Diet and physical activity after liver transplant: a qualitative study of barriers and facilitators to following advice

Short title

Diet and activity after liver transplant

Authors

- 1. Lynsey N Spillman
- 2. Arabella Melville-Claxton
- 3. Gillian Gatiss
- 4. Nicola Fernandez
- 5. Angela M Madden

Institutional Affiliations

- 1. Department of Nutrition and Dietetics, Cambridge University Hospitals NHS Foundation Trust and MRC Epidemiology Unit, University of Cambridge, Cambridge, UK.
- 2. Department of Nutrition and Dietetics, Cambridge University Hospitals NHS Foundation Trust Cambridge, UK¹.
- 3. Department of Nutrition and Dietetics, Cambridge University Hospitals NHS Foundation Trust, Cambridge, UK.
- 4. Department of Nutrition and Dietetics, Cambridge University Hospitals NHS Foundation Trust Cambridge, UK².
- 5. University of Hertfordshire, Hatfield, Hertfordshire, UK

¹ Current organisation: Norfolk and Norwich University Hospitals NHS Foundation Trust, Norwich, UK.

² Current organisation: Oxford University Hospitals NHS Foundation Trust, Oxford, UK.

1 <u>Title</u>

- 2 Diet and physical activity after liver transplant: a qualitative study of barriers and facilitators to
- 3 following advice.

4 Abstract

5 Background

- 6 Liver transplant recipients are given diet and physical activity advice to aid recovery and promote
- 7 long-term health. This study aimed to explore patients' experiences of receiving and implementing
- 8 diet and physical activity advice after liver transplant and identify barriers and facilitators to
- 9 following recommendations.

10 Methods

- 11 A qualitative descriptive design included purposive sampling of thirteen liver transplant recipients.
- 12 Semi-structured audio-recorded interviews and inductive thematic analysis using a framework were
- undertaken concurrently to enable recruitment until saturation of themes occurred.

14 Results

- Overall experiences varied between participants and settings, and over time. Seven themes
- emerged, all representing both barriers and facilitators to implementing advice. Poor capability and
- 17 loss of confidence were barriers which improved in hospital as healthcare professionals enabled
- participants to set and achieve goals but remained key barriers after discharge from hospital. The
- 19 format and consistency of advice influenced participants' confidence in the healthcare team. Social
- support helped participants to return to and implement advice, but social networks could also have a
- 21 negative influence. Advice and modelling of behaviour from other transplant recipients were
- 22 facilitators. Symptoms, side-effects, co-morbidities and the environment presented barriers and
- facilitators. The desire to return to normal and coping strategies were drivers of behaviours, which
- 24 were also influenced by participants' beliefs and values.

Conclusions

- The variation in experiences indicates a need for individually tailored advice that is consistent
- 27 across the multidisciplinary team. Interventions for behaviour change that merit further
- 28 investigation include goal setting, improving coping strategies, peer support and modifying the
- 29 hospital and home environment.

Introduction

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- 31 Immediately following liver transplant, patients are advised to follow a diet that is energy-dense and
- 32 high in protein and to start mobilising to aid recovery (1; 2). However, long-term changes in diet and
- 33 physical activity (henceforth referred to as activity) are recommended to reduce the risk of
- cardiovascular disease, cancer and osteoporosis, which is elevated in this patient group ^(3; 4). Despite
- some transplant centres providing patients with dietary counselling, physical therapy and activity
- advice, research indicates that many liver transplant recipients do not achieve the recommended
- 37 levels of activity (5; 6) or dietary intake (7), evidenced by excessive weight gain (8) and metabolic
- 38 syndrome ⁽⁹⁾ after transplant. Published studies which explore patients' experiences after liver
- transplant have focused primarily on lived experience of transplantation (10) or adherence to medical
- 40 care (11), with paucity of data about patients' experience of implementing diet and physical activity
- 41 advice.
- The purpose of this study was to explore liver transplant recipients' experiences of receiving and
- 43 implementing diet and physical activity advice post-transplant and identify barriers and facilitators
- 44 to following diet and activity recommendations. This knowledge is important to enable healthcare
- professionals to address barriers and better support recipients with these behaviours, and to inform
- 46 the content and theory of lifestyle interventions developed for this specific patient population ⁽¹²⁾.

Methods

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- This qualitative descriptive research (13; 14) used a constructivist research paradigm to inform the
- research methods (15; 16). Further details about the design and approach are reported in
- 50 supplementary information. This manuscript has been prepared using the standards for reporting
- 51 qualitative research (17).

