

1 **A cross-sectional study exploring levels of physical activity and**
2 **motivators and barriers towards physical activity in**
3 **haemodialysis patients to inform intervention development.**
4

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6 **Abstract**
7

8 **Purpose:** To describe physical activity (PA) levels and motivators and barriers to PA among
9 haemodialysis patients and to identify an appropriate approach to increasing their PA.

10 **Methods:** A cross sectional mixed methods study conducted in a tertiary and satellite
11 haemodialysis unit. 101 participants aged 18 years and over, receiving regular haemodialysis
12 for at least four months, were recruited. Patients with recent hospital admission or acute
13 cardiac event were excluded. Participants completed health status (EQ-5D-3L™) and activity
14 (Human Activity Profile) questionnaires. A subgroup were invited to wear accelerometers
15 and wearable cameras to measure PA levels and capture PA episodes, to inform subsequent
16 semi-structured interviews on motivators and barriers. Semi-structured interviews were
17 analysed using the Framework Method informed by constructs of the Health Belief Model.

18 **Results:** 98/101 completed the study (66 male, 32 female). For 68/98 participants, adjusted
19 activity scores from the Human Activity Profile indicated ‘impaired’ levels of Physical
20 Activity; for 67/98 participants, the EQ-5D-3L indicated problems with mobility. Semi-
21 structured interviews identified general (fear of falls, pain) and disease specific barriers
22 (fatigue) to PA. Motivators included tailored exercise programmes and educational support
23 from health care professionals.

24 **Conclusions:** Participants indicated a need for co-development with healthcare professionals
25 of differentiated, targeted exercise interventions.
26

27 **Key words:** Renal dialysis, exercise, wearable devices, monitoring, interview, motivation

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30 **Introduction**

31 Physical activity (PA) is important for health. Maintaining PA in adult life reduces risk of
32 hypertension, maintains bone health, and supports muscular and cardiovascular fitness,
33 amongst other benefits [1]. Estimates suggest a quarter of adults are currently inactive, with
34 high levels of sedentary behaviour. There is strong evidence to suggest this contributes to the
35 growing burden of non-communicable diseases, including cardiovascular disease, diabetes
36 and chronic kidney disease (CKD) [1-8].

37 Approximately 2 million people have CKD stages 1-5 in England, United Kingdom (UK),
38 with approximately a further 1 million undiagnosed [9]. A minority develop end stage renal
39 disease (ESRD) and require renal replacement therapy (RRT). With improved diagnosis and
40 treatment, the prevalent RRT population is increasing [5]. Of the 61,256 patients receiving
41 RRT, 41% are receiving hospital haemodialysis (HD) [5]. HD patients have higher incidence
42 of heart failure, anaemia, fatigue, pain, depression and lower perceived quality of life
43 compared to the general population [11-12]. Studies also demonstrate reduced quality of life
44 and increased incidence of depression in patients attending hospital for HD [10].

45 Higher levels of PA in HD patients are associated with reduced mortality, muscle cramps,
46 cardiovascular instability and improved muscle function [13]. However, despite the well-
47 known benefits of PA, HD patients have lower levels of activity when compared with the
48 general population. This has been attributed to a wide range of physiological and psycho-
49 social factors [14-15]. The majority of published studies demonstrating functional benefits of
50 PA have been conducted in research environments. However, translating these into clinical

51 practice is challenging, with barriers to PA incompletely elucidated [16-17]. Whilst some
52 specific patient-perceived barriers to PA have been identified [18], it remains to be
53 established which factors may act as motivators towards PA. To overcome these barriers and
54 enhance motivators more effectively, the development of an intervention should incorporate a
55 suitable theory of behaviour change which can clearly identify the causes of change. In two
56 previous studies, the Health Belief Model (HBM) [19-20] has been used to understand the
57 health behaviours of renal dialysis patients [21-22].

58 The objectives of this study are to: 1) describe current PA levels and experiences in HD
59 patients and 2) explore perceptions of PA and the motivators and barriers which facilitate or
60 constrain exercise participation. This will inform co-development of targeted education and
61 PA interventions for renal dialysis patients.

