1 *Liver Transplant Recipients' Experiences and Perspectives of a*
2 *Telehealth-delivered Lifestyle Program: A qualitative study*

3 **Amandine Barnett^{1,2}, Katrina L Campbell^{1,2,7}, Hannah L Mayr^{1,2}, Shelley E Keating³,**
4 **Graeme A Macdonald^{4,5,7}, Ingrid J Hickman^{1,6,7}**

5 ¹Department of Nutrition and Dietetics, Princess Alexandra Hospital, Brisbane, QLD, Australia

6 ²Bond University Nutrition and Dietetics Research Group, Faculty of Health Sciences and Medicine,
7 Bond University, Gold Coast, QLD, Australia

8 ³School of Human Movement and Nutrition Sciences, The University of Queensland, Brisbane,
9 QLD, Australia

10 ⁴Queensland Liver Transplant Service, Department of Hepatology and Gastroenterology, Princess
11 Alexandra Hospital, Brisbane, QLD, Australia

12 ⁵Department of Gastroenterology and Hepatology, Princess Alexandra Hospital, Brisbane, QLD,
13 Australia

14 ⁶Mater Research Institute, University of Queensland, Brisbane, QLD, Australia

15 ⁷Translational Research Institute, Brisbane, QLD, Australia

16

17

18 **Corresponding author:**

19 Ingrid J Hickman

20 Princess Alexandra Hospital, Ground floor, Building 15

21 Ipswich Road, Woolloongabba, QLD 4102, Australia,

22 +61 7 3176 5588, i.hickman@uq.edu.au

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ABSTRACT

Introduction: Dietary modification and exercise are encouraged to address cardiometabolic risk factors after solid organ transplantation including for liver transplant recipients (LTRs).

However, the lived experience of attempting positive lifestyle changes is not known. The aim of this study was to explore LTRs' experiences and perspectives of a 12-week telehealth lifestyle program and to assess feasibility of this innovative health service.

Methods: Focus groups and one-on-one interviews were conducted with participants who had completed a 12-week, group based, telehealth-delivered diet and exercise program and thematic qualitative analysis was used to code and theme the data.

Results: Nineteen LTRs participated in the study (25 to 68 years, median time since transplant 4.4 years, 63% male). Overarching themes included 1) *Broad telehealth advantages* which highlighted that telehealth reduced the perceived burdens of face-to-face care; 2) *Impact of employment* which identified employment as a competing priority and appeared to impact involvement with the program; 3) *Adapting Mediterranean eating pattern to meet individual needs* which identified the adaptability of the Mediterranean diet supported by sessions with the dietitian; 4) *Increasing exercise confidence* which recognised that a tailored approach facilitated confidence and acceptability of the exercise component of the program.

Discussion: A telehealth lifestyle program delivered by dietitians and exercise physiologists is an acceptable alternative to face-to-face care that can meet the needs of LTRs. There is a

need to further innovate and broaden the scope of routine service delivery beyond face to face consultations.

INTRODUCTION

Liver transplant recipients (LTRs) have an increased cardiometabolic risk, with more than 20% experiencing post-transplant metabolic syndrome,¹ reducing quality of life and long-term survival.^{2, 3} Excess weight gain is common within 12 months of surgery and recipients with obesity are at increased risk of morbidity from cardiovascular disease (CVD)^{4, 5} new onset type 2 diabetes after transplant (NODAT)⁶ and fatty liver disease.⁷

Although a paucity of literature exists on the diet and exercise behaviours of LTRs, there is some evidence to suggest that unhealthy eating patterns and poor exercise capacity may impact cardiometabolic risk in this patient group.^{8,9} Limited previous studies have investigated the effectiveness of diet and/or exercise interventions for LTRs. The Mediterranean eating pattern has strong evidence for being cardio-protective¹⁰ and has been shown to improve hepatic steatosis and insulin sensitivity in individuals with the metabolic syndrome and non-alcoholic fatty liver disease (a prevalent precursor for liver transplant).¹¹ Combined resistance and aerobic exercise training in LTRs improved aerobic capacity, maximal strength, and quality of life.³

Digital healthcare disruption offers a range of telehealth options to support specialist services to provide ongoing care remotely.^{12, 13} Whilst the use of telehealth is increasingly valued, there remain instances of poor adoption across the health system, with the success of implementing innovative telehealth strategies dependent on the acceptability to end-user.^{14, 15} Telehealth is an appealing strategy for state-wide liver transplant services, to cater for recipients who have been discharged from the hospital setting but require ongoing specialist

monitoring and support. Intensive, face-to-face lifestyle programs are burdensome for the LTR and their carer/s¹⁶ and telehealth has the potential to improve self-care management and offer a great level of engagement between the patient and the health service¹⁷ whilst overcoming geographical and financial barriers.

