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Author

Hickman, Ingrid J, Coran, Donna, Wallen, Matthew P, Kelly, Jaimon, Barnett, Amandine, Gallegos, Danielle, Jarrett, Maree, Mccoy, Simone M, Campbell, Katrina L, Macdonald, Graeme A

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ORIGINAL RESEARCH

‘Back to Life’—Using knowledge exchange processes to enhance lifestyle interventions for liver transplant recipients: A qualitative study

Ingrid J. HICKMAN ^{1,2,7} Donna CORAN,³ Matthew P. WALLEN,⁴ Jaimon KELLY,⁵ Amandine BARNETT,⁵ Danielle GALLEGOS,³ Maree JARRETT,⁶ Simone M. MCCOY,¹ Katrina L. CAMPBELL^{1,5} and Graeme A. MACDONALD^{6,7,8}

Departments of ¹Nutrition and Dietetics, ⁶Queensland Liver Transplant Service and ⁸Hepatology and Gastroenterology, Princess Alexandra Hospital, ²Mater Research Institute, ⁴School of Human Movement and Nutrition Sciences and ⁷Faculty of Medicine, University of Queensland and ³School of Exercise and Nutrition Sciences, Queensland University of Technology, Brisbane and ⁵Faculty of Health Sciences and Medicine, Bond University, Gold Coast, Queensland, Australia

Abstract

Aim: Interventions to prevent excessive weight gain after liver transplant are needed. The purpose of the present study was to enhance a specialist post-transplant well-being program through knowledge exchange with end-users.

Methods: The study used an interactive process of knowledge exchange between researchers, clinicians and health system users. Data were collected as focus groups or telephone interviews and underwent applied thematic analysis.

Results: There were 28 participants (age 24–68 years; 64% male). The results identified experiences that may influence decisions around health behaviours during the course of transplant recovery. Three over-arching themes were identified that impact on liver transplant recipients post-transplant health behaviours. These include (i) *Finding a coping mechanism* which highlighted the need to acknowledge the significant emotional burden of transplant prior to addressing long-term physical wellness; (ii) *Back to Life* encompassing the desire to return to employment and prioritise family, while co-ordinating the burden of ongoing medical monitoring and self-management and (iii) *Tailored, Personalised Care* with a preference for health care delivery by transplant specialists via a range of flexible eHealth modalities.

Conclusions: This person-centred process of knowledge exchange incorporated experiences of recipients into service design and identified life priorities most likely to influence health behaviours post-transplant. Patient co-creation of services has the potential to improve the integration of knowledge into health systems and future directions will require evaluation of effectiveness and sustainability of patient-centred multidisciplinary service development.

Key words: focus groups, health service design, liver disease, obesity, patient engagement, quality of life.

I.J. Hickman, PhD, AdvAPD, Principal Research Fellow
D. Coran, BHSc (Nutr&Diet), APD, Dietitian
M.P. Wallen, PhD, Exercise Physiologist
J. Kelly, PhD, APD, Dietitian
A. Barnett, BHSc (Nutr&Diet), APD, Dietitian
D. Gallegos, PhD, AdvAPD, Professor
M. Jarrett, RN, Nurse Practitioner
S.M. McCoy, APD, Dietitian
K.L. Campbell, PhD, AdvAPD, Principal Research Fellow and Associate Professor
G.A. Macdonald, MBBS, PhD, Senior Staff Specialist Liver Transplant, Gastroenterologist

Correspondence: I.J. Hickman, Department of Nutrition and Dietetics, Princess Alexandra Hospital, Ground Floor, Building 15, Ipswich Road, Woolloongabba, QLD 4102, Australia. Tel.: +61 7 3176 5588. Email: i.hickman@uq.edu.au

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Introduction

Rapid weight gain after liver transplant is a worldwide phenomenon with 16–46% of liver transplant recipients (LTRs) becoming obese in the first year after transplant.^{1–8} There is a higher prevalence of metabolic syndrome in LTRs compared with the general adult population and this appears to predispose to increasing cardiovascular disease risk, graft rejection, infection and other complications.⁹

Adjusting to a liver transplant is a complex process which incorporates both physical and mental components of recovery. LTRs endure significant physical and psychological stress awaiting surgery¹⁰ and group-based psycho-educational strategies appear effective at improving coping strategies and social support pre-transplant.¹¹ There is, however, a paucity of data addressing how best to deliver diet and exercise prescription for post-transplant recovery

and how lifestyle interventions may prevent obesity and cardiometabolic complications post-liver transplant. The development of targeted lifestyle interventions to prevent excessive weight gain and manage cardiovascular risk requires a process of knowledge exchange between service providers and patients, in order to meet the unique needs and life priorities of this cohort.