Research participants

- Patients aged ≥18 years and fluent in English, who had undergone a liver transplant at the
- 54 Cambridge transplant centre 6 weeks or more prior to the study were eligible for inclusion . Patients
- 55 who were unable or unwilling to provide informed consent were excluded. All patients attending
- the outpatient liver transplant clinic over a month were considered for inclusion (n=69). Purposeful
- sampling was used to include participants at different times post-transplant (6 weeks, up to 12
- months and more than 12 months post-transplant) and with different needs for nutrition and
- 59 physical therapy support. Recruitment and data collection continued until saturation of research
- themes was reached, where additional data did not lead to any new themes (18).

- Fourteen patients were invited to participate. Thirteen agreed and were interviewed, including eight
- 62 (62%) women and five (38%) men. Median age was 60 years (range 20-70) and median time post-
- transplant was 17 months (range 6 weeks 14 years). Aetiology of liver disease included primary
- 64 biliary cholangitis (n=4), non-alcoholic fatty liver disease (n=3), alcohol-related liver disease (n=2),
- primary sclerosing cholangitis (n=2), Budd-Chiari syndrome (n=1) and Wilson's disease (n=1)
- 66 (Table 1).

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Data collection

- Data were collected over a three-month period via a semi-structured interview with each participant.
- Data were collected and analysed concurrently. Participants chose a face-to-face or telephone
- 70 interview and the location. Interviews took place in a quiet private room in the hospital, a hotel
- 71 meeting room or in the participant's own home. Each interview was undertaken by one of four
- 72 researchers who were clinical dietitians with experience in working with transplant recipients. Four
- 73 interviewers were required for ethical reasons so participants were interviewed by a dietitian with
- 74 no involvement in their clinical care. The format was informed by a topic guide (supplementary
- 75 information) which was developed by the researchers with patient and public involvement from
- 76 transplant recipients not participating in the study. The topic guide evolved as the study progressed
- 77 to ensure data were collected on new topics that emerged from interviews. Interviews lasted
- between 40 and 120 minutes and were audio-recorded and transcribed verbatim by one of the
- 79 researchers (LS). Identifiable information was removed from the transcripts. To achieve consistency
- between interviewers all were well acquainted with the topic guide, and the lead researcher (LS)
- 81 listened to all recordings and led reflexive meetings after each interview. There was no pattern in
- 82 interview length between interviewers.

Data analysis

- NVivo 11 (19) was used to aid inductive thematic analysis using a framework for data management,
- as described by Ritchie et al. ⁽²⁰⁾. Two researchers (LS and AMC) undertook the analysis. The first
- 86 four interview transcripts were coded independently and used to develop a thematic framework. LS
- and AMC then jointly indexed the remaining transcripts as they became available. For the
- 88 remaining transcripts, new codes were developed for data that did not fit into the framework and the
- 89 framework was adjusted. Previous transcripts were reviewed in order to apply these new codes.
- 90 When all transcripts had been indexed and displayed in charts, LS, AMC and AM reviewed the data
- 91 in each theme, mapped the range and diversity of views and experience, and developed further
- 92 themes to describe links and patterns within the data. Reflexive diaries and a record of analytical

thinking were maintained by the researchers throughout and were used to aid data collection, 93 analysis and interpretation of findings (see supplementary information). 94 **Results** 95 Overall, seven themes were identified that describe participants' experiences after the transplant in 96 hospital, whilst recovering at home and with long-term diet and activity behaviours. Findings are 97 98 illustrated with anonymised quotations. Further illustrative quotes can be found in supplementary information. 99 1. Beliefs and values 100 1.1 Early after transplant 101 102 In the first days following transplant, participants lost confidence in their abilities with diet and physical activity. This led to some feeling incapable and fearful of eating and mobilising. 103 "You don't know anything because you're not a doctor or a, or a nutritionist... I felt 104 constantly inferior... you just seem to forget any contextual knowledge that you ever had" 105 (P7). 106 Encouragement, achieving goals and experiencing benefits of following advice improved self-107 efficacy and motivated participants to continue implementing advice. 108 "You can see the weight going on, you know you, it's something tangible really if it does go 109 on because you think 'oh right this really works'" (P5). 110 1.2 After discharge from hospital 111 Once home, participants were unsure of how to balance sufficient activity to progress, without 112 doing too much and risking injury. This led to fear, uncertainty, lack of confidence and feeling 113 "built up for a fall" (P13). 114 "I seem to have been just left to just fend for yourself and you don't know what [activity] 115 you can or should and shouldn't be doing...I've been scared... and it's frightening not to do 116

1.3 Beliefs about advice 120

further support.

too much and then not to do enough" (P5).