62 **Methods**

63 Local ethics committee approval (Ref 14/EE/1094) was obtained and all patient-facing
64 members of the research team undertook Good Clinical Practice (GCP) training prior to study
65 commencement.

66

67 *Design, setting and participants*

68 This cross-sectional study was conducted in a tertiary and associated satellite renal unit in
69 Oxford, UK.

70

71 Between November 2014 and August 2015, all male and female participants aged 18 years
72 and above, established on HD for at least four months and attending at least twice a week
73 were invited to participate. Exclusion criteria were: unable to give consent, planning to leave
74 geographical area during study period, recent acute deterioration requiring hospital admission

75 or acute cardiac event within 2 days of most recent dialysis treatment. All eligible
76 participants were invited to complete the questionnaire and were informed that they could opt
77 out of the wearable device phase. Informed consent was obtained during a subsequent
78 dialysis session by a trained research team member. The study period was one week with no
79 further follow-up.

80

81 *Data collection and preparation methods*

82 *Self-Report Measures*

83 The EQ-5D-3L™ (Euro-Qol Group, Registration ID 23961) is a self-report health status
84 measure validated in the CKD population [23]. All participants were given the questionnaire
85 during a treatment session and asked to return it the same day, or at a subsequent session. The
86 first part of the EQ-5D-3L™ includes five domains: mobility, self-care, usual activities,
87 pain/discomfort and anxiety and depression. Each domain is scored as follows: 1) no
88 problems, 2) some problems, or 3) extreme problems. The second part is a self-rated visual
89 analogue scale (VAS) of 0-100, with 0 as the worst health state imaginable, and 100 as the
90 best. EQ-5D-3L™ data is presented by dimension and age group as described in the User
91 Guide [23].

92

93 The Human Activity Profile (HAP) is a self-report measure which ranks 94 activities
94 according to the energy expenditure needed to perform the task. The participant specifies
95 whether they currently do the activity, have stopped doing the activity or never did the
96 activity. From this, a maximal activity score (MAS) is obtained, based on the most energy-
97 expending activity that the respondent is still able to perform [24]. The adjusted activity score
98 (AAS) is calculated by totalling the number of activities with lower values than the MAS that

99 the respondent “has stopped doing” and subtracting this from the MAS. The AAS is generally
100 considered a more stable estimate of the individual’s daily activity than the MAS [24].

101

102

103 *Semi-structured interviews*

104 Participants were invited to participate in semi-structured interviews on the motivators and
105 barriers to physical activity. Interviews were conducted between April and July 2015 using a
106 topic guide (Supplementary material Table S1: Topic guide for semi-structured interviews)
107 informed by a previous pilot study [25]. Interviews were carried out in the haemodialysis
108 unit. Other settings (e.g. a clinic room) were offered but declined by all participants.

109 Interviews lasted approximately 40 minutes. Interviews were recorded on a digital recorder,
110 transcribed verbatim by SS and RP and transcripts uploaded to NVivo software (QSR
111 International, Melbourne, Australia) for analysis.

112

113 *Body worn devices*

114 Participants wore Axivity AX3 accelerometers [26-30] and Vicon Autographer wearable
115 cameras [31] for seven days prior to interview. Data obtained was used to inform the
116 interviews. Devices were time synchronised at point of issue and data downloaded to an
117 encrypted computer. Participants were given the opportunity to review and delete images,
118 using a custom software application, which is open-source and free to download [32]. Those
119 who participated in the interviews were given a brief questionnaire to assess the acceptability
120 of wearing these devices (Supplementary material Table S2: post study device acceptability
121 questionnaire). Accelerometer data were processed following UK Biobank data processing
122 guidelines [26].

123

124 Participants were asked about experiences of PA prior to commencing dialysis and current
125 feelings and attitudes towards PA. To prompt participants, the interviewer (SS and RP)
126 selected segments of accelerometer data indicating periods of high and low activity.
127 Participant and interviewer viewed corresponding time stamped images from the camera
128 wearable device. Participants were asked what they were doing at these times and for their
129 reflections on both high and low activity episodes. Previous studies have used images
130 captured by wearable cameras to aid participant memory recall [31-34].

