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

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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1 **“Back to Life” - Using knowledge exchange processes to enhance lifestyle**
2 **interventions for liver transplant recipients: a qualitative study.**

3
4 **Abstract**

5 Interventions to prevent excessive weight gain after liver transplant are needed. **Aim:** The
6 purpose of this study was to enhance a specialist post-transplant wellbeing program
7 through knowledge exchange with end-users. **Methods:** The study used an interactive
8 process of knowledge exchange between researchers, clinicians and health system users.
9 Data were collected as focus groups or telephone interviews and underwent applied
10 thematic analysis. **Results:** There were 28 participants (age 24-68yrs; 64% male). The
11 results identified experiences that may influence decisions around health behaviours
12 during the course of transplant recovery. Three over-arching themes were identified that
13 impact on liver transplant recipients post-transplant health behaviours. These include 1)
14 *Finding a coping mechanism* which highlighted the need to acknowledge the significant
15 emotional burden of transplant prior to addressing long term physical wellness; 2) *Back*
16 *to Life* encompassing the desire to return to employment and prioritise family, while co-
17 ordinating the burden of ongoing medical monitoring and self-management; 3) *Tailored,*
18 *Personalised Care* with a preference for health care delivery by transplant specialists via
19 a range of flexible eHealth modalities. **Conclusion:** This person-centred process of
20 knowledge exchange incorporated experiences of recipients into service design and
21 identified life priorities most likely to influence health behaviours post-transplant. Patient
22 co-creation of services has the potential to improve the integration of knowledge into
23 health systems and future directions will require evaluation of effectiveness and
24 sustainability of patient centred multidisciplinary service development.

25

26 **Key Words:** health service design, patient engagement, focus groups, obesity, liver
27 disease, quality of life

28

29 **Introduction**

30 Rapid weight gain after liver transplant is a world-wide phenomenon with 16-46% of
31 liver transplant recipients (LTR) becoming obese in the first year after transplant. ⁽¹⁻⁵⁾ (6-

32 ⁸⁾ There is a higher prevalence of metabolic syndrome in LTRs compared with the general
33 adult population and this appears to predispose to increasing cardiovascular disease risk,
34 graft rejection, infection and other complications. ⁽⁹⁾

35

36 Adjusting to a liver transplant is a complex process which incorporates both physical and
37 mental components of recovery. Liver transplant recipients endure significant physical
38 and psychological stress awaiting surgery⁽¹⁰⁾ and group-based psychoeducational
39 strategies appear effective at improving coping strategies and social support pre-
40 transplant⁽¹¹⁾. There is however a paucity of data addressing how best to deliver diet
41 and exercise prescription for post-transplant recovery and how lifestyle interventions may
42 prevent obesity and cardiometabolic complications post-liver transplant. The
43 development of targeted lifestyle interventions to prevent excessive weight gain and
44 manage cardiovascular risk requires a process of knowledge exchange between service
45 providers and patients, in order to meet the unique needs and life priorities of this cohort.

46

47 The purpose of this study is to use a process of knowledge exchange to involve knowledge
48 users in research and explore the everyday experience of LTRs to co-create a specialist
49 health and wellbeing program aimed at reducing cardio-metabolic risk factors post-
50 transplant. This study aims to engage with LTRs to define life needs and priorities, and

51 capture the emergence of factors that influence health behaviours across the spectrum of
52 pre- and post-liver transplant health services.

53

54 **Methods**

55 A stakeholder group of five liver transplant specialists, including physicians, nutrition
56 and exercise experts from a single Australian transplant centre (40-55 transplants per
57 year) developed a framework of key factors (enablers and barriers) that could impact on
58 the long-term health of LTR, which informed the development of this study. In
59 preparation for a process of knowledge exchange i.e. imparting meaningful knowledge
60 between knowledge users (LTR) and producers (investigators and health practitioners),
61 this framework drew from components of implementation science, such as level of
62 evidence (determined by literature review), context of health service delivery system
63 (determined by extensive clinical experience working within the system) and unique
64 needs of LTR (determined by both published evidence and clinical experience).⁽¹²⁻¹⁴⁾
65 This framework was further refined with clinical consultation and reference to individual,
66 institutional and systemic factors that impact on health behaviours including patient
67 perceptions of weight gain and 'healthy lifestyle' post-transplant, life priorities, timing of
68 service delivery and acceptance and feasibility of technology-assisted service models (see
69 supplementary material) . The framework then informed the development of semi-
70 structured interview questions designed to promote knowledge exchange and capture
71 LTR lived experience of transplant and perceptions of health priorities in relation to long-
72 term wellbeing (Supplementary material Table A). Data saturation determined when to
73 cease recruitment and was defined as no new information being offered either through
74 the knowledge exchange or prioritisation processes.
75 Interviews were conducted with LTRs through either focus groups or telephone
76 interviews. Participants were offered opportunities to share experience and knowledge

