TRANSPLANT
INTERNATIONAL

Transplant International ISSN 0934-0874

REVIEW

‘Suspended in a paradox’—patient attitudes to wait-listing for kidney transplantation: systematic review and thematic synthesis of qualitative studies

Allison Tong,[1,2] Camilla S. Hanson,[1,2] Jeremy R. Chapman,[3] Fabian Halleck,[4] Klemens Budde,[4]
Michelle A. Josephson[5] and Jonathan C. Craig[1,2]

1 Sydney School of Public Health, The University of Sydney, Sydney, NSW, Australia
2 Centre for Kidney Research, The Children’s Hospital at Westmead, Westmead, NSW, Australia
3 Centre for Transplant and Renal Research, Westmead Hospital, Westmead, NSW, Australia
4 Department of Nephrology, Charité – Universitätsmedizin Berlin, Berlin, Germany
5 Department of Medicine, The University of Chicago, Chicago, IL, USA

Keywords
kidney transplantation, patient-centered care, qualitative research, quality of life, wait-listing.

Correspondence
Allison Tong, Centre for Kidney Research, The Children’s Hospital at Westmead, Westmead, Sydney NSW 2145, Australia.
Tel.: +61 2 9845 1482;
fax: +61 2 9845 1491;
e-mail: allison.tong@sydney.edu.au

Conflicts of interest
The authors have no conflict of interest to declare.

Received: 25 January 2015
Revision requested: 23 February 2015
Accepted: 31 March 2015
Published online: 20 April 2015

doi:10.1111/tri.12575

Summary

Patients on waiting lists for kidney transplantation have higher mortality rates and have specific anxieties about their eligibility, process, and outcomes of wait-listing. We aimed to describe patient experiences and attitudes to wait-listing for kidney transplantation. Electronic databases were searched to September 2014. Thematic synthesis was used to analyze the findings. From 22 studies (n = 795 patients), we identified six themes: accepting the only option (chance to regain normality, avoiding guilt, impulsive decision-making); maintaining hope (determined optimism, appreciating a fortuitous gift, enduring for optimal outcomes, trust in clinical judgment); burden of testing (strenuous commitment, losing the battle, medical mistrust); permeating vulnerability (eligibility enigma, being threatened, angst of timing uncertainty, desperate urgency, living in limbo, spiraling doubt and disappointment, residual ambivalence); deprived of opportunity (unfairly dismissed, unexpected disqualification, self-resignation and acceptance, jealousy, suspicious of inequity); and moral guilt (awaiting someone’s death, questioning deservingness). The waiting list offered hope of restored normality. However, the demands of workup, uncertainty about eligibility, and waiting times that exceeded expectations impelled patients to disillusionment, despair, and suspicion of inequity. Managing patient expectations and ensuring transparency of wait-listing and allocation decisions may allay patient disappointment and skepticism, to improve patient satisfaction and treatment outcomes.

Introduction

The desperate shortage of deceased donor kidneys for transplantation has resulted in burgeoning waiting lists worldwide [1]. In the United States, the median waiting time is approximately 5 years and this is expected to increase annually [2–4]. Patients on the waiting list have higher mortality rates and lower quality of life compared with the general and transplant population [3–7].

To access the deceased donor waiting list, patients are required to attend multiple clinical appointments for medical and psychosocial examinations and treatment of health conditions [8], to ensure that they do not have medical (e.g. cardiovascular disease, active cancer, uncontrolled infection, morbid obesity), surgical or psychosocial contraindications for transplantation [9]. This can be a lengthy process, and for some patients, takes over 1 year to complete. The ongoing burden of medical, surgical, and psychosocial testing in the transplant assessment process, uncertainty of receiving a deceased donor kidney, and fears of discrimination have been reported in kidney transplant candidates [10–13]. To some extent, this may explain the high prevalence of stress and anxiety, which is associated with longer wait-list time [14,15]. Also, patient perceptions of prognosis and transplant candidacy have been found to influence treatment decision-making and goals of care [16]. Despite this, in-depth qualitative data on patients' beliefs and the psychosocial impacts of kidney transplant wait-listing are lacking [10]. The significant geographical, age, gender, social, and ethnic disparities in access to deceased donor kidney transplantation [17–23] suggest that there could be important differences in patient expectations and experiences of wait-listing for kidney transplantation.

A broader spectrum of insights on this phenomenon can be gained through the synthesis multiple primary qualitative studies conducted in different populations and health-care contexts [24,25]. This study aims to describe the expectations, beliefs, and attitudes of patients to wait-listing for kidney transplantation, to inform clinical and policy interventions that address patient preferences, concerns, and informational needs. Understanding and addressing the potential psychosocial and emotional sequelae of waiting for a kidney transplant can help to improve patient-centered outcomes.

Patients and methods

We followed the enhancing transparency of reporting the synthesis of qualitative research (ENTREQ) framework [24].

Selection criteria

Qualitative studies on the experiences, attitudes, and beliefs toward wait-listing for kidney transplantation among adults (aged ≥18 years) with any stage of chronic kidney disease (CKD) were eligible. Studies were included if they covered the following topics: expectations and conceptualization of wait-listing (or of the waiting list), experiences of being refused or accepted onto the waiting list, preferences, preparedness, and acceptance of being offered a deceased donor (include extended criteria kidney). Non-English articles were excluded to minimize misinterpretation of linguistic nuances and meanings.

Data sources and searches

The search strategy is provided in the Data S1. The searches were in MEDLINE, Embase, PsycINFO, and CINAHL from database inception to September 23, 2014. Google Scholar and reference lists of included articles were also searched. We also conducted searches in ProQuest Dissertation and Thesis, British Library Electronic Digital Thesis Online Service (EThOS), and the Europe E-theses Portal for Doctoral Dissertations. AT screened the search results and discarded references that did not meet the inclusion criteria. Full texts of potentially relevant studies were assessed for eligibility.

Data extraction and quality assessment

The comprehensiveness of reporting of each primary study was appraised independently by AT/CSH using the adapted consolidated criteria for reporting qualitative health research (COREQ) framework [26], which items specific to the research team, study methods, study setting, analysis, and interpretations. Any discrepancies were resolved through discussion.

Data analysis

Following the thematic synthesis methods approach [27], the 'results' and 'conclusion/discussion' section of each article were imported into qualitative data management software (HYPERRESEARCH, ResearchWare, Inc. 2009, version 3.0.3, Randolph, MA, USA). AT coded the findings of the primary studies line-by-line, conceptualized the data, and inductively labeled concepts relating to patient's perspectives on wait-listing for kidney transplantation. For subsequent papers, the text was coded into existing concepts or a new concept was created when needed. Similar concepts were grouped into themes and subthemes. AT identified conceptual links among themes to develop an analytical thematic schema. Investigator triangulation was performed whereby CSH also read the papers independently to check that all the data were included in the interpretation, preliminary analysis, and analytical framework and discussed the addition or revision of themes with AT.

Results

Literature search

We included 22 studies (*n* = 795); of which two were doctoral dissertations (Fig. 1). Twenty one studies specified the CKD stage of the participants (CKD Stage 1-5 [*n* = 11]), 5D [*n* = 509], 5T [*n* = 166]). Wait-listing status was reported in eight studies (wait-listed [*n* = 336]; not wait-listed/undergoing workup [*n* = 69]). The study characteristics are provided in Table 1. The studies were conducted in eight countries, including the United Kingdom, United States, Mexico, Brazil, Canada, Sweden, the Netherlands, and Australia. Of note, four studies which were conducted in non-English speaking countries (published in English

Table 1. Characteristics of the included studies.

