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Self-care strategies and barriers among kidney transplant recipients: a qualitative study

Elisa J. Gordon^{*}, Thomas R. Prohaska[†], Mary Gallant[‡], and Laura A. Siminoff[§]

^{*}Institute for Healthcare Studies, Feinberg School of Medicine, Department of Surgery, Division of Organ Transplantation, Northwestern University, 750 N. Lakeshore Drive, 10th Floor, Chicago, IL 60611, USA

[†]Institute for Health Research and Policy (MC 275), School of Public Health, University of Illinois at Chicago, 1747 West Roosevelt Road, Room 558, Chicago, IL 60608, USA

[‡]Department of Health Policy, Management, & Behavior, School of Public Health, University at Albany, SUNY, One, University Place, Rensselaer, NY 12144-3456, USA

[§]Department of Social and Behavioral Health, School of Medicine, Virginia Commonwealth University, PO Box 980149, 1112 E Clay Street, Richmond, VA 23298, USA

Abstract

Objectives—We investigated kidney transplant recipients' self-reported levels of exercise and fluid intake. We also examined attitudes about, barriers to undertaking, and strategies used to initiate and maintain adequate self-care for fluid intake, exercise and dietary practices.

Methods—A qualitative approach was used and supplemented by quantitative data to examine self-care among kidney transplant recipients ($n = 82$), including a semi-structured interview and survey of physical activity.

Results—One-third of patients (33%) reported drinking the recommended 3 L of fluid each day. However, the majority (60%) reported not receiving this or any specific fluid intake recommendation. Twenty percent reported engaging in moderate to regular physical activity while 78% were sedentary. However, many reported that clinicians did not specify the amount of exercise (39%) or did not discuss exercise (15%). Attitudes towards fluid intake, exercise and maintaining a low-salt diet were mostly positive; patients expressed relatively more negative attitudes towards maintaining a low-cholesterol diet. Major barriers to fluid intake were not feeling thirsty, difficulty breaking the habit of limiting fluid intake formed while on dialysis, feeling full and limited access to fluids. Patients devised creative strategies to initiate and maintain appropriate hydration, physical activity and dietary levels, including intentionally drinking when not thirsty, modifying the environment, tracking intake and relying on social supports.

Conclusions—Few kidney recipients practiced optimal self-care for fluid intake or physical activity. Most patients encountered barriers to self-care that should be ameliorated to assist patients with managing their transplant. Understanding barriers and strategies is essential for developing educational interventions.

Keywords

Kidney transplantation; Physical activity; Nutrition; Qualitative research; Self-care

INTRODUCTION

Self-care refers to ‘the range of behaviour[s] undertaken by individuals to promote or restore their health,’¹ including adherence to medication, dietary and exercise recommendations; monitoring symptoms; maintaining physical function; executing medical regimens and making decisions about seeking care.² Self-care encompasses behaviour, attitudes about self-care practice and knowledge of why certain practices may or may not be important to their health. Self-care is especially important for patients with chronic illnesses, which requires daily monitoring and adherence to various treatment regimens.^{3–5}

Little research has been conducted on self-care among kidney transplant recipients. Kidney transplantation is the treatment of choice for patients with end-stage renal disease (ESRD). Transplantation provides a better quality of life and longer length of life,⁶ and is more cost-effective than is haemodialysis.⁷ There are currently over 145,000 renal transplant recipients with working grafts in the US.⁸

The paucity of data is surprising considering the emphasis transplant professionals place on kidney recipients’ ongoing self-care. Kidney recipients are required to practice self-care starting immediately post-transplant and continuing for the life of the kidney to ensure the proper functioning and longevity of their kidney graft. Self-care practices include: taking immunosuppressive medications, staying well-hydrated, exercising, following a low-salt and low-cholesterol diet, vigilant monitoring of vital signs, managing symptoms, wearing sun protection and avoiding contact with people who are ill.⁹

Although self-care is a broad concept, we focus on the self-care practices relating to fluid intake, physical activity and maintaining a low-salt and low-cholesterol diet because these behaviours are critical to self-care management for the kidney transplant. Adequate hydration is important for overall renal health. Exercising is important to prevent cardiovascular disease, which is the primary cause of death among kidney recipients.¹⁰ We also examine barriers to these self-care practices, as has been done for other chronic conditions,^{5,11} and strategies to overcome them.¹² Identifying barriers to self-care is essential for achieving optimal self-care practice.¹³

Conceptual Model

Our study was guided by the self-regulation model of illness management to examine kidney recipients’ approaches to self-care.¹⁴ According to this model, people learn strategies to manage their chronic illness through the self-regulation processes of observations, judgments and reactions.¹⁴ The first stage of the self-regulation process entails primary appraisal of the problem, assessment of the strategies to address the problem and the decision about which strategy to use. Next, people observe their own self-care behaviour, assess whether the behaviour successfully achieved their goal and react to the experience.¹⁵ This framework is a patient-centred approach that focuses on understanding and responding to patients’ perspectives, needs and ability in their efforts to accommodate self-care goals into their lives.¹⁶ This article reports on kidney recipients’ self-care practices of fluid intake and exercise. We describe new kidney recipients’ attitudes about fluid intake and exercise as well as other self-care requirements of maintaining a low-salt and low-cholesterol diet. We also detail the range of self-care strategies kidney recipients marshal to undertake self-care and barriers to self-care for all four activities.

METHODS

Study Population

All adult kidney transplant recipients were recruited in an incidence cohort from Loyola University Medical Center (LUMC) in Maywood, IL (July 2004–May 2006) and Albany Medical Center (AMC) in Albany, NY (September 2006–November 2007). Kidney transplant recipients were eligible for participation if they were 18 years or older, spoke English, had received a kidney transplant within the previous 6 weeks and were currently taking immunosuppressants.