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In contrast, some participants felt capable of setting goals and progressing activity levels without

121	Participants who believed that implementing advice would be beneficial, or that current or past
122	behaviour may have a negative impact on health described following advice.
123	"You've got to do it [have a healthy lifestyle], you're only killing yourself if you don't do
124	it" (P2).
125	Conversely, those who viewed the advice as harmful or not beneficial described not changing their
126	behaviour. Recognising but not valuing the potential impact of behaviour on health, and not being
127	willing to accept the perceived costs or deprivation of behaviour change, such as less enjoyment
128	from food due to reduced fat intake, were also barriers.
129	"If I see a dietitian, that's what she's going to tell me isn't she, 'We don't want you
130	growing overly large', ha, if that happens it happens, I'm not bothered" (P6).
131	1.4 Beliefs about self
132	"Self-determination" was described as a facilitator to implementing advice. Other participants
133	described being "lazy", not "self-motivated" and "not particularly good at following peoples'
134	advice" as barriers.
135	2. Healthcare professional support and advice
136	2.1 Good support
137	For inpatients, support from ward staff was an essential enabler, for example to access supplement
138	drinks and through encouragement to mobilise and eat. However, when support was lacking this
139	was a barrier.
140	"Quite frequently breakfast would be almost at lunch time because there was nobody to help
141	me feed there were some times when they were very much on the ball and would get it
142	done and other times when they just couldn't" (P3).
143	Support from dietitians and physiotherapists enabled participants to follow advice. Participants'
144	ability to implement advice was improved when advice was brief, tailored and regularly adapted as
145	their needs changed.
146	"It's just reiterating, even though you tell us, I tend to forget" (P5).
147	"The fact that it wasn't just a meal plan and then everybody gets the same one, it was very

Getting support at the right time when needed was important, for example when a problem was 149 encountered. However, participants could not always anticipate their support needs in advance. 150 "Being able to ask her [dietitian] about lifestyle stuff was helpful, especially once I had a 151 life again... once you come across a problem, getting the answer to that is, is vital because 152 otherwise you can't move on... Unless I encounter any problems, I don't really know what 153 to say [to the dietitian]" (P7). 154 2.2 Insufficient support 155 Some participants felt better support was needed: in hospital; to be more physically active after 156 discharge from hospital; for preventing unwanted weight gain; and with long-term healthy 157 behaviours. 158 159 "A little bit more help with and a bit more advice on diet and exercise would have been useful" (P11). 160 Participants expressed desire for physical activity guidance and "benchmark" (P5) to know how 161 much they should be able to do and by when, particularly after discharge from hospital. "Vague" 162 advice that was not sufficiently tailored to the individual was difficult to implement. 163 "There was no real advice around exercise, you know, what would be safe to do" (P3). 164 2.3 Healthcare professional approach 165 Participants were reluctant to engage with healthcare professionals who did not have an empathetic 166 approach, whereas those who were confident and knowledgeable with an empathetic and 167 encouraging approach had a positive impact on patients' willingness to listen to and adopt advice. 168 "With the food and the exercise, it's actually your life, you actually have to live it and I 169 think that the empathy that you get for that is really important. If it had been any other way I 170 don't think I would have followed the advice frankly" (P7). 171 2.4 Consistent and clear advice 172 Consistent messages about diet and activity across the healthcare team made participants feel more 173 confident about advice. Participants valued advice more when its importance was highlighted by 174 doctors and surgeons. Participants who experienced advice as conflicting found this confusing and 175 lost confidence in healthcare professionals. 176

177 178	"I was like well that's not what [the other dietitian] saidand I think it's from then I just thought, I'm not even listening to you" (P6).
179	3. Social support and influence
180	3.1 Family and friends
181	3.1.1 Support and encouragement
182 183	Support from family and friends was needed. For example, palatable nourishing food provided by visitors during hospital admission was important for those who disliked the hospital food.
184 185	"It was a good job my sister bought me a big bag of goodies that I could dive into because otherwise I think I would have starved to death" (P13).
186 187 188	Support to shop for and prepare food and with regaining mobility was needed at home as participants were not physically capable of this when first discharged from hospital. Some described their partners' encouragement as the main driver of their activity and dietary intake.
189 190 191	"I was supposed to eat three meals a day and I used to try and push it off and my wife just pushed it back on methe only reason I did things was because of my wife really pushing me. I'd rather sit down and do nothing really" (P4).
192 193 194	Some participants needed permission and support from their family to prevent too much physical activity too soon. Participants' family and friends being present when advice was given enabled them to review this independent of healthcare professionals.
195 196 197 198	"I usually ask questions, and quite frequently with my family around because I just wasn't taking anything in at the time at all, so it was them [family] that kept pushing it, you know and saying you can't do this, you won't be able to do that and, don't worry about it as it comes up we'll deal with it." (P3).
199	3.1.2 Expertise
200 201 202	Participants described receiving advice from family and friends who had knowledge and expertise of diet and physical activity. In some cases, this was sought when support was lacking from healthcare professionals, for example with physical activity.
203 204 205	"I also have a, a fitness instructor for a sonhe had a booklet that had like exercisesso if they'd given me something like that to come home withI think that would be helpful" (P13).

