I'm living with a "foreign body" inside me	Fear/feelings about the kidney itself
	Survivors' guilt
	Feelings of isolation
	Impacts of medication
Why am I distressed?	Expectations of living with a transplant
	Coping with distress
	Lack of information about transplants and support
Different patients want different types of support	

### **I'm living with a "foreign body" inside me**

Fear/feelings about the kidney itself

Living with a transplanted kidney and its associated treatments can evoke many different feelings and difficulties for patients. For many there is the fear and uncertainty of how long the transplant will last: participants talked about their

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3 transplant having a finite life and how this knowledge made them worry about what  
4 would happen in the future. Three participants had experienced a failed transplant  
5 and others understood the status of their transplant could change at any time:  
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9  
10 *“A lot of people I knew before when I was on dialysis who had*  
11 *transplants, they had rejections and all sorts of things. So that’s*  
12 *passing through your mind all the while”*. (P225).  
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21 Among some patients, their fear had escalated the longer they had been with a  
22 transplant, particularly after their transplant exceeded the average lifespan. Some  
23 patients thought the longevity of a transplanted kidney was something of a lottery,  
24 which was perceived to be outside of their control and could therefore cause  
25 distress. A few patients seemed emotionally affected by feeling they had a “foreign  
26 body” inside them (M225). One male patient talked about the possible consequences  
27 for his character of having received a female kidney. Another was anxious that his  
28 transplanted kidney might have come from someone with other health problems:  
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40 *“When I got it I started to get awful thoughts at night. ‘How did this*  
41 *person die, how old were they, did they have anything else, could*  
42 *they possibly have been HIV positive? Could there have been any*  
43 *other things that were underlying that may come forward later on?’*  
44 *and I still get those sort of thoughts at the moment”*. (P1141).  
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55 Survivors’ guilt  
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3 Although a transplant is the gold standard treatment for ESRD, some participants  
4 mentioned feeling guilty about being distressed and some worried this may make  
5 them appear ungrateful. They felt they should be happy because they were lucky to  
6 receive a transplant: *“but you, at the same time you’ve got no reason to feel like*  
7 *that”*. (M389). This guilt and the fear of appearing ungrateful prevented some from  
8 seeking help when they needed it and stopped them from moving forward with their  
9 lives. Some participants worried about the donor, what happened to them and the  
10 family they left behind and others had survivors’ guilt because they had received  
11 their transplant before others who had been waiting longer:  
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24 *“When I had my transplant I felt, I suppose what you’d call it is like*  
25 *in a sense survivors guilt.....And because I had my transplant so*  
26 *quickly I just felt this huge amount of guilt because I thought all*  
27 *those patients that I had met at [hospital] and they’ve been on the*  
28 *list for such a long time, and I thought ‘what’s the difference*  
29 *between me and them?’”*. (P413).  
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## 42 Feelings of isolation

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45 There was a perception amongst several of the participants that after receiving a  
46 transplant they were no longer part of the renal unit. They talked about feeling ‘cut-  
47 off’ and ‘abandoned’ with minimal contact. One patient explained how there had  
48 been no contact with his renal unit for several years following his transplant. Patients  
49 that had transitioned from in-centre haemodialysis (HD) seemed to feel this loss  
50 acutely - they missed the supportive relationship of staff and patients in the dialysis  
51 unit:  
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3       *“Once you’re transplanted, you don’t really have anything to do as*  
4       *such with the renal unit.....the only time I actually only ever was*  
5       *involved with the renal unit was when I was on dialysis. So that sort*  
6       *of like support was gone”.* (P726).  
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16       Some patients experienced feelings of isolation because of the lack of understanding  
17       about their disease and its treatments among family, friends and society in general.

18  
19       They believed only fellow transplant patients understood their feelings:  
20  
21

22       *“It helped the fact talking to a stranger about it. You know, the wife*  
23       *couldn’t understand why I was like it and that, but obviously the*  
24       *stranger could because she knew the experience of it all”.* (P369).  
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#### 34       Impacts of medication