The purpose of the present study was to use a process of knowledge exchange to involve knowledge users in research and explore the everyday experience of LTRs to co-create a specialist health and well-being program aimed at reducing cardio-metabolic risk factors post-transplant. The study aimed to engage with LTRs to define life needs and priorities, and capture the emergence of factors that influence health behaviours across the spectrum of pre- and post-liver transplant health services.

Methods

A stakeholder group of five liver transplant specialists, including physicians, nutrition and exercise experts from a single Australian transplant centre (40–55 transplants per year) developed a framework of key factors (enablers and barriers) that could impact on the long-term health of LTR, which informed the development of the present study. In preparation for a process of knowledge exchange, for example, imparting meaningful knowledge between knowledge users (LTR) and producers (investigators and health practitioners), this framework drew from components of implementation science, such as level of evidence (determined by literature review), context of health service delivery system (determined by extensive clinical experience working within the system) and unique needs of LTR (determined by both published evidence and clinical experience).^{12–14} This framework was further refined with clinical consultation and reference to individual, institutional and systemic factors that impact on health behaviours including patient perceptions of weight gain and ‘healthy lifestyle’ post-transplant, life priorities, timing of service delivery and acceptance and feasibility of technology-assisted service models (Table S1). The framework then informed the development of semistructured interview questions designed to promote knowledge exchange and capture LTR live experience of transplant and perceptions of health priorities in relation to long-term well-being (Table S1). Data saturation determined when to cease recruitment and was defined as no new information being offered either through the knowledge exchange or prioritisation processes.

Interviews were conducted with LTRs through either focus groups or telephone interviews. Participants were offered opportunities to share experience and knowledge during early (within 6 months of transplant) and long-term (>6 months post-transplant) health service follow-up. Participants were asked to prioritise factors that they considered most influenced their health behaviours post-transplant.

The study was approved by the Metro South Hospital and Health Service Human Research Ethics Committee

(HREC/15/QPAH/804). All participants provided written informed consent (received by post for those undertaking telephone interviews).

The study population included adults who had undergone a liver transplant and had ongoing medical review as an outpatient of the service. Transplant registry lists were screened for eligibility with inclusion criteria of ≥ 18 years of age, undergone a liver transplant ≥ 12 months ago and English-speaking. Participants were opportunistically sampled to identify those already scheduled for outpatient visits during the recruitment period (January–June 2015), and purposively recruited to achieve broad demographic diversity including gender and geographical location. Eligible patients were not previously known to the investigators (although were known to the transplant clinic) and contacted via telephone, had the purpose of the study described and invited to participate in the study. Those who agreed to participate were scheduled for a face-to-face focus group (1–1.5 hours) or a telephone interview (30 minutes) based on their preference.

Four focus groups (total participants $n = 17$) were conducted by investigators DC (APD, female, research student) and IJH (PhD, research fellow, female, experienced researcher) over the study period and consisted of seven prepared questions. There were no non-participants present. Each group also developed a list of life priorities to identify the most important influencing factors in their lives at three different time-points across the transplant continuum: pre-transplant; early post-transplant (within 6 months); and ≥ 12 months post-transplant. Participants were encouraged as a group to name life priorities at each of the three time-points until no new priorities were identified. These were listed in order of mention on a whiteboard for all to see. When all participants had considered the group list, they were asked to anonymously write down the top five most relevant issues to them personally for each time-point, in order of priority for them as an individual. This could include priorities that had not been discussed by the group. The participant’s priority list was given to the investigator without sharing with the group.

All discussions were audio-recorded and transcribed for data analysis. Certificates of appreciation were presented to participants on completion.