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3.1.3 Influence

The behaviour of others influenced participants' ability to follow dietary advice in both positive and negative ways, for example the pressure to eat unhealthy meals prepared by others and the positive influence of health and wellbeing amongst friends and social media. When talking about diet and activity for a healthy lifestyle, establishing healthy behaviours with other people was important.

"When I want to lose weight [my wife] helps me and, ur, then she went on a diet and I joined her. We do it very much together" (P2).

3.2 Other transplant recipients

Participants had confidence in advice from other transplant recipients. Modelling of diet and activity behaviours by other recipients encouraged participants to implement advice.

"I got a lot of confidence from [other recipient] because he had his transplant the year before and then went to the transplant games...that's quite...inspiring. It made me think actually if he can do it then I can do it" (P8).

4. Symptoms, side effects and comorbidities

4.1 Symptoms and side effects

Participants described symptoms related to medication, the transplant surgery and liver disease as a barrier to implementing advice, for example, loss of appetite, taste changes, pain, fatigue, diarrhoea, nausea and vomiting. These were most common in the early post-transplant phase and improved for some as they recovered, however, for some ongoing or new symptoms continued to be a barrier for years.

Dietary restrictions due to transplant side effects, such as chyle leaks and hyperglycaemia, posed a challenge to finding suitable foods and meeting nutritional recommendations. In the early stages of recovery poor attention span and retention of information prevented participants from grasping and remembering advice.

"My brain was addled at the time ... I just wasn't taking anything in... I wasn't mentally able to grasp it all in one go" (P3).

233 234	Being physically incapable of activity and eating due to loss of strength and stamina was a barrier and contributed to low self-efficacy and negative emotions for some participants. However, being
235	malnourished and physically incapable could also motivate a desire to improve.
236	"I am probably more dedicated to doing it [exercise] because I want to get the muscle tone
237	back, you know, and I don't want to be on my knees at the top of a flight of stairs because
238	my muscles are so fatigued" (P13).
239	When appetite returned, a strong and difficult-to-control hunger drive that required large volumes of
240	food to satisfy and a change in food preference were described by some participants.
241	4.2 Co-morbidities
242	A range of co-morbidities were barriers to following advice. Some participants needed to avoid
243	certain foods to manage their co-morbidities and some were not able to undertake the recommended
244	levels of activity.
245	"Vegetables and fruit don't suit my ulcerative colitis" (P11).
246	"I don't do a great deal of physical activity because of the [retracted comorbidity] so I'm
247	very limited" (P3).
248	For others, comorbidities, such as diabetes, encouraged the adoption of healthy behaviours to
249	manage the condition.
250	5. Environmental influence
251	5.1 In hospital
252	In hospital there were physical barriers such as being attached to drip-stands, poor access to
253	supplement drinks and a lack of opportunity for upper body exercise. However, the environment
254	was also used as an opportunity to aid physical activity via goal setting and tracking progress.
255	"My aim was to try and get right around the, there's a little block you know where you go
256	all round the ward" (P5).
257	While some participants described good quality hospital food with a wide selection of options,
258	others reported their dislike of hospital food as a barrier to implementing dietary advice.
259	"The food was awful and I don't think that encourages appetite" (P9).

5.2 Recovery at home

Having greater control over food and more opportunity for activity at home, compared to hospital, 261 were described as facilitators. Walking was an activity available to all and used to promote 262 263 recovery. 5.3 Being physically active after recovery 264 Daily tasks of living that required physical exertion encouraged activity. 265 "[Physical activity] comes from things that need activity if you like, as opposed to looking 266 for it...mow the lawn, do some gardening, walk to the shop, just general activities" (P12). 267 The convenience of having a gym at work, the availability of interesting and accessible walks, 268 having a dog and good weather all facilitated activity. Bad weather and not having access to safe or 269 enjoyable walking routes were barriers. 270 "There's no pavements, just hedgerows, so it's difficult to sort of walk" (P12). 271 6. Coping 272 6.1 Threatened coping 273 274 Not recovering as expected threatened participants' ability to cope, which was a barrier to implementing advice. 275 "As time goes on you think when am I going to get better? When all this pain and effort, 276 when am I going to get pay back for that? ... you start to get depressed a little bit and that, of 277 course, affects your ability to eat" (P1). 278 6.2 Coping strategies 279 Achieving diet and activity goals, experiencing benefits of implementing advice, making progress 280 towards 'normal' and sharing experiences with other transplant recipients helped participants to 281 cope. 282 "Once I'd done the walk I felt so much better, I really felt brilliant, you know mentally as 283 well as physically I think, because you think you've achieved something" (P5). 284 "You're starting to get back to doing normal things, eating normal things, walking normally, 285 you start to enjoy life again" (P1). 286 Participants felt responsible to "make the most of the second chance" (P11) which gave them a 287 purpose and motivation with behaviours. For some, adopting healthy behaviours was described as a 288

