






ORIGINAL ARTICLE

Patient-led identification and prioritization of exercise interventions for fatigue on dialysis: a workshop report

Angela Ju^{1,2}, Nicole Scholes-Robertson^{1,2}, David W. Johnson^{3,4,5}, Yeoungjee Cho^{3,4,5}, Anita van Zwieten ^{1,2}, Karine Manera^{1,2}, Martin Howell ^{1,2}, Andrea K. Viecelli^{3,5}, Shilpanjali Jesudason⁶, Nicole Evangelidis^{1,2}, Kevan Polkinghorne⁷, Talia Gutman ^{1,2}, Kate Wyburn⁸, Jonathan C. Craig^{2,9} and Allison Tong^{1,2}, for the M-FIT workshop investigators*

¹Sydney School of Public Health, University of Sydney, Sydney, NSW, Australia, ²Centre for Kidney Research, Children's Hospital at Westmead, Sydney, NSW, Australia, ³Department of Nephrology, Princess Alexandra Hospital, Brisbane, QLD, Australia, ⁴Australasian Kidney Trials Network, University of Queensland, Brisbane, QLD, Australia, ⁵Translational Research Institute, Brisbane, QLD, Australia, ⁶Faculty of Health and Medical Sciences, University of Adelaide, Adelaide, SA, Australia, ⁷Faculty of Medicine, Nursing and Health Sciences, Monash University, Melbourne, VIC, Australia, ⁸Department of Transplantation, Royal Prince Alfred Hospital and University of Sydney, Sydney, NSW, Australia and ⁹Colleges of Medicine and Public Health, Flinders University, Adelaide, SA, Australia

Correspondence to: Angela Ju; E-mail: angela.ju@sydney.edu.au; Twitter handle: @allisontong1

*A complete list of 'Mobile exercise App to improve Fatigue In patients on dialysis: an adaptive trial (M-FIT) Workshop' investigators is provided in the Acknowledgements.

ABSTRACT

Background. Fatigue is one of the most important symptoms among patients receiving dialysis and is nominated as a core outcome to be reported in all clinical trials in this setting. However, few trials of interventions targeting fatigue have been conducted. Patients historically have rarely been involved in the design of interventions, which can limit acceptability and uptake. When asked, they have indicated a preference for lifestyle interventions, such as exercise, to improve fatigue. While some research has focussed on intradialytic exercise for patients receiving haemodialysis, patients have also indicated a preference for a convenient method of exercising with guidance, but on their own time outside of dialysis hours. In response to this, a mobile phone application was proposed as the method of delivery for a home-based exercise intervention targeting fatigue.

Methods. We convened a workshop with five breakout group sessions in Australia, with 24 patients on dialysis (16 haemodialysis and 8 peritoneal dialysis) and 8 caregivers to identify, prioritize and discuss exercise interventions for fatigue in patients receiving dialysis and the delivery of this through a mobile application.

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Results. Of the 21 types of exercise identified, the top-ranked were walking outdoors, walking on a treadmill and cardio and resistance training. Six themes were identified: (i) 'an expectation of tangible gains from exercise', including strengthening and protecting against bodily deterioration related to dialysis; (ii) 'overcoming physical limitations', meaning that comorbidities, baseline fatigue and fluctuating health needed to be addressed to engage in exercise; (iii) 'fear of risks', which reinforced the importance of safety and compatibility of exercise with dialysis; (iv) 'realistic and achievable' exercise, which would ensure initial readiness for uptake; (v) 'enhancing motivation and interest', which expected to support sustained use of the exercise intervention and (vi) 'ensuring usability of the mobile application', which would require simplicity, convenience and comprehensibility.

Conclusion. Exercise interventions that are expected by patients to improve health outcomes and that are safe, realistic and easy to adopt may be more acceptable to patients on dialysis.

Keywords: clinical trials, dialysis, exercise, fatigue, patient perspectives

INTRODUCTION

Fatigue is one of the most debilitating symptoms in patients receiving dialysis [1–5] and ranked by patients on haemodialysis as a critically important outcome, even higher than death [1, 5]. The prevalence of fatigue ranges from 55% to 97% in adult patients on dialysis [6, 7] and is associated with increased mortality [8–10]. From the patient perspective, fatigue has a pervasive impact on their physical and social functioning [11]. Low levels of physical activity on dialysis can aggravate health issues and lead to physical disability, frailty and impaired quality of life [12]. Although the exact causes of fatigue are uncertain, it is likely to be multifactorial and thus a range of interventions may be considered [6, 13]. Despite such importance, the evidence to inform the management of fatigue in patients on dialysis remains very limited.

Patients on dialysis have consistently identified lifestyle interventions to improve symptoms, such as fatigue, as a top research priority [14, 15]. Furthermore, patients who feel in control or are involved in managing their symptoms also experience better health outcomes [16–18]. There is some evidence that regular exercise improves cardiovascular outcomes, physical functioning and quality of life in adults with kidney disease, including patients on dialysis [19].

The majority of the existing literature on exercise focuses on intradialytic exercises where patients participate in exercise programmes during dialysis [20, 21], however, patients on dialysis also have a preference for home-based exercise programmes [22]. In the recent Standardized Outcomes in Nephrology Haemodialysis (SONG-HD) workshop on fatigue, patients reported that exercise outside of dialysis hours, such as walking and team sports, improved fatigue and enabled them to better engage in activities and gain a sense of control over their condition [23].

