Author/s:
Low, JK;Crawford, K;Manias, E;Williams, A

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Stressors and coping resources of Australian kidney transplant recipients related to medication taking: a qualitative study

Authors

Jac Kee LOW
BSc (Hons)
PhD candidate
School of Nursing & Midwifery
Faculty of Medicine, Nursing & Health Sciences
Monash University, Wellington Road, Clayton 3800, Victoria, Australia

Kimberley CRAWFORD
PhD, BSc (Hons)
Research Fellow
School of Nursing & Midwifery
Faculty of Medicine, Nursing & Health Sciences
Monash University, Wellington Road, Clayton 3800, Victoria, Australia

Elizabeth MANIAS
RN, PhD, Master of Nursing, BPharm, MPharm
Adjunct Professor of Medicine, Royal Melbourne Hospital, The University of Melbourne
Honorary Professor, Melbourne School of Health Sciences, The University of Melbourne
Research Professor, School of Nursing and Midwifery, Deakin University
221 Burwood Highway, Burwood 3125, Victoria, Australia
Telephone: +6 1 3 9244 6958
Email: emanias@deakin.edu.au
Twitter username: emanias1

Allison WILLIAMS
RN, PhD, Master of Nursing
Associate Professor
School of Nursing & Midwifery
Faculty of Medicine, Nursing & Health Sciences
Monash University, Wellington Road, Clayton 3800, Victoria, Australia

Conflict of interest statement

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Corresponding Author Information

Jac Kee Low (e-mail: jklow7@student.monash.edu)

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ABSTRACT

Aim. To understand the stressors related to life post-kidney transplantation, with a focus on medication adherence, and the coping resources people use to deal with these stressors.

Background. Although kidney transplantation offers enhanced quality and years of life for patients, the management of a kidney transplant post-surgery is a complex process.

Design. A descriptive exploratory study.

Method. Participants were recruited from five kidney transplant units in Victoria, Australia. From March to May 2014, patients who had either maintained their kidney transplant for ≥ 8 months or had experienced a kidney graft loss due to medication non-adherence were interviewed. All audio-recordings of interviews were transcribed verbatim and underwent Ritchie and Spencer's framework analysis.

Results. Participants consisted of fifteen men and ten women aged 26 - 72 years old. All identified themes were categorised into: 1) Causes of distress and 2) Coping resources. Post-kidney transplantation, causes of distress included the regimented routine necessary for graft maintenance, and the everlasting fear of potential graft rejection, contracting infections and developing cancer. Coping resources utilised to manage the stressors were firstly, a shift in perspective about how easy it was to manage a kidney transplant than to be dialysis-dependent and secondly, receiving external help from fellow patients, family members and healthcare professionals in addition to utilising electronic reminders.

Conclusion. An individual well-equipped with coping resources is able to deal with stressors better. It is recommended that changes, such as providing regular reminders about the

lifestyle benefits of kidney transplantation, creating opportunities for patients to share their experiences and promoting the utilisation of a reminder alarm to take medications, will reduce the stress of managing a kidney transplant.

Relevance to clinical practice. Utilising these findings to make informed changes to the usual care of a kidney transplant recipient is likely to result in better patient outcomes.

SUMMARY BOX

What does this study contribute to the wider global clinical community?

- A chief coping resource required by patients to cope with stressors following kidney transplantation is a shift in their perspective to focus on the lifestyle benefits of kidney transplantation.
- Social support from fellow patients, family members and healthcare professionals was an important external coping resource for patients to manage kidney transplantation related stress.
- Complex medication regimens are hard to adhere to but daily intake of medication is made easier with readily available electronic reminders.

KEY WORDS:
Kidney transplantation; adaptation, psychological; adult; stress, psychological; humans

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INTRODUCTION

Kidney transplantation is the treatment of choice for patients with end-stage kidney disease. Unlike their peers who receive dialysis treatment, most people living with a well-functioning kidney transplant do not have any fluid and dietary restrictions imposed on them. Moreover, kidney transplantation improves survival (Oniscu et al. 2005), reduces hospitalisation episodes (Tonelli et al. 2011) and enhances quality of life (Cameron et al. 2000, Purnell et al. 2013). However, kidney transplantation is not a cure. It does not eliminate the underlying end-stage kidney disease and the comorbid conditions that commonly accompany kidney disease, such as hypertension and diabetes (Wu et al. 2005). As such, even after receiving the

treatment of choice, life as a patient continues – requiring lifelong medical supervision and adherence to a complex medication regimen.

In healthcare, adherence is defined as the extent to which people follow the instructions they are given for prescribed treatment (Haynes et al. 2008), which is essential for achieving the best outcomes. However, non-adherence to the medication regimen in kidney transplantation is common (Terebelo & Markell 2010) and specifically, non-adherence to immunosuppressive medications for more than 4.9% of days is linked to a 60% increased risk of rejection (Pinsky et al. 2009). Given the importance of high medication adherence on graft survival, many related aspects, such as risk factors affecting adherence (Tong et al. 2011), outcomes of poor adherence (Butler et al. 2004) and interventions to promote adherence (Low et al. 2015), have been explored; but simply adhering to medications is not enough.

BACKGROUND

Besides having to manage a complex medication regimen, kidney transplant recipients also need to adhere to a regimen of regular specialist appointments, closely monitor for signs and symptoms of infection or kidney graft rejection, undertake bone density screenings and commit to lifestyle changes such as maintaining adequate hydration and using sun protection (Schmid-Mohler et al. 2014, Jamieson et al. 2016). Although practising these habits can ensure prevention or timely treatment of complications, patient and graft survival is not guaranteed. Also, due to the complex nature of the immune system, patients need to live in a chronically immunocompromised state to protect their kidney graft whilst being exposed to a higher chance of contracting infection (Veroux et al. 2008) and developing cancer (Kyllonen et al. 2000, Gallagher et al. 2010). In addition, more than 10% of organ transplant recipients are living with adverse effects from immunosuppressive medications that threaten the quality of their prolonged life, such as tremors, diarrhoea, oedema, anaemia and insomnia (Chisholm, 2002). These drawbacks are part of the multitude of stressors that negatively impact on patients' lives. How people cope with stressors in life is heavily dependent on the resources they have to counter the demands of these stressors (Lazarus & Folkman 1984).