289	way of regaining control of health, reducing the risk of future ill-health, caring for the donated liver
290	and respecting the donor.
291	"We've been told that, you know, we're high risk of diabetes, high risk of heart disease,
292	high risk of cancer so you just make sure you look after your health because I don't want
293	to be as ill as I wasI can control diet, exercise, you know, not all these other things
294	[medication side effects], so I should, I should try to." (P8)
295	Others did not feel able to consider the impact of their behaviours on their future health as this
296	threatened their ability to cope.
297	"My coping mechanism has been one of this is my liver, I haven't had a transplant, this is
298	my liver that's been with me all my life so therefore to change anything dramatically, um,
299	and lose that mind-set is something that I didn't want to do" (P12).
300	7. Returning to 'normal'
301	7.1 A desire to return to 'normal'
302	A desire to return to normal and the belief that diet and activity were important for this were
303	facilitators to implementing advice.
304	"I wanted to get on with life. I was walking around the block, and it was an effort but I made
305	the effort. I want to get back to something like normal as I used to be" (P1).
306	Some participants returned to their "usual" behaviours. Advice was easier to follow it was similar to
307	their "usual" behaviours.
308	"[Dietary advice] mostly chimed with what I was eating anyway healthy sort of lifestyle
309	and healthy food" (P10).
310	"I have a grounding in, on the exercise side of it because it's something that I've always
311	done" (P13).
312	Participants who found advice wasn't "usual" for them reported it was more difficult to follow. For
313	example, participants who were used to following healthy eating guidance found it challenging to
314	introduce snacks to help manage diabetes or high energy foods to treat undernutrition.
315	"I never used to pick and stuff like that after, sort of, 7, 8 o'clock at night anyway. And
316	when you get asked to eat, have something to eat, you know, just before you go to bed [for
317	diabetes controll, it just wasn't me" (P4).

Others described introducing healthier foods or increasing physical activity as challenging. 318 "Throughout life I haven't, but even, even pre transplant I wasn't exactly over 319 active... If you're not a particularly active person then, you know, you do what you 320 normally do, just live your life how you normally lived it" (P12). 321 7.2 A transition to 'normal' 322 For some participants, transitioning from the diet required for their liver disease and recovery to a 323 "normal" way of eating was challenging as the special diet had become the norm and an important 324 part of managing their condition. Additionally for some participants, coming to terms with a normal 325 body weight after being underweight for a prolonged period was challenging and they were slow to 326 realise when weight may have increased too much as gaining weight was primarily perceived as 327 positive and resolving malnutrition. 328 "Being so thin...you just get used to it, you stop telling yourself that it's so like alien and 329 now that I'm kind of normal sized it's dysmorphic in my mind You know because I had 330 to think the way that I looked when I was ill was kind of acceptable because, you know you 331 have to, and now that I do look acceptable, I try and tell myself that this is actually normal" 332 (P7). 333 However, other participants described no change in their dietary intake or need to adapt to a new 334 335 weight. **Discussion** 336 This study contributes new insight into the topic of diet and activity after liver transplant, providing 337 better understanding of both barriers and facilitators to receiving and implementing diet and activity 338 advice. Barriers included loss of confidence in abilities, fear, inadequate support and conflicting and 339 340 vague advice from healthcare professionals, negative social influence, low self-motivation, not believing in advice, not being willing to accept perceived costs of behaviour change, poor health 341 and slow recovery, a difficult transition from a diet suitable for liver disease to a normal diet, and 342 being slow to realise that weight gain was greater than recommended. 343 Facilitators included good support, encouragement and empathy from healthcare professionals, 344 individualised timely advice that was consistent across the multidisciplinary team, being capable of 345

determination, peer and social support and modelling, environmental opportunity, following advice

setting goals to progress, the belief that implementing advice would be beneficial, self-

as a way to cope, and experiencing benefits of implementing advice.