Qualitative and Quantitative Approaches—We used a combination of qualitative and quantitative methods to: assess levels of self-care activity for fluid intake and physical activity levels only and examine patterns of self-care barriers and strategies for fluid intake, physical activity and maintaining a low-salt, low cholesterol diet.¹⁷ A combined approach offers advantages to collecting and analyzing data: while quantitative approaches enable the researcher to establish relationships among the variables, qualitative components help explain the reasons for those relationships.¹⁸ Qualitative methods are best suited to describe phenomena in depth by considering the role of context in shaping a process or event.¹⁹ Qualitative methods are flexible in that open-ended interviews allow respondents to discuss issues of significance without imposing the researcher's own ideas and thus enable understanding of respondents' point of view.

Interview

Semi-structured interviews were conducted within approximately 2 months post-transplant either in person or by telephone by one author (EJG) or one research staff member. The interview was pilot-tested with four transplant coordinators and two social scientists. All interviews were audiotaped and lasted on average for 2 hours. The data reported herein are part of a larger, longitudinal study examining self-care, social support, finances and kidney graft outcomes. This article reports results from the first interview. Respondents were compensated \$20 for participation. Institutional Review Board approval was obtained from Loyola University Medical Center and Albany Medical Center. Study participants provided written informed consent.

Topics covered in the interview, as they pertain to this article, included: (a) how much fluid patients drink daily and level of physical activity; (b) recall of recommendations for self-care activities from transplant clinicians; (c) attitudes about and perceived barriers to engaging in fluid intake, exercise, low-cholesterol or low-salt diet; (d) strategies patients use to foster each self-care practice and (e) demographics and medical information. Patients' self-care practice levels were not assessed for low-salt or low-cholesterol diets because their dietary requirements vary depending on comorbidity, and antirejection medications increase cholesterol levels, which limits accurate comparison across patients.

Measures

Fluid Intake—Patients were asked how many ounces or litres of fluid they ingested daily. Fluid adherence was determined if patients reported drinking the recommended three or more litres of fluid daily.

Physical Activity—Physical activity was assessed through the use of the Physical Activity Scale for the Elderly (PASE).²⁰ The PASE was designed to assess physical activity in epidemiologic studies of people aged 65 years and older and has been validated on patients on haemodialysis.²¹ This instrument includes activities at the lower end of the activity spectrum, which are expected in the ESRD population.²² The PASE is a self-administered,

21-item instrument that uses 4-point Likert scales to ask about participating in household activities, occupational activities and leisure time activities over the past 7 days. PASE scores range from 0 to 795, with higher values representing more physical activity. Internal consistency of all items was $\alpha = 0.69$ and test-retest reliability coefficient was 0.75.^{22,23} Regular physical activity is defined here as 30 minutes of physical activity three or more times per week (score 151+). Although PASE is analyzed as a continuous variable, for the purpose of presentation, we categorized PASE scores into 'sedentary' (score 0–99), and 'active' (score 100+), which encompasses both 'moderate' (score 100–150) and 'regular' (score 151+) physical activity levels.

Recollections of Transplant Clinicians' Self-care Recommendations—These were assessed using open- and closed-ended questions. First, patients were asked to indicate whether each self-care practice from a checklist was discussed with them by transplant professionals. For patients who indicated that transplant professionals had discussed the importance of having a low-cholesterol or low-salt diet, patients were then asked whether they were told to maintain the diet. For self-care activities of staying hydrated and exercising, patients were asked: Based on what you've heard and/or read, what are all the specific things that were recommended to do about [your fluid intake/doing exercise]? Thereafter, patients were asked, in the case of hydration, 'Do you know, approximately how many fluid ounces you're supposed to drink each day?' In the case of exercise, patients were asked: 'Did they tell you how much exercise to do, like 30 minutes a day, 3 times a week?'

Attitudes about Self-care Practices—Attitudes about self-care practices were assessed using one open-ended question for each activity. For instance, in the case of staying hydrated, patients were asked, 'In general, what are your thoughts or attitudes about these recommendations about fluid intake?' Patients who were on dialysis prior to transplantation were also asked, 'I understand that going from a life on dialysis where you must not drink much at all, to a life with a transplant where you must drink a lot, may be a big transition. What is that like for you to make this transition?'

Barriers to Self-care Practices—Barriers to self-care practices were assessed using closed- and open-ended questions. Closed-ended questions included a list of five barriers to staying hydrated, and nine barriers to exercising (Table 2). The exercise items derived from the literature. One open-ended question asked about barriers to staying hydrated or exercising: 'What are the barriers to [doing the self-care activity]?'

Strategies to Foster Self-care Practices—Strategies to foster self-care practices were assessed using two open-ended questions, first general: 'What do you do to keep yourself healthy?' then specific, as in the case of staying hydrated: 'What are some of the things you do to make sure that you drink enough fluids each day?'

Health Status—A measure of overall self-rated health was assessed with a single global item, 'How would you rate your health compared to people your age with a transplant?' ('excellent,' 'very good,' 'good,' 'fair' and 'poor').

Demographics—Demographics included age, sex, education, income, primary insurer, marital status, race/ethnicity (which was based on self-identification), cause of ESRD, organ donor source and number of transplants.

Data Analyses

Descriptive Statistics—We used simple descriptive statistics to report the frequencies of quantitative measures of self-care. Descriptive analyses were performed using SPSS 15.0

(SPSS, Inc., Chicago, IL). Respondents who did not answer a question were excluded from the analyses.

Content Analysis—The tape-recorded interviews were transcribed verbatim. Open-ended responses were analyzed by content analysis, using Ethnograph 15.0.²⁴ This entails the systematic search for themes and repetitions emergent from the data.²⁵ That is, data were analyzed by topic areas related to key constructs in our model, and by structure, i.e. frequency of topics and domains. Themes and patterns were identified that synthesized data pertaining to strategies for, and barriers to, self-care practices.²⁵ An initial set of the participants' transcripts were coded and a preliminary coding scheme was developed.²⁴ Codes were generated from topics identified in advance²⁶ and from the data. The codes were applied to a new group of patient responses, the coding scheme was revised to adjust for new responses, and modified codes were applied to the previous set of responses. This process was repeated until no new codes emerged and saturation was achieved. One author (EJG) and one member of the research staff separately coded all interviews, then compared and resolved discrepancies in codes to establish inter-rater reliability.²⁶

RESULTS

Demographics

Of 143 eligible patients, 82 participated in an interview for a 57.3% response rate. Twenty-four percent ($n = 35$) refused to participate due to slow recovery from the operation (feeling overwhelmed with the transplant), time commitments (e.g. returning to work, extensive time investment by participating in the study), burden of paperwork involved or disinterest, and 18% ($n = 26$) gave oral consent but failed to set a date in which to do an interview or were unable to be reached for an interview. The sample demographics are presented in Table 1, and reflect the age and gender profile of ESRD and kidney transplant recipients nationally.²⁷ No significant differences in self-care practice levels were found in participants between the two regions.