There is increasing recognition that patient involvement across the full research cycle, from priority setting to implementation, strengthens participant recruitment, retention and acceptance and improves the quality and relevance of findings [24–26]. However, patients are seldom involved in the choice and design of interventions [27], which can limit the use and impact of the interventions assessed in trials. This report summarizes the discussions from a workshop with patients and their caregivers on dialysis that aimed to identify, prioritize and determine an exercise intervention to improve fatigue in patients receiving dialysis to inform a clinical trial of a mobile exercise application.

Context and scope

In response to the demand for exercise interventions that are easy, free and convenient, a group of nephrologists, exercise

physiologists, physiotherapists, researchers and patients came together to examine the types of interventions and modes of delivery most suitable to address fatigue in the dialysis population. The current literature demonstrates inconclusive evidence for any one type of exercise as most beneficial for fatigue in patients receiving dialysis. The workshop was conducted as preliminary work for the Mobile exercise app to improve Fatigue In patients on dialysis: an adaptive Trial (M-FIT). There is mixed evidence regarding the types of exercise that are perceived to be effective and preferred by patients [27–30]. Therefore we aimed to identify patient priorities regarding the types of exercise in which patients would like to engage. Several exercise types chosen by patients in this workshop will be examined in M-FIT for effectiveness.

In response to a call for exercise that offers the flexibility of location and time, a mobile application was chosen as the mode of delivery. Over the past decade there has been substantial growth in the body of evidence indicating the effectiveness of mobile health technology solutions in the management of chronic conditions [31, 32]. While the evidence remains unclear in some conditions due to a lack of high-quality, adequately powered trials, mobile applications are a powerful tool that can enable a convenient, acceptable and feasible method of delivering health interventions [33, 34]. Technical app features such as reminder messages and tracking may also be helpful in facilitating behaviour change [35].

We convened the workshop in a hotel meeting room in Sydney, NSW, Australia, in November 2018.

MATERIALS AND METHODS

Twenty-four patients on dialysis (16 haemodialysis and 8 peritoneal dialysis) and eight caregivers from four states across Australia (Victoria, Queensland, New South Wales and South Australia) attended the workshop. Invitations were sent to patients/caregivers by e-mail through the Better Evidence and Translation for chronic kidney disease, Kidney Health Australia and SONG networks. All attendees were involved as investigators. The full list of M-FIT workshop attendees and contributors is provided in the Acknowledgements.

The workshop programme is provided as [Supplementary data](#), Item S1. The workshop commenced with a presentation on the proposal for M-FIT, a summary of research on exercise in dialysis and a presentation by a patient on the experiences of doing exercise to manage fatigue. To facilitate discussion, the participants were also provided with a summary table of the evidence on exercise in patients receiving dialysis.

For the breakout discussions, participants were allocated to one of five groups of six to seven patients and caregivers. The groups were facilitated by research team members (A.J., A.T., A.V.Z., K.M. and M.H.) who were trained and experienced in qualitative research. All facilitators used a standardized run sheet to guide the discussion (Supplementary data, Item S2). The questions were developed based on a literature review about fatigue, exercise and mobile applications and discussion among the multidisciplinary investigator team.

Breakout session 1: Participants discussed their experiences of fatigue, exercise and mobile phone applications. They generated a list of types of exercise that they would consider acceptable for patients on dialysis and might be effective for reducing fatigue. They also discussed the reasons for their choices. After this session, the facilitators collated a list of different types of exercises that participants had generated.

Breakout session 2: Participants reviewed the collated list of exercise types. They were provided with three sticker dots of different colours to vote for the top three exercise types that they thought were acceptable, effective and important for inclusion in the M-FIT trial. Exercises with ranking '1' (most important) were given a weighting of 3 points, those ranking '2' were given 2 points and those ranking '3' were allocated 1 point. They discussed the reasons for their priorities. After the session, the scores for each exercise type were combined across the breakout groups and presented to all groups.

Breakout session 3: Participants reviewed the results of the voting exercise and discussed ways to optimize the delivery of these exercise interventions through a mobile phone application.

All discussions were audiotaped and transcribed verbatim. The transcripts were entered into Hyper RESEARCH version 3.0 (ResearchWare, Randolph, MA, USA) to facilitate coding and analysis of the data. All participants and contributors received a draft workshop report and were asked to provide feedback. Additional comments were integrated into the final report.

RESULTS

Rankings of exercise types

In total, 21 different types of exercises were generated. The top preferred exercises were walking in outdoor or natural settings (44 points), walking on a treadmill (21 points), mixed cardio and resistance exercise (13 points) and Pilates (11 points). Scores for each type of exercise are provided in Table 1.

Workshop discussions

We identified six main themes that reflected patients' and caregivers' experiences with and perspectives on exercise, including the reasons for their choice and prioritization of exercise types, and priorities for implementation. These were expecting tangible gains, overcoming physical limitations, fear of risks, being realistic and achievable, enhancing motivation and interest and ensuring the usability of the mobile application. Illustrative quotations for each theme are presented in Table 2. The themes and respective subthemes are described below. Table 3 outlines the recommendations for developing and implementing exercise programmes in patients on dialysis.