77 during early (within 6 months of transplant) and longer term (>6 months post-transplant)
78 health service follow-up. Participants were asked to prioritize factors that they considered
79 most influenced their health behaviours post-transplant.

80 The study was approved by the [blinded for peer review]. All participants provided
81 written informed consent (received by post for those undertaking telephone interviews).

82

83 The study population included adults who had received a liver transplant and had ongoing
84 medical review as an outpatient of the service. Transplant registry lists were screened for
85 eligibility with inclusion criteria of ≥ 18 years of age, received a liver transplant ≥ 12
86 months ago, and English-speaking. Participants were opportunistically sampled to
87 identify those already scheduled for outpatient visits during the recruitment period
88 (January – June 2015), and purposively recruited to achieve broad demographic diversity
89 including gender and geographical location. Eligible patients were not previously known
90 to the investigators (although were known to the transplant clinic) and contacted via
91 telephone, had the purpose of the study described and invited to participate in the study.
92 Those who agreed to participate were scheduled for a face-to-face focus group (1-
93 1.5hours) or a telephone interview (30 minutes) based on their preference.

94

95 Four focus groups (total participants $n=17$) were conducted by investigators DC (APD,
96 female, research student) and IH (PhD, research fellow, female, experienced researcher)
97 over the study period and consisted of seven prepared questions. There were no non-
98 participants present. Each group also developed a list of life priorities to identify the most
99 important influencing factors in their lives at three different time-points across the
100 transplant continuum: pre-transplant; early post-transplant (within 6 months); and ≥ 12
101 months post-transplant. Participants were encouraged as a group to name life priorities at

102 each of the three time points until no new priorities were identified. These were listed in
103 order of mention on a whiteboard for all to see. When all participants had considered the
104 group list, they were each asked to anonymously write down the top five most relevant
105 issues to them personally for each time point, in order of priority for them as an individual.
106 This could include priorities that had not been discussed by the group. The participant's
107 priority list was given to the investigator without sharing with the group.
108 All discussions were audio recorded and transcribed for data analysis. Certificates of
109 appreciation were presented to participants on completion.

110

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

117

118 Data Analysis: Data were reported according to the COnsolidated criteria for REporting
119 Qualitative research(15). Interviews and focus groups continued until saturation of
120 themes was reached. Audio recorded data from focus groups and telephone interviews
121 were transcribed verbatim, and entered into NVivo11 (Qualitative Software for Research
122 (QSR) International 2017). Applied thematic analysis was used as an exploratory
123 approach to code broad emergent themes (DC). (16) Subthemes that emerged were
124 augmented using both an inductive approach (developed after consultative interpretation
125 of the analysis) and a deductive approach (bound by the intent of informing the
126 development of a health promotion program). Coding was cross-checked by secondary

127 analysts (IH) and triangulated (DG) to validate interpretations and consistency.

128 Illustrative quotes are from participants in focus groups (FG) and telephone interviews

129 (TI) with multiple options proposed by analysts (DC, IH) and chosen with consensus by

130 all authors.

131

132 The prioritisation exercise whereby patients listed their top 5 life priorities at pre- early

133 post- and post- transplant, was analysed using content analysis to determine the greatest

134 frequency of stated life priorities clustered across the three pre-determined time points.

135 (17) Similar meaning words were collapsed into themes and triangulated by an

136 independent researcher. Frequency of word clusters were matched with identified themes

137 to estimate when subthemes were most likely to emerge or change over the course of

138 recovery.

139

140 **Results**

141 Figure 1 illustrates the recruitment flow diagram with n=28 agreeing to participate.

142 Participants were 24 to 68 years old (mean 53 ± 13 years), and 18 (64%) were male.

143 Median time since most recent transplant was 4 years (range 2 to 5 years). Both focus

144 groups and telephone interviews consisted of participants from local, regional and

145 interstate locations. Geographical residence of participants ranged from 13 (46%) being

146 located within the tertiary hospital catchment area, 6 (21%) within 100km of the hospital

147 and 9 (33%) >100km from the hospital. Average time for focus groups was 82 minutes

148 (range 70 – 90minutes) and individual interviews 27 minutes (range 15 - 48 minutes).