Self-care Practice Levels and Recollections of Clinician Recommendations

Results are organized by self-care activity: fluid management, physical activity, maintaining a low-salt diet and maintaining a low-cholesterol diet. We present kidney recipients': (a) levels of self-care practice, (b) recall of clinician recommendations for each activity, (c) attitudes about self-care, (d) strategies for and (e) barriers to self-care. Assessing patients' recall about clinicians' recommendations for self-care is important because patients' understanding about what was recommended may influence the types and level of self-care activities performed. Presenting recollections about clinicians' self-care directives illuminates the context of self-care practice levels. Representative quotes are provided to illustrate our findings.

FLUID MANAGEMENT

Self-care Practice Levels and Recollections of Clinical Recommendations

All patients reported that they were told to drink plenty of fluids to stay hydrated. However, only a third of patients (33%) reported drinking the recommended 3 L of fluid daily. Not all patients reported being told how much to drink other than 3 L per day, e.g. 70 fluid ounces 12 cups, 6 glasses ($n = 19$). A third (37%) reported that they did not receive any specific recommendations about how much fluid to drink. The following quote illustrates this point:

'They told me to ... drink the proper water and juices and stuff and if I drink any pop make sure it's low sodium. Stuff like that but ... they didn't tell me how much

to take. They just told me what to drink to have a healthy kidney. But they told me to drink plenty of fluids. They just said drink plenty of fluids.’ (10051, 45-year-old African American male)

Attitudes About Staying Hydrated

Most (70%) patients held positive or neutral attitudes about drinking fluids. Positive attitudes included believing that drinking fluids is important ($n = 10$) and helps keep the kidney healthy ($n = 10$). Those who were neutral reported accepting the fluid intake requirement without a problem ($n = 25$), while others reported being ‘naturally’ big drinkers anyway ($n = 12$). As one patient stated:

‘I just think I naturally drink a lot. I don’t really have to, to watch it. ... I don’t really have to force myself. I probably drink a lot more than I would eat solid food. ... I used to have a huge appetite. Now I probably have a medium appetite ... – but I tend to drink a whole lot more.’ (#12294, 44-year-old white male)

Strategies for Staying Hydrated

Patients devised four main self-regulating strategies to ensure that they drank 3 L of fluid a day: (A) psychological, (B) bodily, (C) tracking and (D) environmental strategies. Others stated that they were naturally drinking plenty of fluids anyway, so they did not need to use any strategy *per se*.

(A) Psychological Strategies—Psychological strategies refer to efforts grounded in patients’ cognitive states and emotional dispositions. This includes: mentally focusing on drinking, modifying the timing of fluid intake and psychological approaches.

Patients ensured that they adhered to the fluid requirements by intentionally drinking even if they were not thirsty ($n = 21$). They reminded themselves to drink and stayed aware of the need to drink ($n = 15$). Patients monitored when they drank fluids to ensure that they could drink enough. For example, patients emphasized drinking mostly while at home, upon waking up and not drinking at night time. Patients reported also drinking in response to daily routines. As one patient stated:

‘Every time I eat, I drink a whole glass of water. Every time I exercise I drink at least one glass of water. Six glasses before bed—every time I take my pills, I take a full glass of water with it ...’ (#10053, 24-year-old white female)

Two patients deliberately ate food that had high water content in it, such as melon, jello, rice, salad or soup. Others stopped or reduced drinking coffee or soda because of their caffeine content, which is a diuretic ($n = 3$). Others varied the types of drinks they consumed to make adherence more palatable ($n = 5$). As a psychological approach, patients’ fear of losing their new kidney and returning to dialysis motivated them to drink fluids ($n = 4$).

(B) Bodily Strategies—Bodily strategies refers to efforts grounded in patients’ bodily conditions. A group of patients ($n = 12$) explained that they paid attention to their body’s condition to assess when to drink. For example, they knew to drink when they felt thirsty or dehydrated ($n = 10$) or monitored their skin as a sign of dehydration and cue to drink ($n = 3$). Other patients deliberately ate salty foods to trigger thirst ($n = 3$). For example, patients stated:

‘I watch the time, and when I feel thirsty, I drink. I mean, before I walk, I make sure I drink. I can also tell by my skin, too, if I’m dehydrated or not, too. So if my skin looks a little— like, if it doesn’t bounce back—I do that on my hand. And, if it

doesn't bounce back I drink. Or when I feel thirsty, I drink.' (#12297, 49-year-old white female)

(C) Tracking Strategies—A common strategy patients used to ensure they drank the required amount was to track fluid intake. Measuring fluid intake helped to foster attentiveness to drinking. Patients tracked their intake by: measuring their input, keeping a bottle in view as a reminder of how much to drink, tracking the number of times a drinking glass was used, mentally keeping track of fluid consumed each day, tracking how much was voided and watching the time to remember to drink ($n = 26$).

'It was hard at first. It was real hard at first. Now it's not quite as hard. ... I got a jug that has one liter in it, and I just make sure I fill it up at least two or three times and I empty it. So that's how I keep track of it. ... I'm just saying we just fill this thing up as many times as we can during the day. And we keep track of how many we empty. It's really not that hard. I don't try to add up all the ounces of every juice and thing like that. If I drink two of these quarts of water, then the juices will make up the other quart. Not that hard.' (#12292, 52-year-old white male)

(D) Environmental Approaches—Patients devised environmental or external strategies to help them adhere to the fluid requirements, including modifying the environmental setting and relying on social supports. Patients intentionally kept drinks nearby at all times by carrying water bottles with them ($n = 20$), drinks near them in the house ($n = 14$), a water cooler at work ($n = 2$) or drinks in the car. A statement illustrating this strategy follows:

'Yeah, I usually ... set bottles of water here and there. I got a work vehicle; I'll set one in the work vehicle. I'll put one on my desk, you know, just to make sure, just to remind me to start drinking. 'Cause I'll just go— keep right on going and not stop and drink, take a break or anything. So I got to make myself be aware ...' (#12282, 41-year-old white male)

Few kidney recipients stated that they rely on family members to remind them to drink in order to meet their fluid intake requirements ($n = 6$).