The option of a telephone interview was offered to participants who could not attend face-to-face due to geographical distance or personal commitments and was chosen by 11 participants. The choice to use both focus groups and interviews in this way was to ensure broad participant diversity, and to offer opportunities to voice issues that the participants may have been uncomfortable to discuss in a group setting. Due to lack of group dynamics, the priority listing exercise was modified for individualised interviews.

Data analysis: Data were reported according to the COnsolidated criteria for REporting Qualitative research (COREQ).¹⁵ Interviews and focus groups continued until saturation of themes was reached. Audio-recorded data from focus groups and telephone interviews were transcribed

verbatim, and entered into NVivo11 (Qualitative Software for Research (QSR) International 2017). Applied thematic analysis was used as an exploratory approach to code broad emergent themes (DC).¹⁶ Subthemes that emerged were augmented using both an inductive approach (developed after consultative interpretation of the analysis) and a deductive approach (bound by the intent of informing the development of a health promotion program). Coding was cross-checked by secondary analysts (IH) and triangulated (DG) to validate interpretations and consistency. Illustrative quotes are from participants in focus groups (FG) and telephone interviews (TI) with multiple options proposed by analysts (DC and IH) and chosen with consensus by all authors.

The prioritisation exercise whereby patients listed their top five life priorities at pre- early post- and post-transplant was analysed using content analysis to determine the greatest frequency of stated life priorities clustered across the three pre-determined time-points.¹⁷ Similar meaning words were collapsed into themes and triangulated by an independent researcher. Frequency of word clusters were matched with identified themes to estimate when sub-themes were most likely to emerge or change over the course of recovery.

Results

Figure 1 illustrates the recruitment flow diagram with $n = 28$ agreeing to participate. Participants were 24–68 years old (mean: 53 ± 13 years) and 18 (64%) were male. Median time since most recent transplant was 4 years (range: 2–5 years). Both focus groups and telephone interviews consisted of participants from local, regional and interstate locations. Geographical residence of participants ranged from 13 (46%) being located within the tertiary hospital catchment area, 6 (21%) within 100 km of the hospital and 9 (33%) >100 km from the hospital. Average time

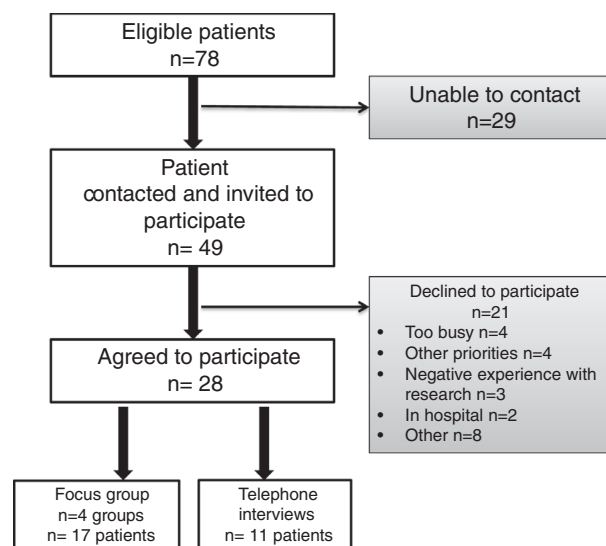


Figure 1 Study participant recruitment flow diagram.

for focus groups was 82 minutes (range: 70–90 minutes) and individual interviews was 27 minutes (range: 15–48 minutes).

Thematic analysis identified three over-arching themes and multiple subthemes (Figure 2). The timing of when each subtheme emerged across the transplant journey was estimated by matching with the frequency of life priorities listed by participants at each of the three pre-defined time-points and was determined by consensus among investigators (DC, IJH, DG and AB) (Figure 2).

Finding a coping mechanism

At every stage of transplant (from pre-surgery to many years post-transplant) participants stated that finding a way to cope emotionally and physically with the transplant experience was a high priority and infiltrated most decisions regarding health behaviours.

Facing an unknown future after near-death: The fear of an unknown future ruminated constantly prior to transplant and left a strong legacy of uncertainty well after transplant that continued to impact on future life plans.