131 Interviews were transcribed verbatim and analysed using the Framework Method [35] which
132 involved familiarisation with the interview, coding, developing and applying an analytical
133 framework, charting data into the analytical framework for analysis. The analytic framework
134 was developed by two researchers based on the constructs of the Health Belief Model [19-20]
135 – including perceived benefits of PA, perceived barriers to PA and cues to action on PA
136 participation – and informed by the themes which had emerged from a pilot focus group of
137 patients with CKD [25]. Interview transcripts were coded using NVivo software. Each
138 interview was independently coded by two reviewers (SS and RP). After coding four
139 transcripts, reviewers compared codes and discrepancies were discussed and resolved prior to
140 coding the remaining transcripts. Interim analysis was conducted following an initial sample
141 of 20 patients to determine whether saturation of themes had been reached [36].

142 ***Statistical analysis***

143 Mean (+/-standard deviation) or median and interquartile range values were used as
144 appropriate to summarise participants' demographic data. Primary diagnoses are summarised
145 as numbers and percentages.

146 **Results**

147 Of 154 eligible participants, 101 (66%) consented to participate. Of these, a total of 98 (97%)
148 participants completed the study, 1 withdrew, 1 received a transplant and 1 did not complete
149 the questionnaires and was excluded from analysis (See figure 1). A sub-group of 20
150 participants consented to the wearable camera and accelerometer and participated in a semi-
151 structured interview.

152

153 [Figure 1 near here]

154

155 Participant baseline characteristics are shown in table 1. There was no significant difference
156 between the non-interview group and the interview group for these characteristics.

157

158 [Table 1 near here]

159

160 ***Self-Report Measure of Health Status***

161 98 participants completed the EQ-5D-3L™. Pain (n=67, 68%), mobility (n=67, 68%) and
162 usual activities (n=64, 65%) were dimensions in which participants experienced some or
163 major problems. Dimensions of self-care (n=23, 23%) and anxiety (n=36, 37%) indicated
164 better health states in which participants indicated they had some or extreme problems
165 (Supplementary table S3: Results from EQ-5D-3L™). Median VAS score was 60/100 (IQR
166 +/- 30).

167

168 ***Self-report Measures of Activity***

169 98 participants completed the HAP questionnaire. Sixty-nine (68%) had impaired PA levels
170 overall, 23 (23%) participants were moderately active and only 6 (6%) were active according

171 to AAS (Supplementary Table S4: Results from Human Activity Profile). Forty nine (50%)
172 participants had an AAS indicating impaired activity. Activities that patients continued to
173 participate in included: 1) for the impaired: household activities such as bed making, carrying
174 light shopping, and able to climb 9-12 stairs; 2) for the moderately active: household chores
175 such as vacuuming, able to walk for 1 mile; and 3) for the active: gardening, swimming and
176 cycling.

177

178 ***Self-report Measure of Acceptability of Worn Devices***

179 Mean daily accelerometer wear time amounted to 8.15 hours and ranged from 3-7 days.

180 Twenty participants completed the device acceptability questionnaires and 18 found device
181 wear acceptable overall. However, concerns included forgetting to wear the devices (8/20),
182 discomfort (2/20) and reactions of others towards the camera (17/20).

183 ***Semi Structured Interviews on Motivators and Barriers to PA***

184 Following analysis of 20 semi-structured interview transcripts it was determined that
185 saturation of themes had been reached. Key themes included: 1) Limited belief in the
186 benefits of PA for dialysis patients, 2) The view that PA is incompatible with dialysis 3) The
187 perception that PA presents specific risks for patients on dialysis and 4) The need for external
188 prompts to engage in PA. These themes are organised under headings based on the constructs
189 of the Health Belief Model and illustrated by representative participant quotes.

190

191 ***1) Perceived benefits of increased PA***

192 ***(i) Mixed views on the benefits of PA for dialysis patients:***

193 Many participants were aware of the benefits of PA in general, commenting that they had
194 enjoyed PA prior to their illness and that it was important to keep active in order to stay well
195 and maintain their independence. However, nine (45%) participants (5 female, age range 35-

196 73, and 4 male, age between 36 and 84) found difficulty in identifying benefits that might
197 arise from increasing PA and some expressed the view that PA offered little or no benefit for
198 patients on dialysis.