The aim of this study was to explore the end-user experiences and perspectives after completing a 12-week telehealth-delivered, videoconference, group lifestyle program for LTRs incorporating the Mediterranean eating pattern with aerobic and resistance exercise.

METHODS

Study design and setting

This qualitative evaluation was part of a larger study investigating the feasibility of a 12-week telehealth-delivered intervention, the LTR Initiative: a Feasibility study to Enhance cardiometabolic health (LIFE study; Australia and New Zealand Clinical Trials Registry: ACTRN12617001260314). The videoconference telehealth service model (two-way video portal) included weekly group contact alternating education on diet and physical activity prescription. A total of 14 offered telehealth appointment contacts which included 6 dietetic and 8 exercise sessions were delivered by dietitians (total dietitians n=3) and exercise physiologists (total exercise physiologists n=2), respectively. The dietary sessions supported the Mediterranean Diet (MedDiet) eating pattern of increased vegetables, fruit, extra virgin olive oil, legumes, fish, wholegrain breads and cereals, and nuts, and low consumption of red meat and processed foods. The exercise appointments involved facilitated exercise sessions and were designed to meet physical activity guidelines to support increased aerobic and resistance exercise capacity.¹⁸ A variety of video-enabled devices were supported for

participants to connect from their preferred location to a centralised health professional located at the specialist centre. The central telehealth portal was hosted by the tertiary health service which used CISCO Tanberg C20 devices to communicate via H.323 communication standards and encrypted with an AES-128 (Advanced Encryption Standard) encryption algorithm. The system is a secure platform, accessible by a private link provided by the researchers to the participants.

Experience, perspectives and program feasibility was assessed by exploring facilitators and burdens of end-users engaging with and adhering to the program; behaviour change as a result of the program; and understanding of the content and satisfaction. The study was reported using consolidated criteria for reporting qualitative research (COREQ).¹⁹

The study was conducted within the Queensland Liver Transplant Service (QLTS), Brisbane, Australia, and Metro South Hospital and Health Service's Human Research Ethics Committee approved the study (HREC/17/QPAH/208) with all participants having provided written informed consent.

Recruitment

Participants considered eligible for the telehealth lifestyle program met the following inclusion criteria: a) adults ≥ 18 years under the care of QLTS, >6 months post-transplant with expected survival >1 year (based on clinical judgement); with b) current access to a mobile phone or computer hardware with Internet and webcam access. Exclusion criteria were: a) food allergy or dietary restriction which would impact on following the MedDiet eating pattern; b) physical disability whereby an increase in physical activity would be deemed

127 inappropriate; c) deemed unsafe to participate by the treating Hepatologist or Transplant
128 Surgeon; and d) non-English speaking and/or unable to read and write in English.

130 On completion of the 12-week telehealth lifestyle program, participants were invited to
131 participate in the qualitative study to evaluate their experience and perspectives. Recruitment
132 was continued until thematic data saturation, defined as no new information emerging from
133 interviews, was reached.

135 **Data collection**

136 Questions were developed by the senior research team, which included a multidisciplinary
137 team of dietitians, exercise physiologists and transplant specialists. The Theoretical Domains
138 Framework²⁰ informed the development of questions which focused on identifying influences
139 on health behaviour during the main study, and assessing enablers and barriers to adhering to
140 the telehealth service intervention including knowledge, skill, beliefs, intentions, goals and
141 social influences on behavioural regulation. The interview schedule was then piloted on an
142 independent individual, which helped to inform structure and order of the questions.

144 A research officer independent of the intervention study (AB) led the semi-structured focus
145 groups via videoconference and one-on-one individual interviews via videoconference or
146 telephone. Assistance was provided by a secondary researcher (IH) for the initial interviews.
147 Both researchers were health professionals but had not delivered any part of the intervention.
148 One-on-one interviews were conducted for participants who could not attend the allocated
149 focus group session times. Utilising both focus groups and interviews ensured maximum
150 participation and diversity and offered an option for participants who felt uncomfortable
151 voicing feedback in a group setting.