‘The foremost thing was getting a transplant, but not knowing what was ahead of me though, so you don’t really know, it’s one of those things that you think... .. is it going to be good or is it going to be bad’ (TI, 16)
 ‘For me every blood test was Russian roulette... there was always someone who was in some degree of rejection... so every blood test was you know, is it my turn to find I’m in rejection. That was all the way through that first 12 months... that weighs very heavy on your mind... only stuff that sticks in your mind is the bad stuff all of a sudden when you’re lying in bed at 2 am’ (FG4, 32)

Emotional and psychological support networks: Participants expressed the need for emotional and psychological support networks to cope with feelings of guilt and uncertainty at all stages of transplant. Family and social influences could significantly impact adherence to health behaviours in either a positive or negative way depending on the degree of perceived emotional and psychological support received. A common topic that emerged was the importance placed on mentoring or peer support from other LTRs, in the form of social and emotional support.

‘People that had had transplants and they used to come up and give a talk too and they’d talk to you about um you know what they went through and how they handled it and you got to actually talk to them face to face and you could ask them whatever questions you wanted to... That’s the best way if there’s someone [another LTR] close that can organise to meet and just have a talk yeah that’s all they need, a bit of support’. (TI, 16)

However, participants also desired greater psychological support from the hospital clinic to develop coping strategies for stress and anxiety, which they perceived to impact on physical wellness even years after transplant.

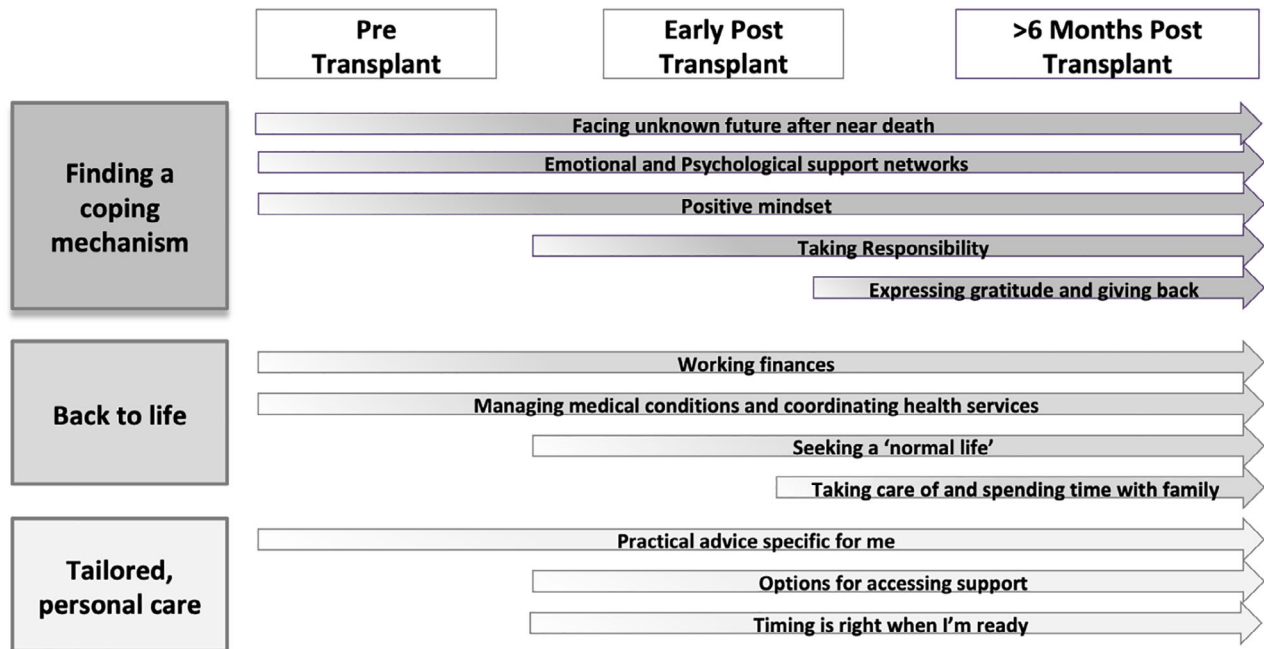


Figure 2 Three overarching themes with subthemes emerging across the liver transplant journey, which have potential to impact the design of diet and exercise wellness programs.