199

200 *“ I don’t think it [PA] would make any difference.....You’re limited in what you can*
201 *do. You know you are coming here for treatment basically. ”* (Participant 35, female,
202 aged 73)

203

204 **2) Perceived barriers to increased PA**

205 *(i) The demands of PA are incompatible with dialysis:*

206 Most participants found that dialysis reduced motivation to undertake PA, including some
207 who felt that if the opportunity arose, they would not take it: Twelve participants (60%) (5
208 female aged 53 to 73 and 7 male aged 36 to 82) believed dialysis reduced their capacity to
209 continue with regular physical activities or muscle wasting.

210

211 *“...you can’t do much especially when you are in a dialysis centre.....dialysis comes in*
212 *and dominates your life a bit...”* (Participant 10, male, aged 80)

213

214 Concern that something may happen to their fistula (dialysis access) if they exercised during
215 dialysis was common. Tiredness was also commonly perceived as a barrier: seventeen
216 participants (85%) (8 female age 35 to 74 and 8 male aged 36 to 82) reported they felt too
217 tired to participate in PA especially on dialysis days.

218

219 *(ii) PA presents a risk for patients on dialysis:*

220 Fourteen (70%) participants on dialysis (6 female aged 35 to 74 and 8 male aged 36 to 82)
221 feared that PA would cause further pain or other adverse consequences. Six (30%)
222 participants (2 female aged 53 and 74 and 4 male aged 54 to 82) found that their fear of
223 falling limited daily activities including walking, although others felt less at risk if they used
224 a stick or other mobility aid.

225 **3) Cues to Action on PA**

226 Some participants reported a desire to engage in more PA and suggested the circumstances in
227 which they would feel more able to do so.

228

229 *(i) PA designed specifically for patients on dialysis:*

230 Seven participants (35%) (3 female aged 53 to 67, 4 male aged 39 to 75) identified the need
231 for tailored, professional help in increasing PA specifically for dialysis which was currently
232 lacking for most participants.

233

234 *“ I think nobody’s sort of helping me with that sort of thing [PA]. No-one is helping*
235 *you to do these things or suggesting doing these things.....I would like more outside*
236 *activity.” (Participant 62, male, aged 68)*

237

238 Others wanted tailored support in maintaining a sense of community and social engagement
239 while continuing in paid employment.

240

241 *(ii) PA supervised by experienced trainer:*

242 Ten participants (50%) (5 female aged 53 to 74, 5 male aged 39 to 82) said that they would
243 like to be offered more physiotherapy, stretching or rehabilitation exercises as these would be
244 suitable to their physical needs. Some had experienced rehabilitation support from previous

245 hospital inpatient admission and felt they would have benefitted from more. They also
246 pointed to the need for supervision, for example by a physiotherapist in a healthcare setting,
247 their own home or another designated area that was not a public space, and suggested that
248 demonstrating the exercises in a group or on a one-to-one basis would also be helpful. Only
249 two participants (10%) (1 female aged 46 and 1 male aged 39) mentioned that they would
250 prefer to attend a gym.

251

252 *(iii) PA in the company of friends:*

253 Eleven participants (55%) (4 female aged 53 to 74 and 8 male aged 36 to 82) felt that having
254 someone to participate in PA with them would be beneficial and motivational and would help
255 maintain a normal lifestyle and sense of community outside of dialysis. Support from family
256 members and good relationships with healthcare professionals were also identified as
257 potentially important cues to action as was the offer of an exercise bicycle on their dialysis
258 days.

259 **Discussion**

260 This study has brought together data from self-report questionnaires, semi-structured
261 interviews and quantitative activity data, to provide greater insight into current activity levels
262 and perceptions of PA among HD patients. We found, as previous studies [37-38] have, that
263 despite being active prior to starting dialysis, this population currently has low overall
264 activity levels with high sedentary behaviour. Non-specific symptoms such as pain and fear
265 of falling and no reason to leave the house were perceived to limit PA, as well as CKD
266 specific barriers such as and muscle wasting. These barriers were identified by both male and
267 female participants across the age range. Some participants did not want to exercise or
268 engage in PA due to perceived poor health, a lack of time due to dialysis commitments or the

269 view that PA would not benefit their wellbeing. Participants also reported that there was
270 limited provision of, or access to, appropriate PA classes or groups suggesting a need for
271 information of suitable PA opportunities or adjustments to existing exercise environments.
272 Five participants were concerned about their fistula if they exercised during dialysis and
273 some also reported a reluctance to engage in public classes as they were worried about
274 changes in their blood pressure would lead to dizziness. Our findings add to previous studies
275 where time constraints associated with dialysis and worries about fistulas[39] were identified
276 as reducing motivation to engage in PA [17].

