



Exploring Transplant Medication-Taking Behaviours in Older Adult Kidney Transplant Recipients: A Qualitative Study of Semi-Structured Interviews

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Abstract

Background Today, older adult patients routinely undergo kidney transplantation. To support graft survival, patients must take immunosuppressant medicines for the rest of their lives. The post-transplant medication regimen is complex, and barriers to medication taking are likely confounded by both functional and intrinsic changes associated with advancing age. To develop diverse and innovative approaches to support best health outcomes in this vulnerable age group, it is imperative that the degree to which patients' needs are currently being met, be identified.

Aim The aim of this study was to examine medication-taking behaviours of kidney transplant recipients transplanted at 60 years of age or older.

Methods This qualitative study used semi-structured patient interviews to explore how kidney transplant recipients currently manage their immunosuppressant regimen and how they cope after transplantation with the complex routine. Data were themed using the principles of Grounded Theory methodology; with interviews conducted until data saturation was reached.

Results Quantitative information was collected from 14 participants who ranged in age from 66 to 77 years (at time of interview), and were prescribed a median of 13 (min: 10, max: 26) medicines. The main themes that emerged from the interview were variability in health literacy toward medicines, the importance of support networks, the need to adjust health expectations, factors that were motivators for self-care, different approaches to medication management, and different approaches to medication taking. Overall, it was found that patients prioritised medication taking above all else, and gratitude to their donor was a powerful motivator to adhere. However, strategies to support medication taking were sometimes ineffective when patients' routine changed.

Conclusions Future interventions should consider approaches to foster adaptable medication taking behaviours that stand up to changes in the day-to-day routine.

Plain Language Summary

Medication taking is complicated in transplant recipients, due to the number of medicines that need to be taken and the complex nature of the treatment regimen. Challenges in older transplant recipients may be more pronounced and varied compared with younger adults. There are multiple factors that may impact medication taking in older adults and each requires consideration, including level of dependence, living arrangements, level of mobility and manual dexterity, vision and memory, and social situation. To better identify the gaps in support, patients' current perspectives around medication taking and how they cope after transplantation must be explored. Therefore, this study aimed to identify how older adult transplant recipients currently manage their anti-rejection medicine regimen. Participants described several strategies around how they manage a complex medication regimen. These included cues such as an alarm and linking the time they should take their

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medication to already established habits such as eating meals. Most participants discussed at length their relationships, and it seems that these relationships are often crucial to post-transplant positivity. Additionally, extreme gratitude to the donor, relative improvement in their life quality (compared with the rapid deterioration in their health when on dialysis), and fear of consequences (particularly graft failure) were important facilitators of self-care and served as timely reminders to prioritise one's own health. To foster more robust medication-taking habits, future education needs to be tailored to each individual patient and include details about how to link medication taking to already established routines (coined 'habit stacking').

Key Points

We found that despite the complexity of the routine, older adult kidney transplant recipients prioritised medication taking, and gratitude to their donor seemed to be a powerful motivator.

Patients did still forget their medicines at times, namely, when out of routine.

Future interventions should consider approaches to foster adaptable medication-taking behaviours, and potentially, follow-up education sessions when patients are further post-transplant (e.g. at 1 year).

1 Background

Kidney transplantation is first-line treatment for patients with kidney failure, regardless of age [1, 2]. When compared with dialysis, kidney transplantation reduces the risk of both morbidity and mortality, increases life expectancy, and improves overall well-being across all age groups [2–5]. Today, the fastest growing age group with kidney failure are patients aged over 65 years [4, 6], with almost half the world's population of patients with kidney failure in this age bracket [7]. In Australia, 28.6% of kidney transplants performed in 2019 were in patients aged 65 years of age and above [8].

Medication taking is already considered complicated in transplant recipients, due to both polypharmacy and the complexity of the regimen [9], but the challenges in older adults are likely both more pronounced and varied when compared with younger adults. Although older adult patients who receive a transplant are considered to be 'robust', barriers to medication taking are likely to be compounded by advancing age [10, 11]. Enabling and supporting the abilities of this population is crucial to post-transplant success [12]. Advanced age does not automatically imply dependence [12]. There is a diversity of characteristics that affect adherence to medical care and require consideration in older adults including level of dependence, living arrangements,

level of mobility (physical constraints and manual dexterity), changes in vision and cognition, and social limits [13, 14]. Whilst kidney transplant candidates are deemed able to cope with a complex post-transplant medicine regimen, there is still a high rate of non-adherence reported in the literature [15, 16].