Barriers to Staying Hydrated

Closed-ended responses revealed that the most commonly reported barriers were not feeling thirsty (38%), not remembering to drink fluids (21%), and not having preferred fluids available (10%) (Table 2). Qualitative analysis of an open-ended question about barriers to staying hydrated confirms the quantitative data and revealed two main barriers: bodily concerns and situational factors.

(A) Bodily Concerns—Bodily concerns pertain to physical sensations or bodily processes that interfere with patients' ability to stay hydrated. These concerns relate to experiencing a difficult transition from dialysis to transplantation regarding hydration habits, not feeling thirsty, feeling full, needing to urinate frequently or at night, and having small digestive organs. Each concern is described below.

Transition in habits: Many patients reported difficulty staying well hydrated due to becoming habituated to the restricted fluid intake required while previously on dialysis ($n = 30$). This subset of patients was on dialysis for on average 3 years, which is 1 year longer than those who did not experience difficulty in transition. For most of these patients, the transition was temporary, lasting several weeks but for others it continues to remain difficult months later. As the following quote shows, the well-formed habits are ingrained into patients' body and mind, making them hard to break and reverse:

'I mean it's totally different, because before, when I was on dialysis, I couldn't drink hardly at all 'cause I didn't go to the bathroom. So now that I go to the bathroom ... I'm still not drinking like I [used to] 'cause I'm still thinking about dialysis. I can't drink because dialysis has got me all worried ... And there's just some days I don't even worry about it and I just drink as much as I can, so ... I don't know. It's hard to explain. ... 'Cause the fluid doesn't come off, and then now that I don't have to go to dialysis ... my body's still, like, 'Whoa, slow down on your fluids,' 'cause half of it says, 'Drink,' and the other half says, 'Don't drink,' 'cause you're not supposed to yet— which I am supposed to drink. So ... my body's still getting used to it.' (#12301, 35-year-old white male)

Not feeling thirsty: Many patients reported not feeling thirsty ($n = 14$). One patient's comment about not being thirsty reveals how the patient–doctor relationship is laden with communication problems that compound barriers to fluid adherence:

'Actually I'm less thirsty than I was initially when I had the operation. [EG: So would you say that applies?] Yeah, I'd say that kind of applies to trying to get that 2.5 liters a day. 'Cause I'm not as thirsty as I was before. And they told me to drink when I'm thirsty. Before they told me to drink— just keep drinking, basically. Try to get a lot of fluids in you. But they said, no, don't force it. So, I'm not really forcing it at this point. And it's kind of hard to track that 2.5 liters if I'm not really forcing myself to get that much fluid in me.' (#12298, 54-year-old white male)

As this statement shows, the patient is relying on the healthcare professional's directive as to when to drink—when thirsty. However, the directive is out of touch with the patient's experience as the patient does not feel thirsty.

Discomfort with feeling full/less hungry: Patients reported discomfort and being tired of feeling full from drinking so much fluid ($n = 18$) or feeling less hungry ($n = 6$). Feeling full of fluid makes it harder to drink even more, as one patient described:

'I'm still probably not drinking quite as much as I should, but making that switch from eating ice all day to gulping water all the time is kind of a big jump and it fills your stomach up and then you don't eat. But I definitely am getting better at it. I'm drinking more and more.' (#10033, 42-year-old white female)

Frequency of urination: Patients reported that drinking so much resulted in them having to urinate frequently throughout the day and night ($n = 7$). Some patients bemoaned that drinking 3 L interferes with their ability to sleep because they wake up multiple times during the night to urinate.

Small digestive organs: A few kidney recipients attributed their difficulty with drinking the required fluid amount to having small digestive organs, including stomach, kidney and bladder ($n = 3$).

(B) Situational Factors—Patients reported experiencing day-to-day circumstances that made it harder to adhere to their fluid requirements, including sleeping in, being out of the house or in a car and being too busy to remember. For example:

'Sometimes if I sleep later, it's harder to get the fluids in, because I don't get as early of a start. ... Yeah. I notice if I sleep later then I seem to be down by a couple hundred cc's. Once I get back to work that won't happen.' (#12304, 52-year-old white female)

For some patients, being outside of the house or in a car or at work challenged their ability to stay hydrated for different reasons ($n = 5$). First, they had less access to fluids, second, they were more likely to go off of their routine and third, they were concerned about having to urinate without easy access to a toilet. Patients' statements attesting to these points are as follows:

'Well, when I'm out away from the house driving then I might not drink as much 'cause my bladder's not that strong and I don't want to have to rush to find a bathroom, or if I'm driving in the car and have a problem. So I try to drink mostly when I'm at home.' (#12284, 39-year-old white male)

Patients reported other barriers such as not having access to clean water at a play-ground fountain or having to boil well water at home ($n = 3$). Patients reported that they forgot to drink or were late in their scheduled time to drink because they became busy or engaged in an activity at home or at work ($n = 4$).

ENGAGING IN PHYSICAL ACTIVITY

Practice Levels and Recollections of Recommendations

Ten percent of patients engaged in regular physical activity, while another 10% engaged in moderate but not enough physical activity and 78% were sedentary.

Kidney recipients received a range of exercise recommendations that spanned from none to the Surgeon General's recommendations.²⁸ However, patients reported that clinicians did not specify the amount of exercise ($n = 32$) and twelve reported that transplant clinicians said nothing about exercise to them or to not exercise in order to recover. For example:

'They really didn't tell me about doing an exercise regimen, so I can't say what I'm not doing.' (#10036, 68-year-old white male)

Others reported that clinicians told them to stay active and move around, but did not specify either the kind of exercise they should do or how much they should do ($n = 19$).