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The process of liver transplantation is medically and surgically complex and liver transplant 349 recipients follow diverse post-transplant recovery trajectories. Their wider health and social needs 350 are also complex and vary substantially between individuals. This diversity is reflected in the range 351 of responses received from participants. Results from this study highlight the potential for 352 353 individualising lifestyle advice. Facilitating recipients to set personalised goals might be a useful method to tailor support for behaviour change. Goal setting is an effective intervention to increase 354 activity in a diverse range of populations, including patients with chronic conditions and recovering 355 from cancer, but there is no published evidence in transplant populations (21). 356 As described in Self-Regulation Theory, individuals need to compare their behaviour to a desired or 357 acceptable standard in order to judge its appropriateness, and believe they are capable of change (22). 358 Our findings suggest inadequate support with, and guidance about, the type and timing of activity 359 that is safe after discharge from hospital is an important barrier that needs to be addressed to enable 360 self-regulation. Similarly, other qualitative research has found uncertainty about how to progress 361 activity due to participants' inability to assess the safety of exercise after liver transplant (23). van 362 Adrichem et al. (24) interviewed solid organ transplant recipients, including liver transplant, and 363 found incapability and fear of injury could be overcome with expertise and training from 364 365 physiotherapists. Participants expressed desire for more support with preventing excessive weight gain after 366 transplant. Post-transplant weight gain results in high levels of overweight and obesity and 367 associated health problems, therefore, there is a need for evidence-based interventions (8). This study 368 has identified factors that could facilitate weight management, for example helping patients to 369 accept a 'normal' body weight after being underweight and support with timely transition to healthy 370 eating. Participants described an excessive appetite during their recovery which was difficult to 371 control. This may help to understand the association between uncontrolled eating and weight gain 372 after liver transplant ⁽²⁵⁾. The cause of increased appetite post-transplant is not understood. 373 Hypotheses include recovery of malnutrition, hunger driven by immunosuppressive drugs (25), an 374 appetite disorder for example due to vagal nerve innervation due to the hepatectomy (26), and/or due 375 to addiction transfer (27). 376 Recipients require support with managing symptoms and side-effects of the transplant as these were 377 378 described as barriers to implementing advice. Some participants experienced resolution of their symptoms and side effects, whereas others experienced ongoing or new issues years after their 379 transplant. Dudley et al. (28) describes the liver transplant as "exchanging one health state for 380 another" (p.1301). Ongoing health problems left participants feeling out of control and threatened 381

their ability to cope with the transplant experience as their expectations of recovery had not been 382 met, and in turn influenced their behaviours (28). In a study exploring lived experience of liver 383 transplant, recipients used activity to manage their symptoms (29). Physical activity is associated 384 with better quality of life after liver transplant (30) and improvement in fatigue is experienced with 385 386 activity (31). Therefore, facilitating behaviour change may be an effective way for healthcare professionals to help patients adapt to or improve symptoms. 387 Participants' coping strategies influenced their behaviours. The desire to look after the transplanted 388 liver has also been identified as a source of motivation for healthy behaviours in other studies (10; 23). 389 However, we found that some participants did not feel able to consider the impact of their 390 behaviours on their health as this threatened their ability to cope. We found no quantitative research 391 with liver transplant recipients that investigates the influence of coping on health behaviours. In 392 research undertaken with other patient groups adaptive coping is associated with positive behaviour 393 change and maladaptive coping with negative behaviour change (32). The influence of coping 394 strategies on health behaviours after liver transplant merits further investigation, such as studying 395 the effectiveness of an intervention that teaches adaptive coping skills. 396 Doctors and surgeons develop trusting relationships with transplant recipients over many years and 397 are influencers as patients hold their advice in high regard. Doctors coordinate overall treatment 398 plans and have an important role with diet and physical activity care including recognising when 399 specialist dietetic and physiotherapy support is required (33). The role of dietitians and 400 physiotherapists is to translate the complex and nuanced nutrition and physical therapy science into 401 effective patient care to facilitate behaviour change. Our findings highlight the importance of this 402 403 multiprofessional involvement in nutrition and physical activity care as participants described need for consistent messages across the team and the value of diet and physical activity highlighted by 404 doctors and surgeons. 405 The positive influence from other transplant recipients on behaviours found in our study suggests a 406 peer support system could be a useful intervention for diet and activity behaviour change and merits 407 further investigation. Hickman et al. also report confidence with activity increased with role 408 modelling from other recipients (23). We identified no studies that have investigated the impact of 409 peer support on health behaviours in transplant populations. 410 Our findings suggest the support of relatives and friends influence behaviours, therefore including 411 them when providing diet and activity advice can be helpful. The provision of food by visitors was 412 described as a facilitator to nutritional intake during inpatient stay, particularly for those who did 413

not like the hospital food. Further investigation into how to optimise this support might be helpful,