According to Antonovsky (1979), resources are elements that precede and influence coping, which in turn buffer the effects of stressors. These can be an internal resource (e.g. positive thoughts) or an external resource (e.g. social support). Whilst coping resources are rarely mentioned in the literature, studies have examined stressors and coping strategies of

adult kidney transplant recipients. An early survey study conducted by Sutton and Murphy (1989) identified fear of rejection, economic concerns and weight gain as the top three stressors for patients in the first four years after kidney transplantation. To cope with the stressors, the most frequently used strategies were prayer, and trying to objectively view the problem and maintaining some control over the situation (Sutton & Murphy 1989). Another survey study, which was conducted by White et al. (1990), examined stress and coping strategies in patients between 3 and 6 months after kidney transplantation surgery. They identified that health-related stress, including fear of kidney graft rejection, heightened risk of infection and the need to adhere to a complex medication regimen coupled with pronounced side effects, were the most concerning factors (White et al. 1990). For these patients, distancing/detachment and self-control/accepting responsibility were the most popular coping strategies (White et al. 1990). A more recent cross-sectional study, which explored the experiences of Taiwanese patients, found that the most salient stressor was the uncertainty of the graft life and associated future health; but coping mechanism was not explored (Chen et al. 2010). Concern over graft outcome, although subsiding over time, remained a main stressor for patients who received a kidney transplant from live donors and emotion-focused strategies were used to cope with this stressor (Gill 2012). Lindqvist et al. (2004) reported that when kidney transplant recipients were compared with the general Swedish population, they used more optimistic and supportive coping styles. However, these studies offered little information about what post-kidney transplantation patients need in order to cope with stressors. More importantly, despite medical advances, factors related to the medication regimen such as cost, side effects and complex regimen remain as salient stressors for decades (Sutton & Murphy 1989, Fallon et al. 1997, Achille et al. 2006).

The main objective of this paper is therefore to obtain an understanding of stressors kidney transplant recipients face, with a focus on medication adherence, and the coping resources they used to deal with these stressors following kidney transplantation. The term "stressor" used in this study refers to a stress-inducing agent that is associated with a negative emotion, such as sadness, fear, anxiety and the like; whilst coping resources are aids which an individual can draw upon to attenuate stress in order to achieve successful coping.

METHODS

Study design and setting

A descriptive exploratory approach using in-depth interviews was conducted from March to May 2014. This approach was considered appropriate because it was designed to reveal a

deeper understanding of human behaviour by allowing individuals who are living with a transplant to express their views. The Theory of Planned Behaviour by Ajzen (1991) was utilised as the framework to analyse the generated narrative data, with a focus on the construct of self-perceived behavioural control. According to Ajzen (1991), self-perceived behavioural control is influenced by the extent to which a person believes to have access to the requisite resources and opportunities to perform the behaviour successfully. For example, the person would have a higher self-perceived behavioural control when equipped with the right resources and opportunities, resulting in an increased likelihood of performing the behaviour. In this paper, the end behaviour of interest is successful management of stressors in life post-kidney transplantation, especially those that are related to medication adherence. The analysis, therefore, was conducted to uncover stressors and also the resources that were used by the participants to respond, manage and overcome stress in life following kidney transplantation.

This study involved all clinical units that offer adult kidney transplant surgery in Victoria, Australia, providing care for at least 2,500 kidney transplant recipients (ANZDATA Registry 2013). These five clinical units are public tertiary hospitals in the metropolitan area of the state of Victoria. For this study, the number of participants recruited was based on the average number of transplants conducted at each site in the past years, from 2008 to 2012, in Victoria (ANZDATA Registry 2009, 2010, 2011, 2012, 2013). The study was approved by the Human Research Ethics Committees of the university and the health networks (Reference: HREC/__/__/__ - anonymised for review). The study was conducted in accordance to the ethical guidelines jointly developed by the National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellor's Committee (2007).

Study participants

A semi-structured interview was conducted with a convenience sample of English-speaking kidney transplant recipients of either gender, aged ≥ 18 years, who self-managed their medication regimen and resided in Victoria, who either had maintained their kidney graft for more than 8 months or had lost the graft due to medication non-adherence. Participants were recruited by the renal transplant coordinator at the partnering sites. Once verbal consent was obtained, the details of potential participants were forwarded to the research team. A total of 27 potential participants agreed to be contacted; one patient was uncontactable and another did not return the signed consent form. For other participants, interviews proceeded after

obtaining written informed consent. As the research team found that repetition of themes started to occur with 25 interviews, no further participants were recruited for the study.

Data collection procedures

The interviews were conducted at a time and a quiet location of the participants' choosing including their home, their workplace or a café for those who lived within a 100-kilometre radius of the Melbourne central business district. Three telephone interviews were conducted with participants who lived outside of this radius. With permission, interviews were tape-recorded; extensive field notes were taken for one participant who did not want to be recorded.

Interviews were conducted by either of two researchers who were not involved in the provision of clinical care for participants. An interview guide, which consisted of 9 open-ended questions (Table 1) adapted from the adherence work of _____ et al. (2008) in co-existing chronic kidney disease and diabetes, was used. The guide covered all factors pertaining to participant perceptions of their medication regimen, coping strategies and the effects of medications on their daily lives. The face-to-face interviews ranged between 31 – 130 minutes, with an average time of 68 minutes. The duration of telephone interviews ranged from 51 to 61 minutes.

Data analysis

Audio-recorded interviews underwent independent verbatim transcription. The transcripts and field notes were imported into the NVivo software (Version 10; QSR International, Doncaster, Victoria) to undergo Ritchie and Spencer's (2002) framework analysis. This inductive analytical approach involved an iterative process of reading each of the transcripts to gain familiarisation followed by identifying a thematic framework to identify themes. Subsequently, contents of the transcripts that corresponded to a particular theme were indexed and once completed; the themes and subthemes were charted. Finally, key characteristics of interviews were mapped for congruence and were used to produce an interpretation of the final data set.