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153 At the commencement of the interviews, AB introduced herself as a research student and
154 informed the participants of the purpose of the session and how the session would run.
155 Participants were informed of their rights and provided verbal consent before commencing
156 the interview questions. The semi-structured interview was followed with additional prompts
157 as needed. At the end of the session participants were given the chance to discuss anything
158 they felt was not covered from the structured part of the interview. Interviews were scheduled
159 between 30 to 45 minutes long and were recorded using an iPod (RøDE Microphone
160 Application, Freedman Electronics PTY LTD, 2012, Sydney). Interviews were conducted
161 within a median time of one week (IQR: 0.4, 1.4 weeks), from December 2017 to March
162 2018.

163

164 **Data Analysis**

165 The audio recordings were transcribed verbatim after each interview and de-identified with
166 participant study number and the order and type (focus group [FG] versus telephone
167 interview [TI]) of interview conducted. Applied Thematic Analysis²¹ was used as an
168 exploratory approach to code broad emergent themes. The primary researcher (AB), through
169 repeated readings and note taking, familiarised with the data set. Meaningful sentences and
170 phrases were extracted from the data, then coded, tabulated and crosschecked with a
171 secondary researcher and triangulated to validate interpretations and consistency. Contested
172 themes were discussed until consensus reached. Similar codes were transformed into initial
173 themes and then refined into key and subthemes. Subthemes that emerged were augmented
174 using both an inductive approach (developed after consultative interpretation of the analysis)
175 and a deductive approach (bound by the intent of evaluating the feasibility of the lifestyle
176 program). Suitable quotes were chosen to illustrate each subtheme.

RESULTS

Nineteen out of 36 LTRs recruited for the LIFE study participated. They were aged between 25 to 68 years (mean 52 ± 15 years) and 63% were male. Participants mean body mass index was $26.8 \pm 4.7 \text{ kg/m}^2$ and median time since transplant was 4.4 years (7 months to 26 years) with median (IQR) attendance of 10 (7, 12) sessions. No statistical difference in characteristic data was found between LIFE study participants who took part versus did not take part in interviews (Table 1). Four focus groups of 2 to 4 people were conducted with a mean duration of 27 ± 8 minutes and seven one-on-one interviews were conducted with a mean duration of 19 ± 8 minutes. All focus groups and one interview were conducted via videoconference, while the remaining interviews were conducted over the telephone in a private office. Four key themes emerged from the data each with one or more subthemes (Figure 1).

Broad Telehealth Advantages

Telehealth was a well-accepted experience by many participants (total participants $n=8$) because it provided a more convenient and comfortable setting in which to receive health care, lessening the perceived burdens of face-to-face appointments.

Less pressure or no different to face to face interactions with health professionals

The perspective of some participants was that telehealth-delivered interactions with health professionals were less confronting than face-to-face appointments, and they felt more at ease. The overall experience was that the lifestyle intervention sessions were as good or better than traditional face-to-face appointments.

201 *“I think sometimes when you are face to face, there is a bit more anxiety, you under a bit*
202 *more pressure to look a certain way or to be a certain way, where when it was Telehealth,*
203 *you could be lounging on the sofa and it was ok” (TI4, 2)*

204

205 *“It is like the person is with you in the room but you are just on the computer” (TI5, 31)*

206

207 *Reduced burden to travel or make appointments*

208 Previous negative experiences of travelling and arranging multiple appointments influenced
209 the common perception that telehealth was advantageous due to the reduced burden
210 associated with meeting obligations of frequent health service attendance.

211

212 *“The fact that you are not face to face it is really outweighed by the fact that you don’t have*
213 *to make the trip into the hospital, I mean me who lives in Brisbane, it is still like a 45 minute*
214 *journey to get there and there are people who live further out...” (FG1, 7)*

215

216 **Impact of employment**

217 The commitment and responsibilities of employment were considered as a competing priority
218 for some participants (total participants n=5), which appeared to impact their involvement
219 with the study due to accessibility and impact of fatigue.

220

221 *Flexible access desired*

222 Participants who were employed experienced perceived inequity of access to the lifestyle
223 program as they consistently prioritised work commitments above attending telehealth
224 appointments if they overlapped. Employment responsibilities also resulted in participants
225 experiencing fatigue and reduced motivation to exercise after work. Participant’s insights

226 identified a broad desire to be offered flexible access to more appointment options outside
227 usual working hours.

