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Liver Transplant Recipients' Experiences and Perspectives of a 1

Telehealth-delivered Lifestyle Program: A qualitative study 2

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24

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- 25 Mediterranean diet, Exercise, Qualitative, Cardiometabolic, Telehealth, Feasibility, Organ 26 Transplantation 27
- 28
- 29
- 30
- 31
- 32 33

34 ABSTRACT

Introduction: Dietary modification and exercise are encouraged to address cardiometabolic 35 risk factors after solid organ transplantation including for liver transplant recipients (LTRs). 36 However, the lived experience of attempting positive lifestyle changes is not known. The aim 37 of this study was to explore LTRs' experiences and perspectives of a 12-week telehealth 38 lifestyle program and to assess feasibility of this innovative health service. 39 Methods: Focus groups and one-on-one interviews were conducted with participants who 40 had completed a 12-week, group based, telehealth-delivered diet and exercise program and 41 thematic qualitative analysis was used to code and theme the data. 42 Results: Nineteen LTRs participated in the study (25 to 68 years, median time since 43 transplant 4.4 years, 63% male). Overarching themes included 1) Broad telehealth 44 advantages which highlighted that telehealth reduced the perceived burdens of face-to-face 45 care; 2) Impact of employment which identified employment as a competing priority and 46 appeared to impact involvement with the program; 3) Adapting Mediterranean eating pattern 47 to meet individual needs which identified the adaptability of the Mediterranean diet supported 48 by sessions with the dietitian; 4) Increasing exercise confidence which recognised that a 49 tailored approach facilitated confidence and acceptability of the exercise component of the 50 program. 51

52 Discussion: A telehealth lifestyle program delivered by dietitians and exercise physiologists
53 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 faceconsultations.

56 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 longterm 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

62

Although a paucity of literature exists on the diet and exercise behaviours of LTRs, there is 63 64 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 65 investigated the effectiveness of diet and/or exercise interventions for LTRs. The 66 Mediterranean eating pattern has strong evidence for being cardio-protective¹⁰ and has been 67 68 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 69 70 Combined resistance and aerobic exercise training in LTRs improved aerobic capacity, 71 maximal strength, and quality of life.³

72

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.

83

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.

87

88 **METHODS**

89 Study design and setting

90 This qualitative evaluation was part of a larger study investigating the feasibility of a 12-91 week telehealth-delivered intervention, the LTR Initiative: a Feasibility study to Enhance 92 cardiometabolic health (LIFE study; Australia and New Zealand Clinical Trials Registry: 93 ACTRN12617001260314). The videoconference telehealth service model (two-way video 94 portal) included weekly group contact alternating education on diet and physical activity 95 prescription. A total of 14 offered telehealth appointment contacts which included 6 dietetic 96 and 8 exercise sessions were delivered by dietitians (total dietitians n=3) and exercise 97 physiologists (total exercise physiologists n=2), respectively. The dietary sessions supported 98 the Mediterranean Diet (MedDiet) eating pattern of increased vegetables, fruit, extra virgin 99 olive oil, legumes, fish, wholegrain breads and cereals, and nuts, and low consumption of red 100 meat and processed foods. The exercise appointments involved facilitated exercise sessions 101 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 102

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.

109

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

114

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.

119

120 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 Transplant128 Surgeon; and d) non-English speaking and/or unable to read and write in English.

129

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.

134

135 Data collection

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

143

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.

At the commencement of the interviews, AB introduced herself as a research student and 153 154 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 within a median time of one week (IQR: 0.4, 1.4 weeks), from December 2017 to March 161 162 2018.

163

164 Data Analysis

The audio recordings were transcribed verbatim after each interview and de-identified with 165 166 participant study number and the order and type (focus group [FG] versus telephone interview [TI]) of interview conducted. Applied Thematic Analysis²¹ was used as an 167 168 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 secondary researcher and triangulated to validate interpretations and consistency. Contested 171 172 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) and a deductive approach (bound by the intent of evaluating the feasibility of the lifestyle 175 176 program). Suitable quotes were chosen to illustrate each subtheme.