Table 1. Prioritization of the types of exercise interventions

Exercise	n ^a	Points ^b
Walking—outside (shops, parks, etc.)	15	44
Walking—inside (treadmill)	9	21
Mixed cardio/resistance exercise (lunges, star jumps, body-bearing exercises, resistance bands and squats)	7	13
Pilates	4	11
Cycling—stationary (gym bike)	4	10
Cycling—outdoors	3	7
Aqua-aerobics	3	7
Gardening	4	6
Stretching	3	5
Yoga	4	5
Deep breathing	3	5
Swimming (for HD)	2	4
Weights	2	4
Tai chi	2	4
Zumba	1	2
Meditation	1	2
Musical instrument	3	1
Child-minding	0	–
Progressive muscle relaxation	0	–
Dancing	0	–
Running	0	–

^aNumber of participants who voted for the exercise.

^bPoints calculated by adding the votes with their weighting where 1 = 3 points, 2 = 2 points and 3 = 1 point.

Expecting tangible gains

Strengthening and protecting against physical deconditioning from end-stage kidney disease. Patients and caregivers believed that exercise would slow or prevent bodily deterioration due to dialysis and end-stage kidney disease. Some patients reported that exercise enabled them to counteract the deleterious effects of dialysis on muscle mass and maintain their strength. Others also noted that exercise could prevent falls by improving strength and balance.

Pushing beyond the barriers of dialysis. Some patients were motivated to exercise to improve their health and physical activity, but this would require them to overcome health problems associated with dialysis that serve as limitations to exercise. They explained that 'you need to push yourself a little bit more to get that little more fitter'. However, others were concerned that 'pushing too hard' until the 'point of no return' would aggravate their health.

Eligibility and resilience for transplantation. Some patients stated that exercise was important to improve their fitness and to reduce their weight so they would be eligible for deceased or living kidney donor transplantation. One patient was motivated to exercise after being told by a nephrologist—'you have to lose five kilos, otherwise we won't be able to do your transplant'. Thinking ahead, patients were determined to maintain strength and health enough to prevent deterioration even after their transplant because 'life is dependent on it'.

Overcoming physical limitations

Managing disabling comorbidities. Some patients with comorbidities, including cardiovascular disease and neuropathy, were

Table 2. Illustrative quotations for themes identified in the workshop discussions

Themes	Quotations
Expecting tangible gains from exercise	<p>Strengthening and protecting against bodily deterioration from end-stage kidney disease</p> <ul style="list-style-type: none"> • Exercising [major] muscles should help with fatigue, I think. Because you've got walking for your heart, but if you do these other types... it helps with your balance too.—P1 • It's exercising my muscles... muscles in the shoulder to treat my bad shoulder.—P1 <p>Pushing beyond the limits of dialysis</p> <ul style="list-style-type: none"> • Because anybody who exercises, you need to push, but you need to push with safety.—P1 • You want to push yourself, but also you don't want to... you've got to find a balance.—P2 <p>Eligibility and resilience for transplantation</p> <ul style="list-style-type: none"> • The doctor said, oh, you have to lose five kilos otherwise we won't be able to do your transplant.—P2 • I guess when your life's dependent on it because if they won't give you a transplant because you're not at a BMI.—P2
Overcoming physical limitations	<p>Managing disabling comorbidities</p> <ul style="list-style-type: none"> • The hip is fine, but now I have issues with my knees.—P2 • Except that my bones are giving way, my bones are creaky. I don't know what's causing that with the bones. It started here, now all the joints, the pelvis.—P2 • Every time I go in I ask them, regarding fatigue, I just ask the people who are doing the operation to put me back to an 18-year-old when I come out but it hasn't happened.—P3 <p>Combating debilitating baseline fatigue</p> <ul style="list-style-type: none"> • I now am tired all the time and I mean all the time.—P2 • By the time I get home at night [after work], I'm so tired. During winter, as soon as I get home, I just go to bed. I don't have any energy to do anything.—P2 • It's a vicious cycle because fatigue itself, or being tired, even when there's a glimmer of time, you might not be feeling up to exercising.—P4 • That negotiation, because you might already be tired.—P4 • I talked to my doctor and said this is not me, this is not what's happening. He says well, that's renal failure.—P2 <p>Fluctuating health constraining activity</p> <p>Part of it is rating how you felt on that day too. Some days I could do 20 000 steps no worries, and other days 5 is really tough.—P2</p> <p>Building confidence in exercise</p> <ul style="list-style-type: none"> • My head gets confused, they say this muscle and I think, how do I control that muscle?—P1 • Even if you needed some guidance to say okay, I'm here at the gym, I'm motivated enough, now I need to do this, there's no one who's specialised and understands our condition enough.—P4
Fear of risks	<p>Aggravating health</p> <ul style="list-style-type: none"> • Yeah, considering the age group, a lot of people can get frozen shoulders and they have to be very careful.—C1 • I used to do [7 km walks] but now I'm scared to go on my own... because once you start, you don't know if you're going to be able to come back. So that's the thing, how far do I go? Do I go, hit the wall, and then... what do I do? How do I get back?—P4 • Am I damaging myself by going on? I feel like I'm going to do some damage to myself because I'm just so exhausted with it.—P4 • Even if you're motivated enough, there is the uncertainty of how far do I push myself.—P4 <p>Uncertainty about the compatibility of exercise with dialysis</p> <ul style="list-style-type: none"> • The upper body stuff, that's the stuff I shy away from because I'm not sure of the risks or the damage I might do to the fistula.—P1 • Mainly the tubes, because the tubes move at a different angle. Even over the arm of the chair, the machine goes off.—P2 • But [my partner] relaxes when [they are] on the machine, so we're talking about trying to work out an exercise plan while you're on the machine, and I'm just thinking okay, [they] just shook a blanket and [the tubes] came out.—C2
Realistic and achievable	<p>Affordable and feasible</p> <ul style="list-style-type: none"> • Lovely to say I'd love to go dancing, but if you're going to damage yourself, no, it's not really practical.—P1 • Swimming, something I can do with my son again that doesn't require a lot of supervision, I guess. They're easy, cheap, and accessible for me.—P2 • There are no barriers as far as time is concerned, as far as resources are concerned, walking is very cheap.—P2 • Everyone is telling me to go for a walk. My kidney doctor, my diabetes doctor, cardiologist.—P1 • One of our doctors gives out a leaflet... but are we going to then? Are we going to do them?—P1 <p>Flexibility around the dialysis schedule</p> <ul style="list-style-type: none"> • The other thing too is with haemodialysis, I mentioned earlier, I've got that five-hour period afterwards where I can't do a thing. Effectively I'm only looking at alternate days anyway.—P3 • I prefer to... be active during the day, and then get on dialysis. The next day, after dialysis, I wake up and I feel fine normally. But if I do dialysis in the morning, I know I'm a write-off for the rest of the day.—P4 • You can't do a lot movement-wise [while on dialysis].—P4