228

229 *“I work full time, its full on, you know, you know I would prefer, I do a 7.30 start through*
230 *work hours, it didn’t work for me, I’m not retired or anything, I have a very full, full time job”*
231 *(VII, 6)*

232

233 *“To be quite honest with you when you got home at night the last thing you want to do is*
234 *entering into an exercise component” (TII, 10)*

235

236 **Adapting Mediterranean eating pattern to meet individual needs**

237 The adaptability of the Mediterranean eating pattern was broadly recognised as a positive
238 experience with many participants (total participants n=13) using the dietary sessions to
239 facilitate experimentation with incorporating Mediterranean-style foods within regular family
240 recipes.

241

242 *Reinforced confidence with existing healthy food choices*

243 Participants valued the dietitian recognising LTR established knowledge regarding healthy
244 eating. This facilitated confidence in dietary decision-making and confidence to further
245 enhance diet quality by incorporating a wider variety of Mediterranean-style food choices.

246

247 *“I follow more or less the Mediterranean diet before I joined the program, I thought it*
248 *reinforced what I’m eating” (FG2, 9)*

249

250 *“I had what I thought was pretty good diet, you know with whole grains, you know lean*
251 *meats and you know vegetables and fruit and a little bit of olive oil and the Mediterranean-*
252 *style so since then we have reduced the meats and increased the grains and fruits and*
253 *definitely olive oil is in everything we have now which is great” (V1, 6)*

254

255 *Discovering alternative healthy food options*

256 Adapting to an eating pattern that includes liberal inclusion of healthy foods that may have
257 been well intentioned, yet unnecessarily, excluded previously e.g. extra virgin olive oil and
258 avocados, was challenging for some. However, it resulted in the pleasant discovery of healthy
259 and palatable additions to the diet and reinforced knowledge that the Mediterranean eating
260 pattern is a diet of inclusion rather than exclusion.

261

262 *“Bringing to light to me other foods I could eat that I could actually eat and what I quite*
263 *addicted to, umm, and knowing for fact that they are healthy for me and its not a umm I know*
264 *its not a weight gain.” (FG2, 8)*

265

266 *Finding practicalities to facilitate dietary change*

267 At first, participants were apprehensive about the accessibility of foods and the expense of
268 the Mediterranean eating pattern, however, following adoption of the diet they perceived it to
269 be cost neutral and practical.

270

271 *“I think eating healthy and eating Mediterranean-style diet is really accessible these days,*
272 *you know at Aldi you can get, you can get frozen meals that has quinoa, Mediterranean-style*
273 *vegetables and umm you know like it’s really, really accessible to continue eating like that*
274 *without having to do all this meal prep” (TI4, 2)*

275

276 “No, I probably spent less money on food, because, not going to take away and you become
277 more conscious to buy sweets, yeah probably cheaper than what I was doing” (T15, 31)

278

279 *Broader family involvement*

280 The participants experienced a broad acceptance for integration of the Mediterranean eating
281 pattern into family meals. The dietary changes did not seem to impact established food
282 preparation roles within shared households. Acceptability by both participants and their
283 social support roles seemed to significantly influence the perceived feasibility of dietary
284 change.

285

286 “No, it probably improved because the kids like the food, the Mediterranean diet with all the
287 pastas and the different red sauces and the garlic, they love all that sort of thing.” (T15,31)

288

289 “...so, he [brother] was on the Mediterranean-style diet too and he enjoyed it, he really liked
290 trying new foods, he is not big on trying new foods so he really, really enjoyed it and was
291 really supportive” (T14,2)

292

293 “That [food preparation roles] hasn’t changed for us, hubby and I share... mainly dinner, we
294 both work and kids are at school, it’s mainly dinner, that we, that hasn’t really changed, it’s
295 really whoever is home first” (FG1, 11)

296

297 **Increasing exercise confidence through a tailored approach**

298 Increased exercise confidence was an important outcome from the lifestyle intervention and
299 was facilitated by a tailored approach to the patient’s healthcare. The acceptability of the

exercise prescription as appropriate to support sustainable behaviour change can be recognised in the participants desire to continue exercising after the program ending. A total of 12 participants contributed to this theme.