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36       Feeling down and finding their situation difficult to deal with was widespread  
37       amongst the participants. These feelings were often present when participants were  
38       dealing with the physical side effects of the anti-rejection medications such as,  
39       weight gain, puffy appearance and excessive hair growth. Other peoples’ reactions  
40       to the physical changes were often difficult to deal with:  
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49       *“You know like the new face and excessive hair ..... and I found*  
50       *that I think the most difficult for me was that change and*  
51       *unfortunately when I went back to school I had a bit of , a bit of*  
52       *bullying went on, because of physically changing so much from*  
53       *what I was previously as well”.* (P687).  
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6 Participants explained how when they were on dialysis they felt in control of their  
7  
8 body, their treatment and their lives but following transplant many felt they no longer  
9  
10 had command of their body or life in general and yearned to take back control. Such  
11  
12 as, not wanting to leave the house because of lack of bladder control. For the  
13  
14 following patient the feeling of helplessness ended with her sabotaging her  
15  
16 treatment:  
17  
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19  
20  
21 *“So the reason my kidney failed was because I felt like I didn’t have*  
22  
23 *much control, so I kind of stopped taking my pills, my*  
24  
25 *immunosuppressant. I stopped taking them for a while”.* (P413).  
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### 31 **Why am I distressed?**

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34 Expectations of living with a transplant

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37 Following their transplant, participants did not expect to experience distress because  
38  
39 they regarded a transplant as the best treatment option for an improved quality of  
40  
41 life. Some patients had waited many years for the opportunity to receive the ‘gift’ of a  
42  
43 transplant and had been optimistic:  
44  
45

46  
47 *“I’m coming at it first time with an expectation that once you get a*  
48  
49 *transplant and you start feeling better again, life is rosy, life can get*  
50  
51 *back to normal”.* (P389).  
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58 Whilst experiencing distress, many participants did not initially relate it to their  
59  
60 transplant. The data suggest that the reasons for this were two-fold. Firstly, following

1  
2  
3 a transplant there is an expectation from family, friends, clinicians and society in  
4  
5 general that life will return to 'normal' and be 'wonderful' again.  
6  
7

8 *"I never did link it to – there was something in your paperwork that I*  
9 *had. I thought I've never associated it with the kidney operation".*  
10  
11  
12  
13 (P369).  
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19 Secondly, renal staff did not forewarn the participants they might experience  
20  
21 distress after receiving a transplant. Some only made the connection after  
22  
23 agreeing to take part in this research study:  
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29 *But being in the hospital and then having all sorts of side effects*  
30 *which is effecting me emotionally now. And that things could have*  
31 *been told to me before, you know, I would have prepped myself up.*  
32  
33 *Some of those things could have been addressed before. It could*  
34 *have been helpful to have been told beforehand. (P129).*  
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#### 44 Coping with distress

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47 Renal disease and its lifecycle can make it hard for patients to be positive  
48  
49 about their transplant. Several participants explained how it was difficult to  
50  
51 cope with their emotions, to move on with their lives and how they perceived  
52  
53 family and friends, in particular, were defining them by their health condition:  
54  
55

56 *"(Sighs) Ah, again I suppose it comes back to the fact that I don't*  
57 *want to like, yes like I know I've got an illness, but I don't want to be*  
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3 *that's who I am like. You know that's what I'm all about sort of*  
4  
5 *thing". (P726).*  
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11 The majority of participants developed ways of accepting post-transplant life  
12 and found ways to cope with their distress. For some, distractions in the form  
13 of hobbies and pastimes such as gardening or reading helped them to adjust  
14 and for others it was important to maintain a positive outlook about their  
15 transplant:  
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23 *"I've always had this positive outlook on the transplant and that."*  
24  
25 (P225).  
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### 32 Lack of information about transplants and support

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34 Many participants wished the renal team had explained to them the possibility  
35 of experiencing post-transplant distress and lamented the lack of information  
36 about this and the lack of available support. Many felt that "forewarned is  
37 forearmed" and were upset they missed the opportunity to plan, in advance,  
38 coping strategies. This lack of information provision was associated with a lack  
39 of continuity of care, and participants felt that staff regarded transplant patients  
40 as a lower priority compared to those on dialysis:  
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51 *"Time is precious, resources are scarce, I suspect that probably it*  
52 *never feels as though it's a big priority". (P389).*  
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### 60 **Different patients want different types of support**