Rigour

To obtain rigour during the data collection process, two researchers (XXX & YYY - anonymised for review) attended the interviews together initially alternating roles as interviewer and observer at each interview. The observer remained quiet throughout the interview and participant was informed that the observer was present to learn interviewing

techniques. All interviews were conducted using a semi-structured interview guide (Table 1). To check for consistency, three researchers (XXX, YYY & ZZZ) listened to the interview audio files separately and then a post-interview debrief session was undertaken with the whole research team. All transcripts were read and discussed (XXX, YYY & ZZZ), who also debated emergent key themes identified initially (by XXX). The analysis was then carried out independently by two researchers (XXX & YYY) using NVivo software and debated until an agreement was reached on the final analysis.

RESULTS

Study sample

A total of fifteen men and ten women aged 26 - 72 years were interviewed (Table 2). Of those who had never experienced graft loss (n = 21), they had successfully maintained their first kidney transplant for a duration of 8 months to 44 years. Two participants were living with a second kidney transplant which they had maintained for approximately 4 and 6 years. Of the 25 participants, 20 were from larger hospitals which had more than 50 new kidney transplant recipients surgeries conducted annually.

Themes

Participants' discussions about their life after kidney transplantation were grouped into two distinct categories: 1) Causes of distress and 2) Coping resources. Four core themes and subthemes for each category are summarised in Table 3.

Category 1: Causes of distress

Theme 1 – Regimented routine of doctor appointments, laboratory tests and medications

Participants understood that hospital check-ups and the daily requirement of medications were an inevitable part of life. However, the processes involved in the routine were constraining, time-consuming and often stressful, as described by one participant:

> You get there, and you have to wait an hour or an hour and a half, and you park your car and it costs you money. (Participant 1)

It is hard to live a *'normal'* lifestyle

In the early post-transplantation period, life of a graft recipient was regimented and especially during the first month post-discharge, time was taken up by hospital visits. Some participants voiced their frustration about the waiting time, whether it be for the specialist appointment, for blood collection at the pathology or even to wait for hospital pharmacy to refill their prescriptions. "The only thing that annoys me is the fact - the particular things [medications]

that I've got to get from the hospital only, and the wait. You put it in in the morning, you wait an hour after, get one script." (Participant 3). Also, the daily visit to the hospital was exhaustive.

> Well, going into the clinic every morning to be there for, what, 7 o'clock for blood tests and 8 o'clock for clinic, it was bloody hard, actually. (Participant 7)

Sleeplessness was common among all participants but for three participants, sleeplessness was the most difficult side effect they confronted. They knew that nothing could be done to change their situations because prednisolone, which caused insomnia, was also essential in preventing kidney graft rejection. One participant described her experience as "debilitating" due to fatigue and she loathed the process of trying to make herself fall asleep, as she recounted:

> Look, to tell you the truth, you'd get to the stage where you didn't even really want to go to bed because you knew you were going to lay there and be awake most of the time. (Participant 6)

The medication regimen is hard to manage

All participants were prescribed at least three categories of anti-rejection medications (a calcineurin inhibitor, an anti-proliferative agent and a corticosteroid), and other medications to manage comorbid conditions and to reduce the risk of complications caused by anti-rejection medications, such as infection and gastrointestinal disorders. As the risk of rejection is highest in the early post-transplantation period, all anti-rejection medications were prescribed at higher doses than would had been required for maintenance therapy and hence, patients required more medications to counter the coupled adverse effects. For the participants, this meant an added complexity.

> It was hard at first, when I had the transplant and you had, like, 30-something tablets, you know what I mean? You had to take them every day; morning, lunch and evening. That was difficult and it was a bit frustrating, having so many tablets. (Participant 4)

Participants spoke about the need to monitor their medication supplies constantly to ensure that they filled their prescription before they ran out of medications. Most medications could be dispensed by a community pharmacist. However, commonly prescribed anti-rejection

medications (tacrolimus and mycophenolate) were generally restricted to hospital pharmacies, making the process of obtaining medication more complex.

> I phone up the hospital pharmacy and say, "Can you get me some pills ready?" … Then if they say … "You haven't got a prescription with us," then I phone up the transplant clinic to talk to the nurse (to get a prescription done for the medication). … So I'll go in there [to the clinic], collect the prescription, take it down to pharmacy and then wait two hours for it. (Participant 1)

Variation with timing of medications due to the patients*' life situation*

Sticking to a specific time for taking medications was a significant inconvenience for some people. Nine participants (36%) admitted outright that timing of medication intake was not strictly adhered to, although they knew it was better to take their medications consistently at about the same time every day. The timing of medication intake varied according to their routine and was highly dependent on the time they woke up, had dinner and went to bed.

> My night medication … could vary quite a lot. Because it depends when I go to bed, which is basically around the same time, other than if I'm doing something, and then it could be later. So, that varies in time-wise – whether that has any effect on the tablets or not, I don't know. (Participant 2)

For most participants, the variation in timing of medication intake emerged over time. Taking medications at the same time daily was impossible, especially on days when blood samples were needed for monitoring purposes. Through this process, participants learnt that the variation in medication-intake timing did not appear to impact on their graft function, as indicated by the results of their pathology test results. They began to rationalise that such variation was acceptable. One participant, whose normal medication-intake times were 9:30am and 10:30pm, admitted to not being strict with his timing, as he described:

> Since if I have to go for a clinic, I've got to be at the hospital at 9:30(am), I've got to go early to give blood, so I might have it [tacrolimus] at 7:00 (pm the night before). So I'm not fussy about the time I take it. That is not showing up in my results either, right? (Participant 24)

Afraid that people will think I am sick

Having to take medications was a daily task and at times, it would be necessary to take medications in public. However, some participants regarded their kidney transplant recipient identity a private matter. For example, three out of 25 participants spoke about their fear of taking out their medications in front of people. One of them (Participant 4, male, 41 years old, received a kidney from a live donor) preferred to "not make a big scene" when he had to take his medications during his meals with others. He would usually "sneak it [the pill box] under the table" to remove the medications then take them swiftly. This tendency to hide medications was also how another participant said she would behave because she described herself as a "private person" and that "people don't tend to know what's going on in my life". (Participant 25)

> If I'm out, I'd do it discretely. Like, I wouldn't pull out my tablets and spread them across the table. I don't think anyone would know I was taking them [the medications], unless I told them. (Participant 25)

The lack of courage to explain illness to friends was a barrier to medication adherence. From the perspective of the patient, it might mean receiving different treatment from friends. Because of this reason, one participant (female, 26 years old, dialysis-dependent) was reluctant to take medications in front of her friends. Instead, she chose to deliberately miss or alter her medications dosing time, as she described:

> I didn't have any friends that were sick like me. I was a little bit - not embarrassed but I think I might have been a bit uncomfortable to pull out all these tablets, 20 tablets or something, and have to explain to them, "I've got to take these tablets," in front of them and have them look at me funny or go, "Why?". (Participant 10)

Theme 2 – Fear of the unknown

From the perspectives of participants, although kidney transplantation was the best option, it was not the perfect solution for kidney failure. The potential risk of graft rejection, contracting infections and developing cancer were constant threats to their wellbeing, which remained a constant stressor.