Medication-taking behaviours can be considered unique to individuals [15]. In best practice, health care systems' decisions about individual patients need to be made using a structured, evidence-based baseline approach [17–20]. Over time, this approach should be further tailored based on individual experience and active feedback mechanisms [21, 22]. To do this, patients' current perspectives around medication taking and how they cope after transplantation must be explored. To better characterise potential barriers to medication taking in older adult kidney transplant recipients, this study aimed to identify how older adult recipients currently manage their immunosuppressant regimen, determine what strategies they use to cope, and explore how their feelings toward their donor kidney may drive behaviour. The main objective of the study was to investigate the behaviours patients adopted or described in coping with a complex medication regimen and how these behaviours helped them to manage their medicines.

2 Methods

This study involved semi-structured patient interviews with older adult kidney transplant recipients. The study was designed to obtain a rich and detailed understanding of how recipients manage their medicines post-transplant, as well as their feelings toward their donor kidney. Ethical approval was obtained from Metro South Health Service Human Research Ethics Committee (HREC/19/QMS/51168) and the University of Queensland Human Research Ethics Committee (2019001690/HREC/19/QMS/51168). Written, informed consent was obtained from all participants prior to interview. Results have been reported in line with the consolidated criteria for reporting qualitative studies (COREQ framework [23]).

2.1 Study Setting and Participant Recruitment

Older adult kidney transplant recipients were eligible for study inclusion if they received regular follow-up and care from the Queensland Kidney Transplant Service (QKTS)

Table 1 Semi-structured seeding questions used to guide the interviews

1. Can you start by showing me the anti-rejection medicines you currently take? Can you explain what each is for and how would you normally take them?
2. As you know, a big part of receiving a transplant is having to take lots of medicines every day, particularly your anti-rejection ones. How do you feel about having to take anti-rejection medicines and every day?
3. We all at times, really struggle to remember to take our medicines. Can you tell me about a time when you found it challenging to take your medicines?
4. So now I'd like you to tell me about your daily routine with respect to taking your anti-rejection medicines. Do you have a set routine/How do you remember to take your medicines?
5. Do you think you take your medicines consistently? How do you know?
6. Has your routine, in terms of taking your medicines, changed since having your transplant?
7. You are **X** weeks post-transplant; I want to get a sense of how you see your health at present. Can you tell me about this please?
8. Now, I'd like you to think about your life before you had the transplant and now... Having a transplant has obviously given you a new kidney, but how do you think your life has changed?
9. Similarly, we would like to get a sense of how you feel about your donor. Can you describe how you feel?
10. From the literature, some people have found that having a transplant puts strain on their relationship with their family, whilst others have found their relationships to improve, because they felt empowered and supported by their family or doctors. So, thinking about your relationships with your family and your doctors here at the hospital, has your transplant changed your relationships?
11. Before you receive a transplant, you learn about all the potential risks, including the risk of your new kidney failing or your body rejecting it. You are now **X** weeks post-transplant, have you thought about your kidney failing? Do you have any concerns or worries?

at the Princess Alexandra Hospital, Brisbane, Australia. Patients had to be 65 years or older at the time of interview but could be up to 5 years post-transplant (i.e. transplanted at 60 years of age or older). Patients were excluded if they had an impaired capacity to consent or did not manage their own medicines. All eligible patients were approached and recruited during a routine outpatient appointment by a nephrologist (either face-to-face or via telephone).

2.2 Data Collection

The Theory of Planned Behaviour, which is based on a physio-cognitive model that was developed to predict patterns of health behaviour [24], was used to guide development of interview seeding questions (Table 1). Semi-structured interviews were conducted either face-to-face after a routine clinic appointment, or over the telephone at a mutually suitable time. All interviews were conducted by the principal investigator (AC) for consistency. Interviews were audio-recorded using an audio recorder or Zoom Cloud®. Each interview was transcribed verbatim, with any identifiers anonymised, for ease of analysis. Data was collected until saturation was reached, when no new ideas or thoughts were being generated in the interviews.

2.3 Data Analysis

The principles of Grounded Theory were used to analyse the data. Grounded Theory methodology centres on lived experiences, where themes are not built on pre-conceptions. Each transcript was coded by the same member of the research team (AC) based on the principles of Grounded Theory. Coding was applied to the transcripts manually, using NVivo software v.12, then refined and streamlined in Excel

v.16.53. Reliability testing was conducted by an independent researcher (NC) with extensive qualitative experience, who further refined the themes based on a random selection of transcripts. After the final themes were determined, exemplars were chosen both to illustrate each theme and subtheme, as well as support reporting transparency [23].

2.4 Reflexivity

The primary investigator (AC), who is a pharmacist, acknowledges that she has her own opinions about medication taking and has prior knowledge of the poor overall adherence in this cohort. This may have influenced interpretation of the data. AC also takes daily medication, and at times is non-adherent, which could also have been a source of potential bias when interpreting the data. For transparency, the principal investigator (AC) disclosed at the beginning of each interview her credentials (Bachelor of Pharmacy; but no affiliations with QKTS), and that this research was being conducted as part of a Doctor of Philosophy degree.