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3 There were, however, diverse views amongst the participants about the types of  
4 support they would like to receive, and who should deliver it. For example, one  
5  
6 participant described how she thought talking to other patients might have provided  
7  
8 the support she sought.  
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13 *“So with other patients in your situation, so that you could liaise with*  
14 *each other to see what new life is all about”.* (P494).  
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21 There were mixed views about the role of healthcare professionals (HCPs), with  
22 some suggesting that HCPs should be more proactive in identifying distress in renal  
23 transplant patients and directing them to appropriate sources of help and support.  
24  
25 Whereas others did not see this as the role of the renal team – they are there to  
26 provide medical assistance and advice not psychological and emotional support.  
27  
28 Many suggested that specialist psychological services should be available as in  
29 integral part of care for renal transplant patients:  
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38 *“I think you need psychologists as part of the renal team, a*  
39 *psychologist with renal expertise”.* (P781).  
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46 However, because of the sensitive and personal nature of distress or for fear  
47 of showing weakness there were those who were reluctant to talk about their  
48 distress to anyone, making it difficult for HCPs to assess the support needs of  
49 these patients:  
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3                   *“You know, it might have been something to do with medication –*  
4  
5                   *I’m just guessing. But I should have told them but as I say, I mean*  
6  
7                   *it’s not the sort of thing I tell people” (P369).*  
8  
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## 13                   **DISCUSSION**

16                   This research has highlighted the complex relationship that renal transplant patients  
17                   have with their new kidney, their largely unanticipated experience of their distress  
18                   and the diverse opinions on the types of support they would like to help them through  
19                   their distress. Current research has shown that the prevalence of distress in renal  
20                   transplant patients is 25% and although this is lower than the 33% of dialysis  
21                   patients, it is still substantial and shows that many transplant patients experience  
22                   ongoing issues.<sup>5</sup> There is a range of reasons why despite all expectations of living  
23                   an improved life, some patients became uneasy with their transplanted kidney and  
24                   why some did not associate their distress with their transplant and/or  
25                   immunosuppressant medication.  
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43                   Patients found it difficult to accept their new kidney because of a number of different  
44                   situations including: the side effects of medication, fear of transplant rejection and  
45                   feeling obliged to make the most of life because of the “gift” of a transplant.<sup>24-27</sup> It  
46                   has been reported that concern about potential lifespan of the transplanted kidney  
47                   may be the biggest stressor immediately after transplant, this fear subsides with  
48                   time.<sup>8</sup> However, our findings do not reflect this: the majority of our participants,  
49                   regardless of time since transplant, reported some level of emotional distress.<sup>5</sup>  
50                   Emotional problems such as depression, anxiety, stress, and concerns about body  
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3 image are known indicators of poor medication adherence.<sup>3 6</sup> and as discussed, may  
4 result in patients wishing they were back on dialysis and in some cases sabotaging  
5 their treatment. Gill,<sup>8</sup> Suzuki <sup>28</sup> and Fox <sup>29</sup> found that those receiving a kidney from a  
6 living donor had a vested interest in each other's well-being and were motivated to  
7 comply with their medication regimes and enjoyed an improved quality of life. For  
8 those receiving a cadaver kidney, thoughts about who their kidney came from were  
9 forefront in their mind and for some this had a negative effect on their relationship  
10 with their kidney – making them feel as though they had a “foreign body” inside  
11 them. The emotional distress patients feel may be down to unrealistically high  
12 expectations of life post-transplant and there is a need for these expectations to be  
13 managed by renal services.<sup>8 25 30</sup>