'He said do as much as I feel I can do. Don't overdo it. Don't lift anything over ten pounds. Don't do any situps and stuff like that. 'Cause that's what I asked him "When can I start doing some sit-ups?" You know, get my gut. But what else? Basically, a lot of walking, you know.' (#10028, 36-year-old African American female)

Few patients reported receiving exercise recommendations from the transplant team consistent with the Surgeon General's recommendations about exercise ($n = 11$). Three of these cases gave time frames slightly different than the Surgeon General's recommendations. Two patients reported learning about exercise recommendations from their patient manual.

Attitudes about Exercising

Patients' attitudes about exercising ranged from positive to negative to frustrated. Most patients recognized that exercise is healthy for the body ($n = 10$), reported feeling better after exercise ($n = 4$) or were generally favourable towards it ($n = 50$). This group reported that they used to be physically active and wanted to get back into exercise, as the following quote illustrates:

'I wanna get into exercise. I mean, I used to be very active, so I'm trying to work myself up to what I used to do.' (#12313, 46-year-old white female)

Relatively few patients reported disliking exercise or had no discipline for it ($n = 7$).

'How do I feel about it? I feel about it like watching grass grow. Does that tell you? Bo-ring ... But do I know I need to do it to maintain a proper lifestyle? Absolutely, so I'm gonna make myself do it. But I'd much rather go watch grass grow, that's not how much I want to do it.' (#12324, 51-year-old white male)

Some patients who were highly active prior to the transplant expressed frustration about having to limit their post-transplant exercise routines ($n = 5$). They preferred to have an individualized regimen suitable to their own level of fitness rather than a generic regimen applied to everyone. The following quote illustrates this:

'It ought to be based upon the individual rather than applying the same standards to every patient. I mean, you got a real cross-section here in society with some 70, 80 year-old people that haven't exercised in 40 years. And, like I said, I was exercising 6 days a week. I'm relatively young for a transplant patient. ... I'm not saying I should be exercising 6 days a week, that's definitely too extreme, but I think, a more reasonable idea of what I can and can't do should be looked at. ...' (#12285, 43-year-old white male)

Strategies for Engaging in Physical Activity

Because participants were still recovering from the transplant and were told to be generally active, they were not engaging in rigorous physical activity. Nonetheless, patients developed several strategies to ensure they stayed active, including doing house chores and moving around at home ($n = 18$), going out of the house (i.e. walking at the mall, walking the dog) ($n = 18$), setting a routine for exercise ($n = 12$), exercising with someone or receiving encouragement to exercise ($n = 7$), exercising on the job ($n = 7$), going to the gym ($n = 5$) and making a point of exercising ($n = 5$). These strategies are exemplified in the following quote:

'Right. In general, I am a very active person. Even around the house, I do cleaning, cooking, running to the store and here and there. I never try to park my car next to the store—far away, so this helps.' (#10018, 66-year-old white female)

Barriers to Physical Activity

Based on the closed-ended question about barriers to exercise, the three leading barriers to exercising were: being too sick to exercise (40%), lack of motivation (39%) and bad weather, (32%), as is listed in Table 2. A few patients reported having no barrier to undertaking physical activity ($n = 8$).

Responses to the open-ended question revealed three types of barriers that prevented patients from undertaking physical activity: (A) physical, (B) psychological and (C) external factors. These barriers confirmed the quantitative responses noted above and provide broader insights into their experience.

(A) Physical Factors—Patients reported physical health concerns that hinder their ability to exercise, including: experiencing physical pain ($n = 20$), feeling tired ($n = 4$) and having an open incision ($n = 5$). As one patient stated:

'He said I can ride on the bike, different things like that. But all I've been doing right now because I still have the pain there and it still kinda gets tight like a ball on my side. Basically what I've started to do is walk around the house several times. Maybe three, four times a day. And like I said, I get up and try to do little things to get exercise- do housework a little bit, taking it slow. I do so much and if I feel tired or it starts hurting or something, I sit down and rest. I'm working my way into it.' (#10012, 44-year-old African American female)

(B) Psychological Factors—Psychological barriers to exercising include having little motivation for doing exercise, i.e. being lazy ($n = 11$), not feeling confident to exercise due to health limits ($n = 4$) and being afraid of hurting oneself from exercise ($n = 4$). One patient explained how fear of getting hurt prevented her from exercising:

‘No. I think it’s just fear. Like, just that I’m gonna pull something. Because I’m cautious. You know, like, I just don’t want to pull my leg or twist something, you know what I mean? It’s just, like, I’m not sitting on the floor doing any kind of exercises because I don’t want to hurt myself. And I know walking is safe.’
(#12296, 47-year-old white female)

(C) External Factors—External factors pertain to conditions beyond the patients’ control. Patients reported bad weather ($n = 16$), not having enough time to exercise ($n = 3$), having to avoid being in direct sunlight given high risk of skin cancer when taking immunosuppressants ($n = 1$) and not having a safe place to exercise nearby ($n = 1$). A few patients ($n = 2$) reported they were not exercising because the transplant team did not tell them to do exercise or give them specific recommendations about how much exercise to do.