for example the type of food provided by visitors and whether guidance should be provided so it 415 meets dietetic recommendations. 416 We found the physical environment could be both an enabler and barrier to following advice. The 417 importance of environment on behaviour is reflected in socioecological models of health promotion 418 (34) with most research focusing on the macro-environment, such as the neighbourhood (35). There is 419 limited evidence for the effectiveness of changes to the micro-environment, including the home and 420 hospital settings (36). For patients with cancer, environmental opportunity for activity in the hospital 421 is associated with the time spent in intentional physical activity (37). Equipment at home is correlated 422 with increased activity in patients with diabetes (38). Healthcare professionals are well placed to 423 enable patients to set up environmental opportunities and problem-solve environmental barriers that 424 are relevant to their individual situation. The effectiveness of interventions that modify the home 425 and hospital setting to promote behaviour change for transplant recipients is an area requiring 426 research. 427 Strengths and limitations 428 The strengths of this research include the development of the topic guide with input from transplant 429 recipients and healthcare professionals with appropriate expertise to ensure all relevant topics were 430 covered. An inductive approach allowed the interview topics to evolve and the interviewers to 431 explore experience in greater depth and breadth. The purposive sampling method ensured 432 participants with a range of diet and activity support needs were included. The researchers kept 433 reflexive diaries throughout the research process and the influence of their experiences, thoughts 434 and preconceptions on the research were carefully considered to minimise bias. 435 Study limitations include undertaking the research at a single transplant centre where practice may 436 not be representative across all centres. It would be valuable to triangulate these findings with wider 437 research involving other transplant centres. All the researchers were dietitians and the participants 438 were aware they were being interviewed by a dietitian. This could have led to social desirability 439 bias in their responses ⁽³⁹⁾. To minimise this the interviewers were independent of the participants' 440 care team. Patients who did not speak fluent English were excluded from the study which 441 represented approximately 3% of the study site's liver transplant recipient population. 442 443 **Conclusions** In conclusion, the barriers and facilitators to following diet and physical activity advice described 444 by liver transplant recipients varied between individuals and with their stage of recovery. The 445

variation expressed indicates a need for individually tailored advice that is delivered at a personally

- relevant time, which could be years after transplant, and in a manner that the patient finds
- acceptable. Consistent diet and activity advice that is reinforced by different members of the
- multidisciplinary team, but especially by doctors and surgeons, is important. The influence of
- family, friends and other patients on behaviours should be considered when providing advice.
- 451 Interventions that might facilitate behaviour change and merit further investigation include
- 452 individualised goal setting, improving coping strategies, peer support and modifying the hospital
- and home environment.

454 **Conflict of interest statement**

455 No conflicts of interest.

Transparency Declaration

- The lead author affirms that this manuscript is an honest, accurate, and transparent account of the
- 458 study being reported. The reporting of this work is compliant with SRQR guidelines. The lead
- author affirms that no important aspects of the study have been omitted and that any discrepancies
- 460 from the study as planned have been explained.

461 <u>References</u>

- 1. Merli M, Berzigotti A, Zelber-Sagi S *et al.* (2019) EASL Clinical Practice Guidelines on nutrition in chronic liver disease. *J Hepatol* **70**, 172-193.
- 2. Plauth M, Bernal W, Dasarathy S *et al.* (2019) ESPEN guideline on clinical nutrition in liver disease. *Clin Nutr* 38, 485-521.
- 3. Millson C, Considine A, Cramp ME *et al.* (2020) Adult liver transplantation: A UK clinical guideline part 1: pre-operation. *Frontline Gastroenterol*, flgastro-2019-101215.
- 4. Millson C, Considine A, Cramp ME *et al.* (2020) Adult liver transplantation: UK clinical guideline part
 2: surgery and post-operation. *Frontline Gastroenterol*, flgastro-2019-101216.
- 5. Krasnoff JB, Vintro AQ, Ascher NL *et al.* (2005) Objective measures of health-related quality of life over 24 months post-liver transplantation. *Clin Transplant* **19**, 1-9.
- 472 6. Jagielska A, Jankowski K, Okręglicka K *et al.* (2017) Lifestyle risk factors of non-communicable diseases
 473 among patients after liver transplantation a pilot study. *Family Medicine & amp; Primary Care Review* 474 19, 214-220.
- 7. Anastacio LR, Ferreira SC (2018) Nutrition, dietary intake, and eating behavior after liver transplantation.
 Curr Opin Clin Nutr Metab Care 21, 381-387.
- 8. Richards J, Gunson B, Johnson J *et al.* (2005) Weight gain and obesity after liver transplantation. *Transpl* Int 18, 461-466.
- 9. Fatourou EM, Tsochatzis EA (2019) Management of metabolic syndrome and cardiovascular risk after
 liver transplantation. *The Lancet Gastroenterology & Hepatology* 4, 731-741.
- 481 10. Forsberg A, Backman L, Moller A (2000) Experiencing liver transplantation: a phenomenological approach. *J Adv Nurs* **32**, 327-334.
- 11. Moayed MS, Khatiban M, Nassiri Toosi M et al. (2019) Barriers to Adherence to Medical Care Programs
 in Liver Transplant Recipients: A Qualitative Study. International journal of organ transplantation
 medicine 10, 115-126.
- 12. Craig P, Dieppe P, Macintyre S *et al.* (2008) Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ* **337**, a1655.
- 488 13. Sandelowski M (2000) Whatever happened to qualitative description? *Res Nurs Health* 23, 334-340.