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32 The majority of participants did not expect to experience distress after a transplant.  
33 This may be that patients naively perceive that by having a transplant their quality of  
34 life will improve quickly and they will return to a normal life.<sup>31</sup> Consequently, patients  
35 are often ill-prepared and feel helpless when trying to cope with their distress.<sup>32</sup>  
36  
37 Evidence has shown that improving coping skills,<sup>33</sup> education before and after  
38 transplantation,<sup>34</sup> and active information seeking by patients can have a beneficial  
39 effect on patients' medical and psychological problems.<sup>8 25 35</sup> The National Institute  
40 for Health and Care Excellence (NICE) advocate keeping patients informed at all  
41 stages of treatment and encourage the promotion of self-care and self-management  
42 skills.<sup>36</sup> However, HCPs can find it difficult to recognise distress or anxiety in patients  
43 and are unsure at which point in the disease trajectory to discuss this with their  
44 patients.<sup>37</sup> When a patient is informed, it empowers them to take control of their  
45 condition and having control can itself lower the chances of distress.<sup>6</sup> It is therefore  
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3 important that HCPs provide and share information and discuss all possible  
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5 outcomes and coping strategies at the appropriate time in the treatment pathway.<sup>3 30</sup>  
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13 Not all renal transplant patients will experience distress and not all of those who do  
14  
15 will want to receive support. This research has shown that some patients do not wish  
16  
17 to talk about their feelings for fear of appearing ungrateful or weak, making it difficult  
18  
19 for HCPs to understand, assess and procure appropriate support.<sup>37</sup> Even when  
20  
21 patients do want to talk about their feelings, there is “no one size fits all” solution to  
22  
23 the provision of support.<sup>38</sup> Different patients have different emotional needs  
24  
25 indicating that any support offered to patients should be individualised in order to  
26  
27 meet this variance of need.<sup>39</sup>  
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36 There were no discernible differences in the depth of data and the length of interview  
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38 between those conducted face-to-face and those conducted over the telephone. A  
39  
40 limitation of this study is that the interview data analysed for this research is a sub-  
41  
42 set of a larger set of data. Although the 15 in-depth interviews provided sufficient  
43  
44 data to answer the research questions and were more representative of the wider  
45  
46 group of transplant patients, it is important for future research to explore these areas  
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48 with a more diverse and carefully stratified sample.  
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## 55 **CONCLUSIONS**

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3 Our research has highlighted a number of points: firstly, it is important to talk to  
4 patients and their families pre-transplant about the possibility of experiencing mild-to-  
5 moderate post-transplant distress. Secondly, patients should be encouraged to think  
6 about potential coping strategies and finally, transplant patients with mild-to-  
7 moderate distress should be able to choose from a variety of support options: peer  
8 support; HCPs with augmented skills in detecting and managing distress; access to  
9 psychology services.  
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28 time to talk to us.  
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42 interpretation of data, methodology, validation, writing (original draft); GC: formal  
43 analysis, validation, writing (critical review and editing); SD, & KA: interpretation of  
44 data, writing (critical review and editing), JN & JB: Conceptualisation, validation,  
45 writing (critical review and editing). All authors have approved the final version.  
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58  
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4 the author(s) and not necessarily those of the NIHR or the Department of Health and  
5  
6  
7  
8 Social Care.  
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10  
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14 **Competing interests:** -None  
15

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18  
19 **Ethical approval:** The Coventry and Warwickshire Research Ethics Committee  
20 granted approval for this and the wider study in October 2015 [Ref 15/WM/0288].  
21  
22 The Research Governance office at each of the participating hospital trusts also  
23  
24  
25  
26  
27 gave approval for the study.  
28

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32 **Data availability:** The research data is confidential. Participants did not give consent  
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## REFERENCES

1. UK Renal Registry 21st Annual Report - data to 31/12/2017. Bristol, UK, 2019.
2. Soni RK. Health-related quality of life outcomes in chronic kidney disease. *Curr Opin Nephrol Hypertens*;19(2):153-60. doi: <https://doi.org/10.1097/MNH.0b013e328335f939>
3. Schell JO, Patel UD, Steinhauser KE, et al. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *American journal of kidney diseases : the official journal of the National Kidney Foundation* 2012;59(4):495-503. doi: <https://doi.org/10.1053/j.ajkd.2011.11.023> [published Online First: 01/04]
4. Murtagh FEM, Addington-Hall J, Higginson IJ. The Prevalence of Symptoms in End-Stage Renal Disease: A Systematic Review. *Advances in Chronic Kidney Disease* 2007;14(1):82-99. doi: <https://doi.org/10.1053/j.ackd.2006.10.001>
5. Damery S, Brown C, Sein K, et al. The prevalence of mild-to-moderate distress in patients with end-stage renal disease: results from a patient survey using the emotion thermometers in four