3 Results

A summary of patient demographic and clinical characteristics is shown in Table 2. A total of 21 recipients were approached from February 2020 to August 2021 with a total of 14 older adult kidney transplant recipients participating in the interviews (nine of the 14 interviews were conducted via telephone). Overall, 50% of participants were male and 86% were of Caucasian ethnicity, with a median age at transplant of 68 years. Participants were prescribed an average of 11 medicines overall, with 79% prescribed

Table 2 A summary of participant demographic and clinical characteristics

Characteristic	Value [min–max]
Number of patients (<i>n</i>)	14
Median age at transplant (years)	68 [64–73]
Median age at time of study (years)	71 [66–77]
Male (<i>n</i> , %)	7 (50)
Race (<i>n</i> , %)	
White	13 (93)
Asian	1 (7)
Transplant number (<i>n</i> , %)	
First	14 (100)
Cause of kidney failure (<i>n</i> , %)	
Polycystic kidney disease	4 (29)
IgA nephropathy	2 (14.5)
Diabetes	2 (14.5)
Hypertensive nephrosclerosis	3 (21)
Unknown	3 (21)
Immunosuppressant regimens (<i>n</i> , %)	
Tacrolimus/mycophenolate/prednisolone	11 (79)
Ciclosporin/prednisolone	1 (7)
Ciclosporin/everolimus/prednisolone	1 (7)
Tacrolimus/prednisolone	1 (7)
Median number of medicines ^a	13 [10–26]

One patient was prescribed slow-release tacrolimus, and 10 patients were prescribed dual tacrolimus therapy

IgA Immunoglobulin A

^aThis count includes immunosuppressant medicines and describes the total number of different medicines prescribed (the pill count may be higher due to multiple doses per day)

triple immunosuppressant therapy consisting of tacrolimus, mycophenolate, and prednisolone. However, there was some variability in this immunosuppressant regimen, with some recipients taking the once-daily tacrolimus formulation, and others taking mycophenolate three times daily (to limit side effects).

Overall, six key themes emerged from the analysis to describe the medication-taking behaviours of our older adult kidney transplant patients. These themes and sub-themes are outlined in Table 3 and described in detail below with exemplars.

3.1 Theme 1—Perceived Health Literacy Toward Medicines

Validated tools were not used to explore the theme; thus, our findings really only reflect perceived patient health literacy. We chose to label this theme accordingly because we felt that this term most accurately summarised the rich detail that was described by patients in their interviews. Some patients were more inclined to demonstrate and prioritise building their knowledge base about their medicines and take an active role in their healthcare. Other patients were less inclined to understand their medicines and learn about their condition. Further exemplars to support these statements around ‘Perceived Health Literacy’ are provided in the following results.

3.1.1 Education

Patients described how they felt empowered when they educated themselves about their condition and their medicines

Table 3 A summary of final themes and subthemes

Theme	Subtheme
Perceived health literacy toward medicines	Education Self-efficacy
Support networks	Comaraderie with other recipients Familial support
Adjusting health expectations	Implicit trust in doctors' knowledge Donor kidney is functioning well Fear of consequences Responsibility to self and kidney Improved quality of life
Motivators for self-care	Accepting of side effects Disheartened by slow recovery
Medication management	Physical limitations to activity Feeling overwhelmed
Approaches to medication taking	Changes in routine Automated cues and reminders Habit stacking Organisational strategies

and felt more in control of their own health. This also led them to prioritise educating their significant others, such as extended family and friends.

“I think it's important to understand what the medications are for, and you know, things, things that they could cause. And I, I just find it interesting.” [P04]

“A lot of people just think ‘Oh you've had that transplant now. That's great! Congratulations.’ They think that's the end of it. I've had to explain, this is a process and this is just one step... I see it as an education thing.” [P13]

3.1.2 Self-Efficacy

Patients were highly inquisitive, and most were trusting of their healthcare team, but not often implicitly trusting; they needed to understand the process before accepting a decision.

“I've been in hospital. And I know exactly what I'm supposed to have, and then they turn round, and something's missing. ‘Oh no, they're withholding that for this time’. ‘Oh yeah, why?’ And then I've got to chase them up...” [P10]

[when sees Doctor] “I just make sure I get all my questions answered, and then find out what news I need to know..., I actually insist in being totally involved in my care...” [P08]

Some of our patients described how they felt empowered to learn and understand the ‘why’, and with support, they described how their belief in their own ability then led to the successful implementation of a behaviour.