		CKD stage			Wait listing status								
Study ID	n	1–5	5D	5T	Y	N	Sex M:F	Age range	Country	Methodology	Data collection	Data analysis	Topic
Peer-reviewed journal articles													
Amerena (2009) [36]	8	0	0	8	NA	NA	3:5	35–55	UK	Grounded theory	Semi-structured interviews	Grounded theory analysis	Psychological experience of kidney transplantation
Calestani (2014) [10]	53	NS	7	6	16	10	30:23	23–73	UK	Qualitative	Face-to-face, semi-structured interviews	Thematic	Kidney transplant listing
Crowley-Matoka (2005) [29]	50	NS	NS	NS	NS	NS	28:22	17–62	Mexico	Qualitative (illness narrative)	Face-to-face in-depth interviews, observations	Content analysis	Promise and perils of living with kidney transplantation
Da Silva Nhihs (2013) [12]	20	0	20	0	20	0	12:8	NS	Brazil	Phenomenology	Semi-structured interviews	Content analysis	Waiting for a transplant
Gordon (2012) [32]	162	0	162	0	162	0	100:62	19–77	US	Qualitative	Semi-structured interviews	Thematic	Understanding of increased risk kidneys
Gordon (2001) [35]	79	0	79	0	NS	NS	39:40	19–73	US	Ethnography	Semi-structured interviews	Content analysis	Treatment decision making
Karamanidou (2014) [52]	7	0	7	0	NS	NS	3:4	32–68	UK	Phenomenology	Face-to-face, semi-structured interviews	Interpretive phenomenology	Burden of hemodialysis
Klassen (2002) [42]	114	0	114	0	70	44	64:50	21–70	US	Mixed-methods	Face-to-face, semi-structured interviews	NS	Wait-listing decisions (disadvantage, discrimination)
Lawrence (2013) [40]	15	0	15	0	0	15	7:3	NS	UK	Grounded theory	Focus groups, semi-structured interviews	Grounded theory	Process of transplant allocation
Lock (2002) [31]	30	0	0	30	NA	NA	NS	NS	Canada	Ethnography	Interviews, observations	Grounded theory	Organ transplantation
Louis (1997) [11]	33	0	0	0	33	0	18:15	22–56	US	Qualitative	Face-to-face/telephone, semi-structured interviews	Thematic	Allocation
Martin (2010) [13]	18	NS	NS	15	NA	NA	16:22	28–76	US	Grounded theory	Face-to-face semi-structured interviews, focus groups	Grounded theory analysis	Uncertainty in transplantation
Moran (2010) [30]	16	0	16	0	16	0	9:7	30–65	UK	Phenomenology	In-depth interviews	Qualitative interpretive	Hemodialysis
Ros (2012) [28]	19	0	15	NS	19	0	14:5	NS	US	Grounded theory	Focus groups	Thematic	High infectious risk donor kidneys
Sanner (2003) [43]	23	0	0	23	NS	NS	13:10	23–65	Sweden	Qualitative	Face-to-face/telephone in-depth interviews	Thematic	Organ donation, organ donor, transplantation

Table 1. continued

Study ID	n	CKD stage			Wait listing status		Sex M:F	Age range	Country	Methodology	Data collection	Data analysis	Topic
		1–5	5D	5T	Y	N							
Schell (2012) [53]	29	11	18	0	0	0	16:13	65–92	US	Qualitative	Face-to-face, semi-structured interviews, focus groups	Thematic	Kidney disease trajectory
Schipper (2014) [37]	30	0	0	30	NA	NA	16:14	27–70	The Netherlands	Qualitative	Face-to-face, semi-structured interviews, focus groups	Thematic	Consequences of kidney transplantation
Sloan (1999) [54]	12	0	NS	NS	NS	NS	NS	NS	US	Hermeneutical	Face-to-face, in-depth interviews	Hermeneutical	Failure to receive an anticipated kidney transplant
Tong (2012) [41]	37	0	13	24	NS	NS	20:17	25–71	Australia	Mixed-methods	Nominal Group Technique	Thematic	Preferences for kidney allocation
Weems (1989) [33]	14	0	0	14	NA	NA	10:4	20–59	US	Grounded theory	Semi-structured interviews	Grounded theory analysis	Waiting for a kidney transplant
Doctoral dissertations													
Gordon (2001) [38]	16	0	0	16	NA	NA	8:8	28–62	US	Grounded theory	Face-to-face, semi-structured interviews	Grounded theory	Uncertainty and psychosocial adaptation in kidney transplantation
Humphreys (2012) [34]	10	0	10	0	NS	NS	5:5	39–64	US	Grounded theory	Semi-structured interviews, observation	Grounded theory	Kidney transplant evaluation

NS, not stated; NA, not applicable; M, male; F, female; n, number of patients with CKD; CKD, chronic kidney disease; UK, United Kingdom; US, United States; mixed methods, include quantitative and qualitative methods; phenomenology, to study peoples' understanding and interpretations of their experiences in their own terms and emphasizing these as explanations for their actions; ethnography, to discover and describe individual social and cultural groups; hermeneutical study, to understand and interpret linguistic and nonlinguistic communication; nominal group technique, structured group process that elicits contributions from all participants; thematic analysis, concepts, and theories are inductively derived from the data.