- 1  
2  
3 hospital Trusts in the West Midlands, UK. *BMJ open* 2019;9(5):e027982. doi:  
4 <https://doi.org/10.1136/bmjopen-2018-027982>
- 5  
6 6. Cukor D, Rosenthal DS, Jindal RM, et al. Depression is an important contributor to low medication  
7 adherence in hemodialyzed patients and transplant recipients. *Kidney Int* 2009;75(11):1223-29. doi:  
8 <https://doi.org/10.1038/ki.2009.51>
- 9  
10 7. Combes G, Allen K, Sein K. Evaluation of case study sites for home therapies for people with  
11 chronic kidney disease Birmingham: University of Birmingham: West Midlands Central Health  
12 Innovation and Education Cluster; 2013 [Available from:  
13 <http://www.birmingham.ac.uk/research/activity/mds/projects/WMC-HIEC/publications.aspx>  
14 accessed May 19.
- 15  
16 8. Gill P. Stressors and coping mechanisms in live-related renal transplantation. *J Clin Nurs*  
17 2012;21(11-12):1622-31. doi: <https://doi.org/10.1111/j.1365-2702.2012.04085.x>
- 18  
19 9. Kohlsdorf M. Coping Strategies Adopted by Patients With Chronic Kidney Disease in Preparation  
20 for Transplant. *Psychol Comm health* 2015;4(1):27-38. doi: <https://doi.org/10.5964/pch.v4i1.103>  
21 [published Online First: 2015-03-31]
- 22  
23 10. Cukor D, Newville H, Jindal R. Depression and immunosuppressive medication adherence in  
24 kidney transplant patients. *General hospital psychiatry* 2008;30(4):386-7. doi:  
25 <https://doi.org/10.1016/j.genhosppsy.2007.12.003> [published Online First: 2008/07/01]
- 26  
27 11. Department of Health, The National Service Framework for Renal Services Part 2: Chronic kidney  
28 disease, acute renal failure and end of life care. London: Department of Health 2005.
- 29  
30 12. Department of Health, Closing the gap: priorities for essential change in mental health. London:  
31 Department of Health 2014
- 32  
33 13. Spencer BW, Chilcot J, Farrington K. Still sad after successful renal transplantation: are we failing  
34 to recognise depression? An audit of depression screening in renal graft recipients. *Nephron Clinical*  
35 *practice* 2011;117(2):c106-12. doi: <https://doi.org/10.1159/000319657> [published Online First:  
36 2010/08/10]
- 37  
38 14. Almgren M. The meaning of being in uncertainty after heart transplantation - an unrevealed  
39 source to distress. *European Journal of Cardiovascular Nursing* 2017;16(2):167-75. doi:  
40 10.1177/1474515116648240
- 41  
42 15. Mauthner OE. Heart transplants: Identity disruption, bodily integrity and interconnectedness.  
43 *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine* 2014;19(6):578-  
44 95. doi: 10.1177/1363459314560067
- 45  
46 16. Taylor F, Taylor C, Baharani J, et al. Integrating emotional and psychological support into the end-  
47 stage renal disease pathway: a protocol for mixed methods research to identify patients' lower-level  
48 support needs and how these can most effectively be addressed. *BMC Nephrol* 2016;17(1):111. doi:  
49 <https://doi.org/10.1186/s12882-016-0327-2> [published Online First: 2016/08/04]
- 50  
51 17. Mitchell AJ, Baker-Glenn EA, Granger L, et al. Can the Distress Thermometer be improved by  
52 additional mood domains? Part I. Initial validation of the Emotion Thermometers tool. *Psycho-*  
53 *Oncology* 2010;19(2):125-33. doi: <https://doi.org/10.1002/pon.1523>
- 54  
55 18. K C, L B. Qualitative interviewing and grounded theory analysis. In: Gubrium JF, Holstein AB,  
56 McKinney KD, eds. The SAGE Handbook of interview research: The Complexity of the Craft.  
57 California, USA: Sage publications 2012.
- 58  
59 19. Braun V, Clarke V. Successful Qualitative Research: a practical guide for beginners. Thousand  
60 Oaks, CA: Sage 2013:174-179.
20. Caelli K, Ray L, Mill J. 'Clear as Mud': Toward greater clarity in generic qualitative research. *Int J Qual Methods* 2003;2(2):1-24.
21. Cooper S, Endacott R. Generic qualitative research: a design for qualitative research in emergency care? *Emergency Medicine Journal : EMJ* 2007;24(12):816-19. doi: 10.1136/emj.2007.050641
22. Alley S, Jackson SF, Shakya YB. Reflexivity: A Methodological Tool in the Knowledge Translation Process? *Health Promotion Practice* 2015;16(3):426-31. doi: 10.1177/1524839914568344