MAINTAINING A LOW-SALT DIET

Attitudes About Maintaining a Low-salt Diet

Some patients reported positive attitudes about maintaining a low salt-diet ($n = 9$). Many had been following a low-salt diet for a long time so they were already used to it; continuing to do so was not considered a problem ($n = 30$). For example:

‘I knew while I was on dialysis that you can’t eat any salt. I made everything without salt. I am accustomed to that.’ (#10036, 68-year-old white male)

Others reported they did not crave or like salt, so they did not use it ($n = 11$). Some knew that salt was not good for the body or kidney, or that a low-salt diet prevented other problems, which helped them not use it ($n = 11$). In contrast, a minority of patients found the low-salt diet difficult to maintain because the habit was difficult to change ($n = 3$), foods have high salt content ($n = 3$) or they liked salt ($n = 3$). For example:

‘Right now it’s pretty tough. I don’t use the salt shaker or anything. But a lot of foods already have a lot of salt in them. I try to buy, like, low salt products, which unfortunately there’s not that many on the market.’ (#12298, 54-year-old white male)

Strategies used to Maintain a Low-salt Diet

Kidney recipients devised strategies to ensure that they did not consume too much salt by: not adding salt to food ($n = 40$), reading labels for sodium content ($n = 19$), limiting their intake of salt ($n = 14$), buying low-salt foods ($n = 10$), not buying processed or frozen foods ($n = 10$), not eating food that has salt in it or watching what they ate ($n = 9$) and rinsing canned goods to reduce salt levels ($n = 2$). Some used food preparation techniques to reduce salt content including using herbs to help flavour foods, using sea salt, which has lower levels of sodium, and eating salty foods infrequently as a treat ($n = 13$). One patient’s comment illustrates these strategies:

‘I avoid the salt shaker. I try to read labels in the store to see what’s low on sodium. I don’t like canned vegetables, I like frozen. Because canned vegetables are really high in salt. (#12307, 54-year-old white female)

Barriers to Maintaining a Low-salt Diet

Sixty-seven (82%) patients reported barriers to maintaining a low-salt diet, including personal, situation and external factors.

(A) Personal Factors—Personal factors pertain to individual dispositions that make adherence to a low-salt diet difficult, including having preferences for salty foods, i.e. pickles, popcorn and enjoying the taste of salt ($n = 9$). One patient conveyed this point well:

‘Barriers? Yeah, I mean it’s good. Salt tastes good. You know, I mean, it seasons and it gives flavor. I mean, I’m not naïve to believe that it doesn’t. I wish there was a substitute for (unclear) but it gives flavor and- especially if you can’t get out to the store.’ (#10028, 36-year-old African American female)

(B) External Factors—External factors are those beyond an individual’s control and commonly found throughout society, including the lack of available low-salt dishes at restaurants ($n = 10$) or low-salt foods in markets ($n = 3$), and when other people cook using salt ($n = 3$). Additionally, canned foods, vegetables and lunch meats have high salt content ($n = 3$). One patient commented on these factors:

‘I think that one of the problems is there’s not really a lot of low salt products on the market. I try to buy, like, low salt whenever I can. I like ham, so I try to buy—they do have low salt ham out there. I think that’s probably the biggest barrier, is trying to find products that are low salt. Sometimes I eat, like, TV dinners, you know, I don’t really have a lot of time to cook a meal. Unfortunately, I know they’re not very good for you either. ... But I haven’t really used the salt shaker in—probably, 10, 15 years.’ (#12298, 54-year-old white male)

(C) Lifestyle Factors—Lifestyle factors were the least commonly mentioned theme ($n = 5$) and pertain to aspects of patients’ everyday lives that are difficult for individuals to predict or manage, such as having no time to cook and eating prepared, high-salt meals instead.

MAINTAINING A LOW-CHOLESTEROL DIET

Attitudes About Maintaining a Low-cholesterol Diet

Several patients ($n = 20$) were favourable about maintaining a low-cholesterol diet. Some of these patients stated that following a low-cholesterol diet was beneficial in preventing further problems from developing (e.g. high blood pressure, cardiac problems) ($n = 9$). As one patient stated,

‘Well, it’s very essential because of the heart. I don’t want to have ... I had a heart triple bypass and I don’t want to go through that again. It’s <chuckles> an experience’ (#10049, 74-year-old Hispanic male).

Many patients were neutral and worked hard to follow directives ($n = 12$). Several patients ($n = 12$) reported negative attitudes about maintaining a low-cholesterol diet. These patients stated that a low-cholesterol diet was more difficult to maintain than a low-salt diet because loved foods were no longer allowable. For example:

‘It’s harder than the salt. Because so many things I like have fat in them. So I have a harder time with that than with the salt.’ (#12292, 52-year-old white male)

Confusion about physician directives contributed to inappropriate self-care. Some patients indicated that they were not following a low-cholesterol diet because they were already

taking cholesterol-lowering medications and/or their physicians did not tell them to maintain a low-cholesterol diet ($n = 4$). As one patient stated:

‘As far as the diet, they really didn’t give me too much of a restriction. They just gave me the medicine.’ (#12319, 50-year-old white male).

Several patients expressed confusion about the cause of cholesterol and why their cholesterol levels fluctuate, as follows:

‘No [I’m not maintaining a low-cholesterol diet.]. They told me my cholesterol was high. Let me tell you something. It wasn’t Dr. X. ... She [the doctor] told me high cholesterol does not come from foods you eat. She said it comes from medications that you take. Now, that’s what she told me at my last visit. I always thought it came from food, but is that true or what? I mean, I’d like to know. I [was] always told it came from food.’ (#10038, 50-year-old African American male)

Others reported being used to maintaining a low-cholesterol diet from before the transplant ($n = 3$).

Strategies used to Maintain a Low-cholesterol Diet

Patients reported four key strategies for maintaining a low cholesterol diet: (A) decreasing their intake of high cholesterol foods ($n = 38$), (B) watching their diet in general ($n = 36$), (C) increasing their intake of healthy foods and cholesterol-lowering foods ($n = 33$) and (D) monitoring food portion sizes ($n = 15$).

(A) Decreasing Cholesterol Intake—Patients reduced their intake of high cholesterol foods by not purchasing, cooking and eating high-cholesterol foods including meat, eggs, butter, fried foods, baked sweets, oil, fat, pizza, chicken skin, sugar and baked goods ($n = 31$). Additionally, some of these and other patients avoided buying high-cholesterol and pre-packaged foods from the supermarket ($n = 7$). One patient’s statement represents these strategies well:

‘I restrict the amount of meat that I eat. I do not eat the skin off of the chicken. I eat turkey. I do not eat eggs. I really watch my food ... I eat a lot of vegetables and stay away from any kind of Polish sausage even though I really like them but now I have to watch out for it.’ (#10027, 53-year-old white female)

(B) Monitoring Diet—Patients watched their diet in general. Many did so by monitoring their cholesterol intake when cooking and eating out ($n = 15$). Patients ensured that they ate low-cholesterol foods by cooking food themselves or by their spouse ($n = 5$). They prepared foods by cooking with olive oil or canola oil ($n = 6$), substituting another product for butter ($n = 3$), broiling or grilling rather than frying food ($n = 2$) and boiling fatty meat ($n = 1$). Many relied on reading food labels to monitor their intake ($n = 11$). As one patient stated, “I watch as much as possible the content of the food. Like I say, you read labels. That’s the only help you can get.” (#10049). Further, patients avoided eating at restaurants which tend to cook with high fat and high salt ($n = 5$). Only two patients explicitly mentioned exercise as a way to ensure that they maintain a low-cholesterol diet.