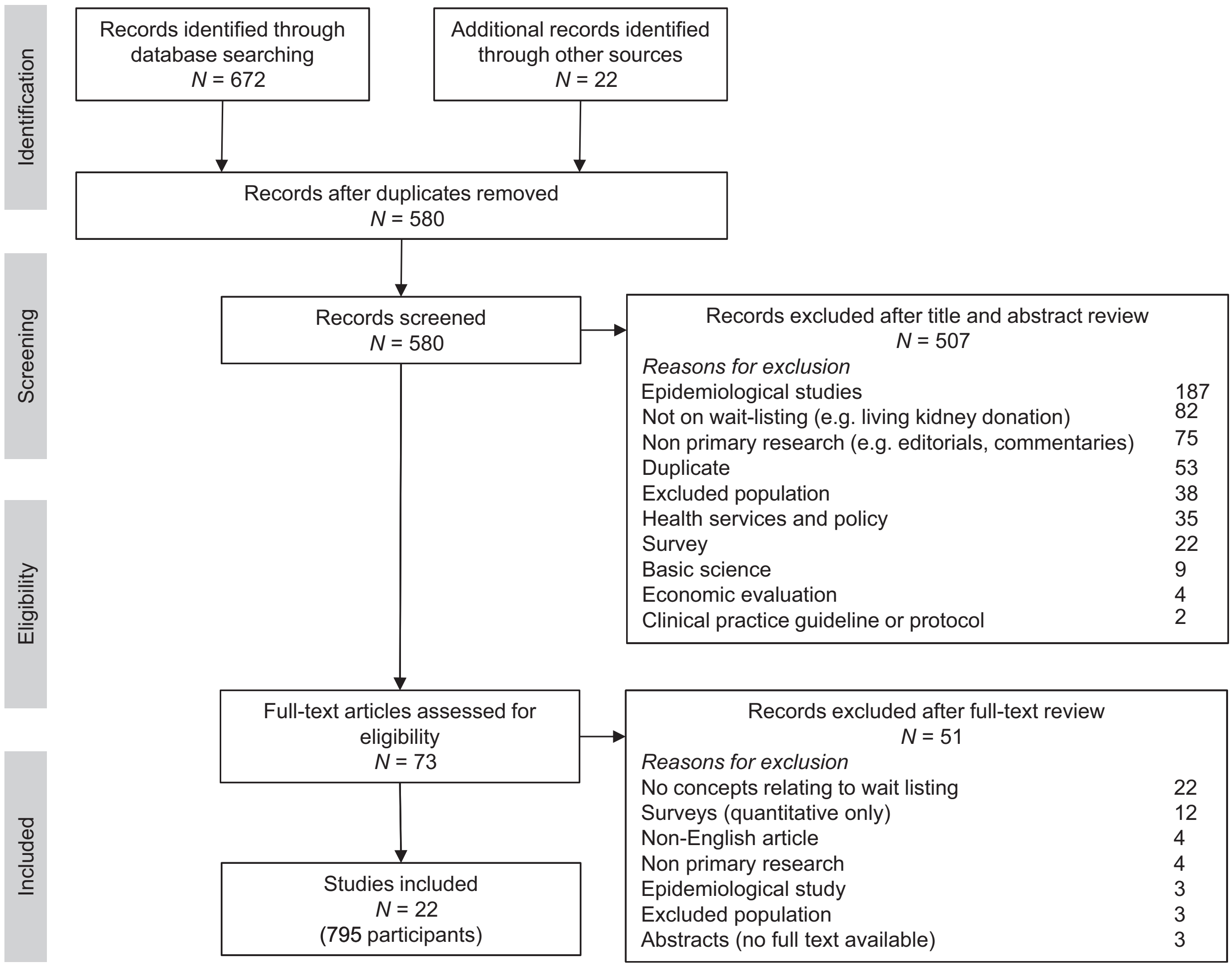

Figure 1 Search results.

language). Interviews, focus groups, nominal group technique, and observations were used to collect the data.

Transparency of reporting

Studies reported on 3–20 items in the adapted 26-item COREQ framework (Table 2). The participant selection strategy was described in 15 (68%) studies. Audio-taping and transcription was stated in 21 (95%) studies. Investigator triangulation was reported in 16 (73%) studies. Participant quotations to support the findings were available in all 22 studies. The four studies conducted in non-English-speaking populations (published in English) did not report the language in which the data were collected and analyzed.

Synthesis

We identified six themes: accepting the only option, maintaining hop, burden of testing, permeating vulnerability, deprived of opportunity, and moral guilt. The themes and subthemes are described below with supporting quotations provided in Table 3, with conceptual links among the themes depicted in Fig. 2.

Accepting the only option

Chance to regain normality: The waiting list was perceived as the only route to 'normality [10]' and freedom from the constraints of dialysis. It offered participants the promise of restoring health and being able to lead a productive life in terms of pursuing career opportunities, travel, and taking care of their family and thus dispelled any uncertainties some had felt about transplantation. Some participants would risk accepting an extended criteria kidney as it meant they would 'get off that [dialysis] machine [28].'

Avoiding guilt: The thought of approaching a family member for living kidney donation was described by some participants as 'emotionally excruciating (or even impossible)

Table 2. Comprehensiveness of reporting in included studies.

Item	References	Number of studies
Researcher characteristics		
Interviewer/facilitator identified	[13,29,30,32–35,37,38,40–43]	13
Occupation	[12,30,33,34,36,38,40]	7
Experience or training in qualitative research	[30]	1
Relationship with participants		
Relationship established prior to study commencement	[29,34,40]	3
Participant Selection		
Selection strategy *(e.g. snowball, purposive, convenience)*	[10–13,30,32–38,41–43]	15
Method of approach or recruitment	[10,12,13,32,34–38,40, 42,53]	12
Sample size	[10–13,28–38,40–43,52–54]	22
Number/reasons for nonparticipation	[12,32,35,40–43,52,53]	9
Setting		
Venue of data collection	[10–13,29,30,32–35,37,38,40,41, 43,52–54]	18
Presence of nonparticipants (e.g. clinical staff)	[29,33,38,41]	4
Description of the sample	[10–13,28–30,32–38,40–43,52–54]	21
Data Collection		
Questions, prompts or topic guide provided	[10–13,28,30,32–37,38,40–42,52,53]	18
Repeat interviews/observations	[10–13,28–30,32–38,40–43,52–54]	21
Audio/visual recording	[10–13,28–30,32–38,40–43,52–54]	21
Field notes	[11,28,29,32,34,35,37,38,41,42,54]	11
Duration of data collection	[10,11,13,29,32–38,40–43,52,54]	17
Translation and interpretation *(NA if English speaking)*	-	0
Protocol for data preparation and transcription	[10–13,28–30,32–38,40–43,52–54]	21
Data (or theoretical) saturation	[28,32,33,37,38,40,41,53]	8
Data Analysis		
Researcher/expert triangulation (multiple researchers involved in coding and analysis)	[10,11,13,28,30,32–34,37,38, 40,41, 43,52–54]	16
Translation (specifies language in which analysis was performed—NA if English)	-	0
Derivation of themes or findings (e.g. inductive, constant comparison)	[10–13,28–30,32–37,38,40,41, 43,52–54]	20
Use of software (e.g. NVIVO)	[10,30,34,35,37,41,53,54]	8
Participant feedback on findings	[34,37,38]	3
Reporting		
Participant quotations or raw data provided *(picture, diary entries)*	[10–13,28–38,40–43,52–54]	22
Range and depth of insight into patient perspectives on wait-listing for kidney transplantation *(thick description provided)*	[10–13,29,30,32–35,37,38,40]	13

[29].' Opting to be on waiting list for a deceased donor kidney was the only way of avoiding the guilt.

Impulsive decision-making: In one study, participants felt that the decision to be wait-listed was made in haste without detailed discussion—'I don't really think I had time to think about it because it all happened so quickly [10].'

Maintaining hope

Determined optimism: Entry onto the waiting list was described as enabling patients to see 'the light at the end of tunnel [10,30].' At times, participants felt like giving up but remained resolute in believing that transplant was inevitable. Some referred to dialysis as a temporary 'short-term [30]' solution and expected to receive a transplant soon. This determination drove some to be vigilant in maintaining their health.

Appreciating a fortuitous gift: One participant 'felt really lucky to go right to the top of the list of waiting people just because I happened to be the best match [31].'

Enduring for optimal outcomes: When asked about preferences for extended criteria kidneys (including kidneys

Table 3. Illustrative quotations.

Theme	Selected quotations*	Contributing Studies
Accepting the only option		
Chance to regain normality	*I can have a normal life after the transplantation and I don't have to be attached to the machine from, like three times a week and you know generally you might well be better once you've had the transplant and you'd be out and about doing normal things* [10]. *I can't wait for my transplant . . .I am like broken cup now, without a handle. And with a transplant I will be whole again and healthy. I will be able to work and take care of my family* [29]. *[I'll accept an increased risk donor kidney] just to get back to a normal life . . . It's a good gamble. Dialysis is crappy and time consuming.* [32] A transplant was regarded as the optimal outcome of the illness for the majority of the patients as it was regarded as a unique chance of regaining a normal life. The future was in many cases synonymous to the hope for a transplant. Successful transplantation was seen as the miraculous cure signifying the end of the illness course [52].	[10,12, 28,29,32,36,37,38,52]
Avoiding guilt	For years the [consultant] was trying to encourage me to get a family member to [donate] and I was going, no, absolutely not, I'm not going to ask anybody for a kidney. Because my fear was that if I take one of their kidneys, their other one would pack up and then they're in a position that I was in, and I couldn't do that to somebody [10]. Some patients were unwilling to ask a family member for a kidney. This is a task usually left to patients themselves, and one which some approached with ease, while others found emotionally excruciating (or even impossible) [29].	[10,29]
Impulsive decision-making	*The consultant mentioned transplant to me and would I like to go on the list and I said yes; we didn't sit down and have a conversation about it . . . It was just, Do you or don't you? That's all* [10].	[10]
Maintaining hope		
Determined optimism	*I'm afraid and I think about giving up, but I know hemodialysis is even worse* [12]. *Transplantation is everything for me, so I have much hope that I'll soon get out of this condition* [12]. *If you're on the list there's hope, there's light at the end of the tunnel* [30]. *I had my suitcase packed for 3 years* [33].	[10,12,29,30,33,36,37,52]
Appreciating a fortuitous gift	*I felt really lucky to go right to the top of the list of waiting people just because I happened to be the best match. I didn't want to lose this chance this seemed really to be a gift of love and health*[31].	[31]