149

150 Thematic analysis identified three over-arching themes and multiple sub-themes (Figure

151 2). The timing of when each sub-theme emerged across the transplant journey was

152 estimated by matching with the frequency of life priorities listed by participants at each
153 of the three pre-defined time points and was determined by consensus amongst
154 investigators (DC, IH, DG, AB)(Figure 2).

155

156 **Finding a Coping Mechanism**

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

160

161 *Facing an unknown future after near-death*

162

163 The fear of an unknown future ruminated constantly prior to transplant and left a strong
164 legacy of uncertainty well after transplant that continued to impact on future life plans.

165 *“The foremost thing was getting a transplant, but not knowing what was ahead*
166 *of me though, so you don't really know, it's one of those things that you*
167 *think.....is it going to be good or is it going to be bad”(TI,16)*

168

169 *“For me every blood test was Russian roulettethere was always someone*
170 *who was in some degree of rejection so every blood test was you know, is it*
171 *my turn to find I'm in rejection. That was all the way through that first 12*
172 *months.....that weighs very heavy on your mind..... only stuff that sticks in your*
173 *mind is the bad stuff all of a sudden when you're lying in bed at 2am” (FG4,*
174 *32)*

175

176 *Emotional and psychological support networks*

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

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

189
190 However, participants also desired greater psychological support from the hospital
191 clinic to develop coping strategies for stress and anxiety, which they perceived to
192 impact on physical wellness even years after transplant.

193
194 *“The psychological aspect as well I’m a big advocate for that I don’t think we*
195 *do enough in that area as well simply because you know, the transplant friends*
196 *I have, none of us have ever had any sort of support or anything like that. I*
197 *think that it’s a big factor that’s sort of overlooked.” (FG,31)*

198
199 *“So it was really, also the questions of how to actually maintain a balance in terms*
200 *of your thinking, you’re sort of in a healing process, yes the physical stuff but also*
201 *your sort of spiritual healing shall we say.” (FG1, 3)*

202

203 ***Keeping a positive mindset***

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

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

209

210 ***Expressing gratitude and giving back***

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

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

221

222 ***Taking Responsibility***

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

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

230

231 **Back to Life**

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

237

238

239

240

Work and Finances

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

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

247

248 *Taking care of and spending time with family*

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

251 *“Yeah it’s the best thing that ever happened to me you know, one yes I’m still*
252 *alive but the lifestyle choices that I’ve made now whereas before we were um*

253 *driven by material things now we're not. It's more about family and lifestyle*
254 *and you know doing what we actually enjoy rather than you know keeping up*
255 *with the Jones's.*"(FG,31)

256

257 ***Managing medical conditions and coordinating health service***

258 ***interactions***

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

267

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

273

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

276

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

280

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

283

284 **Tailored, Personalised Care**

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

288

289 *Practical advice specific for me*

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

295

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

300

301 *Options for accessing support*

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

310

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

316 *(FG,13)*

317

318 ***Timing is right when I'm ready***

319

320 Preferences for the timing of receiving post-transplant diet and exercise education
321 ranged considerably. Some participants emphasised the importance of receiving
322 post-transplant diet and exercise information prior to transplantation, while most
323 reported being best placed to receive support within six months of receiving their
324 transplant. There was agreement that if the presentation of a post-transplant
325 wellbeing program is mistimed, unintended consequences could occur, with patients
326 disregarding information or resenting health professionals.

327

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

335

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

340

341

342 **Discussion**

343 This qualitative study used a process of knowledge exchange between researchers,
344 clinicians and health system users and highlights the value of using implementation
345 science for the design of new health services. It identified experiences that may influence
346 decisions around health behaviours and informed elements of a post-transplant wellness
347 program for LTR.