The kidney does not last forever

Graft rejection was a common fear amongst the participants regardless of whether one had previous experience of graft loss or not. For example, a 72-year-old male participant

(Participant 1), who received a kidney transplant from a cadaveric donor and had never experienced graft loss, described that his kidney transplant was buying him "a little bit more time" and that his kidney transplant could "back out" anytime even if he was doing everything right. Similarly, a 41-year-old male participant, who had previously experienced graft loss due to medication non-adherence, was afraid of going to the clinic because he did not want to hear any bad news related to his kidney transplant. He knew that if his current graft was to fail, the chances of him receiving another kidney transplant was slim and going back onto dialysis treatment was something that he feared most, as conveyed below:

> I'm afraid that they're going to say to me, "Your kidney's not doing well." It's always in the back of my mind. I don't want to lose this kidney, because I really don't want to see that dialysis machine. (Participant 23)

Participants understood that routine hospital checks were essential to monitor their tacrolimus trough levels and to detect graft rejection. Therefore, for participants, to hear that their laboratory test results were 'looking good' was a major relief. They learnt the name of the tests and what was tested albeit not necessarily why the tests were important. A first-time transplant recipient described her personal experience:

> Initially, you just go to the clinic and you hope to God your bloods are good and your kidney is good … - you know, you really do hang on. You know, what's me creatinine, what's this doing, what's that doing? You really like to hear the stats [statistics]. They are almost meaningless to you, because you don't understand them, but for some unknown reason, you need to hear about them. (Participant 11)

Dealing with the Catch-22

One of the major downsides of receiving a kidney transplant, was the increased risk of malignancy due to long-term use of anti-rejection medications. The medications which helped to "protect" the kidney transplant were the same ones that would make them more vulnerable to cancer. It was unavoidable as patients could only choose either to stay on dialysis, which was the less preferred treatment modality, or to be exposed to an increased rate of malignant disorders.

> "I try not to think about that too much, to be honest. But I know that they are shortening my life - as in, the life of the kidney and the life of everything else as

well, and… my chance of getting cancer and all that sort of stuff is dramatically increased." (Participant 21)

Other than malignancy, participants were informed about the risk of long-term complications of kidney transplantation, such as infection, osteoporosis, hyperglycaemia and cardiovascular disease. The only thing that could be done was to attend all check-ups regularly and to take supplements when prescribed. It was part of a routine to which they had to maintain.

> Over a long period of time - and everyone does it, they go on the Internet and look at the long-term effects of medication. I wonder what - I'm 50-odd now - what effect it's going to be having in 15, 20 years' time…. That's why I see the potential there to have some detrimental effects. So that's probably the only thing, why I worry about taking the medications. (Participant 20)

Category 2: Coping resources

Theme 1 – *Realising a kidney transplant is a visa to escape "illness"*

Commonly, viewing a kidney transplant as the only means to 'escape' end-stage kidney disease was an important psychological resource for participants. The 'escape' was equivalent to not needing dialysis treatment and this was a strong reason for participants to want to cope with post-transplantation stressors. For example, one participant would like to "hang onto" her kidney transplant for as long as possible because of the lifestyle that kidney transplantation could offer (Participant 11).

I want to stay away from dialysis and be well

To participants, their ability to enjoy the trivial things in life, such as rolling out of bed without unplugging the dialysis machine, drinking a cup of coffee, tea or alcohol without fluid restrictions, going on long holidays and feeling well were indicators of good health. They associated life going through dialysis treatment as a life dealing with illness whilst living with a kidney transplant was equivalent to living more like a healthy individual. Participants were aware that their "normal" lifestyle was fully dependent on the functioning of their kidney transplant, which in turn was partly dependent on the medications.

> If it [the medication] makes me well then I'll take it. If you tell me that I have to have it then that's what I'm doing, because I don't want to be unwell and I don't want to spend my life on dialysis. (Participant 8)

Participants knew that their only alternative was dialysis treatment, which was the less preferred treatment option. Utilising the description of Participant 12 who had maintained his kidney graft for 44 years, his experience with the "kidney machine wasn't very pleasant", which also "severely inhibited" his day-to-day activities. Participants believed that taking the medications was a better way to live than having to receive dialysis treatment, as described below:

> What's the alternative? Having to go and do dialysis every day? That's even a bigger burden. The medications, it doesn't affect my life in any way… All it takes is one minute to swallow these pills and drink half a glass of water ... The kidney transplant is a blessing to me. (Participant 16)

I am lucky

Some participants perceived themselves as the lucky people. Although their reasons varied, most compared their situations to others who were under different circumstances such as those with other chronic conditions they believed had a higher number of prescribed medications. For example, "I know people who have cancer who take heaps and heaps, so I'm pretty lucky" (Participant 8). Participants also compared themselves to those who had not been offered the opportunity to receive a kidney transplant or even those who received a kidney transplant but had a worse graft outcome.

> I'm lucky enough, because … it's what, 14 months I've had it … I had a mate that it only lasted three months. Kidney went, he's back on dialysis. So, you know, I've got to keep myself lucky and do the right thing [take medications at the right time]. (Participant 1)

Regardless of whether a kidney graft came from a cadaveric or living organ donor, participants knew they were fortunate to have the opportunity to receive a kidney transplant. Kidney transplants were therefore viewed as a precious gift from someone else, which needed to be protected and the only way to prevent the kidney transplant from failing was to take the medications as prescribed.