“But it was a good learning experience to do it [pack the dosette box]. When we did them up in front of me, I could work it out. There's a saying, if you tell me about something, I'll remember it, if you show me how to do it, I'll know about it, if you make me do it, I'll remember it forever. It was one of those moments. And I really haven't had much trouble filling it out since then.” [P08]

3.2 Theme 2—Support Networks

3.2.1 Camaraderie With Other Recipients

The camaraderie and rapport developed between transplant recipients was found to be extremely powerful. Recipients described how sharing concerns or advice with someone in the same situation (i.e. a fellow transplant recipient) grounded them, whilst a similar interaction with a family member was sometimes seen as an empty platitude.

“If you're talking to somebody who knows exactly what you're talking about, it does make a difference.” [P09]

Furthermore, by participating in group discussions or catching up with other recipients, it was shown that our patients began to draw comparisons to their own health and contrast their experiences with others', which seemed to focus their mindset to a more positive outlook.

“There's no colour, race, anything. It's just everybody's a big family. It is, it really is. I've met some beautiful people.” [P03]

3.2.2 Familial Support

Familial support seems integral to success post-transplant, with many recipients explaining how acts of service was one way family showed their support.

“I think as far as my husband goes... he's been very supportive. He's always been there for me” [P04]

“Thankfully, I had my daughter. She came in every day. And she was in on all the conversations [about how to pack and take medicines].” [P13]

However, despite family being key support groups, as identified by the majority of participants, some felt that their words were placating rather than comforting.

“I've got another friend, whose daughter had a double lung transplant many years ago, so again, she understands completely what's going on with me... If you're talking to somebody who knows exactly what you're talking about, it does make a difference.” [P09]

3.2.3 Implicit Trust in Doctors' Knowledge

A positive, active dialogue between the clinicians and patients was identified, which encouraged active participation from patients in their own health journey. The patients respected their healthcare teams' decisions, and were confident in their knowledge, which built implicit trust.

“Normally it's explained to me, you know, the doctor says ‘Oh we're gonna have to have that. Or stop the other, or whatever’. They explain it at the time” [P10]

3.3 Theme 3—Adjusting Health Expectations

3.3.1 Accepting of Side Effects

Most patients were quick to detail the side effects they experienced from their immunosuppressants. Despite this, patients overall still seemed to prioritise medicine taking. Some patients reflected that this was due to their

overwhelming gratitude for having received a transplant, and not having to remain on dialysis.

“Yes. I’ve got the shakes – tacro[limus]. And you get a numb mouth – tacro[limus]. You get numb feet – tacro[limus]... It doesn’t stop me taking them. If you want to live, you gotta take them.” [P03]

“It’s in the back of my mind, the side effects but, you know like, what’s the choice? There isn’t one unless I want to go back on dialysis.” [P05]

3.3.2 Disheartened by Slow Recovery

Some patients stated that they were still coming to terms with having a chronic illness. Pre-transplant, the majority were on dialysis which massively impacted their quality of life, and patients assumed that their health would return to pre-dialysis levels after transplantation.

“It was a big shock to the system... the transplant itself took a real lot out of me. I sort of found walking even really hard and going to the PA every day was... we [referencing partner] were both exhausted.” [P14]

Some patients believed that transplantation was only a hurdle in their health journey and were understandably devastated when they realised that health deterioration is par for the course with advancing age, and not only attributable to kidney disease. They acknowledged that they understood the post-transplant regimen is critical to graft survival, however, they felt overwhelmed with the complexity of the medication regimen. Furthermore, managing the rigorous, life-long post-transplant regimen was described as exhausting, with diet and eating habits, medicine taking, and exercise, each requiring careful management to support best health outcomes.

“Because of my age, I’m taking longer to get over the operation... um, than I thought I would. But every day, I’m getting stronger.” [P03]

“I mean really you’ve got so much happening to you. And you’re in a whole new world where you’re, you’re... I mean sore, you’re groggy. And every time you turn around you just want to go to sleep. And because we have to be at the pathology and then the clinic, you know by half past six in the morning, every single day for nearly a month... it’s like, you just spend your whole time trying to work yourself out. You’re really not mentally capable of taking in anymore.” [P09]

In addition, because some patients had seen transplantation as the panacea, they described how they developed depression, or depression-type symptoms post-transplant, as they felt utterly devastated when their hopes did not align

with reality. These recipients were often slow to recover post-transplant and thus their perception was that the transplant had not resulted in a profound improvement in their overall health.

“I think one of the things that really hit me with the transplant, and when I got home was the psychological impact of it. Because I got so depressed. Because of the limits. As I could see it, from the, after the transplant yeah my immediate thoughts were ‘well, what am I going to do now? I don’t know what my capabilities are physically, as far as work goes’.” [P05]

3.3.3 Physical Limitations to Activity

Patients described how they struggled to adjust to their ‘new normal’ and often had to lower their expectations.