Table 3. continued

Theme	Selected quotations*	Contributing Studies
Enduring for optimal outcomes	*[I] just wouldn't want a kidney that old. It is like getting a 25-year-old car for free. It could be in good condition . . . until it breaks* [32]. *If we don't get the best match it's not good to put it in the body. If the spices aren't right then the pot won't cook, right?* [11] I *think that life expectancy is much more important than waiting time. I'd rather wait, but then again I think that's because I'm doing well on dialysis. Maybe I'd feel differently if I wasn't doing well. But I am, so I'd rather wait for a better kidney* [11].	[11,12,28,32,34]
Trust in clinical judgment	"*I put my faith into my doctor's hand. If he says this is good for you, he's the doctor*" [28]. *Many assumed that their physician could serve as their advocate* [33].	[11,28,32,33,40,41]
Burden of testing		
Strenuous commitment - perseverance	*I used to dread, obviously, going for the tests because never having had so many extensive tests done I had a slight worry in the back of my mind that something might impact on having a transplantation; so obviously having the tests, I'd always worry unnecessarily* [10]. *I was unsure at first. But you take each test and you think, maybe this will be the one where they tell me no. And then when they don't and you go on to the next one, you start to have a little hope. Until toward the end, waiting for the results of those last tests I could barely stand it. I was so scared that something would go wrong after everything we had been through. That's when I knew how much I wanted a transplant* [29]. *But I had to go through a lot of testing before they put me on the transplant list to make sure that I was a good risk. And that took several months to get through all those tests. In the meantime, I started the dialysis and I got along pretty good with it and I just kept telling myself that this isn't forever, you're getting a transplant and this is just something I had to do and I just wouldn't let myself get really depressed about it.*[38]. *I was getting tired of all of the appointments* [34].	[10,29,34,35,38]
Losing the battle	*I've got to a stage where I say, Why am I trying so hard to get on this thing [transplant list]? There's no hope for me getting on it . . . I just feel, Is my day ever going to come?*[30] *I've been to [the transplant unit] twice . . . they [medical team] say I'm overweight . . . I'm really trying so hard, but it's impossible to get the weight down . . . the longer it [waiting for a transplant] goes on, the worse you feel about it . . . at the beginning, you have no knowledge of what's happening at all . . . but after being on dialysis for two years, I feel I'm going to be stuck here and that's it* [30].	[30,34]
Medical mistrust	*While some patients expressed suspicion that there was financial benefit for physicians to have patients go through many tests, others expressed frustration with having to undergo testing and then waiting a long time for a kidney.* [35]	[35]

Table 3. continued

Theme	Selected quotations*	Contributing Studies
Permeating vulnerability		
Eligibility enigma	*I honestly don't know [why I've been suspended]. I honestly don't know. So they made the phone calls and found out, and then I was told that I'd been suspended on the list* [10]. *I was dialysing for two years and it wasn't until I moved from this hospital to [other hospital] that [doctor] came and saw me and said are you thinking about going on the waiting list? and I said that I thought I was on the waiting list [slight laughter] and he said no. So no one told me, you know, no one told me about it or anything, I just assumed I was on it* [10]. *Only I find this putting me on the transplant list without having taken any tests, how is that going to help me? I don't know, because although they say I'm on the list, I haven't had any tests done* [10].	[10,34,40]
Being threatened	*I daren't say this otherwise they might... put me down as verging on a nervous breakdown and therefore take me off or not put me on the [transplant waiting-] list. And, I mean doctors are slightly threatening aren't they?*[36] *I don't really want a transplant right now. But I don't tell that to the doctors, I go along with the tests, just in case* [29].	[29,34,36]
Angst of timing uncertainty	*They can call me at any time to undergo transplantation. I hope all the time but they do not call me, and then hemodialysis comes again (E10); ah! I'm always turned on. When phone rings, I get scared. I think maybe it's now* [12]. *I'm waiting and I think it's [the transplant] never going to happen . . . I get a bit depressed at times . . . and I've got to a stage where I say, Why am I trying so hard to get on this thing [transplant list]? There's no hope for me getting on it . . . I just feel, Is my day ever going to come?*[30] *If you have the initial consult then you get put on a list. And as far as the time frame goes, every thing is a waiting game. It has to be the right time, the right circumstances, the right person* [34].	[12,13,28,30,33–35,37,42]
Desperate urgency	*I knew some colleagues who died during hemodialysis while they waited for a transplant* [12]. *I'm afraid time won't be enough, and I can die before* [12]. *Will the kidney be in time and what if I miss the call when they offer me a kidney?*[37]	[12,13,32,37]
Living in limbo	*I look at life as if it's on hold until I get a transplant . . . because you're not doing what you want to do . . . it [dialysis] gets in the way of work, it gets in the way of a normal routine . . . it's like I'm bonded to it [dialysis] . . . and when you do get the transplant, it's like the shackles are gone* [30]. *My life is on hold . . . very, very much so . . . I can't plan anything, can't go anywhere . . . I'm waiting for the phone to ring . . . I might get a days work but what happens if the phone rings . . . I could earn a bit more money but there's always the chance I might be called for a transplant* [30].	[30,33,37,38]

Table 3. continued

Theme	Selected quotations*	Contributing Studies
Spiraling doubt and disappointment	*At the beginning it was only joy, but now it seems it won't happen anymore. I count the hours and days that pass. Each time my phone rings, I hope it's their call telling me to undergo transplant. Sometimes I even think they have forgotten me* [12]. *Well, in the beginning, I was told that the average waiting list [for a transplant] was around 12 to 18 months, so when I started on dialysis I had two years left out in my head for it all to be over . . . but I'm nearly two years on dialysis now, so you just don't now . . . it's waiting all the time* [30]. *The doctors said I'd be waiting for a year and a bit to get the transplant . . . then it became two years and a bit, three years and a bit, and now it's four years . . . people shouldn't listen to this! Because you think, OK, I can do a year or two years on dialysis, but then it's devastating when you pass the two years* [30]. *Before I started dialysis, I'd ask [the healthcare team] what was the average [waiting time for a transplant], and it was 18 months to two years, but I've heard of people having transplants just after a few months, and then there's people that have been waiting five to six years . . . It's hard not to think, Well, why not me?*[30] *The doctors gave us hope by saying that a kidney would become available in the near future. What they said gave us hope, but it wasn't really worth much . . . their words were empty* [37]. The long waiting period made me feel rebellious [37].	[12,33,36,37,38]
Residual ambivalence	*I don't want to go through rejection even if there is no guarantee that I won't. I don't want to take my chances so I'll wait as long as it takes. I'd be discouraged but I'll have to deal with it* [11]. *Really, in a ways, its' (a transplant) like walking in the dark. If you don't know what is ahead of you, you're going to back up and go where the light is, instead of taking a chance over yonder* [33].	[11,13,32,33,42]
Deprived of opportunity		
Unfairly dismissed	*I was never offered [listing and transplantation] and I think that's because of my age, and I must admit, it annoys me and makes me angry* [10]. *Because when they called and told me about taking me off the activation list because of the two pounds, the first thing that came to my mind was to ask them this question. I said so you're telling me if I was sick to the point of dying and a transplant would have saved me and I was not activated because of that two pounds you all would not have given me that kidney and she said well, if you don't meet the criteria, no we wouldn't. I kind of feel like when I make a mistake dealing with my sickness I pay* [34]. *Basically my doctor said to me, Oh you're the healthiest patient I've got. I said, well what does that mean? At the end I was like what he said, it's not good. Because, that means you get put behind because other patients are sicker than you and I thought ok.*[41]	[10,34,40,41]
Unexpected disqualification	*I went for a biopsy and they said oh no, the cancer's occurred again so that's it. Then they told me that it was through the cancer starting again and I can't go on the transplant list . . . disappointed, that's it. Can't do nothing about it* [40].	[10,40]