Increasing self-directed exercise routines

A common experience among participants was that they had increased the amount of regular self-directed physical activity since completing the program. The group program was able to tailor advice to individual preferences and encouraged participants to increase their physical activity outside of appointment sessions. A wide variety of exercise types, not simply a replication of telehealth-based activities, were continued after facilitated sessions were completed.

“I play netball now Mondays and Wednesdays because that is really easy sort of, work up a sweat without having to think about it too much... and I walk to work and I walk home and that takes about half an hour every day and that is really intentional now” (T14, 2)

Awareness of exercise capabilities

An uncertainty existed among participants around their exercise capabilities before they entered into the program. Whilst undertaking the program, participants gained a greater awareness of their physical capabilities and confidence to exercise. Participants recognised that despite some limitations, they found alternative exercises to suit their individual needs.

323 *"I was a bit sceptical about it because I used to walk a lot, but to do the exercises made me*
324 *more aware that you can do a lot of things to help yourself out, which is quite good"* (TI5,
325 31)

326

327 *"I think it is more than what I thought I could do but more than what I can do.... so, it has*
328 *definitely pushed me more than what I would have realised, definitely* (FG, 11) "

329

330 *Prioritising exercise*

331 Participants' prioritised exercise because of enjoyment, a desire to engage with health
332 behaviours and an acceptance that their health condition required their attention to physical
333 fitness.

334

335 *"I have factored in time, you know now I've got chores to do or house work when I'm home*
336 *or even when I go to work, I sort of think I make time to do the exercises"* (FG1, 11)

337

338 **DISCUSSION**

339 The shared experiences of LTRs undertaking a telehealth lifestyle intervention may help to
340 enhance future telehealth services for this patient group and also be useful for other cohorts
341 with complex chronic disease. The overarching themes identified in this study include 'broad
342 telehealth advantages', 'impact of employment', 'adapting Mediterranean eating pattern to
343 meet individual needs' and 'increasing exercise confidence through a tailored approach'.

344

345 In this study, patients acknowledged the advantage of not having to travel to receive
346 specialist healthcare. This was expressed not just by those living a significant distance from
347 the transplant centre but also from those living locally. This desire to receive health care that

eliminates burdens of travel has also been expressed in other patient groups with multi-morbidities. In heart failure patients who undertook a telerehabilitation lifestyle program, reduced travel burden was a motivating influence to participate.²² Furthermore, there was greater attendance and completion rates in individuals with chronic heart conditions engaging with a telehealth lifestyle program compared to a centre-based program.^{23, 24} Travel time is one driver of the need to incorporate modern-day technology into the delivery of health care to meet changing expectations of the population. Despite the rapid emergence of eHealth literature and acceptance of virtual technologies across a range of patient groups,²⁵⁻²⁷ the implementation and sustainability of telehealth lifestyle programs across specialist health services remains challenging.^{28, 29}

This study also highlighted that an added benefit of the telehealth service delivery was the perception that the lifestyle advice was less confronting compared to face-to-face appointments at the hospital clinic. This was also recognised by patients with type 2 diabetes who participated in a group lifestyle program, who considered videoconferencing to be more relaxed than face-to-face group discussions.³⁰ Thus, health services offered within the comforts and familiarity of an individual's chosen environment has the potential to facilitate sustained behaviour change.

Some participants identified how employment could affect participation in intensive interventions. We previously identified that employment is a high priority for individuals post-transplant, to regain a sense of normality after undergoing a life-shifting event.¹⁶ It highlights the importance of co-designing treatment plans that meet the end-users' needs, including prioritisation of employment commitments within lifestyle prescriptions and innovating service delivery options within the tertiary hospital system.

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Previous evaluations of poorly adopted telehealth interventions for chronic disease have found that success is highly dependent on the end-user’s perceived need for the service³¹ and their belief that their health condition warranted the need for ongoing engagement with specialist health professionals. Despite the need to prioritise employment, the current study highlighted that LTRs were committed to ongoing engagement with specialist services to support decision making around health behaviours. The current study also found that LTRs were not threatened by the potential for telehealth to disrupt their existing services, but rather perceived it as an enhancement of the partnership with the specialist centre.