'The psychological aspect as well I'm a big advocate for that I don't think we do enough in that area as well simply because you know, the transplant friends I have, none of us have ever had any sort of support or anything like that. I think that it's a big factor that's sort of overlooked'. (FG, 31)

'So it was really, also the questions of how to actually maintain a balance in terms of your thinking, you're sort of in a healing process, yes the physical stuff but also your sort of spiritual healing shall we say'. (FG1, 3)

Keeping a positive mindset: Participants placed a high importance on optimism and maintaining a positive mindset as a strategy for coping before and after transplant.

'I've got a second chance. I've still got these underlying issues; I've really got to keep on top of it so you can't really do that unless you stay positive'. (FG, 10)

Expressing gratitude and giving back: After the early post-transplant recovery, participants had a strong emotional connection related to a deep gratitude for the 'gift of life' and expressed need to 'give back'. This was nuanced by personal expression that may have been inward looking such as motivation to look after the new liver through a healthy diet or outward looking such as adhering to prescribed hospital advice or offering reciprocal support for others.

'I'm guessing that most of us go through stages where we feel like you know why us, and you know we're like eternally grateful for what was sort of given to us so I started to think that what I could do to give something back you know... How could I show that I was just being grateful you know'. (TI, 12)

Taking responsibility: By later stages of recovery (>6 months post-transplant), participants predominantly wanted to take responsibility for their actions, and take ownership of their own health. This was a coping strategy that made them feel in control of their health.

'I think maybe just people having, needing, to take the responsibility themselves and owning what's going on in their life. You know what I mean you can have all these people tracking you and following you and advising you but if you don't take that responsibility and own it, it doesn't work'. (FG, 20)

Back to Life

Participants described a renewed outlook on life and expressed their desire to return to 'normality' and 'stability'. The word 'life' was used in the context of rebuilding life, getting back to 'normal' life, 'making the most of life' and social life. Seeking a 'normal life' included recovering physically and emotionally, gaining back independence and returning to their ordinary day-to-day activities and way of living.

Work and finances: Returning to employment post-transplant was of critical importance. It was a prominent thought well before transplant and greatly influenced the prioritisation of health behaviours that impact on employment or managing finances after transplant.

'It was just trying to get back to work yeah cos you know being sick and being away from work and being in hospital quite a lot yeah it puts quite a lot of pressure on the family for bills and stuff like that' (TI, 15)

Taking care of and spending time with family: Participants valued family and social connections, and expressed a desire to take care of and spend time with their family after transplant.

'Yeah it's the best thing that ever happened to me you know, one yes I'm still alive but the lifestyle choices that I've made now whereas before we were um driven by material things now we're not. It's more about family and lifestyle and you know doing what we actually enjoy rather than you know keeping up with the Jones's'. (FG, 31)

Managing medical conditions and coordinating health service interactions: From an early stage, participants placed a high priority on their long-term wellness and linked that to living a 'normal life'. The management of ongoing medical issues, medications and side effects was a significant burden for participants, and outside what most people would consider 'normal'. Participants accepted the need for regular follow-up post-transplant, however, expressed a desire for receiving care outside of the hospital/clinic environment. They wanted integration of a wider range of support services such as general practitioners, dietitians and exercise specialists into their post-transplant care schedule.

'Probably educate the GPs a little bit better... the regime as to what the recipient should be doing so that the GP becomes effectively a part of your team. On exactly the same wave length of what recipients should be doing as you. Even down to little things like the GP should be getting you to get your blood tests done, should know the frequency of that'. (TI, 8)

'A long-term issue for me to deal with is staying well in regards to having a to keep on top of all the other medical stuff that's going on as well'. (FG3, 20)

Hospitalisations and outpatient appointments are burdensome, and participants described eagerly anticipating a decrease in frequency of hospital appointments, which was a common metric that they used to gauge their progress.

'I started off like you monthly and then 3 monthly and then 6 monthly for a couple of years and now its yearly. Yeah its great it's a good feeling'. (FG, 20)

Tailored, Personalised Care

Participants acknowledged their uniqueness in the community due to their specific requirements relating to long-term health advice and diet and exercise information specific for LTR.