Table 3. continued

Theme	Selected quotations*	Contributing Studies
Self-resignation	*I don't think it's worth it, not at my age. It just seems like so many complications. I've heard about all the medications, it's a lot more extensive than what we have to do now... If I was 25 and [ESRD] happened, I would do it [get a transplant]. I'm not going to be here much long[er]* [32]. *They ask me why I'm not putting myself on the list. I tell them because of my age and plus... when I had my leg amputated and I had open heart surgery... I have been cut through here and cut through there. I'm not going that route* [53].	[34,35,40,53]
Jealousy	*Sometimes people suddenly didn't arrive at the dialysis unit anymore because they had had a transplant. I had mixed feelings: I was, of course happy for them, but it also made me feel a little bit jealous. They had a kidney and I was still waiting ....*[37]	[37]
Suspicious of inequity	*It's not fair because of race. They give it to other people first and then they come after black people. I'm wondering what's going on. Did they forget us?*[11] *The fact that I kept seeing more white patients than black patients getting transplants worried me. I didn't know if people were getting preferential treatment. But I guess the part that scared me the most was that I looked around and all I saw was black patients and only one or two white people in the unit. They'd be here for a short period of time and then they'd be gone.*[11] *I noticed that the young people were going, and the males were going, and the favorite people at the units were going ... a lot of people started after me had gone, got their transplant and come back, and I'm still sitting here* [33].	[11,41,42]
Moral guilt		
Awaiting someone's death	*And I talked to a therapist and she had asked me if I ever prayed for a kidney and I said well, no, I don't because I feel like I'd be praying for somebody to die, because I was going to have a cadaver kidney. And she said well, people are going to die anyway but I still even after talking to her, I couldn't pray for a kidney. I felt I kept thinking someone, some family is going to lose a loved one, someone is going to die for me to get the kidney and I couldn't pray for that* [38]. *I just prayed that I would get a kidney soon but I said, Lord, I wish there was some way I could get a kidney without someone having to die* [38]. *I ain't gonna say, OK, I wish somebody would hurry and die so I can have a kidney. I ain't wishing that nobody would get killed so I can have a kidney. I'd rather die myself than wish somebody would die so I can have a kidney* [33].	[12,33,38,43]
Questioning deservingness	*I think if I see somebody who looks sicker than me, I would want them to have it (the kidney transplant) faster than me no matter what* [34]. *I seen a little boy when I went when they called me to come in for some blood testing when they thought they may have a kidney for me, and when I was waiting there was a little boy. And we be wondering if he be tested to see if the kidney be good for him. And you kind of wondering if I get it before he gets it I would rather give it to him because he looked sicker than I did. I want to tell them they can give it to him first and not me* [34].	[34,35,40,41]

Italicized quotations are from study participants.
*Full list of quotations is available on request

Table 4. Suggestions for clinical care.

Focus	Suggestions for practice*
Physician-patient communication	Emphasize the importance of self-management and provide practical resources to support self-management behaviors.
	Discuss and address patient expectations of waiting time.
	Devise individualized transplant evaluation pathways to minimize the burden of transplant workup.
	Explain test results to patients in the context of eligibility thresholds for wait-listing.
	Provide justification if patients are deemed ineligible and ensure patients comprehend and are able to accept the explanation.
	Provide regular follow-up (i.e. annually) to confirm the patient's wait-list status.
Education	Distribute standardized information materials or hold information seminars about wait-listing and allocation policies.
	Appoint "patient navigators" (e.g. trained kidney transplant recipients) who can provide tailored information and assistance in completing the transplant workup for deceased donation [8].
Ancillary psychosocial support services	Offer access to psychological services to address depression, anxiety, guilt, or emotional trauma relating to wait-listing.
	Facilitate access to support groups.

*Based on the findings of the systematic review and literature.

from high infectious risk donors) or kidneys that were not optimally matched, some participants, particularly if they were doing well on dialysis, would wait longer on the list for a kidney in 'good condition [32]' or one that was the 'best match [11].' One participant said 'If the shoe doesn't fit … you going to squeeze your foot in there anyway? [11]' Some were fearful of life-threatening complications and did not 'want somebody else's problems.'

Trust in clinical judgment: While on the waiting list, participants trusted their physician to be their 'advocate [33]' and make decisions about accepting offers of deceased donor kidneys on their behalf, which they trusted would be based on maximizing the recipient's chance of survival and transplant success.

Burden of testing

Strenuous commitment: The extensive transplant assessment process demanded a significant investment of time, energy, and emotion during which participants were constantly anxious about 'whether they were fit enough to get on the waiting list [10].' Some felt overwhelmed and began to question whether it was worth the effort to commence or continue with the arduous transplant assessment. One participant who had health problems became particularly frustrated at having to 'start over again [34]' with tests.

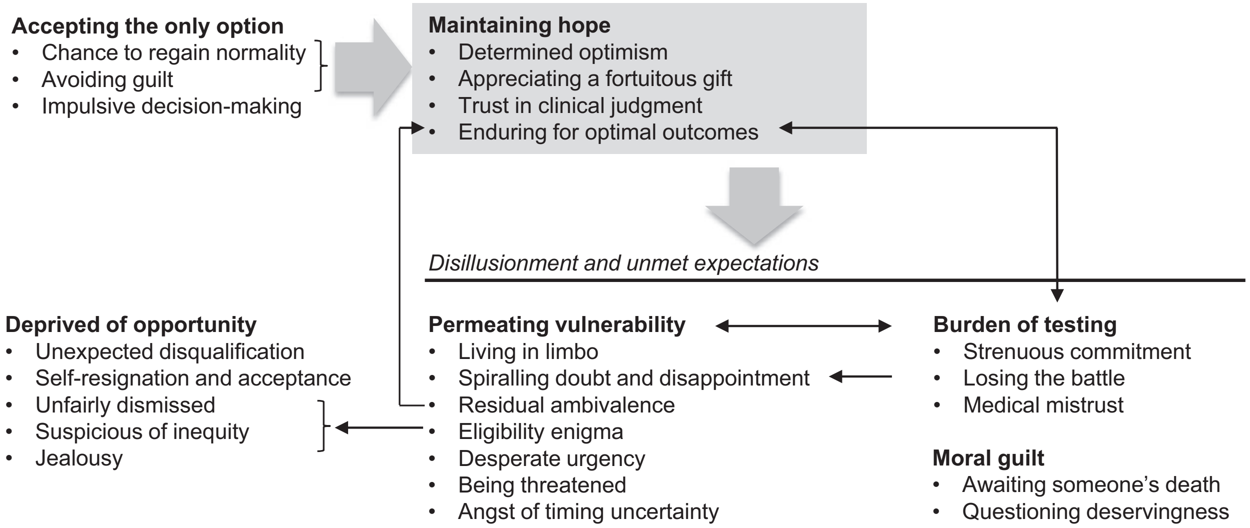

Figure 2 Thematic schema. The waiting list offered participants hope of restored normality and some maintained hope for transplantation. However, some participants developed a sense of disillusionment which deepened as the waiting time extended beyond their expectation. They questioned whether the grueling demands and burden of testing were worth the agonizing uncertainties of receiving a transplant on time, unpredictable transplant outcomes, and disappointment of not receiving a kidney transplant. Lack of clarity about the eligibility criteria for wait-listing and the process of transplantation lead to a suspicion of inequity and feeling unfairly rejected from waiting list.