348

349 While quality of life improves after transplant, participants of this study described
350 ongoing issues associated with mental health and emotional resilience that may impact
351 on health-related decision making. ⁽¹⁸⁾ Unique emotional stressors such as survivor guilt
352 and post-traumatic stress are recognised in organ transplant recipients. ⁽¹⁹⁻²²⁾ Study
353 participants indicated that before they could address their diet and exercise needs, they

354 needed better strategies to cope with the insecurity and uncertainty associated with
355 survival; and also needed the physical and emotional resources to deal with their current
356 medical issues. Regular exercise and improving diet quality are effective strategies for
357 fostering good mental health and cognitive function after significant health events such
358 as cardiac arrest. ⁽²³⁻²⁵⁾ However, participants in this study did not identify such health
359 behaviours as coping mechanisms *per se*. This finding has significant implications for
360 transplant services that may not typically offer psychological support or peer mentoring
361 programs as standard care. The desire for professional emotional support emphasises the
362 need for multi-disciplinary teams before and after transplant. The provision of group
363 psychotherapy to patients awaiting liver transplant has uncovered some reluctance to
364 engage with these strategies but warrants further investigation due to the potential benefits
365 such as reduced anxiety and sharing experiences with others⁽²⁶⁾.

366

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

374

375 Participants placed a high priority on getting back to 'normal life' despite reconciling
376 their reality that interacting with health services and self-monitoring will be a life-long
377 burden that others do not bear. The importance of regaining independence, such as being
378 able to drive and travel, and returning to work, are common themes post-organ transplant.

379 (29) The experience of this cohort was that re-entering the workforce was a high priority,
380 contributed to financial recovery, social functioning and establishing a work-life balance
381 that reflects emerging wellness. These results can inform the structure of program
382 delivery whereby the need for recipients to prioritise and balance work commitments with
383 recommended health behaviours are acknowledged and accomodated.

384

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

392

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

400

401 Considering the stated financial concerns of LTR, and the geographical dispersion of a
402 state-wide transplant service; utilising telehealth platforms and technology to offer

403 hospital-to-home group support for long term health behaviour change may improve
404 effectiveness and equitable access. ⁽³⁰⁻³³⁾

405

406 This study highlighted the need for some degree of patient-led process for how and when
407 post-transplant health services are engaged by LTR. Recipients desire an awareness of
408 available resources at early stages of the transplant experience, however the readiness to
409 engage differs for each LTR. In addition, it was identified that life priorities change over
410 the course of recovery, which may impact on readiness to engage with wellness programs.

411 There is likely to be greater uptake and effectiveness if the health system can support an
412 inherently flexible user-led approach to uptake of service delivery and potentially
413 screening LTR and their carers for readiness to engage may be worthwhile to improve
414 uptake.

415

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

420

421 The study has used robust qualitative methods to involve knowledge users in research.
422 Many aspects of this study decreased barriers to inclusion such as giving participants
423 options for data collection methods (phone interviews or focus groups) including regional
424 and metropolitan residents, and increased face validity by secondary analysts performing
425 data triangulation. Question development involved a multidisciplinary team, which
426 increased internal consistency. Due to the voluntary nature of the study, it is possible that
427 the participants were over-represented by those who have had a positive transplant and/or

428 healthcare experience. In addition, all participants were asked to recall their pre-transplant
429 experiences and perceptions which may have been more than 12 months prior for some
430 participants and introduces recall bias for pre- and early-post transplant time points. The
431 results are contextual to an Australian, English-speaking transplant population and may
432 not be generalizable to other countries and cultures.

433

434 **Conclusion**

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

441

442 **Acknowledgment**

443 The authors would like to acknowledge the liver transplant recipients who shared their
444 stories and life experience to improve the health services for others.