(continued)

Table 2. Continued

Themes	Quotations
Enhancing motivation and interest	<ul style="list-style-type: none"> • The thing is if you're feeling well enough, you do do a bit extra.—P5
	Tailoring to individual capacity
	<ul style="list-style-type: none"> • There's a lot of little things that you could put in that some person could do and another person can't do.—P1 • Push within your limits, not someone's perceived.—P1 • [These exercises] Are for us, and then the others are what other people that we know would benefit from.—P5 • At different stages of our lives, meaning in another five years, I may not be able to walk on a treadmill or do cardio.—P5 • I've never been one to go to the gym to do exercise, if you're in that mode that's fine.—P5
	Finding incentives
	<ul style="list-style-type: none"> • Carrots and sticks, your wife nagging is a stick.—P1 • I spent that money on [a gym membership], I might as well use it.—P1 • Something that affects my motivation is sleep quality. . . if I have a really good night's sleep, that is a better day. Exercise in the morning happens automatically.—P4
	Battling boredom
	<ul style="list-style-type: none"> • An hour 4 days a week [of walking] is ridiculous for me. I just can't see it happening. Boredom sets in, there's got to be a reason [to move].—P3 • If it's just hard and fast one thing, I know I'd get bored witless.—P3 • We do have a treadmill set up the way you would set a treadmill up, with a TV in front of it. As I said, it's got to be the most boring thing in the world, a treadmill.—P3 • It's become boring, you know what I mean? It's the same walk.—P3
	Tracking progress
	You can actually see, I've got to do this and this, then as you're doing it you get that feedback of your progress.—P5
	Ensuring usability of the mobile application
<ul style="list-style-type: none"> • Whatever app. . . has got to be simple, it's got to be easy to see.—P1 • I like it simple. Something has to be simple and not too much, and not change a lot.—P2 • I will use the app if it's simple to use, simple, that's it.—P2 • Something where it's like dummy-proof.—P2 • Ease of use. Easy to understand, something that's quite simple. I think visuals are really good. . . visuals that you can play, something that's very step one, two, three. Something that tracks what you're doing.—P4 • [My partner's] parents are in their 80s. . . [mobile phones/technology] is so hard, isn't it. It's so foreign. I find it hard when things change.—P2 • I just like the convenience of them [apps], I'm able to do stuff that id onto have to go onto a computer and log onto the internet, log onto the laptop, set it up, plug it in, whatever. It's just easy, just on your phone, bang. It's so convenient.—P2 	
Informative and comprehensible	
<ul style="list-style-type: none"> • Sometimes you look at things and you go oh, it's a stagnant picture with a description, and I'm like, what am I supposed to do?—P2 • I'm motivated by someone guiding you and showing you, even. . . YouTube.—P5 • I think having videos is a thing. . . [videos in the app] is probably a really good option.—P2 • Virtually showing everybody what the physio does to you. That would be an ideal thing as far as I'm concerned. . . having an app showing you exactly what you should do.—P1 	

conscious of their limited capacity to exercise. The severe symptoms and complications associated with these comorbidities and kidney disease, such as pain, unstable blood pressure, cramps and muscle atrophy, were identified as major barriers to exercise—'that's the problem, because I go [walking] and my heart [rate] can go up very high all of a sudden'.