Others, however, became more motivated as they passed each test—'a hurdle successfully vaulted [29].'

Losing the battle: Some participants who were ineligible for wait-listing because of their weight despaired—'I'm really trying so hard, but it's impossible to get the weight down . . . the longer it [waiting for a transplant] goes on, the worse you feel about it . . . I feel I'm going to be stuck here and that's it [30].' They felt frustrated and angry with themselves because of their inability to lose weight [30,34].

Medical mistrust: Participants in one study were skeptical about the necessity of undergoing plethora of tests. They suspected that physicians derived financial benefit for issuing tests [35].

Permeating vulnerability

Eligibility enigma: Some were not aware of their wait-listing status, or about the criteria for acceptance onto the waiting list, or why they were suspended or rejected. Some perceived that they were placed on the list without having undergone any assessment, which meant they were unsure about how to remain on the waiting list. Participants wanted to know the outcome of the tests, to receive periodic reassurance about their status, and to understand 'how the waiting list system worked [10].' Another participant actively searched for information about testing to avoid being 'eliminated [34].'

Being threatened: The potential to jeopardize their wait-listing status was of imminent concern. For example, one participant would not disclose their depressive thoughts—'I daren't say this otherwise they might... put me down as verging on a nervous breakdown and therefore take me off or not put me on the [transplant waiting-] list [36].'

Angst of timing uncertainty: For wait-listed participants, the indefiniteness of when they would receive transplant was the 'biggest concern [13]' and was aware that the offer of transplantation was contingent on many factors—'it has to be the right time, the right circumstances, the right person [34].' During this 'waiting game [34],' they would remain alert for the possibility of receiving a phone call but also worried they may 'miss [37]' the call. Some participants became 'scared [12]' each time the phone rang, as they did not know what to expect.

Desperate urgency: Some wait-listed participants lived in fear that they would die before being offered a transplant and were particularly distressed when they saw other dialysis patients die on the waiting list. They were afraid that 'time won't be enough [12]'. Older or sensitized patients indicated that they would accept a high-risk donor kidney as this could be the only chance of receiving a transplant [32].

Living in limbo: Being on the waiting list meant that participants had to put their life 'on hold [30,38]' as they were still 'bonded [39]' to dialysis waiting for the transplant to remove their 'shackles [30].' Some could not maintain work and were unable to 'plan anything or go anywhere [39].' Waiting was just a 'matter or survival [37].'

Spiraling doubt and disappointment: As participants remained on the waiting list, they felt an agonizing sense of doubt which intensified to devastation when the waiting period exceeded the time they had 'expected [30]' to wait. Some participants stated that their physicians told them a kidney would become available in the near future but regarded this as an 'empty [37]' promise, and some believed they had been 'forgotten [12,33].' The long wait caused one participant to feel 'rebellious [37].'

Residual ambivalence: For some wait-listed patients, transplantation was 'like walking in the dark [33].' They questioned whether their quality of life would improve, had fear of surgery and its complications, and were anxious about the possibility of rejection and losing the transplant after investing so much time and energy into the evaluation process; therefore, they wanted to receive a better matched kidney and did not want to take a chance on an increased risk kidney.

Deprived of opportunity

Unfairly dismissed: Some participants who perceived they were not offered the option to go on the waiting list, or were deemed ineligible for wait-listing, or had been 'suspended [10]' felt that they had not been given fair consideration. In particular, some felt they were unjustifiably removed from the active waiting list because they had gained 'two pounds [34].' They acknowledged that age and comorbidities could be contraindications for wait-listing but urged that these needed to be discussed 'explicitly [40],' and some believed they should have the 'opportunity to be assessed before a final decision was taken based on age [10].' Some participants who felt well believed that they were at a disadvantage as medically urgent patients were prioritized—'I'm really healthy so I'm staying on this list for a long time while they look after everybody else [41].'

Unexpected disqualification: Unexpected discovery of comorbidities that rendered them ineligible for the waiting list was disheartening for participants.

Self-resignation and acceptance: Some participants who were older or had comorbidities believed they were 'too old [35]' or that it would be too 'risky [40]' to undergo transplantation. To cope, some refused to 'get their hopes up for it [34]' and chose to appreciate that dialysis was 'life saving [40].'

Jealousy: Participants in one study felt some jealousy when they saw other patients receive a transplant—'they had a kidney and I was still waiting [37].'

Suspicious of inequity: Some participants thought that celebrity status, money, race, gender, and younger age gave people an advantage in accessing kidney transplantation [11,33,41,42]. Among African American patients, there was suspicion of being forgotten or discriminated against—'the fact that I kept seeing more white patients than black patients getting transplants worried me [11].'

Moral guilt

Awaiting someone's death: The anathema of waiting for someone to die in order to receive a transplant was emotionally difficult as longing for a transplant was 'equated [43]' to a wish for somebody to die [12,38,43]—'Some family is going to lose a loved one, someone is going to die for me to get the kidney and I couldn't pray for that [38].' Some thought that recipients could in some sense be held culpable for donor's death [43].

Questioning deservingness: Some wait-listed participants held a notion that patients who were younger, sicker, or got kidney failure 'naturally [34]' (not because of lifestyle choices) were more deserving of a transplant because they were yet to live life or were not at fault of having kidney disease.

Discussion

Entry onto the kidney transplant waiting list offers patients hope of restored normality and better survival outcomes and motivates patients to be vigilant in self-management. However, prolonged waiting times extending beyond the expected duration triggered a sense of disillusionment. Some patients became ambivalent about transplantation, questioning whether the physical, financial, and emotional burden of undergoing tests for transplant assessment was worth the agonizing uncertainty of whether they would receive a timely transplant, the unpredictability of transplant outcomes, and potential disappointment of not receiving kidney. Also, some patients were in a constant state of vulnerability because of their tenuous eligibility for wait-listing. Perceived ambiguities about the eligibility criteria for the waiting list and their own wait-list status caused some patients to become suspicious of inequity, injustice, and discrimination. A number of those who were deemed ineligible or removed from the active waiting list felt unfairly dismissed, particularly if they were just under the threshold for acceptance, were unclear about the reasons for their ineligibility, or if they felt powerless to achieve 'unattainable' criteria such as weight thresholds.

Some variability in perceptions of wait-listing for kidney transplantation was apparent. Suspicions of racial discrimination were expressed, namely by African American patients who observed that more 'white' patients were receiving transplants. While this is perhaps unsurprising given the extensively documented racial disparities in access to deceased kidney donor transplantation [44–46], our review highlights how such disparities can provoke and spur distrust among ethnic minority groups toward transplantation services. Older patients or those with comorbidities appear to contend with more uncertainties about their eligibility. They perceive a strong urgency of need for a kidney transplant but at the same time believe they have limited chances of receiving a transplant.