23. Berger R. Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research* 2015;15(2):219-34. doi: 10.1177/1468794112468475
24. Achille MA, Ouellette A, Fournier S, et al. Impact of Transplant-Related Stressors and Feelings of Indebtedness on Psychosocial Adjustment Following Kidney Transplantation. *Journal of Clinical Psychology in Medical Settings* 2004;11(1):63-73. doi: 10.1023/B:JOCS.0000016271.10786.ee
25. Chilcot J, Spencer BWJ, Maple H, et al. Depression and Kidney Transplantation. *Transplantation* 2014;97(7):717-21. doi: <https://doi.org/10.1097/01.TP.0000438212.72960.ae>
26. Shemesh Y, Peles-Bortz A, Peled Y, et al. Feelings of indebtedness and guilt toward donor and immunosuppressive medication adherence among heart transplant (HTx) patients, as assessed in a cross-sectional study with the Basel Assessment of Adherence to Immunosuppressive Medications Scale (BAASIS). *Clinical Transplantation* 2017;31(10):e13053. doi: 10.1111/ctr.13053
27. Poole J, Ward J, Deluca E, et al. Grief and loss for patients before and after heart transplant. *Heart & lung : the journal of critical care* 2016;45(3):193. doi: 10.1016/j.hrtlng.2016.01.006
28. Suzuki A, Kenmochi T, Maruyama M, et al. Changes in quality of life in deceased versus living-donor kidney transplantations. *Transplant Proc* 2012;44(1):287-9. doi: <https://doi.org/10.1016/j.transproceed.2011.11.056> [published Online First: 2012/02/09]
29. Fox RC. Through the lenses of biology and sociology: Organ replacement. In: Williams SJ, Birke L, Bendelow GA, eds. *Debating Biology: Sociological reflection on health, medicine and society*. London: Routledge 2003.
30. Pinter J, Hanson CS, Craig JC, et al. 'I feel stronger and younger all the time'—perspectives of elderly kidney transplant recipients: thematic synthesis of qualitative research. *Nephrol Dial Transplant* 2016;31(9):1531-40. doi: <https://doi.org/10.1093/ndt/gfv463>
31. Boaz A, Morgan M. Working to establish 'normality' post-transplant: a qualitative study of kidney transplant patients. *Chronic illness* 2014;10(4):247-58. doi: <https://doi.org/10.1177/1742395313504789> [published Online First: 2013/09/28]
32. Cormier NR, Gallo-Cruz SR, Beard RL. Navigating the new, transplanted self: how recipients manage the cognitive risks of organ transplantation. *Sociology of health & illness* 2017;39(8):1496-513. doi: <https://doi.org/10.1111/1467-9566.12610> [published Online First: 2017/10/11]
33. Been-Dahmen JMJ, Beck DK, Peeters MAC, et al. Evaluating the feasibility of a nurse-led self-management support intervention for kidney transplant recipients: a pilot study. *BMC nephrology* 2019;20(1):143. doi: <https://doi.org/10.1186/s12882-019-1300-7> [published Online First: 2019/04/29]
34. Curcani M, Tan M. the factors affecting the quality of life of patients who have undergone kidney transplants *Pakistan Journal of Medicine* 2012;27(5):1092-97.
35. Muehrer RJ, Becker BN. Life after transplantation: new transitions in quality of life and psychological distress. *Semin Dial* 2005;18(2):124-31. doi: <https://doi.org/10.1111/j.1525-139X.2005.18214.x> [published Online First: 2005/03/18]
36. National Institute for Health and Clinical Excellence, CG138 Patient experience in NHS services: improving the experience of care for people using adult NHS services Manchester: National Institute for Health and Clinical Excellence 2012 [Available from: <http://guidance.nice.org.uk/cg138> accessed July 2019.
37. Damery S, Sein K, Combes G. The prevalence, experience and management of mild to moderate distress in patients with end stage renal disease: results from a multi-centre, mixed methods research study: NIHR CLAHRC-WM, University of Birmingham, 2019.
38. Been-Dahmen JMJ, Grijpma JW, Ista E, et al. Self-management challenges and support needs among kidney transplant recipients: A qualitative study. *Journal of advanced nursing* 2018;74(10):2393-405. doi: <https://doi.org/10.1111/jan.13730> [published Online First: 2018/06/06]
39. Grijpma JW, Tielen M, van Staa AL, et al. Kidney transplant patients' attitudes towards self-management support: A Q-methodological study. *Patient Educ Couns* 2016;99(5):836-43. doi: <https://doi.org/10.1016/j.pec.2015.11.018> [published Online First: 2015/12/20]

## COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**