Combating debilitating baseline fatigue. Participants described having to endure extremely debilitating fatigue on a daily basis, which prevented them from doing exercise. For some, it was a 'negotiation battle with your mind', in which they forced themselves to push past the fatigue in order to exercise. It was seen as 'a vicious cycle' in that fatigue prevented them from exercising, but the physical inactivity also worsened their fatigue.

Fluctuating health constraining activity. Patients explained that the instability of their health, attributed to kidney disease and dialysis, was a deterrent to exercise. Their capacity for exercise

was 'very up and down' because their health was unpredictable—'some days I can do twenty thousand steps no worries, and other days five is really tough'. Some did not feel like they were seeing any 'appreciable improvements' in their health even with exercise, as the fluctuations were too severe.

Building confidence in exercise. Patients believed they would be more willing to exercise if they were better informed about how and what to do at home or at the gym. Patients were unsure about whom to ask for help, and there was limited guidance from their healthcare professionals, as they were told to 'just do exercise'. Consequently, patients felt unable to exercise safely and effectively on their own.

Fear of health risks

Aggravating health problems. Due to the uncertainties around their own health and limitations, patients were afraid of

Table 3. Summary of recommendations to consider in developing exercise interventions for patients on dialysis

Implications for exercise interventions in dialysis

- Provide the option for patients to choose when to participate in exercise (during or outside of dialysis sessions)
- Address dialysis-related fatigue
- Provide options for exercise that are feasible for patients with comorbidities
- Explain the potential benefits and risks associated with the exercise, and address concerns about safety
- Ensure the exercise is compatible with dialysis (e.g. minimal risk to the fistula)
- Ensure that exercises are interesting and feasible
- Highlight the potential benefits of exercise that may be particularly important and relevant to patients on dialysis (e.g. to be eligible and maintain fitness for transplant, to protect against deterioration due to dialysis)

inadvertently worsening their condition by doing exercise. They were concerned about safety and remained apprehensive about exercise, as they were unsure about when their 'body's just going to turn around and say no'. Even with simple exercises, such as walking, some patients were unsure if they were 'going to be able to come back' to where they had started.

Uncertainty about the compatibility of exercise with dialysis. Some patients felt they lacked knowledge about the type, duration and intensity of exercise that would be suitable given their physical limitations related to being on dialysis. Some were interested in resistance training using light weights, but some were concerned about the possible effects it may have on aspects of their dialysis treatment: 'I've got the question mark of how does [exercise] impact your fistula'. Those who were on peritoneal dialysis were concerned more specifically about affecting their bags. Patients appreciated the option to exercise outside of their dialysis sessions because they had concerns about moving while being 'hooked up' to the dialysis machine and instigating cannulation and catheter complications.

Realistic and achievable

Affordable and feasible. Patients and caregivers indicated that exercise needed to be affordable in terms of cost and time. Feasibility was crucial in ensuring that the patients were willing and able to participate. Some patients expressed preferences for types of exercise, such as walking outside, because they were free. Others preferred swimming, as it was something they could do with their children without having to find a babysitter.

Flexibility around the dialysis schedule. Having the exercises on a mobile phone application meant that patients could choose the day, time and location of their exercise. Patients believed this would improve flexibility around their dialysis days and allow them to exercise more frequently throughout the week as they were able to choose a time during which they were less fatigued.

Tailoring to individual capacity. Patients emphasized the importance of having options to increase or decrease the level of intensity and explained that patients receiving dialysis had different levels of fitness and capacity for exercise. Patients wanted to be able to make incremental progress at their own

pace, taking into consideration their baseline fatigue, health status and overall well-being.

Enhancing motivation and interest

Finding incentives. Patients emphasized the need to find motivation and reasons to start and continue exercise to obtain long-term benefits for their health. Some mentioned that when they paid for a gym membership, it motivated them to use the facilities. Others were driven by their desire to stay healthy for their children and grandchildren. Social motivation, such as walking with friends and being able to see each other's progress were also suggested to encourage patients receiving dialysis to exercise.

Battling boredom. Some patients preferred varying exercise routines over repetitive movements, as participants noted that exercise could get tedious, and maintaining interest was critical for sustained and long-term use. Some patients had tried different ways to entertain themselves, such as installing a television in front of their treadmill, playing different music or going to a different park every week.

Tracking progress. Participants suggested that the mobile application should include a feature that allows them to track their own progress. This feature would allow them to feel a sense of accomplishment because 'you can see you're getting fitter'. They believed it would keep them accountable because they would be able to see their progress or lack thereof, since it 'is just there, you can't get around it'.

Ensuring usability of the mobile application

Simple and convenient to use. For some patients, the discussion about the mobile applications raised concerns for those who were not familiar with the technology. To ensure usability across all levels of technology users, patients emphasized the need for a simple, 'dummy-proof' app that could be navigated with minimal clicks.

Informative and comprehensible. Patients preferred to have both videos and a written explanation for each type of exercise. It was critical for the videos to be easy to follow with minimal supervision. With each video, patients believed it would be helpful to have a written explanation of the muscle groups involved and an outline of the benefits that patients can expect from doing that particular exercise. One patient said that this would be 'a good idea... because nine times out of ten, I don't know why I'm doing [the exercise]. I just do what I'm told'.