“Yeah, I keep moving, I keep doing you know, doing what I have to do. And going, going for a walk, I think that really helps. I’m sure, I’m absolutely certain exercise makes me feel better but yeah... I, I, I feel quite tired.” [P04]

Patients assumed they would be ‘well healthy’ post-transplant but were still impeded by reduced strength and energy capabilities and this resulted in physical limitations. For example, some patients were still struggling to walk long distances, unable to travel, or partake in hobbies (such as fishing). These patients had been forced to acknowledge that they still have a chronic illness which requires robust management, and they seemed disappointed by this.

“I would like to be a bit more active; I would like to get this all over, and feel this is not a burden anymore, ... I’d like to get back to my routine. I used to get up every morning and walk on a treadmill. I used to clean up the backyard.” [P01]

3.4 Theme 4—Motivators for Self-Care

3.4.1 Donor Kidney is Functioning Well

Patients described how they required validation that their kidney was robust and healthy, and they described waiting for ‘news’ (e.g. blood test results).

“I just make sure I get all my questions answered, and then find out what news I need to know... check my bloods, we go through that together... I actually insist in being totally involved in my care. And [nephrologist] is a.. an absolute supporter of that.” [P08]

The patients were cautious about returning to some everyday activities which may put their kidney at risk.

“And also, I’ve got to be confident that, you know, that the kidney is like okay. I still feel that it’s early days.” [P13, reflecting on why they were yet to go out into public spaces e.g., the cinema or a shopping centre]

3.4.2 Fear of Consequences

The fear of potential consequences seemed to be yet another motivator for some patients to prioritise medication taking and other self-care activities.

“I don’t see there’s any choice, you know? I don’t want to lose my, my kidney. I couldn’t bear to lose and have to start all over again so no. No, nothing would stop me taking them.” [P04]

Participants described how there were periods when they worried about their kidney graft failing. This was particularly evident when they were unwell, or other recipients lost their graft. However, the majority emphasised that they actively chose not to dwell on their potential life expectancy, as it is out of their control. Some believed that destiny decides when we die, and thus, worrying was only wasting the time they had left.

“Yeah, I think it’s always in the back of mind. I don’t care, anybody who’s had a transplant must think that, and I do think that. But I don’t dwell on it.” [P01]

3.4.3 Responsibility to Self and Kidney

Patients seemed to feel that the only way to appropriately honour both the donor’s family and the hard work of their transplant healthcare team was to take their medicines as prescribed and follow the post-transplant routine.

“Some donor somewhere, and their family have given me a huge gift, and I have an absolute responsibility to look after that gift. I do feel a moral obligation to honour that family, all the pain they went through, to say that ‘yes I will take good care of that kidney’.” [P08]

Donor kidneys were repeatedly described as ‘precious gifts’ and patients explained how they felt that it was their responsibility to prioritise their own health, because if they didn’t, it would be both unjust and disrespectful to the sacrifices others have made.

“Well just you gotta take them if you want to keep your kidney, you got to take them. I’ve been given a second chance of life. And if you’re stupid about it, and not taking pills... well you know, somebody else could have had that kidney.” [P03]

3.4.4 Improved Quality of Life

Again, a validated tool was not used to explore this theme, and our findings can only represent our interpretation of the data collected during the interviews. However, we felt that the description, ‘Quality of Life’, most accurately summarised important aspects of patients’ views regarding their health changes post-transplant. Exemplars are provided to support our use of the term ‘Quality of Life’ in the following results.

Despite having to moderate their health expectations post-transplant, with many still residually frail, some patients highlighted how their life post-transplant was infinitely better.

“And suddenly it’s almost like you’ve regained your whole life – you can go out, you can go on holidays. You can go out for lunch with your friends and walk the length of the Shopping Centre... I mean it’s, it’s just amazing I’m telling you. Anybody who says it’s not a good thing, they’re not doing it right.” [P09]

“I’m a lot more confident. I’m very relieved that I don’t have to go through dialysis three times a week. ... You don’t realise the limitations ... the dialysis places upon you until you, you get involved with it and, and even though it is a, it is a lifesaving process... lots of chemical reactions are going on in the body that tend to degrade your lifestyle, for example.” [P12]

3.5 Theme 5—Medication Management

3.5.1 Feeling Overwhelmed

Some patients described how they felt wearisome and overwhelmed by the rigorous and complex post-transplant care regimen required to support their kidney health, as well as the amount of new information they had to process and action.

“Yeah, it was overwhelming. And it was like in one ear and out the other. I couldn’t concentrate on what they [doctors] were saying.” [P13]

Those patients who described being overwhelmed were also less likely to express a desire to learn more about their medicines and were less inquisitive about the process, relying on their healthcare team to make decisions.

“No, I don’t particularly go ahead and read the side effects of a tablet, because you will start to show them, if you do.” [P01]

“Yeah no, well I don’t even consider that [when asked about understanding each different medicine]. I’ve got to take them. That’s it. Full stop... You know, I

haven't got the knowledge about the pills so... so in other words, I'm trusting that they're giving me the right stuff and I'll go with that." [P07]

3.5.2 Changes in Routine

Changes in routine were repeatedly described by our patients as a hallmark of dose skipping (i.e. missing one or more doses of a prescribed medicine; can be intentional or unintentional).