Practical advice specific for me: The need for diet and exercise advice to be tailored to the specific needs of liver transplantation and personalised to the individual's circumstances became evident throughout the data. Participants identified a wide variety of preferences for long-term health care and support but always with a focus on practical advice for approaches to diet and exercise.

'The information that they give you is just like, it needs to be more tailored to individuals... What information that suits one person probably doesn't suit everyone. It depends [on] the circumstances you had your transplant under'. (TI, 21)

Options for accessing support: Participants' preferences varied for how they thought diet and exercise support post-transplant should be provided. Some had a preference for group-based education; while others wanted one-on-one interactions with health professionals. Participants valued in-person interactions with health professionals and suggested video conferencing for LTR who are not located close to the hospital. There were contrasting views on engaging with technology for diet and exercise support with some LTRs open to innovative technologies, while others objected strongly to this strategy and would prefer telephone follow-up or written resources.

'I love the electronics but it's not the same as a personal discussion... You've got to use a whole range of things and you know... a website where some generic information goes and then there's more personalised one-on-one contact and whether that one-on-one is actually sitting here face to face or whether its though skype or something like that because of distance factors'. (FG, 13)

Timing is right when I'm ready: Preferences for the timing of receiving post-transplant diet and exercise education ranged considerably. Some participants emphasised the importance of receiving post-transplant diet and exercise information prior to transplantation, while most reported being best placed to receive support within 6 months of receiving their transplant. There was an agreement that if the presentation of a post-transplant well-being program is mistimed, unintended consequences could occur, with patients disregarding information or resenting health professionals.

'You need that [lifestyle related] info pretty much straight away after the transplant to get yourself on the right track. That first 12 months is a real transitional phase for you because you are going through all the healing and stuff. And you don't really have your head in the place of planning your new life. You have your head in getting through day to day whereas 12 months down the track your mindset has changed by then and you're starting to focus on what you are going to do with your new life.....' (TI, 8)

Based on a translation of the thematic analysis, key factors informing the development of a post-transplant well-being program are identified in Table 1. These include practical recommendations for clinicians to consider when implementing post-liver transplant health services.

Discussion

This qualitative study used a process of knowledge exchange between researchers, clinicians and health system

users and highlights the value of using implementation science for the design of new health services. It identified experiences that may influence decisions around health behaviours and informed elements of a post-transplant wellness program for LTR.

While quality of life improves after transplant, participants of the present study described ongoing issues associated with mental health and emotional resilience that may impact on health-related decision making.¹⁸ Unique emotional stressors such as survivor guilt and post-traumatic stress are recognised in organ transplant recipients.^{19–22} Study participants indicated that before they could address their diet and exercise needs, they needed better strategies to cope with the insecurity and uncertainty associated with survival; and also needed the physical and emotional resources to deal with their current medical issues. Regular exercise and improving diet quality are effective strategies for fostering good mental health and cognitive function after significant health events such as cardiac arrest.^{23–25} However, participants in the present study did not identify such health behaviours as coping mechanisms *per se*. This finding has significant implications for transplant services that may not typically offer psychological support or peer mentoring programs as standard care. The desire for professional emotional support emphasises the need for multi-disciplinary teams before and after transplant. The provision of group psychotherapy to patients awaiting liver transplant has uncovered some reluctance to engage with

these strategies but warrants further investigation due to the potential benefits such as reduced anxiety and sharing experiences with others.²⁶

Based on the responses from this cohort of LTRs it seems important at the outset of a health promotion program to formally recognise the emotional burden of receiving a transplant and the influence of post-traumatic growth on well-being and health behaviours post-transplant.²⁷ Incorporating LTR peers into the delivery of the program will offer another vehicle for emotional support and also serve as a mechanism to develop partnerships with knowledgeable users who acknowledge a responsibility to live a healthy life.^{19,28}

Participants placed a high priority on getting back to 'normal life' despite reconciling their reality that interacting with health services and self-monitoring will be a life-long burden that others do not bear. The importance of regaining independence, such as being able to drive and travel, and returning to work, are common themes post-organ transplant.²⁹ The experience of this cohort was that re-entering the workforce was a high priority, contributed to financial recovery, social functioning and establishing a work-life balance that reflects emerging wellness. These results can inform the structure of program delivery whereby the need for recipients to prioritise and balance work commitments with recommended health behaviours are acknowledged and accommodated.