277 Our observations further augment existing evidence suggesting that information and guidance
278 for renal patients on how best to look after their fistula when exercising would enable them to
279 be more active in the community or at home. Participants further report the need for support
280 from either PA instructors or their family to initiate, continue and adapt a structured and safe
281 exercise programme on dialysis and at home.

282

283 Wearable cameras and accelerometers have been used in previous studies both in healthy and
284 disease cohorts [40-42]. To our knowledge, this was the first time accelerometers and
285 cameras have been used together in dialysis patients. Participants found these methods of data
286 collection acceptable. Some reported difficulties in remembering to turn the camera on/off.
287 Feedback suggested it would be helpful to have a light on the wearable camera to confirm
288 whether the device was on or off. Participants had minimal issues with the accelerometer
289 although some forgot to wear the device. Use of wearable cameras in image-based research
290 and health behaviour research can be deemed intrusive. Participants were able to block the
291 camera with a swivel lens to ensure privacy. While this may reduce the volume of data
292 collected, it provides autonomy in research participation [43]. Wearable cameras are
293 currently the most objective method to capture and identify episodes of PA behaviour [40]

294 [43]. The research team found camera images were useful prompts to engage participants and
295 add context to interviews.

296

297 Interviews identified a number of modifiable factors such as individualised support and
298 educational approaches that could increase PA. Current strategies to engage HD patients in
299 PA are broad and include counselling by nephrology staff and referrals for physical therapy,
300 routine care planning and follow up assessments of physical functioning [44]; however,
301 effectiveness of these strategies remains inadequately described [45]. Our findings indicate
302 that health professionals may be necessary to support patients engaging in PA on non-dialysis
303 days as well as dialysis days. Most current research focuses on intra-dialytic PA interventions
304 and research on factors affecting PA participation outside the clinical environment is essential
305 to develop these interventions [46] so they are efficacious in real-world settings. Walking
306 programs have been found to improve post-dialysis fatigue, and exercise rehabilitation
307 programs have improved general physical function [16][47] suggesting a place for combined
308 programs which incorporate both general mobility and strength and conditioning
309 components. Our findings support an approach towards PA management in HD that is
310 individualised and guided by professionals with expertise in HD. The British Renal Society
311 Rehabilitation Network [48] has a roll in informing and supporting renal clinicians and health
312 professionals including the implementation of PA strategies such as intradialytic cycling [13].
313

314 Dialysis patients have indicated they would benefit from the involvement and encouragement
315 of healthcare professionals (HCPs). However, not all HCPs have the appropriate skills and
316 knowledge to provide support and advice to renal patients regarding safe exercise
317 participation [49] and this would be needed [46]. With up to three times a week contact with
318 HCPs, there is an opportunity here to engage with this patient group in a sustainable way.

319 Education is needed for both patients and their carers about the benefits of PA and that it is
320 safe for HD patients.

321 Our findings highlight individual motivators, and the importance of determining what matters
322 to each person in order to tailor PA preferences appropriately. For example, PA enables HD
323 patients to do their own activities of daily living (ADLs), or spend more time out and about in
324 the community. Future clinical interventions should focus, in addition to intradialytic cycling,
325 on activities that patients can do outside the dialysis clinic setting such as exercise
326 programmes but studies on appropriate types of exercise are needed [46].

327 The dialysis clinic provides the opportunity to monitor patient progress but also the
328 opportunity for activity. Active promotion of PA in dialysis units involves sharing positive
329 and good practice at local, regional and national level. For example, the BRS rehabilitation
330 network is a leading online resource for kidney patients on the benefits of PA and the
331 provision of tailored exercise prescriptions. However, our findings suggest there is a need for
332 professional support and guidance as part of this approach so that patients know their exercise
333 is beneficial and safe.