We generated a comprehensive analytical thematic framework that reflects a wide range of patient attitudes and experiences of wait-listing for kidney transplantation. Investigator triangulation was performed whereby multiple investigators were involved in the data analysis to ensure that analysis captured the full breadth and depth of the data reported in the primary studies. A potential limitation was the exclusion of non-English articles. Also, the majority of studies 16 of 22 (73%) were conducted in the United Kingdom or United States, thus potentially restricting the transferability of the findings to other regions with different healthcare contexts. It was not always feasible to draw comparisons across different population by CKD stage, socioeconomic status, or wait-listing status as these were not reported in all of the studies.

Our findings underline the central role of patient expectations in treatment decision-making about kidney transplantation and emotional outcomes of wait-listing for kidney transplant. Suggested for clinical care are summarized in Table 4. Effective pretransplant education and counseling is needed to manage patient expectations for a deceased donor kidney transplant, but the inherent uncertainties of medical prognostication and unpredictability or organ availability makes this discussion challenging. We suggest that clinical conversations validate and respond to patient concerns, address 'unrealistic' expectations, emphasize the importance of health management, and identify ways to access psychological services or support groups. Patients also need reassurance and clarity about their eligibility for wait-listing warranting detailed explanations of their test results or defensible reasons for being deemed ineligible. Annual or regular follow-up may reassure patients that they are not 'forgotten.' A recent trial has shown that patient navigators (i.e. ongoing one-on-one peer support) may be used to help monitor the patient's wait-listing status and results of transplant workup evaluations [8].

Psychological interventions can improve quality of life in patients awaiting kidney transplantation. A recent study found that quality of life therapy, which entailed a therapist-facilitated integrative and comprehensive approach to identify and address the causes of patient dissatisfaction, improved psychosocial outcomes in transplant candidates [15]. The therapist developed specific strategies to facilitate change in the patient's subjective circumstance (i.e. problem solving) [15]. Similar benefits of quality of life therapy have also been shown in lung transplant candidates [47]. The concerns identified in our review could be used to identify quality of life domains or sources of distress, such as the burden of transplant evaluation, medical distrust, vulnerability, doubt and disappointment, decisional conflict, jealousy, and guilt, which could be addressed by a specialized psychological therapist.

Providing patients with information about wait-listing eligibility and the allocation process may help to resolve ambiguities and fears about discrimination. Transplant centers or allocation organization could provide standardized information materials or information seminars. Our findings are timely given that a new national kidney allocation policy was instituted in December 2014 in the United States [48]. In this policy, kidneys from donors with a kidney donor profile index (KDPI) of ≤20% (i.e. kidneys associated with better post-transplant survival) would be allocated to candidates in the top 20th percentile of estimated post-transplant survival. Other features include the addition of waiting time from dialysis initiation, assignment of priority points, and broader sharing for highly-sensitized patients [49]. It has been suggested that this will improve access for highly sensitized or younger patients and improves access to transplantation for certain disadvantaged patients [49]. However, there are concerns that this new policy will decrease the percentage of older patients who receive a transplant because older age is a strong predictor of mortality and a shorter life expectancy reduces transplant priority [50]. It is also speculated to decrease the number of living donation for younger patients and lead to higher discard rates as there is no incentive to accept a kidney with a high KDPI if the patient can wait for a better kidney. Attention is needed to address the complexities in discussing the possible consequences for waiting time and equity in the provider-patient dialog. For these reasons, an understanding of the attitudes among wait-listed patients is needed to inform the design of allocation schemes also.

We suggest that further research is needed to gain detailed understanding about expectations of the transplant waiting list among patients who are highly sensitized, have been relisted after multiple graft failures, live further away from a dialysis or transplant center; as they were not explicitly included in previous study populations. Our findings also show that more research is needed to enable comparisons of patients' expectations and attitudes based on demographic characteristics (gender, educational status, geographical location), clinical characteristics (estimated waiting time), and access to health care (size and transplant volume of the transplant center). Also, perspectives on wait-listing may influence patients' choice of transplant center and this could also be explored. Nephrologists have felt compelled to wait-list patients who have threatened suicide if they were refused entry [51], although this is yet to be reported from the patients' perspective. Also, more focus could be given to the perspectives of patients from different geographic regions, socioeconomic status, and educational attainment, given that these characteristics are predictors or disparities in access to kidney transplantation [3].

While the kidney transplant waiting list offers patients hope of a normal life without dialysis, the onerous demands of completing the transplant assessment workup, uncertainty about eligibility, and waiting times that exceed expectations can be demoralizing and impel patients to disillusionment, despair, and suspicion of inequity in wait listing and allocation. Managing patient expectations of access to kidney transplantation and ensuring transparency of wait-listing and allocation decisions may allay patient disappointment and skepticism, and thereby improve patient satisfaction and treatment outcomes.

Funding

AT is supported by a National Health and Medical Research Council Fellowship (ID 1037162).

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Data S1. Search strategies.

References

1. Garcia GG, Harden P, Chapman J, World Kidney Day Steering Committee 2012. The global role of kidney transplantation. *Transplant* 2013; **93**: 337.
2. UNOS. *Organ Procurement and Transplantation Network*. Richmond, VA, USA: US Department of Health and Human Services, 2014. Available at http://optn.transplant.hrsa.gov/converge/latestData/rptData.asp (Accessed November 3, 2014).
3. Davis AE, Mehrotra S, McElroy LM, *et al.* The extent and predictors of waiting time geographic disparity in kidney transplantation in the United States. *Transplant* 2014; **97**: 1049.
4. Matas AJ, Smith JM, Skeans MA, *et al.* OPTN/SRTRS 2012 Annual data report: kidney. *Am J Transplant* 2014; **14**: 11.
5. Wolfe RA, Ashby VB, Milford EL, *et al.* Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med* 1999; **341**: 1725.
6. Norman SP, Kommareddi M, Luan FL. Inactivity on the kidney transplant wait-list is associated with inferior pre- and post-transplant outcomes. *Clin Transplant* 2013; **27**: e435.
7. Glander P, Budde K, Schmidt D, *et al.* The 'blood group O problem' in kidney transplantation–time to change? *Nephrol Dial Transplant* 2010; **25**: 1998.
8. Sullivan C, Leon JB, Sayre SS, *et al.* Impact of navigators on completion of steps in the kidney transplant process: a randomized, controlled trial. *Clin J Am Soc Nephrol* 2012; **7**: 1639.
9. Batabyal P, Chapman JR, Wong G, Craig JC, Tong A. Clinical practice guidelines on wait-listing for kidney transplantation: consistent and equitable? *Transplant* 2012; **94**: 703.
10. Calestani M, Tonkin-Crine S, Pruthi R, *et al.* Patient attitudes towards kidney transplant listing: qualitative findings from the ATTOM study. *Nephrol Dial Transplant* 2014; **29**: 2144.
11. Louis ON, Sankar P, Ubel PA. Kidney transplant candidates' views of the transplant allocation system. *J Gen Intern Med* 1997; **12**: 478.
12. da Silva Nhihs N, Sartori DL, Zink V, de Aguiar Roza B, Schirmer J. The experience of patients who need renal transplantation while waiting for a compatible organ. *Text Context Nurs* 2013; **22**: 1160.
13. Martin SC, Stone AM, Scott AM, Brashers DE. Medical, personal, and social forms of uncertainty across the transplantation trajectory. *Qual Health Res* 2010; **20**: 182.
14. Silva AN, Moratelli L, Costa AB, *et al.* Waiting for a kidney transplant: association with anxiety and stress. *Transplant Proc* 2014; **46**: 1695.
15. Rodrigue JR, Mandelbrot DA, Pavlakis M. A psychological intervention to improve quality of life and reduce psychological distress in adults awaiting kidney transplantation. *Nephrol Dial Transplant* 2011; **26**: 709.
16. Wachterman MW, Marcantonio ER, Davis RB, *et al.* Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists. *JAMA Intern Med* 2013; **173**: 1206.
17. Stel VS, Kramar R, Leivestad T, *et al.* Time trend in access to the waiting list and renal transplantation: a comparison of four European countries. *Nephrol Dial Transplant* 2012; **27**: 3621.
18. Stel VS, Kramar R, Leivestad T, *et al.* Social deprivation, ethnicity, and access to the deceased donor kidney transplant waiting list in England and Wales. *Transplant* 2010; **90**: 279.
19. Arce CM, Goldstein BA, Mitani AA, Lenihan CR, Winkelmayer WC. Differences in access to kidney transplantation between Hispanic and non-Hispanic whites by geographic location in the United States. *Clin J Am Soc Nephrol* 2013; **8**: 2149.
20. Kutner NG, Zhang R, Huang Y, Johansen KL. Impact of race on predialysis discussions and kidney transplant preemptive wait-listing. *Am J Nephrol* 2012; **35**: 305.
21. Axelrod DA, Dzebisashvili N, Schnitzler MA, *et al.* The interplay of socioeconomic status, distance to center, and interdonor service area travel on kidney transplant access and outcomes. *Clin J Am Soc Nephrol* 2010; **5**: 2276.
22. Szeifert L, Bragg-Gresham JL, Thumma J, *et al.* Psychosocial variables are associated with being wait-listed, but not with receiving a kidney transplant in the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Nephrol Dial Transplant* 2012; **27**: 2107.
23. Malek S, Keys BJ, Kumar S, Milford E, Tullius SG. Racial and ethnic disparities in kidney transplantation. *Transplant Int* 2011; **24**: 419.
24. Tong A, Flemming K, McInnes E, Oliver S, Craig JC. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* 2012; **12**: 181.
25. Tong A, Palmer S, Craig JC, Strippoli GF. A guide to reading and using systematic reviews of qualitative research. *Nephrol Dial Transplant* 2014; pii: gfu354. [Epub ahead of print]
26. Tong A, Sainsbury P, Craig JC. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; **19**: 349.
27. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008; **8**: 45.
28. Ros RL, Kucirka LM, Govindan P, Sarathy H, Montgomery RA, Segev DL. Patient attitudes toward CDC high infectious risk donor kidney transplantation: inferences from focus groups. *Clin Transplant* 2012; **26**: 247.
29. Crowley-Matoka M. Desperately seeking "normal": the promise and perils of living with kidney transplantation. *Soc Sci Med* 2005; **61**: 821.
30. Moran A, Scott A, Darbyshire P. Waiting for a kidney transplant: patients' experiences of haemodialysis therapy. *J Adv Nurs* 2010; **67**: 501.