DISCUSSION

Patients and caregivers regarded exercise as necessary and beneficial to reduce their fatigue, protect against deterioration related to kidney disease and dialysis, access transplantation and maintain their health for their family. They recognized the value in exercises such as weight training and walking in improving their fatigue. However, major barriers to uptake and sustained exercise included lack of guidance and confidence in exercise, being without time and energy to exercise because of their dialysis schedule, limitations due to physical comorbidities and fear of unknown risks that may aggravate their health condition. Walking (in outdoor or natural settings) was the most preferred type of exercise, as it is free and easy for patients

to do on their own terms. However, other exercise types, such as resistance training and Pilates, also had a high priority due to the protective benefits against falls and weak muscles. A mobile application with simple instructions and user-friendly interface was perceived to be an acceptable and feasible mode of delivery.

Many important features of mobile applications were raised during the workshop, which was considered crucial to optimize the mode of delivery. Patients and caregivers noted that they varied in terms of the level and type of technology that they felt confident in using. Thus a user-friendly interface that requires minimal navigation was deemed critical to ensure that the interventions were accessible for everyone. They suggested that exercise videos and text should be easy to follow. A feature that allows one to keep track of his/her own and/or others' progress was suggested as a means to keep patients motivated in using the intervention.

Patients in studies conducted in other chronic conditions have also identified physical limitations and uncertainty about how to exercise as barriers to exercise [36, 37]. However, patients in our workshop articulated additional and specific concerns about the suitability of exercise related to their dialysis treatment. Patients wanted to know about exercises that they could do without causing harm to their fistula and peritoneal dialysis bags. It is well known that being aware of the benefits of exercise can motivate patients to engage with exercise [36, 37]. In this workshop, patients also mentioned that they were interested in exercise to improve quality of life, reduce fatigue and combat further deterioration caused by kidney disease and treatment, as well as to be eligible for a kidney transplant and maximize post-transplant outcomes. Dialysis-related fatigue and was noted as a 'paradoxical' barrier to exercise for patients on dialysis, in that it prohibited patients from doing exercise, which further exacerbated their fatigue.

Most trials of exercise interventions in patients receiving dialysis have been conducted in the haemodialysis population with a focus on intradialytic exercise programmes [20, 21]. In trials, intradialytic programmes have better adherence and lower dropout rates compared with exercise programmes that are implemented between dialysis sessions [38, 39], as it is easier to track adherence to the exercise interventions. However, during dialysis may not necessarily be a time that patients want to exercise. Some patients in this workshop preferred interdialytic exercises, for reasons including the need to rest while dialysing and concerns about the harms of being active while on dialysis. Further evidence is needed to determine the effectiveness of more flexible exercise programmes that patients prefer and to address potential challenges of adherence to exercise programmes that are not supervised. Having a flexible and convenient self-administered programme would allow them to decide where and when they want to exercise. Furthermore, providing a mechanism to monitor individual progress by giving patients flexibility to choose when to exercise and at what intensity according to their level of fitness will help to ensure they are not overwhelmed by the physical requirements of exercise. This highlights the need to involve patients in designing interventions to ensure they meet their individual needs. A summary of suggestions for developing exercise interventions identified from the workshop is provided in Table 3.

There is recognition that patients should be involved across the stages of research from priority-setting through to implementation [40], but examples of patient involvement in the identification, prioritization, selection and design of interventions are limited [41]. The discussion and ranking of exercise

interventions and their optimal delivery from this workshop will directly inform the design of the interventions for the M-FIT trial. A multidisciplinary team of exercise physiologists, physiotherapists, nephrologists, researchers, information technology experts and patient partners will design the intervention (a range of different types of exercise), which will be embedded into a mobile application. The final set of exercises to be embedded into the mobile application will be reviewed and checked by exercise physiologists to ensure safety. We acknowledge that patients who were non-English speaking or with severe mobility limitations or cognitive impairment were not able to attend the workshop. Thus, to ensure maximum usability for a wide range of patients, we will seek feedback from patients of diverse backgrounds through focus groups and a pilot trial to assess its feasibility in a trial setting. Assessing interventions prioritized by patients is likely to help maximize the impact of the intervention by improving its acceptability, feasibility and sustainability.

We involved patients as named investigators in this workshop and for this reason we did not collect demographic characteristics from the attendees. While we can confirm that attendees were different ages and genders, received different dialysis modalities (HD and PD) and provided a broad range and breadth of perspectives, we are unable to provide specific demographic data. Thus the transferability of the findings to other patient populations may be difficult to ascertain. We also recognize that patients who attended the workshop may preclude those who have mobility limitations, severe cognitive impairment or are unable to participate in exercise.

CONCLUSION

Patients on dialysis have interest and motivation in being physically active to combat dialysis-related fatigue and protect against further bodily deterioration. However, they experience many barriers to exercise, including baseline fatigue, comorbidities, fear of uncertainties and risks and lack of time. These factors need to be considered in identifying and developing exercise interventions to help maximize acceptability, uptake and sustainability, which in turn may help to enhance overall patient outcomes.

SUPPLEMENTARY DATA

Supplementary data are available at [ckj online](http://ckj.online).