445

446 References

- 447 1. Anastacio LR, Ferreira LG, de Sena Ribeiro H, Lima AS, Vilela EG, Toulson
448 Davisson Correia MI. Body composition and overweight of liver transplant recipients.
449 *Transplantation*. 2011;92(8):947-51.
- 450 2. Kouz J, Vincent C, Leong A, Dorais M, Rakel A. Weight gain after orthotopic
451 liver transplantation: is nonalcoholic fatty liver disease cirrhosis a risk factor for greater
452 weight gain? *Liver transplantation : official publication of the American Association for
453 the Study of Liver Diseases and the International Liver Transplantation Society*.
454 2014;20(10):1266-74.
- 455 3. Richards J, Gunson B, Johnson J, Neuberger J. Weight gain and obesity after
456 liver transplantation. *Transplant International*. 2005;18(4):461-6.
- 457 4. Watt KD, Charlton MR. Metabolic syndrome and liver transplantation: a review
458 and guide to management. *Journal of hepatology*. 2010;53(1):199-206.
- 459 5. McCoy SM, Campbell KL, Lasseillante AM, Wallen MP, Fawcett J, Jarrett M,
460 et al. Changes in dietary patterns and body composition within 12 months of liver
461 transplantation. *Hepatobiliary Surg Nutr*. 2017;6(5):317-26.
- 462 6. Desai R, Jamieson NV, Gimson AE, Watson CJ, Gibbs P, Bradley JA, et al.
463 Quality of life up to 30 years following liver transplantation. *Liver transplantation :
464 official publication of the American Association for the Study of Liver Diseases and the
465 International Liver Transplantation Society*. 2008;14(10):1473-9.
- 466 7. Jones JB. Liver Transplant Recipients' First Year of Posttransplant Recovery: A
467 Longitudinal Study. *Progress in Transplantation*. 2005;15(4):345-52.
- 468 8. Levitsky J, Cohen SM. The liver transplant recipient: What you need to know
469 for long-term care. *J Fam Pract*. 2006;55(2):136-44.
- 470 9. Pagadala M, Dasarathy S, Egtesad B, McCullough AJ. Posttransplant
471 metabolic syndrome: an epidemic waiting to happen. *Liver transplantation : official
472 publication of the American Association for the Study of Liver Diseases and the
473 International Liver Transplantation Society*. 2009;15(12):1662-70.
- 474 10. Swanson A, Geller J, DeMartini K, Fernandez A, Fehon D. Active Coping and
475 Perceived Social Support Mediate the Relationship Between Physical Health and
476 Resilience in Liver Transplant Candidates. *Journal of clinical psychology in medical
477 settings*. 2018;25(4):485-96.
- 478 11. Craig JA, Miner D, Remtulla T, Miller J, Zanussi LW. Piloting a Coping Skills
479 Group Intervention to Reduce Depression and Anxiety Symptoms in Patients Awaiting
480 Kidney or Liver Transplant. *Health & social work*. 2017;42(1):e44-e52.
- 481 12. Stetler CB, Damschroder LJ, Helfrich CD, Hagedorn HJ. A Guide for applying a
482 revised version of the PARIHS framework for implementation. *Implementation
483 Science*. 2011;6(1):99.
- 484 13. Mitton C, Adair CE, McKenzie E, Patten SB, Wayne Perry B. Knowledge
485 transfer and exchange: review and synthesis of the literature. *The Milbank quarterly*.
486 2007;85(4):729-68.
- 487 14. Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, et al. Lost
488 in knowledge translation: time for a map? *The Journal of continuing education in the
489 health professions*. 2006;26(1):13-24.
- 490 15. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative
491 research (COREQ): a 32-item checklist for interviews and focus groups. *International
492 journal for quality in health care : journal of the International Society for Quality in
493 Health Care*. 2007;19(6):349-57.