Participants in the present study desired tailored, personalised health care, with practical guidance to help them self-manage diet and exercise. Rather than a lack of understanding around the benefits of exercise, participants expressed uncertainty around how best to commence strenuous physical activities due to feeling ill-equipped to judge the safety of exercise. Fear associated with physical capabilities post-transplant has been recognised in other organ transplant groups.²⁸ Guided, tailored prescription of exercise pre- and early post-transplant may overcome this barrier.

A tension exists between participants' preference to maintain relationships and monitoring by specialist health professionals with the desire for a life free from hospital appointments. While the LTRs wanted expert advice for key aspects of care such as emotional needs and exercise prescription, there was a commitment to take responsibility for the long-term self-management of their well-being. This paradox may be addressed with flexible telehealth access to specialist care within the context of predominantly home-based, self-directed support programs.

Considering the stated financial concerns of LTR, and the geographical dispersion of a state-wide transplant service; utilising telehealth platforms and technology to offer hospital-to-home group support for long-term health behaviour change may improve effectiveness and equitable access.^{30–33}

The present study highlighted the need for some degree of patient-led process for how and when post-transplant health services are engaged by LTR. Recipients desire an awareness of available resources at early stages of the transplant experience, however, the readiness to engage differs for each LTR. In

Table 1 Key insights from liver transplant recipients (LTRs) to inform the design of a post-transplant diet and exercise program

Key insights

- Consider the psychological and emotional health of the patient at entry to the program, and the influence of mental health status on decision-making related to health behaviours
 - Include mentoring and networking with other LTR to share experiences and facilitate group interactions with people at different stages of recovery
 - Potential recipients should be made aware of available post-transplant diet and exercise resources prior to transplant, but be able to choose when and how to engage with these resources
 - Service delivery options that include telehealth and video connections for face to face contact should be included, with flexible access times to suit employment and family commitments
 - Program to be delivered by health professionals with expertise in liver transplant
 - Program information to be pitched with positivity regarding maintaining health and well-being rather than reminding patients of links with illness and chronic disease
-

addition, it was identified that life priorities change over the course of recovery, which may impact on readiness to engage with wellness programs. There is likely to be greater uptake and effectiveness if the health system can support an inherently flexible user-led approach to uptake of service delivery and potentially screening LTR and their carers for readiness to engage may be worthwhile to improve uptake.

The results of the present study contribute to person-centred health care design by creating partnerships between researchers and the people for whom the research is ultimately meant to be of use.³⁴ This challenges assumptions of experts and values the consideration of LTR life priorities during the course of recovery.

The study has used robust qualitative methods to involve knowledge users in research. Many aspects of the present study decreased barriers to inclusion such as giving participants options for data collection methods (phone interviews or focus groups) including regional and metropolitan residents, and increased face validity by secondary analysts performing data triangulation. Question development involved a multidisciplinary team, which increased internal consistency. Due to the voluntary nature of the study, it is possible that the participants were over-represented by those who have had a positive transplant and/or healthcare experience. In addition, all participants were asked to recall their pre-transplant experiences and perceptions which may have been more than 12 months prior for some participants and introduces recall bias for pre- and early post-transplant time-points. The results are contextual to an Australian, English-speaking transplant population and may not be generalisable to other countries and cultures.

In conclusion, this interactive qualitative process of knowledge exchange focused on the experiences of LTRs and identified life priorities most likely to influence decision-making related to health behaviours post-transplant. Users' co-creation of services has the potential to improve the integration of knowledge into health systems and improve patient outcomes. The future direction of this patient engagement process will involve the implementation and evaluation of technology-assisted lifestyle intervention for LTRs.

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Conflict of interest

The authors declare no conflict of interest.

Authorship

All authors were involved in the project design. DC and IJH were responsible for data collection and interpretation, and manuscript development. All authors critically reviewed the manuscript prior to submission for publication. All authors are in agreement with the final manuscript and declare that the content has not been published elsewhere. The authors

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Supporting information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Table S1. Focus group questions.