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CONFLICT OF INTEREST STATEMENT

None declared.

The M-FIT workshop investigators:

First name	Last name	Affiliation (organization/institute) ^a	Country
Allison	Tong	University of Sydney	Australia
Amelie	Bernier-Jean	University of Sydney	Australia
Andrea	Viecelli	University of Queensland	Australia
Angela	Charalambous	-	-
Angela	Ju	University of Sydney	Australia
Anita	van Zwieten	University of Sydney	Australia
Barrymore	Beach	-	-
Bernard	Larkin	-	-
Carmel	Hawley	University of Queensland	Australia
Carol	Beach	-	-
Cornish	Clive	-	-
Danilo	Dingle	-	-
Danny	Thomas	-	-
David	Blake	-	-
David	Johnson	University of Queensland	Australia
Deane	Baker	-	Australia
Debbie	Underwood	-	Australia
Dianne	McLaren	-	Australia
Faye	Demagante	-	Australia
Gaye	Jennings	-	Australia
Helen	Jeff	-	Australia
Irene	Mewburn	-	Australia
Jonathan	Craig	Flinders University	Australia
Joy	Wooldridge	-	Australia
Julianne	Ellis	-	Australia
Karine	Manera	University of Sydney	Australia
Kass	Widders	-	Australia
Kay	Young	-	Australia
Ken	McLaren	-	Australia
Ken	Yew	-	Australia
Kevan	Polkinghorne	Monash University	Australia
Martin	Howell	University of Sydney	Australia
Melinda	Ellis	-	Australia
Michelle	Blake	-	Australia
Neil	Boudville	-	Australia
Neil	Scholes-Robertson	-	Australia
Nicki	Scholes-Robertson	University of Sydney	Australia
Nicole	Evangelidis	University of Sydney	Australia
Paul	Grant	-	Australia
Paul	Kennedy	-	Australia
Pauline	Walter	-	Australia
Pauline	Yew	-	Australia
Raymond	Jeff	-	Australia
Shilpa	Jesudason	University of Adelaide	Australia
Talia	Gutman	University of Sydney	Australia
William	Wooldridge	-	Australia
Yeoungjee	Cho	University of Queensland	Australia

^aNo affiliation specified for patients/caregivers.

REFERENCES

1. Evangelidis N, Tong A, Manns B et al. Developing a set of core outcomes for trials in hemodialysis: an international Delphi survey. *Am J Kidney Dis* 2017; 70: 464–475
2. Manera KE, Johnson DW, Craig JC et al. Patient and caregiver priorities for outcomes in peritoneal dialysis: multinational nominal group technique study. *Clin J Am Soc Nephrol* 2019; 14: 74–83
3. Manera KE, Tong A, Craig JC et al. An international Delphi survey helped develop consensus-based core outcome domains for trials in peritoneal dialysis. *Kidney Int* 2019; 96: 699–710
4. Tong A, Manns B, Hemmelgarn B et al. Establishing core outcome domains in hemodialysis: report of the Standardized Outcomes in Nephrology–Hemodialysis (SONG-HD) consensus workshop. *Am J Kidney Dis* 2017; 69: 97–107
5. Urquhart-Secord R, Craig JC, Hemmelgarn B et al. Patient and caregiver priorities for outcomes in hemodialysis: an international nominal group technique study. *Am J Kidney Dis* 2016; 68: 444–454