"I do miss them. It's very rare...when I get overly involved in something, when I see the __ activity, the phone goes off, I take the pills straight away. But if I'm busy doing something else, ... the alarm goes off and then you forget about it, I go on with the activity [and don't take the tablets]." [P08]

It seems that the more forgetful patients relied on baseline strategies suggested by the healthcare team such as dosette packing and alarms. However, these strategies were not robust or adaptive, and often did not withstand a disruption to the usual daily routine.

"And I can't remember what it was, but something was going on and the [alarm] went off, and I thought, 'I must take those tablets' ... I think somebody was here. And so, I sort of said 'Oh they're going to go in a minute, I'll take them as soon as they're gone' and, and they didn't go! And then it was probably about three o'clock in the afternoon, I suddenly thought 'I never took those!'" [P09]

3.6 Theme 6—Approaches to Medication Taking

3.6.1 Automated Cues and Reminders

Many of the patients used automated cues and reminders to support medication taking, such as an alarm clock.

"I have the ubiquitous phone, and it's got a calendar on it and I went along and I had a chat to the people who know about the phones, and they showed me how to put the reminders on the calendar. So, I've got reminders... I've got reminders." [P09]

The high uptake of reminder cues may in part be because aids such as a dosette box and carry bag are provided as part of the post-transplant care package.

"And you know, you carry your bag wherever you go. So you know if you sit down... if you go out and you have lunch out, you know that you've got to take your pill at lunchtime." [P03]

However, these currently employed strategies were not infallible and patients repeatedly acknowledged that they miss medication doses when out of routine. For some patients, it seems that these automated processes have become almost routine, and some recipients described how they almost pre-empt their alarm.

"No, no it's just... I'm set in it, about seven and seven." [P11, in response to the researchers asking if they use an alarm to remind them to take their medicines]

3.6.2 Habit Stacking

Some patients described how they linked their medication taking to currently established routines such as eating breakfast or feeding the cat. This is described as habit stacking, where a new routine is linked to an established habit, rather than a particular time or location. This is considered a robust, well thought-out strategy to foster medication taking, as it more effectively builds medication taking into daily activities [25].

"You have to have, well I had little tricks to prompt me. It used to be feed the cat, take my warfarin, pour a glass of wine... see then, if there was a night when we didn't have a wine, I'd forget my tablets." [P14]

However, it must be acknowledged that no method is fool-proof, and this particular recipient [P14] stated that on wine-free evenings, tablets were sometimes forgotten.

3.6.3 Organisational Strategies

It was highlighted that the majority of the patients used the organisational methods taught early post-transplant, such as a 7-day dosette box, and storing medication in a transplant clinic-issued carry bag.

"Once I had done the 7 days boxes, I've got a little trolley thing that everything goes... I put them there. I take out of the morning that days, and it sits on the table." [P02]

For patients who recognised forgetfulness as a barrier to their medication taking, aids such as the dosette box became a secondary checking mechanism, because if filled correctly, patients could then identify if they'd taken their tablets. However, this approach is heavily reliant on accurate filling, and one patient described how they no longer used the dosette box as they had repeatedly made mistakes.

"Because what happens... is when I'm putting them in the boxes, every time I've done it, I've made a mistake... it doesn't matter how I line them all up and everything, I always made a mistake. So I thought 'Nup,

I'm over this. I'm better off just doing it in separate blocks.' So every morning and night, I count them out, and that way, I haven't made any mistakes." [P05]

Because participants take so many medicines, many described how organisational strategies are an excellent tool to simplify the overall daily routine. Some also identified that they stored their medicines in a prominent location in the house, for example in the kitchen, which in turn served as a secondary reminder when eating (a form of 'habit stacking').

"I take the morning ones out and I take the evening ones out and put them next my bed... So I know if I had forgotten to take them then they remind me there." [P01]

4 Discussion

To our knowledge, this is one of the first studies to specifically examine medication-taking behaviours in older adult kidney transplant recipients, aged 65 years and over. In this sample of older adult kidney transplant patients, several strategies were identified around how patients manage a complex medication regimen. These included automated cues such as alarms and linking medication taking to already established habits such as eating meals. Patients perceived transplantation as a panacea, and many described how they had believed a transplant had drastically improved their quality of life. However, some were disappointed with their health at the time of interview and were struggling to reconcile their assumed and expected physical skills, with reality. Throughout the interviews, all recipients discussed at length the power of their relationships with significant others, and it seems that these relationships are crucial to patients' post-transplant positivity, and a key driver of their post-transplant health-related success. Additionally, extreme gratitude to the donor, relative improvement in their life quality (compared with the rapid deterioration in their health when dialysing), and fear of consequences (particularly graft failure) were raised by all patients as additive and synergistic facilitators of self-care and served as timely reminders to prioritise their own health.