31. Lock M. Human body parts as therapeutic tools: contradictory discourses and transformed subjectivity. *Qual Health Res* 2002; **12**: 1406.
32. Gordon EJ, Reddy E, Ladner DP, Friedewald J, Abecassis MM, Ison MG. Kidney transplant candidates' understanding of increased risk donor kidneys: a qualitative study. *Clin Transplant* 2012; **26**: 359.
33. Weems J, Patterson ET. Coping with uncertainty and ambivalence while awaiting a cadaveric renal transplant. *ANNA J* 1989; **16**: 27.
34. Humphreys SL. *Shifting Life's Focus: African American Dialysis Patients' Experiences with Kidney Transplant Evaluation*. Fairfax, VA, USA: School of Nursing, George Mason University, 2011: 167 pp.
35. Gordon EJ. Patients' decisions for treatment of end-stage renal disease and their implications for access to transplantation. *Soc Sci Med* 2001; **53**: 971.
36. Amerena P, Wallace P. Psychological experiences of renal transplant patients: a qualitative analysis. *Couns Psychother Res* 2009; **9**: 273.
37. Schipper KAT, Koops C, Bakker I, Sanderman R, Schroevers MJ. Sweet and sour after renal transplantation: a qualitative study about the positive and negative consequences of renal transplantation. *Br J Health Psychol* 2014; **19**: 580.
38. Gordon JL. *Role of Uncertainty in the Psychosocial Adaptation to End-stage Renal Disease in Renal Transplant Patients*. Minneapolis, MN, USA: Walden University, 2001: 298 pp.
39. Moran PJ, Christensen AJ, Ehlers SL, Bertolatus J. Family environment, intrusive ideation, and adjustment among renal transplant candidates. *Ann Behav Med* 1999; **21**: 311.
40. Lawrence C, Sharma S, Da Silva-Gane M, Fletcher BC, Farrington K. Exploring the views of patients not on the transplant waiting list: a qualitative study. *J Ren Care* 2013; **39**: 118.
41. Tong A, Jan S, Wong G, *et al.* Patient preferences for the allocation of deceased donor kidneys for transplantation: a mixed methods study. *Transplant* 2012; **94**: 342.
42. Klassen AC, Hall AG, Saksvig B, Curbow B, Klassen DK. Relationship between patients' perceptions of disadvantage and discrimination and listing for kidney transplantation. *Am J Public Health* 2002; **92**: 811.
43. Sanner MA. Transplant recipients' conceptions of three key phenomena in transplantation: the organ donation, the organ donor, and the organ transplant. *Clin Transplant* 2003; **17**: 391.
44. Bratton C, Chavin K, Baliga P. Racial disparities in organ donation and why. *Curr Opin Organ Transplant* 2011; **16**: 243.
45. Modlin CS Jr, Alster JM, Saad IR, *et al.* Renal transplantations in African Americans: a single-center experience of outcomes and innovations to improve access and results. *Urology* 2014; **84**: 68.
46. Alexander GC, Sehgal AR. Barriers to cadaveric renal transplantation among blacks, women, and the poor. *J Am Med Assoc* 1998; **280**: 1148.
47. Rodrigue JR, Baz MA, Widows MR, Ehlers SL. A randomized evaluation of quality-of-life therapy with patients awaiting lung transplantation. *Am J Transplant* 2005; **5**: 2425.
48. OPTN. Information for OPOs preparing for new kidney allocation system (Available at: http://optn.transplant.hrsa.gov/news/information-for-opos-preparing-for-new-kidney-allocation-system/; Accessed November 15, 2014). U.S. Department of Health & Human Services, Organ Procurement & Transplantation Network, 2014.
49. Israni AK, Salkowski N, Gustafson S, *et al.* New national allocation policy for deceased donor kidneys in the United States and possible effect on patient outcomes. *J Am Soc Nephrol* 2014; **25**: 1842.
50. Schold JD, Reese PP. Simulating the new kidney allocation policy in the United States: modest gains and many unknowns. *J Am Soc Nephrol* 2014; **25**: 1609.
51. Tong A, Howard K, Wong G, *et al.* Nephrologists' perspectives on waitlisting and allocation of deceased donor kidneys for transplant. *Am J Kidney Dis* 2011; **58**: 704.
52. Karamanidou C, Weinman J, Horne R. A qualitative study of treatment burden among haemodialysis recipients. *J Health Psychol* 2014; **19**: 556.
53. Schell JO, Patel UD, Steinhauser KE, Ammarell N, Tulsky JA. Discussions of the kidney disease trajectory by elderly patients and nephrologists: a qualitative study. *Am J Kidney Dis* 2012; **59**: 495.
54. Sloan RS, Gittings J. Hearing the silence of patients who did not receive an anticipated organ transplant: "being second in line". *ANNA J* 1999; **26**: 375, 448; discussion 380, 444.