- 494 16. Guest G, MacQueen KM, Namey EE. *Applied Thematic Analysis*: SAGE
495 Publications; 2011.
- 496 17. Drisko J, Maschi T. *Content Analysis: Pocket Guide to Research Methods*:
497 Oxford University Press USA 2015.
- 498 18. Werkgartner G, Wagner D, Manhal S, Fahrleitner-Pammer A, Mischinger HJ,
499 Wagner M, et al. Long-term quality of life of liver transplant recipients beyond 60 years
500 of age. *Age (Dordrecht, Netherlands)*. 2013;35(6):2485-92.
- 501 19. Thys K, Schwering KL, Siebelink M, Dobbels F, Borry P, Schotsmans P, et al.
502 Psychosocial impact of pediatric living-donor kidney and liver transplantation on
503 recipients, donors, and the family: a systematic review. *Transpl Int*. 2015;28(3):270-80.
- 504 20. Pérez-San-Gregorio MÁ, Martín-Rodríguez A, Borda-Mas M, Avargues-
505 Navarro ML, Pérez-Bernal J, Gómez-Bravo MA. Coping Strategies in Liver Transplant
506 Recipients and Caregivers According to Patient Posttraumatic Growth. *Frontiers in*
507 *Psychology*. 2017;8:18.
- 508 21. Annema C, Roodbol PF, Stewart RE, Porte RJ, Ranchor AV. Prevalence of
509 psychological problems and associated transplant-related variables at different time
510 periods after liver transplantation. *Liver transplantation : official publication of the*
511 *American Association for the Study of Liver Diseases and the International Liver*
512 *Transplantation Society*. 2015;21(4):524-38.
- 513 22. Baranyi A, Krauseneck T, Rothenhausler HB. Posttraumatic stress symptoms
514 after solid-organ transplantation: preoperative risk factors and the impact on health-
515 related quality of life and life satisfaction. *Health Qual Life Outcomes*. 2013;11:111.
- 516 23. Smith PJ, Sherwood A, Mabe S, Watkins L, Hinderliter A, Blumenthal JA.
517 Physical activity and psychosocial function following cardiac rehabilitation: One-year
518 follow-up of the ENHANCED study. *Gen Hosp Psychiatry*. 2017;49:32-6.
- 519 24. Hurley MC, Arthur HM, Chessex C, Oh P, Turk-Adawi K, Grace SL. Burden,
520 screening, and treatment of depressive and anxious symptoms among women referred to
521 cardiac rehabilitation: a prospective study. *BMC Women's Health*. 2017;17:11.
- 522 25. Molendijk M, Molero P, Ortuno Sanchez-Pedreno F, Van der Does W, Angel
523 Martinez-Gonzalez M. Diet quality and depression risk: A systematic review and dose-
524 response meta-analysis of prospective studies. *Journal of affective disorders*.
525 2018;226:346-54.
- 526 26. Ramirez P, Febrero B, Martinez-Alarcon L, Abete C, Galera M, Cascales P, et
527 al. Benefits of Group Psychotherapy in Cirrhotic Patients on the Liver Transplant
528 Waiting List. *Transplantation proceedings*. 2015;47(8):2382-4.
- 529 27. Gangeri L, Scignaro M, Bianchi E, Borreani C, Bhoorie S, Mazzaferro V. A
530 Longitudinal Investigation of Posttraumatic Growth and Quality of Life in Liver
531 Transplant Recipients. *Progress in transplantation (Aliso Viejo, Calif)*. 2018;28(3):236-
532 43.
- 533 28. van Adrichem EJ, van de Zande SC, Dekker R, Verschuuren EAM, Dijkstra PU,
534 van der Schans CP. Perceived Barriers to and Facilitators of Physical Activity in
535 Recipients of Solid Organ Transplantation, a Qualitative Study. *PLoS ONE*.
536 2016;11(9):e0162725.
- 537 29. Forsberg A, Cavallini J, Fridh I, Lennerling A. The core of social function after
538 solid organ transplantation. *Scandinavian Journal of Caring Sciences*. 2016;30(3):458-
539 65.
- 540 30. Appel LJ, Clark JM, Yeh H-C, Wang N-Y, Coughlin JW, Daumit G, et al.
541 Comparative Effectiveness of Weight-Loss Interventions in Clinical Practice. *New*
542 *England Journal of Medicine*. 2011;365(21):1959-68.

- 543 31. Azar KM, Aurora M, Wang EJ, Muzaffar A, Pressman A, Palaniappan LP.
544 Virtual small groups for weight management: an innovative delivery mechanism for
545 evidence-based lifestyle interventions among obese men. *Transl Behav Med*.
546 2015;5(1):37-44.
- 547 32. Ordin YS, Karayurt O. Effects of a Support Group Intervention on Physical,
548 Psychological, and Social Adaptation of Liver Transplant Recipients. *Exp Clin*
549 *Transplant*. 2016;14(3):329-37.
- 550 33. AlDossary S, Martin-Khan MG, Bradford NK, Smith AC. A systematic review
551 of the methodologies used to evaluate telemedicine service initiatives in hospital
552 facilities. *International Journal of Medical Informatics*. 2017;97:171-94.
- 553 34. Jull J, Giles A, Graham ID. Community-based participatory research and
554 integrated knowledge translation: advancing the co-creation of knowledge.
555 *Implementation Science : IS*. 2017;12:150.
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566 **Table 1: Key insights from LTRs to inform the design of a post-transplant diet**
567 **and exercise program**

Key Insights
<ul style="list-style-type: none">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 behaviors

- 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 tele-health 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 wellbeing rather than reminding patients of links with illness and chronic disease

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570 **Figure Headings**

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572 **Figure 1:** Study participant recruitment flow diagram

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575 **Figure 2:** Three overarching themes with subthemes emerging across the liver

576 transplant journey, which have potential to impact the design of diet and exercise

577 wellness programs.

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