> Oh, well, just the fact that I'm protecting the kidney by taking them. You know, I'm looking after it. I mean, it's a gift. Wherever it came from, it's a huge gift, and I think you're obligated to, you know, treat it as best you can - for yourself, but also out of - I don't know, maybe out of some kind of respect for what somebody

has done for you. Or - so yes, that helps me take my medication, the fact that I do want to look after it, I don't want it to fail. (Participant 11)

The medications keep me alive

Given that participants knew that end-stage kidney disease was an irreversible and incurable condition, they accepted living with a kidney transplant as the best way to live. To live with a kidney transplant, they understood medications played a major role in determining the long-term success of the kidney graft. Therefore, medication and kidney transplantation were part of a non-negotiable routine that allowed them to live their preferred lifestyle. For those who had a well-functioning kidney transplant at the time of the interview, they were hoping to be able to live with their kidney transplant for as long as possible, with some even expressing their wish to be able to die with their functioning kidney transplant. It was therefore unsurprising that several participants regarded the medications as their 'life-saving pills'.

I need to take them [the medications] to survive, obviously. Do you know what I mean? It's survival. (Participant 23)

Participants were grateful for what medications could do to extend their lives. They knew that the medications were 'good' for the kidney, which were suppressing their immune system enough to ensure that it did not recognise their kidney transplant as foreign. The medications therefore helped them to keep their kidney graft 'alive'. The safeguarding role that medications played in kidney transplantation was undeniable. For many participants, this would mean their functioning kidney transplant enabled them to spend more quality time with their family or to lead a more fulfilling life.

If you don't do what you're told, things go astray … I've got a good reason to be here - four grandkids … to me, the doctor says, "You do that [take your medications]," I do. (Participant 3)

Theme 2 – Moving along: with a little help

Recovery from kidney transplantation was a long process. The participants mentioned that along the way, they used external resources to help them to cope with the process, such as making friends with fellow patients and learning about others' experiences of kidney transplantation to better prepare themselves long-term. Some had a kidney transplant 'buddy' who received a kidney transplant from the same deceased donor and were able to support each other through the recovery period. Additionally, the support that they received from

their family members and healthcare professionals was notable, whereas for taking medications, which was the responsibility of the participants, an electronic alarm was deemed as the most reliable reminder.

The camaraderie

Participants from larger hospitals mentioned that attending specialist appointments frequently was aggravating. One of the main issues was the unpredictable length of waiting time, which was often not justified by the length of consultation time. The waiting time however was a good time to connect with people alike. The waiting room at the clinic was described as a friendly setting because they would see familiar faces, who they could share similar stories about their recovery progress. They were able to discuss common medication side effects they were having and it was comforting to know that they were not alone.

> I think if you were on your own and you didn't have anybody to talk to, I think that would be difficult. But that friendship you develop with these people, it's very helpful and very comforting. (Participant 6)

In the hospital setting, there was a mixture of patients. Some were more experienced than others and were therefore able to offer an insight into how life after kidney transplantation was like. Being able to receive anecdotes from someone that lived the experience was extremely useful, especially if it included problems and issues that all kidney transplant recipients would face. As what one participant said, "Because the more knowledge you have, the less scared you are" (Participant 8). It was therefore common that kidney transplant recipients exchanged tips and words of encouragement if someone was to ask for help.

> It's [the challenges are] happening to them [one person] as it is to the (other) person … - and say, "Well, this is how I deal with it." (Participant 16)

The role of my family

According to participants, the immediate post-transplantation period was the hardest time. Eight participants received a kidney transplant from a living related relative, with spouse being the most common donor. It could be a difficult time for both the recipient and the donor during the recovery period at home. However, many participants' family members reorganised the roles they played, especially the primary caregiver who had to deal with the increased workload. The primary caregiver took over home duties, provided to-and-fro transport for daily hospital visits during the first month, and sometimes provided repeated

assistance with arranging the participants' medications into a dose administration aid whilst other family members occasionally reminded participants about their medications. The participants were appreciative of the sacrifices and support provided by their family. Some admitted that they would not be able to make it through without their support.

> Without him [my husband], I'd be hopeless. I'll be very honest with you, with that. (Participant 17)

In rare cases, family members could even share experiential information. In our study, a mother and son pair (Participants 11 and 13) were interviewed separately and they both received their kidney transplants from live donors. Being three months ahead of his mother, the son could always provide her with his firsthand experience and was able to ease her mind.

> He was a few months ahead of me, so I'd say, you know, "Did this happen to you?" – especially with the first biopsy. I said to him, "I'm not sure about this biopsy." He said, "Mum, it's nothing. Don't worry about it." You know, it's nothing. So that was just lovely, having someone who was going through it - who had been a little bit ahead of me in the experience. (Participant 11)

The role of healthcare professionals

Some participants spoke about the assistance they received from their regular community pharmacists who they highly complimented. The most helpful aspect was that the participants were able to obtain a few days of medications urgently on a weekend or public holiday, even when they had no prescription. Pharmacists in the community were also seen to be reliable and meticulous. The pharmacists would make sure their customers were getting the correct prescriptions to avoid medical errors. In addition to helping participants to pack their medications into dose administration aids, some participants were provided with reminder services through text messaging when it was time to refill their prescription or when the medication was ready to be picked up.

> We're lucky with the pharmacy we've got nearby. They've got an SMS [short message service] system … I leave all my medication [prescriptions] with them … and they text me when my tablets are due, as in my prescriptions are coming up. They'll text me and they'll say, "Your Vitamin E is ready for picking up," or, "You're getting close to needing another script." They are very good that way. (Participant 17)

Healthcare professionals provided warnings about the potential side effects, such as hand tremors from a calcineurin inhibitor and insomnia from a corticosteroid medication, from which many participants were suffering. Even though some participants knew which medications were causing unwanted effects, they chose not to discontinue these medications because they were well-informed about the need for their medications. They were also repetitively assured by kidney transplant care team that the medications would be adjusted and they would gradually be on a lower dose and the side effects would resolve.

> Initially, with the higher doses of some of the medications, I'd have the shakes and various side effects that were pretty horrendous at times. But that was … expected. I was warned, I knew. (Participant 22)

Alarm is my safety net

> The number of medications prescribed for participants ranged up to 19 different agents, with some being administered multiple times per day. It was therefore not surprising that the majority of participants mentioned that they had missed their medication-taking time before. These occasional lapses were undesired and so, one third of participants used an alarm on their mobile phone as a safety net.