RESULTS

179 Nineteen out of 36 LTRs recruited for the LIFE study participated. They were aged between 180 25 to 68 years (mean 52 \pm 15 years) and 63% were male. Participants mean body mass index was 26.8 ± 4.7 kg/m² and median time since transplant was 4.4 years (7 months to 26 years) 181 182 with median (IQR) attendance of 10 (7, 12) sessions. No statistical difference in characteristic 183 data was found between LIFE study participants who took park versus did not take part in 184 interviews (Table1). Four focus groups of 2 to 4 people were conducted with a mean duration 185 of 27 ± 8 minutes and seven one-on-one interviews were conducted with a mean duration of 186 19 ± 8 minutes. All focus groups and one interview were conducted via videoconference, 187 while the remaining interviews were conducted over the telephone in a private office. Four 188 key themes emerged from the data each with one or more subthemes (Figure 1).

189

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.

194

195 Less pressure or no different to face to face interactions with health professionals 196 The perspective of some participants was that telehealth-delivered interactions with health 197 professionals were less confronting than face-to-face appointments, and they felt more at ease. 198 The overall experience was that the lifestyle intervention sessions were as good or better than 199 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

identified a broad desire to be offered flexible access to more appointment options outsideusual 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

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" (TI1, 10)*

235

236 Adapting Mediterranean eating pattern to meet individual needs

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

241

242 *Reinforced confidence with existing healthy food choices*

Participants valued the dietitian recognising LTR established knowledge regarding healthy
eating. This facilitated confidence in dietary decision-making and confidence to further
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)

250 "I had what I thought was pretty good diet, you know with whole grains, you known lean meats and you know vegetables and fruit and a little bit of olive oil and the Mediterranean-251 252 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* At first, participants were apprehensive about the accessibility of foods and the expense of 267 the Mediterranean eating pattern, however, following adoption of the diet they perceived it to 268 269 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)

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" (TI5, 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 300 exercise prescription as appropriate to support sustainable behaviour change can be 301 recognised in the participants desire to continue exercising after the program ending. A total 302 of 12 participants contributed to this theme. 303 304 305 *Increasing self-directed exercise routines* 306 A common experience among participants was that they had increased the amount of regular 307 self-directed physical activity since completing the program. The group program was able to 308 tailor advice to individual preferences and encouraged participants to increase their physical 309 activity outside of appointment sessions. A wide variety of exercise types, not simply a 310 replication of telehealth-based activities, were continued after facilitated sessions were 311 completed. 312 313 "I play netball now Mondays and Wednesdays because that is really easy sort of, work up a 314 sweat without having to think about it too much... and I walk to work and I walk home and 315 that takes about half an hour every day and that is really intentional now" (TI4, 2) 316 317 *Awareness of exercise capabilities* 318 An uncertainty existed among participants around their exercise capabilities before they 319 entered into the program. Whilst undertaking the program, participants gained a greater 320 awareness of their physical capabilities and confidence to exercise. Participants recognised 321 that despite some limitations, they found alternative exercises to suit their individual needs. 322

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)

338 **DISCUSSION**

The shared experiences of LTRs undertaking a telehealth lifestyle intervention may help to enhance future telehealth services for this patient group and also be useful for other cohorts with complex chronic disease. The overarching themes identified in this study include 'broad telehealth advantages', 'impact of employment', 'adapting Mediterranean eating pattern to 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 348 eliminates burdens of travel has also been expressed in other patient groups with multi-349 morbidities. In heart failure patients who undertook a telerehabilitation lifestyle program, 350 reduced travel burden was a motivating influence to participate.²² Furthermore, there was 351 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 352 353 one driver of the need to incorporate modern-day technology into the delivery of health care 354 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 355 356 implementation and sustainability of telehealth lifestyle programs across specialist health services remains challenging.^{28, 29} 357

358

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.

366

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.

Previous evaluations of poorly adopted telehealth interventions for chronic disease have 374 375 found that success is highly dependent on the end-user's perceived need for the service³¹ and 376 their belief that their health condition warranted the need for ongoing engagement with 377 specialist health professionals. Despite the need to prioritise employment, the current study 378 highlighted that LTRs were committed to ongoing engagement with specialist services to 379 support decision making around health behaviours. The current study also found that LTRs 380 were not threatened by the potential for telehealth to disrupt their existing services, but rather 381 perceived it as an enhancement of the partnership with the specialist centre.