(C) Increasing Intake of Healthy Foods—Patients increased their intake of healthy or ‘natural’ foods ($n = 17$). Patients also reported eating chicken, turkey or fish instead of red meat, limiting the intake of red meat, or eating lean meat ($n = 14$), cutting fat off meat ($n = 5$) and eating fewer eggs or eggs without the yolk ($n = 8$).

(D) Monitoring Portion Size—Patients reported eating smaller portions of fattening foods, i.e. steak, lunch meats and cheese ($n = 10$), and eating sweets or fatty meats less frequently or in moderation ($n = 6$). For example, one patient stated how he loves cheese but used this method to both meet his craving and maintain a low cholesterol diet:

‘Try to stay away from all (unclear) the bologna, the hams, the cheese. As much as possible. I still eat cheese, but instead of eating a (unclear) cheese, I’ll buy, like, a gouda cheese, which is a lot better, and a lot tastier, and you don’t have to eat as much. You can’t eat as much. Or at least you don’t eat as much as the ... American cheeses, which are just pressed fat. The better cheeses, they have better flavors, and you eat less.’ (#12280, 54-year-old white male)

Barriers to Maintaining a Low-cholesterol Diet

Sixty-eight (83%) patients reported barriers to maintaining a low-cholesterol diet, including (A) personal, (B) situational and (C) structural barriers.

(A) Personal Factors—Personal factors include negative attitudes about having to eat low-fat foods (described above), difficulty not eating the foods patients love ($n = 17$) and freedom from dietary restrictions ($n = 2$). An example of patients’ frustration with having to avoid loved foods follows:

‘Well, it’s not as easy as the no salt, but ... it’s doable. Just pay attention to all the fatty stuff. ... ‘Cause salt I can do without, but there’s stuff that are high cholesterol that are very good to eat. ... I’d say, like, a good steak. Seafood, I love seafood. Lobster. I mean all that stuff. And then some— the snack foods. You know, potato chips, dip, brownies that my wife keeps making.’ (#12282, 41-year-old white male)

(B) Situational Factors—Situational factors are contextual factors directly related to transplant management that contribute to difficulties maintaining a low-cholesterol diet, including taking immunosuppressants which substantially increase cholesterol level ($n = 7$) and recuperating at home where a lot of fatty food is available ($n = 3$).

(C) Structural Factors—Structural factors pertain to societal-based contextual factors unrelated to the transplant that serve as barriers to maintaining a low-cholesterol diet, including the unavailability of low fat foods, the lack of food labels, eating at restaurants ($n = 10$). The following quote illustrates problems with accessing low-cholesterol foods:

‘Well, one barrier is that here at work ... Unfortunately, the cafeteria has this ... thing here where you go serve yourself and it’s all high fat. I mean, it’s really bad. But I try to avoid that and eat, you know, go for a sandwich. ... I don’t know how people don’t even complain about it, but it’s really like all high fat stuff.’ (#12318, 41-year-old Hispanic male)

DISCUSSION

To our knowledge, this is the first study that examines strategies and barriers to fluid intake, exercise, and dietary self-care among kidney transplant recipients. We found that most patients are not appropriately engaging in self-care practices. Only a third (33%) of the patients were adherent to the fluid requirements and 22% were engaging in moderate to regular physical activity. This represents a gap between actual and recommended self-care behaviours and highlights the need to improve self-care practices in this population.

The qualitative data revealed newly identified barriers and innovative strategies to engaging in self-care activities. Patients struggled with making the transition from drinking limited

amounts while on dialysis to ingesting large amounts of fluid with the transplant and identified problems with access to low-salt and low-cholesterol foods. We found that on average, patients experiencing a difficult transition in fluid intake spent longer periods on dialysis compared with the rest of the sample. It may be that the longer the time on dialysis, the more difficult the transition. We also found barriers to exercise that were unique to the transplant context, i.e. fears of hurting the graft incision. This latter finding on the concern over physical activity exacerbating existing chronic conditions has been reported for other chronic conditions.^{5,11} Common barriers across self-care practices include: difficulty remembering to practice self-care; bodily conditions that make self-care practice difficult, e.g. lack of thirst or sickness; financial access problems, e.g. unavailability of funds to purchase fluids or to join a gym; and environmental access problems, e.g. unavailability of low-salt or low-cholesterol foods or places to exercise. Identifying common barriers across self-care practices is valuable for informing interventions that can address many barriers using simpler strategies.

We found inconsistency in patients' reports of clinicians' self-care directives for fluid intake or physical activity, and appropriate foods for maintaining a low-salt or low-cholesterol diet. Other research corroborates our findings. Glasgow *et al.* noted that less than one-third of US adults in a national survey reported receiving physician advice to increase their level of physical activity and less than half of these received a specific activity plan or follow-up care.²⁹ Our findings on self-care communication by physicians are also similar to those by Arar *et al.*, who reported that patient-provider communications about self-care in primary care outpatient encounters in the Veterans Healthcare system focused primarily on medication use (100%), physical distress (76%) and disease symptoms (76%).³⁰ Less frequently discussed were self-monitoring activities (62%), exercise (60%) and diet (46%).³⁰

Poor patient recall and/or inconsistency in transplant clinicians' directives about self-care may have undermined patients' efforts to achieve appropriate self-care goals. It should be noted that poor recall may have contributed to inconsistent reporting of clinician directives. The fact that patients expressed no, or confusing, clinicians' recommendations pertaining to self-care suggests the need for greater clarity in clinician communication or patient education about self-care. Other research supports our findings in that inadequate communication with providers and lack of knowledge about treatment were identified as barriers to optimal self-care.¹¹

We recommend that transplant clinicians improve communication about self-care and help patients to overcome barriers to self-care. Several of the creative methods reported for maintaining appropriate self-care may be helpful, including providing kidney recipients with kits containing fluid jugs with ounces printed on them, pedometers to foster attentiveness to exercise and education materials that directly address the misperceptions identified in this study.