> I think the alarm is really the main, the main thing. Because even if I forget, you know, then the alarm will come on. (Participant 13)

Taking medications gradually became part of an established routine for participants, which required minimal effort to remember. However, disruptions to the usual routine were sometimes unavoidable due to work or personal commitments. Most participants admitted that if it was not for the alarm, they would have missed the timing of their medications on a frequent basis. With the alarm, taking the medications at the right time became a less stressful task.

> It's habit now. In the morning, we get up, get the kids ready. I remember, before I walk out the door, I have my drugs. But at night, I can be out for dinner or I can be distracted with - on a phone call, or I can be - , if people are over, or whatever's going on. So, it makes more sense - and I always have my phone with me, so it makes more sense to have an alarm. (Participant 21)

DISCUSSION

In this study, participants' perspectives highlighted the complexity of kidney graft management and the resources utilised to help them cope with the inherent stressors after kidney transplantation. Stressful events included attending frequent clinic appointments and routine checks, managing medication changes, organising medication supplies, managing their daily medication-intake, psychological adjustment to the impermanence of kidney transplantation, having frequent side effects coupled with the prescribed medications, and dealing with the fear of dialysis resumption. However, participants were able to master the challenges by believing that given their situation, living as a kidney transplant recipient was a better way to live than to be dialysis-dependent. Kidney transplantation improved the physical well-being, employability and disease-specific health status of a patient with end-stage kidney disease (Purnell et al. 2013). Besides that, the comradeship with people alike, the role adjustment of family members, the assistance from healthcare professionals and the unfailing electronic reminder made the complex management of a kidney graft easier.

Medication taking, dosage and timing adherence are the main components that are commonly used to assess medication adherence. In this study, no formal assessment was conducted but the findings suggest that patients had no problem with having to take medications every day but they were less strict about the timing of medication intake. A high proportion of those living with a successful kidney transplant (39%) admitted to not taking their medications at about the same time every day. Another cross-sectional study involving 250 adult kidney transplant recipients also reported that 28% of participants deviated from the dosing schedule by at least 2 hours for more than once a week; but the reasons for deviation were not examined (Lennerling & Forsberg 2012). The compounding consequence of varying medication-intake time in a chronic fashion can potentially lead to an adverse outcome. Of note, minor deviations from the prescribed medication schedule were associated with higher late acute rejection episodes (Nevins & Thomas 2009) and graft loss (Pinsky et al. 2009) in kidney transplantation. To address this issue, the kidney transplant care team can negotiate the best dosing times together with their patients, with an aim to reflect the real world of taking medications, and to ensure their patients understood the importance of dosing at the correct time.

Even after a patient is treated with the treatment of choice, kidney transplantation, permanent kidney failure has no cure and exposes patients to multiple problems and burdens.

Like other organ transplantation, recovery from the surgery is a lengthy process with newly introduced medications, risk of complications and procedures such as frequent dose alteration according to immunosuppressive assays. Kidney transplant recipients have to make frequent lifestyle accommodations and establish their own routine. However, not only the patients themselves had to adjust their ways of living, so did their family members who were informal caregivers. In this study, the majority of participants had supportive family members, who readily assumed new responsibilities. Our findings are consistent with those reported by Rodrigue et al. (2010) who found that most spouses of kidney transplant recipients adjusted well to the caregiving role.

This study discovered that some patients preferred to take their medications discreetly or even to the extent of altering dosing time so that they did not have to disclose information related to their illness. This is a common issue faced by people with chronic illness wanting to be seen as normal, choosing to conceal signs and symptoms related to their illness (Miller 2000). The need for medications everyday marks one out as different from others and is self-perceived to be negatively regarded. The difference is more apparent in recipients at a younger age than those that are older as a participant stated that "once you hit 50 to 60, everyone is on some form of medication" (Participant 18), which makes a kidney transplant recipient the same as everyone else who require multiple medications. As such, there is a need for renal transplant care team to examine their patients' attitude towards taking medications in public. For those who display more resistance, they need to be reassured it is not an embarrassment to require prescribed medications to maintain their kidney transplant. If they are questioned about their health status, they could treat it as an opportunity to educate others about the benefits of organ donation.

According to Lazarus and Folkman (1984), a resourceful individual has more ways to cope with stress. Findings of the current study reported that the key internal coping resources used by patients was the shift in perspective. Instead of dwelling on how hard it was to manage a kidney transplant, patients shifted their perspective to thinking how much easier it was to maintain a kidney transplant than being reliant on dialysis treatment. The other category of coping resource was accessing external resources. Participants sought out support from individuals, family members and healthcare professionals. In addition, the availability of modern technology, including the mobile phone, enabled patients to set an alarm to remind them about the time to take their medications.

Limitations

This study has several limitations. Because of ethical considerations, members of the research team were not permitted to recruit participants at the partnering sites and were therefore unable to ascertain whether all patients were given equal opportunity to participate in the project. The possibility of bias, such as choosing patients with better graft outcomes or those that had better relationship with the recruiter, could not be ruled out. These patients might be more positive than those who were facing transplant-related complications and encountered more barriers to be adherent to their medications. Additionally, rural participants were interviewed over the phone. However, it was found that the data elicited via telephone mode were as rich as face-to-face interviews.

CONCLUSION

After undergoing renal transplantation, patients with end-stage kidney disease still experience uncertainty regarding their physical health and potential complications such as kidney graft function and the many side effects of long-term immunosuppressive medication. In a way, the experience of kidney transplant recipients in the early post-surgery period resembles a new chronic condition. In long-term kidney graft recipients, the risks of rejection, infection and cancer are ever-present regardless of how well the kidney transplant is functioning. At times, it may be difficult for patients to handle the stress related to kidney transplant management. Hence, it is important to recognise the patient's experience in order to establish strategies that support effective coping. Patients that are successful in coping with stress may lead a more satisfactory life with increased strength to deal with the complex regimen of graft management.