382

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}

390

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

398 Many participants expressed initial uncertainty about their exercise capabilities before 399 commencing the program. This concern about the type and intensity of exercise that is safe 400 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-401 402 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 403 404 exercise capabilities and reintroduce exercise with an individualised approach that improved 405 their confidence and self-efficacy.

406

407 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 408 409 capabilities. Participant choice for unsupervised exercise was also facilitated during group 410 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 411 412 choose exercise according to individual contextual preferences, alongside support from an 413 exercise professional, may contribute to increased long-term adherence to physical activity in 414 LTRs. This issue warrants further investigation.

415

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 422 423 including focus groups and interviews. It also included data triangulation and the use of a 424 multidisciplinary team to develop the interview schedule and interpret the results. 425 Furthermore, conducting the interviews via telephone and videoconferencing, continued to 426 lessen the burden for participants. Despite participants being familiar with videoconferencing 427 as a group, it is unknown if the lack of physical co-location with the investigator impacted the 428 dynamics of the focus groups. All participant data was relevant to an Australian health care 429 setting and may not be generalisable to other countries or cultures. Furthermore, given the 430 voluntary nature of the study, participants represent those LTRs who were initially willing to 431 experiment with a technology-assisted lifestyle program. The exclusion of those without 432 video enabled devices and non-English speaking people may have biased the participants' 433 experiences and inclusion of broader representation in future implementation of technology-434 assisted lifestyle interventions should be considered.

435

436 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.

441

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449

450 Authorship

Amandine Barnett made substantial contribution to the concept and design of the work, 451 acquisition, analysis and interpretation of the data, drafted the article and approved the final 452 version. Katrina L Campbell made substantial contribution to the concept and design of the 453 work, analysis and interpretation of the data, and approved the final version. Hannah L Mayr 454 made substantial contribution to the analysis and interpretation of the data, drafting of the 455 article and approved the final version. Shelley E Keating made substantial contribution to the 456 analysis and interpretation of the data and approved the final version. Graeme A Macdonald 457 made substantial contribution to the concept and design of the work, analysis and 458 interpretation of the data and approved the final version. Ingrid J Hickman made substantial 459 contribution to the concept and design of the work, analysis and interpretation of the data, 460 drafting the article and approved the final version. 461

462

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470 Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest.

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Characteristic <i>Measure</i>	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) Median (IQR)	4 (2, 6)	4 (2, 6)	0.83
BMI (kg/m ²) Mean (SD)	26.7 (4.7)	28.4 (8.1)	0.47

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

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

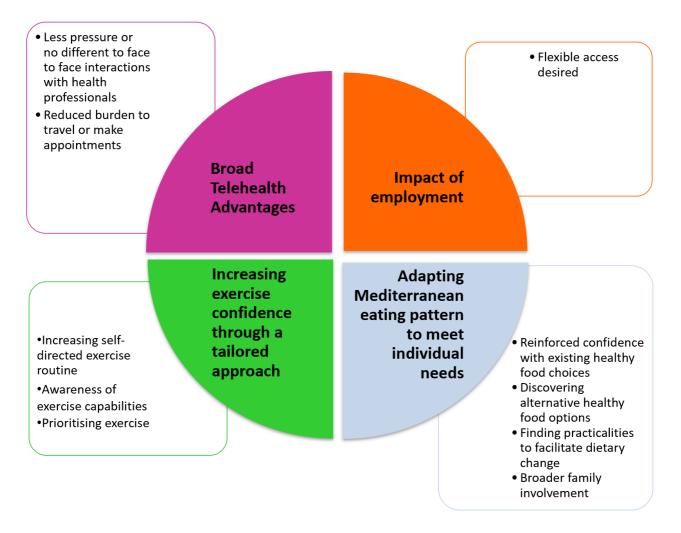


Figure 1: Four key themes with subthemes that emerged from the semi-structured focus groups and one-one-one interviews with LIFE study participants (n=19)