334

335 ***Limitations***

336 Our region may not be representative of the HD population in other geographical regions.
337 The interview sub-study recruited a small non-random sample who were all Caucasian and
338 may not represent views or experience of other the wider population. Activity monitoring
339 devices had poor wear-time compliance. Self-report PA questionnaires may be prone to recall
340 bias.

341 **Conclusion**

342 Our participants reported low overall activity levels with high levels of sedentary behaviour,
343 and perceived both general and disease-specific barriers to PA. There is a need for education
344 regarding the benefits of PA for dialysis patients and ways of undertaking PA safely, with the
345 support of carers and HCPs. Our findings suggest the need for the co-development and co-
346 implementation of tailored PA interventions, delivered with the support of an experienced
347 instructor on dialysis or non-dialysis days, or both, to support CKD/HD patients to increase
348 their PA levels.

349

350

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356

357 **Declaration of interest**

358 The authors report no declarations of interest.

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368

369

370 **Contributorship Statement**

371 SS, RP, AD, CWP and JN were involved in the design of the study. SS and RP over saw the
372 Data Collection. SS, RP, AD, ZM, MB, HD, CWP and JN were involved in data analysis and
373 interpretation. SS, RP, AD, ZM, MB, HD, CWP and JN were involved in drafting the article.
374 SS, RP, AD, ZM, MB, HD, CWP and JN were involved in the critical revision of this
375 manuscript.

376

377

378

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380 **Data Sharing Statement**

381 Will individual participant data be available (including data dictionaries)?

382 No

383

384 What data in particular will be shared?

385 None, as our NHS ethics granted in 2014 states that "The images, along with other study data
386 (except participant ID) will be viewable only to identified members of the research team."

387

388 What other documents will be available?

389 Study protocol

390

391 When will data be available (start and end dates)?
392 Beginning immediately after publication, and ending 3 years after article publication

393

394 With whom?

395 Researchers who provide a methodologically sound proposal.

396

397 For what types of analyses?

398 Any health-related research deemed to be in the public good.

399

400 By what mechanism will data be made available?

401 Please contact Sutherland Sheera (RTH) OUH <Sheera.Sutherland@ouh.nhs.uk> who can
402 send the protocol by email.

403

404

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549 Table 1: Characteristics of study participants

	Non Interviewed Group(n=78)	Interviewed Group (n=20)
Male: Female	55:23	11:9
Age, years median (IQR)	68 (55-79)	59.7 (47-74)
RRT Vintage months, median (IQR)	42 (18-102)	48 (18-120)
HD Vintage months, median (IQR)	24.5 (6-51.7)	23.5 (7-54.7)
<i>Ethnicity</i>		
Caucasian	63	20
Black	9	0
South Asian	6	0
Other	0	0
<i>Primary Diagnosis</i>		
Glomerulonephritis/ IgA Nephropathy/ FSGN	14 (18%)	5
Diabetic Nephropathy	18 (23%)	3
Hypertensive/Renovascular	7 (9%)	0
Polycystic Disease	1 (1%)	2
Pyelonephritis	2(3%)	2
Renal Dysplasia	1 (1%)	0
Other or Unknown	35(49%)	8

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RRT= Renal Replacement Therapy, HD = Haemodialysis, IQR = Interquartile Range

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FSGN = Focal Segmental Glomerulonephritis

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554 **Figure 1:** Progression of study. In the non-camera group, one patient withdrew due to a decline in
555 health. One voluntary withdrew as they received a kidney transplant during the study. 1 did not
556 return pre-intervention HAP questionnaire.

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154 eligible patients of whom 110 were invited to participate in study ($n=110$)

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Informed consent obtained ($n=101$)

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Participants completed pre-intervention HAP and EQ5D3L questionnaires ($n=98$)

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Subgroup consented to wear camera and wrist worn accelerometer and interview
($n=20$). Devices asked to be worn for 7 days.

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Wearable devices downloaded on same dialysis day of return

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Semi structured interviews completed ($n=20$)

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Post intervention HAP and EQ5D questionnaires completed ($n=20$)
Patient device and satisfaction questionnaire completed ($n=20$)

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Semi structured interviews coded and camera data annotated by 2 independent
researchers

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