RELEVANCE TO CLINICAL PRACTICE

The findings of this study can inform decision makers about the changes that are relatively simple and inexpensive to implement to improve patients' ability to deal with kidney transplant-related stressors, which in turn may improve their medication adherence. Firstly, a systematic plan can be put in place to remind patients about the positive benefits of kidney transplant on their lives. Secondly, opportunities can be created by setting up a mentorship system for patients who demonstrate optimal adherence to encourage patients to share their experiences during clinic waiting time, especially for newly transplanted kidney recipients. Lastly, making it mandatory to set up an electronic reminder together with newly transplanted patients may greatly help patients to adapt to their routine at home after they are discharged.

References

Achille MA, Ouellette A, Fournier S, Vachon M, & Hebert MJ (2006) Impact of stress, distress and feelings of indebtedness on adherence to immunosuppressants following kidney transplantation. Clinical Transplantation, **20**(3), 301-306. doi: 10.1111/j.1399-0012.2005.00478.x

Ajzen I (1991) The theory of planned behavior. Organizational Behavior and Human Decision Processes, **50**(2), 179-211.

Antonovsky A (1979) Health, stress, and coping. Jossey-Bass, San Francisco.

ANZDATA Registry (2009) Appendix I Australia and New Zealand 2008 data. In S McDonald, L Excell & B Livingston (Eds.), ANZDATA Registry Report 2009 (pp. 33). Adelaide, Australia: Australia and New Zealand Dialysis and Transplant Registry.

ANZDATA Registry (2010) Appendix I Australia and New Zealand 2009 data. In S McDonald, L Excell & B Livingston (Eds.), ANZDATA Registry Report 2010 (pp. 33). Adelaide, Australia: Australia and New Zealand Dialysis and Transplant Registry.

ANZDATA Registry (2011) Appendix I Australia and New Zealand 2010 data In S McDonald & K Hurst (Eds.), ANZDATA Registry Report 2011 (pp. 33). Adelaide, Australia: Australia and New Zealand Dialysis and Transplant Registry.

ANZDATA Registry (2012) Summary. In S McDonald & K Hurst (Eds.), ANZDATA Registry Report 2012 (pp. S-3). Adelaide, Australia: Australia and New Zealand Dialysis and Transplant Registry.

ANZDATA Registry (2013) 36th report, preliminary report 2012: summary of Australia and New Zealand dialysis & transplantation. In S McDonald, P Clayton & K Hurst (Eds.), (pp. S-3). Adelaide, Australia: Australia and New Zealand Dialysis and Transplant Registry.

Butler JA, Roderick P, Mullee M, Mason JC, & Peveler RC (2004) Frequency and impact of nonadherence to immunosuppressants after renal transplantation: a systematic review. Transplantation, **77**(5), 769-776.

Cameron JI, Whiteside C, Katz J, & Devins GM (2000) Differences in quality of life across renal replacement therapies: a meta-analytic comparison. American Journal of Kidney Disease, **35**(4), 629-637. doi: 10.1016/S0272-6386(00)70009-6

Chen KH, Weng LC, & Lee S (2010) Stress and stress-related factors of patients after renal transplantation in Taiwan: a cross-sectional study. Journal of Clinical Nursing, **19**(17-18), 2539-2547. doi: 10.1111/j.1365-2702.2009.03175.x

Fallon M, Gould D, & Wainwright SP (1997) Stress and quality of life in the renal transplant patient: a preliminary investigation. Journal of Advanced Nursing, **25**(3), 562-570.

Gallagher MP, Kelly PJ, Jardine M, Perkovic V, Cass A, Craig JC, Eris J, & Webster AC (2010) Long-term cancer risk of immunosuppressive regimens after kidney transplantation. Journal of the American Society of Nephrology, **21**(5), 852-858. doi: 10.1681/ASN.2009101043

Gill P (2012) Stressors and coping mechanisms in live-related renal transplantation. Journal of Clinical Nursing, **21**(11-12), 1622-1631. doi: 10.1111/j.1365-2702.2012.04085.x

Haynes RB, Ackloo E, Sahota N, McDonald HP, & Yao X (2008) Interventions for enhancing medication adherence. Cochrane Database of Systematic Reviews(2), CD000011. doi: 10.1002/14651858.CD000011.pub3

Jamieson NJ, Hanson CS, Josephson MA, Gordon EJ, Craig JC, Halleck F, Budde K, & Tong A (2016) Motivations, challenges, and attitudes to self-management in kidney transplant recipients: a systematic review of qualitative studies. American Journal of Kidney Diseases, **67**(3), 461-478. doi: 10.1053/j.ajkd.2015.07.030

Kyllonen L, Salmela K, & Pukkala E (2000) Cancer incidence in a kidney-transplanted population. Transplant International, **13 Suppl 1**, S394-398. doi: 10.1111/j.1432-2277.2000.tb02068.x

Lazarus RS, & Folkman S (1984) Stress, appraisal, and coping. Springer publishing company, New York, 157 - 164.

Lennerling A, & Forsberg A (2012) Self-reported non-adherence and beliefs about medication in a Swedish kidney transplant population. The Open Nursing Journal, **6**, 41-46. doi: 10.2174/1874434601206010041

Lindqvist R, Carlsson M, & Sjoden PO (2004) Coping strategies of people with kidney transplants. Journal of Advanced Nursing, **45**(1), 47-52. doi: 10.1046/j.1365-2648.2003.02859.x

Low JK, Williams A, Manias E, & Crawford K (2015) Interventions to improve medication adherence in adult kidney transplant recipients: a systematic review. Nephrology Dialysis Transplantation, **30**(5), 752-761. doi: 10.1093/ndt/gfu204

Miller JF (2000) Coping with chronic illness: overcoming powerlessness. (3rd edn.), FA Davis Company, Philadelphia.

Nevins TE, & Thomas W (2009) Quantitative patterns of azathioprine adherence after renal transplantation. Transplantation, **87**(5), 711-718. doi: 10.1097/TP.0b013e318195c3d5

Oniscu GC, Brown H, & Forsythe JL (2005) Impact of cadaveric renal transplantation on survival in patients listed for transplantation. Journal of the American Society of Nephrology, **16**(6), 1859-1865. doi: 10.1681/ASN.2004121092

Pinsky BW, Takemoto SK, Lentine KL, Burroughs TE, Schnitzler MA, & Salvalaggio PR (2009) Transplant outcomes and economic costs associated with patient noncompliance to immunosuppression. American Journal of Transplantation, **9**(11), 2597-2606. doi: 10.1111/j.1600-6143.2009.02798.x

Purnell TS, Auguste P, Crews DC, Lamprea-Montealegre J, Olufade T, Greer R, Ephraim P, Sheu J, Kostecki D, Powe NR, Rabb H, Jaar B, & Boulware LE (2013) Comparison of life participation activities among adults treated by hemodialysis, peritoneal dialysis, and kidney transplantation: a systematic review. American Journal of Kidney Diseases, **62**(5), 953-973. doi: 10.1053/j.ajkd.2013.03.022

Ritchie J, & Spencer L. (2002). Qualitative data analysis for applied policy research. In A Huberman, & Miles, MB (Ed.), The qualitative researche*r's companion* (pp. 305-329). Thousand Oaks: Sage Publications.