6. Jhamb M, Weisbord SD, Steel JL et al. Fatigue in patients receiving maintenance dialysis: a review of definitions, measures, and contributing factors. *Am J Kidney Dis* 2008; 52: 353–365
7. Ossareh S, Roozbeh J, Krishnan M et al. Fatigue in chronic peritoneal dialysis patients. *Int Urol Nephrol* 2003; 35: 535–541
8. Bossola M, Di Stasio E, Antocicco M et al. Fatigue is associated with increased risk of mortality in patients on chronic hemodialysis. *Nephron* 2015; 130: 113–118
9. Jhamb M, Argyropoulos C, Steel JL et al. Correlates and outcomes of fatigue among incident dialysis patients. *Clin J Am Soc Nephrol* 2009; 4: 1779–1786
10. Jhamb M, Pike F, Ramer S et al. Impact of fatigue on outcomes in the Hemodialysis (HEMO) Study. *Am J Nephrol* 2011; 33: 515–523
11. Jacobson J, Ju A, Baumgart A et al. Patient perspectives on the meaning and impact of fatigue in hemodialysis: a systematic review and thematic analysis of qualitative studies. *Am J Kidney Dis* 2019; 74: 179–192
12. Bennett PN, Thompson S, Wilund KR. An introduction to exercise and physical activity in dialysis patients: preventing the unacceptable journey to physical dysfunction. *Semin Dial* 2019; 32: 281–282
13. Horigan AE. Fatigue in hemodialysis patients: a review of current knowledge. *J Pain Symptom Manage* 2012; 44: 715–724
14. Manns B, Hemmelgarn B, Lillie E et al. Setting research priorities for patients on or nearing dialysis. *Clin J Am Soc Nephrol* 2014; 9: 1813–1821
15. Tong A, Crowe S, Chando S et al. Research priorities in CKD: report of a national workshop conducted in Australia. *Am J Kidney Dis* 2015; 66: 212–222
16. Bodenheimer T, Lorig K, Holman H et al. Patient self-management of chronic disease in primary care. *J Am Med Assoc* 2002; 288: 2469–2475
17. Curtin RB, Mapes DL. Health care management strategies of long-term dialysis survivors. *Nephrol Nurs J* 2001; 28: 385–392 discussion 93–4
18. Shinkman R. Is “empowered dialysis” the key to better outcomes? 2018. <https://catalyst.nejm.org/empowered-self-dialysis-better-outcomes/> (1 June 2019, date last accessed)
19. Heiwe S, Jacobson SH. Exercise training for adults with chronic kidney disease. *Cochrane Database Syst Rev* 2011; 10: CD003236
20. Pu J, Jiang Z, Wu W et al. Efficacy and safety of intradialytic exercise in haemodialysis patients: a systematic review and meta-analysis. *BMJ Open* 2019; 9: e020633
21. Suhardjono UV, Umami V, Tedjasukmana D et al. The effect of intradialytic exercise twice a week on the physical capacity, inflammation, and nutritional status of dialysis patients: a randomized controlled trial. *Hemodial Int* 2019; 23: 486–493
22. Moorman D, Suri R, Hiremath S et al. Benefits and barriers to and desired outcomes with exercise in patients with ESKD. *Clin J Am Soc Nephrol* 2019; 14: 268–276
23. Ju A, Unruh M, Davison S et al. Establishing a core outcome measure for fatigue in patients on hemodialysis: a Standardized Outcomes in Nephrology–Hemodialysis (SONG-HD) consensus workshop report. *Am J Kidney Dis* 2018; 72: 104–112
24. US Food and Drug Administration. *Learn About Patient Engagement at the FDA*. 2018. <https://www.fda.gov/ForPatients/PatientEngagement/default.htm> (4 June 2018, date last accessed)
25. Lloyd J, McHugh C, Minton J et al. The impact of active stakeholder involvement on recruitment, retention and engagement of schools, children and their families in the cluster randomised controlled trial of the Healthy Lifestyles Programme (HeLP): a school-based intervention to prevent obesity. *Trials* 2017; 18: 378
26. Sacristán JA, Aguarón A, Avendaño-Solá C et al. Patient involvement in clinical research: why, when, and how. *Patient Prefer Adher* 2016; 10: 631–640
27. Carman KD, Maurer M, Sofaer S et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs* 2013; 32: 223–231
28. Afshar R, Shegarfy L, Shavandi N et al. Effects of aerobic exercise and resistance training on lipid profiles and inflammation status in patients on maintenance hemodialysis. *Indian J Nephrol* 2010; 20: 185–189
29. Scapini KB, Bohlke M, Moraes OA et al. Combined training is the most effective training modality to improve aerobic capacity and blood pressure control in people requiring haemodialysis for end-stage renal disease: systematic review and network meta-analysis. *J Physiother* 2019; 65: 4–15
30. Valenzuela PL, de Alba A, Pedrero-Chamizo R et al. Intradialytic exercise: one size doesn't fit all. *Front Physiol* 2018; 9: 844–844
31. Free C, Phillips G, Galli L et al. The effectiveness of mobile-health technology-based health behaviour change or disease management interventions for health care consumers: a systematic review. *PLoS Med* 2013; 10: e1001362
32. Hartin PJ, Nugent CD, McClean SI et al. The empowering role of mobile apps in behavior change interventions: the Gray Matters randomized controlled trial. *JMIR Mhealth Uhealth* 2016; 4: e93
33. Payne HE, Lister C, West JH et al. Behavioral functionality of mobile apps in health interventions: a systematic review of the literature. *JMIR Mhealth Uhealth* 2015; 3: e20
34. Stevenson JK, Campbell ZC, Webster AC et al. eHealth interventions for people with chronic kidney disease. *Cochrane Database Syst Rev* 2019; 8: 1465–1858
35. Schoeppe S, Alley S, Rebar AL et al. Apps to improve diet, physical activity and sedentary behaviour in children and adolescents: a review of quality, features and behaviour change techniques. *Int J Behav Nutr Phys Act* 2017; 14: 83
36. Bethancourt HJ, Rosenberg DE, Beatty T et al. Barriers to and facilitators of physical activity program use among older adults. *Clin Med Res* 2014; 12: 10–20
37. Clifford BK, Mizrahi D, Sandler CX et al. Barriers and facilitators of exercise experienced by cancer survivors: a mixed methods systematic review. *Support Care Cancer* 2018; 26: 685–700
38. Kouidi E, Grekas D, Deligiannis A et al. Outcomes of long-term exercise training in dialysis patients: comparison of two training programs. *Clin Nephrol* 2004; 61(Suppl 1): S31–S38
39. Nonoyama ML, Brooks D, Ponikvar A et al. Exercise program to enhance physical performance and quality of life of older hemodialysis patients: a feasibility study. *Int Urol Nephrol* 2010; 42: 1125–1130
40. Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence. *Lancet* 2009; 374: 86–89
41. Bridgelal Ram M, Grocott PR, Weir HC. Issues and challenges of involving users in medical device development. *Health Expect* 2008; 11: 63–71