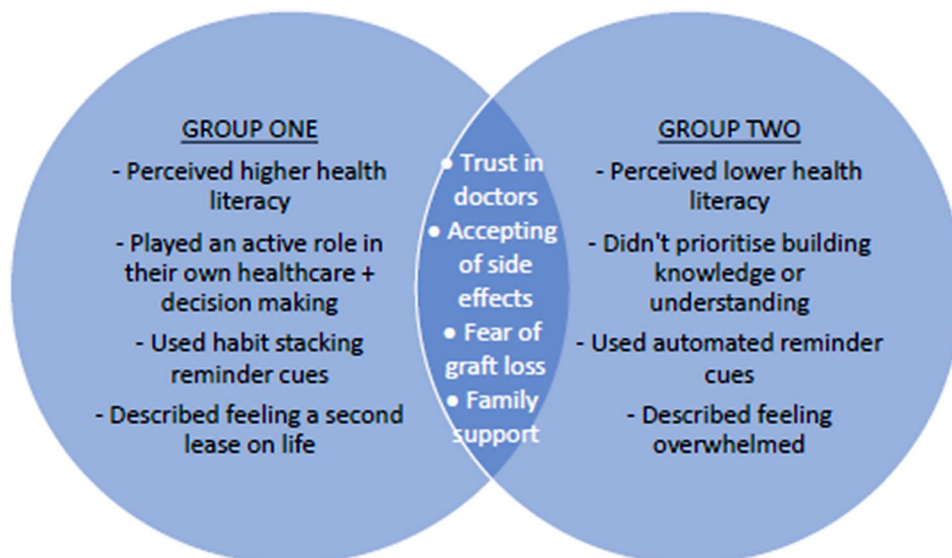
Many of our patients reported that they only forgot their medicines when out of routine. Changes in routine resulting in forgetfulness towards medicines has been reported in the literature [26, 27]. Forgetfulness may be due to impulsivity or distractions, or mindlessness [27], or disruptions or loss of routine [26], particularly where people assign low importance to a task [26]. Forgetfulness has been associated with being burdened by the post-transplant regimen [28], with this being described in the literature as learned helplessness [29]; patients grow despondent because they

perceive that their best efforts have not accomplished the task or goal and often, as a result, they become intentionally non-adherent [29]. Our patients described a feeling of being overwhelmed early post-transplant and planned behaviour education and self-management strategies have been described as approaches to overcome this feeling and may facilitate medication taking [30].

Some of our patients described linking their medication taking to an already established sequence of behaviours, such as preparing and eating breakfast. This behaviour is colloquially termed 'habit stacking' [25], and has been shown to have a positive impact on adherence [31]. Some of our patients had linked their medication taking to habits that shifted post-transplant, or were not daily, and thus, their process of habit stacking was sometimes ineffective. Resultantly, older adult patients may require additional support in the weeks following discharge, to ensure they adapt their medicine routine in their own everyday environment, as this is likely the key to establishing solid, exacting medication taking behaviours that hold up to changes in routine. Additionally, the majority of education around medication taking occurs pre- and early post-transplant. Introducing 'Refresher' education sessions, to take place when patients have an established routine (e.g., at 6-9 months post-transplant), may help patients cope with the routine.

Locus of control considers if self-control, the influence of significant others (i.e. family, friends or the healthcare team), or external forces such as luck or God, drive beliefs. Some of our patients identified 'a greater power' or 'destiny' as a key locus of control belief. A review by Rebaafka showed that patients who consider luck or destiny to control their health outcomes were more likely to be non-adherent [32]. Instead, it was evident that our patients framed this locus of control belief as a positive—they prioritised living life to the fullest, rather than worrying about potential graft duration (because 'destiny' decides their time of death). Social support also seemed to be a key locus of control belief and a component of post-transplant success in our study, with patients describing strong support networks with their fellow recipients, family, friends, and the healthcare team. Denhaerynck and researchers described the impact of social support and concluded that social support is subjective, but a strong support network is integral to fostering adherent behaviours [33]. This study identified a similar trend and showed that some recipients initially placed a lot of responsibility on their family in terms of physical management of their health condition, as they felt overwhelmed and out of their depth. However, emotionally, experiential insight and learning from peers seemed to allay fears more effectively. Schmid-Mohler and researchers echoed this belief and showed that peer exchanges helped with feelings of isolation and marginalisation, as well as reframing negative thoughts

Fig. 1 A summary of the two different patterns of medication behaviour identified in this study and their differences and commonalities



regarding graft survival [26]. Resultantly, nurturing this peer support network should be of priority.