- 489 14. Sandelowski M (2010) What's in a name? Qualitative description revisited. Res Nurs Health 33, 77-84.
- 490 15. Kulkla A (2000) *Social Constructivism and the Philosophy of Science*. 1e ed, *Philisophical issues in science*. Abingdon: Routledge.
- 492 16. Flick U, Kardorff Ev, Steinke I (2004) A Companion to Qualitative Research: Sage Publications Ltd.
- 493 17. O'Brien BC, Harris IB, Beckman TJ *et al.* (2014) Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* **89**, 1245-1251.
- 18. Saunders B, Sim J, Kingstone T *et al.* (2018) Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & quantity* **52**, 1893-1907.
 - 19. NVivo 11 QSR International (2015). https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home (accessed 30 August 2017
 - 20. Ritchie J, Lewis J, McNaughton Nicholls C et al. (2014) Qualitative research practice. A guide for social science students and researchers. 2e ed. London: Sage Publications ltd.
 - 21. McEwan D, Harden SM, Zumbo BD *et al.* (2016) The effectiveness of multi-component goal setting interventions for changing physical activity behaviour: a systematic review and meta-analysis. *Health Psychol Rev* **10**, 67-88.
 - 22. Kanfer FH, Gaelick L (1991) Self-management methods. In *Helping people change: A text book of methods*, pp. 305-360 [FH Kanfer and G A.P., editors]. New York: Pergamon Press.
 - 23. Hickman IJ, Coran D, Wallen MP *et al.* (2019) 'Back to Life'—Using knowledge exchange processes to enhance lifestyle interventions for liver transplant recipients: A qualitative study. *Nutr Diet* **76**, 399-406.
 - 24. van Adrichem EJ, van de Zande SC, Dekker R *et al.* (2016) Perceived Barriers to and Facilitators of Physical Activity in Recipients of Solid Organ Transplantation, a Qualitative Study. *PLoS One* **11**, e0162725-e0162725.
- 511 25. Ferreira SC, Penaforte FRO, Cardoso ASR *et al.* (2019) Eating behaviour patterns are associated with excessive weight gain after liver transplantation. *J Hum Nutr Diet* **32**, 693-701.
 - 26. Colle I, Van Vlierberghe H, Troisi R et al. (2004) Transplanted liver: Consequences of denervation for liver functions. The Anatomical Record Part A: Discoveries in Molecular, Cellular, and Evolutionary Biology 280A, 924-931.
- 27. Brunault P, Salamé E, Jaafari N et al. (2015) Why do liver transplant patients so often become obese?
 The addiction transfer hypothesis. Med Hypotheses 85, 68-75.
 - 28. Dudley T, Chaplin D, Clifford C *et al.* (2007) Quality of life after liver transplantation for hepatitis C infection. *Qual Life Res* **16**, 1299-1308.
 - 29. Vidnes TK, Wahl AK, Andersen MH (2013) Patient experiences following liver transplantation due to liver metastases from colorectal cancer. *Eur J Oncol Nurs* 17, 269-274.
- 522 30. Yang LS, Shan LL, Saxena A *et al.* (2014) Liver transplantation: a systematic review of long-term quality of life. *Liver Int* **34**, 1298-1313.
- 31. van den Berg-Emons RJ, van Ginneken BT, Nooijen CF *et al.* (2014) Fatigue after liver transplantation:
 effects of a rehabilitation program including exercise training and physical activity counseling. *Phys Ther* 94, 857-865.
- 527 32. Park CL, Edmondson D, Fenster JR *et al.* (2008) Positive and negative health behavior changes in cancer survivors: a stress and coping perspective. *J Health Psychol* **13**, 1198-1206.
- 33. Adamski M, Gibson S, Leech M *et al.* (2018) Are doctors nutritionists? What is the role of doctors in providing nutrition advice? *Nutr Bull* **43**, 147-152.
- 34. McLeroy KR, Bibeau D, Steckler A *et al.* (1988) An ecological perspective on health promotion programs. *Health Educ Q* 15, 351-377.
 - 35. National Institute for Health and Care Excellence (2018) Physical activity and the environment [NG90].
- 36. Kaushal N, Rhodes RE (2014) The home physical environment and its relationship with physical activity and sedentary behavior: A systematic review. *Prev Med* **67**, 221-237.
- 536 37. Chang IY, Yi E-S (2018) The influence of environmental constraints within hospitals on physical activity level of cancer patients. *Journal of exercise rehabilitation* **14**, 382-386.
- 38. De Greef K, Van Dyck D, Deforche B *et al.* (2011) Physical environmental correlates of self-reported
 and objectively assessed physical activity in Belgian type 2 diabetes patients. *Health Soc Care Community* 19, 178-188.
- 39. Collins M, Shattell M, Thomas SP (2005) Problematic Interviewee Behaviors in Qualitative Research.
 West J Nurs Res 27, 188-199.

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