Rodrigue JR, Dimitri N, Reed A, Antonellis T, Pavlakis M, Johnson SR, & Mandelbrot DA (2010) Spouse caregivers of kidney transplant patients: quality of life and psychosocial outcomes. Progress in Transplantation, **20**(4), 335-342; quiz 343. doi: 10.7182/prtr.20.4.g65r17525j278251

Schmid-Mohler G, Schafer-Keller P, Frei A, Fehr T, & Spirig R (2014) A mixed-method study to explore patients' perspective of self-management tasks in the early phase after kidney transplant. Progress in Transplantation, **24**(1), 8-18. doi: 10.7182/pit2014728

Sutton TD, & Murphy SP (1989) Stressors and patterns of coping in renal transplant patients. Nursing Research, **38**(1), 46-49.

Terebelo S, & Markell M (2010) Preferential adherence to immunosuppressive over nonimmunosuppressive medications in kidney transplant recipients. Transplantation Proceedings, **42**(9), 3578-3585. doi: 10.1016/j.transproceed.2010.08.027

The National Health and Medical Research Council, the Australian Research Council, & the Australian Vice -Chancellors' Committee (2007) National statement on ethical conduct in human research 2007. Canberra, Commonwealth of Australia.

Tonelli M, Wiebe N, Knoll G, Bello A, Browne S, Jadhav D, Klarenbach S, & Gill J (2011) Systematic review: kidney transplantation compared with dialysis in clinically relevant outcomes. American Journal of Transplantation, **11**(10), 2093-2109. doi: 10.1111/j.1600-6143.2011.03686.x

Tong A, Howell M, Wong G, Webster AC, Howard K, & Craig JC (2011) The perspectives of kidney transplant recipients on medicine taking: a systematic review of qualitative studies. Nephrology Dialysis Transplantation, **26**(1), 344-354. doi: 10.1093/ndt/gfq376

Veroux M, Giuffrida G, Corona D, Gagliano M, Scriffignano V, Vizcarra D, Tallarita T, Zerbo D, Virgilio C, Sciacca A, Cappello D, Stefani S, & Veroux P (2008) Infective complications in renal allograft recipients: epidemiology and outcome. Transplantation Proceedings, **40**(6), 1873-1876. doi: 10.1016/j.transproceed.2008.05.065

White MJ, Ketefian S, Starr AJ, & Voepel-Lewis T (1990) Stress, coping, and quality of life in adult kidney transplant recipients. American Nephrology Nurses' Association Journal, **17**(6), 421-424, 431; discussion 425.

Williams A, Manias E, & Walker R (2008) Adherence to multiple, prescribed medications in diabetic kidney disease: A qualitative study of consumers' and health professionals' perspectives. International Journal of Nursing Studies, **45**(12), 1742-1756. doi: 10.1016/j.ijnurstu.2008.07.002

Wu C, Evans I, Joseph R, Shapiro R, Tan H, Basu A, Smetanka C, Khan A, McCauley J, & Unruh M (2005) Comorbid conditions in kidney transplantation: association with graft and patient survival. Journal of the American Society of Nephrology, **16**(11), 3437-3444. doi: 10.1681/ASN.2005040439

Table 1 Semi-structured interview guide

1. How are you generally? How is your health?
2. Now could you please tell me how you take all your medicines every day?
3. How do your medicines affect you, your family and your social life?
4. How do you seek help for the management of any medicine problems, such as medicine side-effects or missing a dose?
5. People who have a kidney transplant have many pills or medicines to take at different times during the day.
    a. Can you tell me what helps you to take your medicines?
    b. What don't you like about taking your medicines?
6. Do you think you have ever taken the wrong medicine by mistake and what did you do?
7. What do you think would help other kidney transplant patients take their medicines as prescribed?

Table 2 Demographics of participants (N=25)

Characteristics	n (%)
Male	15 (60)
Continent of birth	
Australia	14 (56)
Europe	7 (28)
Asia	3 (12)
Africa	1 (4)
Vision	
Not at all	1 (4)
Not well	6 (24)
Well	11 (44)
Very well	7 (32)
Cadaveric donor	17 (68)
Functioning kidney transplant	
First graft	21 (84)
Second graft	2 (8)
Dialysis-dependent	2 (8)
Cause of first graft loss	
Kidney cancer	1
Medication non-adherence	3
Highest level of education	
Secondary	12 (48)
Tertiary	13 (52)
Experienced dialysis treatment	18 (72)
Age at first kidney graft transplant	
Age < 30	7
30 ≤ age ≤ 39	3
40 ≤ age ≤ 49	1
50 ≤ age ≤ 59	8
60 ≤ age ≤ 69	5
Age ≥ 70	1
Time since current transplant, years [median (SD)]	2.9 (8.75)
Age, years [median (SD)]	57.0 (14.5)
Age range, years	26 - 72

Table 3 Themes and subthemes

Category 1: Causes of distress
Theme 1 – Regimented routine of doctor appointments, laboratory tests and medications
It is hard to live a 'normal' lifestyle
The medication regimen is hard to manage
Variation with timing of medications due to the patients' life situation
Afraid that people will think I am sick
Theme 2 – Fear of the unknown
The kidney does not last forever
Dealing with the Catch-22
Category 2: Coping resources
Theme 1 – *Realising a kidney transplant is a visa to escape "illness"*
I want to stay away from dialysis and be well
I am lucky
The medications keep me alive
Theme 2 – Moving along: with a little help
The camaraderie
The role of my family
The role of healthcare professionals
Alarm is my safety net