When considering the medication-taking behaviours described by our patients, we identified two different emerging patterns of behaviour (Fig. 1). Eight patients had the first pattern of behaviour and were perceived to demonstrate higher health literacy, as they prioritised understanding, and educating both themselves and others about their condition. These patients wanted to play an active role in their own healthcare and decision making; however, they still implicitly trusted their healthcare team, and with reasoning and explanations were accepting of medical decisions. These patients seemed to have a more sophisticated approach to medication taking and developed adaptive methods to try and prevent forgetfulness when out of routine. Six patients had the second pattern of behaviour—they were less inclined to understand their medicines and could be perceived to have poorer health literacy in comparison with the first group. For these patients, medicine knowledge was not sought or prioritised, with some even describing how they believed an increased knowledge base would lead to side effects. For example, one patient believed if informed that a side effect is a headache, they would suffer a headache. These patients had complete trust in their healthcare team and did not question any decision. This group were more likely to rely on organisational strategies such as alarms to support medication taking.

These differing patterns of medication-taking behaviour demonstrate how important it is to find the distinction between an automated task and a habit that has been linked to an existing routine; planning ties into self-regulation [34]. In order to foster more robust habits, it seems that we need to better explore and quantify the link between anticipating risk and acceptable coping responses for each individual

patient, because coping styles may have a profound impact on medication taking. Consequently, education centred on habit stacking and coping planning may better support more mindful medication taking, which could reduce the impact of changes in routine.

4.1 Strengths and Limitations

As described in the methods, steps were taken to support research rigour. A qualitative method allowed a richer analysis of the data, which ultimately should give greater insight into the drivers of different behaviour. However, qualitative data is open to researcher interpretation, and the themes summarised herein could not be objectivised with validated tools. The COREQ framework was followed to support the robustness of the findings and reduce potential sources of bias. Additionally, interviews were conducted until it was believed data saturation had occurred.

Nonetheless, only one transplant site was involved in the study, although the QKTS services all of Queensland and northern New South Wales; it would be premature to assume that the themes generated in this study reflect the entire older adult transplant population.

In interviews conducted by telephone, it was not possible to observe participant body language. To counter this, additional check-in statements were made such as “if you feel comfortable, can you describe...”. Telephone interviews also had advantages in that the interview could be conducted in the participant’s own home at a time suitable to them which meant that some participants were more willing to take part in the study.

Patients were only eligible for study inclusion if able and willing to consent and participate in the interview and managed their own medicines. We were unable to examine the

behaviours of patients with cognitive decline (a particular subgroup of recipients who likely need a different, tailored intervention).

Finally, we were unable to explore medication-taking behaviours over time post-transplant, and this should be a priority for future research. This would have been interesting as there is some thought that attitudes may shift over time due to the incidence of side effects and potential exhaustion associated with the rigorous management of overall health to support graft survival. The majority of our patients were early post-transplant and therefore the themes we identified can largely be considered homologous and not prone to bias associated with time post-transplant.

5 Conclusion

It is imperative that patient perceptions, including both the facilitators and barriers to medication taking, were explored so that the most effective, targeted support strategies can be implemented to foster medication taking. Older adult kidney transplant recipients are confronted with many challenges post-transplant, particularly the emotional impact of a transplant, physical limitations, self-perception, and adapting to their new post-transplant lifestyle. Our recipients had strong support networks and prioritised self-care; however, when it came to medication taking, although they coped well with the post-transplant routine, strategies were largely automated cues and did not always stand up to changes in routine. Future interventions should consider repeating education sessions further after transplant when patients have established routines. Additionally, education should be individualised and take into consideration a patient's coping style so that medication taking becomes a routine that stands up to changes in daily activity.

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Author contributions Amelia R. Cossart participated in research design, interview collection, interview transcribing, data analysis, and manuscript writing and preparation. W. Neil Cottrell participated in research design, data analysis, and manuscript writing and preparation. Nicole M. Isbel participated in research design, and manuscript writing and preparation. Scott B. Campbell participated in research design, and manuscript writing and preparation. Christine E. Staatz participated in research design, and manuscript writing and preparation.

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Declarations

Conflict of interest There are no conflicts of interest for any author listed in the manuscript.

Ethics approval Ethics approval was obtained from Metro South Hospital Service, Brisbane Australia (HREC/19/QMS/51168), site/governance approval from the Princess Alexandra Hospital (SSA/19/QMS/51168) and the School of Pharmacy Human Research Ethics Committee, UQ (2019001690/HREC/19/QMS/51168).

Consent to participate Written informed consent was obtained prior to study participation for each participant, as required by Ethics.

Consent for publication By signing consent, participants were aware that their de-identified data would be disseminated, including publication in a peer-reviewed journal.

Availability of data and materials Not applicable.

Code availability Not applicable.

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