Overall, the participants highlighted the feasibility of the Mediterranean eating pattern, which supports findings from other Australian patient cohorts with chronic disease that have improved adherence to the MedDiet following dietetic intervention in a research setting.³²⁻³⁴ Specifically, the LTR participants experienced an acceptance in integrating the Mediterranean eating pattern into their family’s household. Support through family involvement has previously been recognised as an effective strategy to facilitate dietary and lifestyle change in LTRs.^{35, 36}

Previous research has found that adoption of a Mediterranean eating pattern by healthy individuals in the UK was perceived to be practical and cost effective, with a desire to continue eating this way.³⁷ Our analysis complements findings in patient populations that decisions to sustain dietary behaviour changes are related to reinforcement of knowledge, and the ability to facilitate integration of dietary choices with broader family and financial considerations.³⁶

Many participants expressed initial uncertainty about their exercise capabilities before commencing the program. This concern about the type and intensity of exercise that is safe and appropriate after liver transplant is consistent with a previous report and may reflect a lack of guidance from health professionals on this important topic.¹⁶ This low exercise-related confidence has been shown to preclude exercise uptake in other chronic liver disease conditions.³⁸ Thus, an integral role of the exercise program was to reassure LTRs of their exercise capabilities and reintroduce exercise with an individualised approach that improved their confidence and self-efficacy.

The exercise intervention employed in this study was prescribed as per national physical activity guidelines,¹⁸ tailored by an exercise physiologist to meet individual needs and capabilities. Participant choice for unsupervised exercise was also facilitated during group telehealth sessions. Preferences for exercise format/type, location and social settings have been shown to be different for different populations.³⁹ It is therefore likely that being able to choose exercise according to individual contextual preferences, alongside support from an exercise professional, may contribute to increased long-term adherence to physical activity in LTRs. This issue warrants further investigation.

There is now considerable evidence that telehealth services for complex chronic disease must facilitate engagement and partnerships between the patients, peer groups and health professional and deliver the service within the social and health system context relevant to the patient.⁴⁰ Continuing to engage the end-user within the design of interventions is important to deliver patient-centred care services.

This study has been strengthened by the use of multiple methodologies for data collection including focus groups and interviews. It also included data triangulation and the use of a multidisciplinary team to develop the interview schedule and interpret the results. Furthermore, conducting the interviews via telephone and videoconferencing, continued to lessen the burden for participants. Despite participants being familiar with videoconferencing as a group, it is unknown if the lack of physical co-location with the investigator impacted the dynamics of the focus groups. All participant data was relevant to an Australian health care setting and may not be generalisable to other countries or cultures. Furthermore, given the voluntary nature of the study, participants represent those LTRs who were initially willing to experiment with a technology-assisted lifestyle program. The exclusion of those without video enabled devices and non-English speaking people may have biased the participants' experiences and inclusion of broader representation in future implementation of technology-assisted lifestyle interventions should be considered.

Conclusion

This study has identified that a telehealth lifestyle program is an acceptable strategy to provide advice to LTRs on healthy lifestyle behaviours. Acknowledging and integrating the patients broader social support systems and work priorities are important factors to success and broadening accessibility options may improve program adoption.

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Authorship

Amandine Barnett made substantial contribution to the concept and design of the work, acquisition, analysis and interpretation of the data, drafted the article and approved the final version. Katrina L Campbell made substantial contribution to the concept and design of the work, analysis and interpretation of the data, and approved the final version. Hannah L Mayr made substantial contribution to the analysis and interpretation of the data, drafting of the article and approved the final version. Shelley E Keating made substantial contribution to the analysis and interpretation of the data and approved the final version. Graeme A Macdonald made substantial contribution to the concept and design of the work, analysis and interpretation of the data and approved the final version. Ingrid J Hickman made substantial contribution to the concept and design of the work, analysis and interpretation of the data, drafting the article and approved the final version.

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470 **Declaration of Conflicting Interests**

471 The Authors declare that there is no conflict of interest.

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Table 1: Characteristics of LIFE Study participants who took part versus did not take part in interviews

Characteristic Measure	Interview (n=19)	No interview (n=17)	p-value*
Gender, male <i>n (%)</i>	12 (63)	13 (76)	0.39
Age (years) <i>Mean (SD)</i>	52 (15)	48 (15)	0.35
Time since transplant (years) <i>Median (IQR)</i>	4 (2, 6)	4 (2, 6)	0.83
BMI (kg/m ²) <i>Mean (SD)</i>	26.7 (4.7)	28.4 (8.1)	0.47

*Tests were Independent t-test, Mann-Whitney *U* test or Chi Square test.

Figure 1: Four key themes with subthemes that emerged from the semi-structured focus groups and one-one-one interviews with LIFE study participants (n=19)