As institutions seek to reduce transplant-related costs, there may be disincentives to reviewing self-care practices with patients because of the increased time needed³¹ or the costs associated with providing self-care aids listed above. However, studies of the Chronic Care Model suggest that institutional efforts to promote self-care result in improved health outcomes.³² Changes to the organization of care, such as physical activity programs and educational support systems that support patients in managing their chronic illness are necessary quality care measures.³³ Although these suggested changes may increase costs in the short-term, they can decrease long-term costs due to improved health.³⁴ As well, improved health outcomes of transplant recipients can help secure transplant centre accreditation with Centers for Medicare and Medicaid Services.

Future research is needed to devise interventions to increase fluid intake and physical activity levels. While few interventions have been devised to improve physical activity of kidney transplant recipients,^{35,36} none has been devised to increase fluid intake. Future research should also examine whether kidney recipients' self-care practices change over time, as has been found among patients with arthritis.³⁷ It is possible that fluid intake levels decrease as patients become less adherent to physicians' recommendations, as occurs with medication taking.³⁸

The present study has several limitations. First, the recruitment rate of 57% may have resulted in a biased sample. That the sample was relatively highly educated may be a vestige of characteristics of patients willing to participate in the study. It is also possible that the recruitment rate may be related to poor health, which may be correlated with poorer adherence to recommended self-care behaviours. As a multi-site study conducted in the Midwest and Northeast, the findings may not be generalizable to other geographic areas in the US. However, no significant differences in adherence levels were found between the two regions. Third, we relied on patients' self-report and did not independently validate their actual self-care practices or clinicians' recommendations. Research shows that patients recall 80% of lifestyle recommendations for diabetes care,³⁹ suggesting that kidney recipients' recollections may not be spurious. The accuracy of kidney recipients' recall of clinician medication and lifestyle recommendations remains to be determined. Patients' estimates of fluid intake are likely relatively accurate, given they are required to track the millilitres of fluid they drink and void for the first 2 weeks post-transplant. Fourth, we recognize that the absence of data on patients' practices of maintaining a low-salt and low-cholesterol data is a limitation preventing comparison across self-care practices.

CONCLUSIONS

Few kidney transplant recipients practiced optimal self-care for exercise or fluid intake. Most patients encountered barriers to adequate self-care that should be ameliorated to assist patients in managing their transplant. Notably, many patients were unclear what the recommendations were and patient education tended to follow a 'one-size fits all' format. This study highlights the importance of listening to patients describe behaviours in their own voices in order to understand their needs. Through qualitative research, we can better identify and devise strategies to overcome barriers and inform educational interventions that enhance self-care in the future.

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TABLE 1

Characteristics of study participants ($n = 82$)

Variable	N (%)
Demographics	
Age, Mean (SD), (Range) (years)	47.3 (12.3) (18–74)
18–48	44 (53.7)
49–74	38 (46.3)
Sex	
Female	35 (42.7)
Male	47 (57.3)
Ethnicity/Race	
White	56 (68.3)
African American	15 (18.3)
Hispanic/Other	11 (13.4)
Marital status	
Married	52 (63.4)
Not married	30 (36.6)
Education, Mean (SD) (Range) (years) ^a	14 (3.33) (6–27)
High School	31 (37.8)
High School Grad/GED	50 (61.0)
Gross Household income ^a	
< \$14,999–\$29,999	21 (25.6)
\$30,000–\$59,999	22 (26.8)
\$60,000+	32 (13.4)
Primary insurer ^a	
Private insurance	42 (51.9)
Medicare/Medicaid	39 (48.1)
Health status	
Cause of ESRD ^b	
Diabetes	7 (8.5)
Hypertension	20 (24.4)
Glomerulonephritis	18 (22.0)
Other	37 (45.1)
Organ donor source	
Deceased donor	46 (56.1)
Living donor	36 (43.9)
Number of transplants	
1	65 (79.3)
2+	17 (20.7)
Time on dialysis, Mean (SD) (Range) (months) ^c	29.5 (30.07) (0.25–150)

Variable	N (%)
Self-rated health	
Excellent	13 (16.0)
Very good	30 (37.0)
Good	28 (34.6)
Fair	9 (11.1)
Poor	1 (1.2)
Fluid intake ^a	
Adherent	27 (33.0)
Non-adherent	53 (65.0)
PASE, Mean (SD) (Range) ^a	74.4 (64.87) (0–367)
Sedentary	63 (78.0)
Moderate, but not enough	9 (11.0)
Regular physical activity	9 (11.0)

^aTotal *n* does not add up to 82 because participant(s) did not know or disclose information;

^bESRD = end-stage renal disease;

^cOnly 66 of 82 patients were on dialysis prior to the transplant. The mean and SD do not account for those with pre-emptive transplants.

TABLE 2

Barriers to fluid intake and exercise*

Fluid intake barriers	N	%	Exercise barriers	N	%
Not being thirsty	31/82	38	Being too sick	31/78	40
Not remembering to drink fluids	17/82	21	Lack of motivation	30/78	39
Not having the fluids you like available	8/82	10	Bad weather	25/78	32
Not getting access to stores to buy fluids	7/82	9	Dislike exercise	20/78	26
Not having enough money to buy the fluids you like	4/81	5	Lack of time	12/78	15
			Cost too much to join a gym	13/77	17
			No transportation to a gym	7/77	9
			No place close by to exercise	6/78	8
			Not remembering	10/79	13

* Only patients who experienced listed barriers were included in the frequencies. Those who did not experience the barrier were not counted.