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

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Abstract

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

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

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

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

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

Abstract Word count: 200
Main Body: 3429

Introduction

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

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

Higher levels of PA in HD patients are associated with reduced mortality, muscle cramps, cardiovascular instability and improved muscle function [13]. However, despite the well-known benefits of PA, HD patients have lower levels of activity when compared with the general population. This has been attributed to a wide range of physiological and psycho-social factors [14-15]. The majority of published studies demonstrating functional benefits of PA have been conducted in research environments. However, translating these into clinical practice is challenging, with barriers to PA incompletely elucidated [16-17]. Whilst some specific patient-perceived barriers to PA have been identified [18], it remains to be established which factors may act as motivators towards PA. To overcome these barriers and enhance motivators more effectively, the development of an intervention should incorporate a suitable theory of behaviour change which can clearly identify the causes of change. In two previous studies, the Health Belief Model (HBM) [19-20] has been used to understand the health behaviours of renal dialysis patients [21-22].

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

Methods

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

Design, setting and participants

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

Between November 2014 and August 2015, all male and female participants aged 18 years and above, established on HD for at least four months and attending at least twice a week were invited to participate. Exclusion criteria were: unable to give consent, planning to leave geographical area during study period, recent acute deterioration requiring hospital admission or acute cardiac event within 2 days of most recent dialysis treatment. All eligible participants were invited to complete the questionnaire and were informed that they could opt out of the wearable device phase. Informed consent was obtained during a subsequent dialysis session by a trained research team member. The study period was one week with no further follow-up.

Data collection and preparation methods

Self-Report Measures

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

The Human Activity Profile (HAP) is a self-report measure which ranks 94 activities according to the energy expenditure needed to perform the task. The participant specifies whether they currently do the activity, have stopped doing the activity or never did the activity. From this, a maximal activity score (MAS) is obtained, based on the most energy-expending activity that the respondent is still able to perform [24]. The adjusted activity score (AAS) is calculated by totalling the number of activities with lower values than the MAS that the respondent “has stopped doing” and subtracting this from the MAS. The AAS is generally considered a more stable estimate of the individual’s daily activity than the MAS [24].

Semi-structured interviews

Participants were invited to participate in semi-structured interviews on the motivators and barriers to physical activity. Interviews were conducted between April and July 2015 using a topic guide (Supplementary material Table S1: Topic guide for semi-structured interviews) informed by a previous pilot study [25]. Interviews were carried out in the haemodialysis unit. Other settings (e.g. a clinic room) were offered but declined by all participants. Interviews lasted approximately 40 minutes. Interviews were recorded on a digital recorder, transcribed verbatim by SS and RP and transcripts uploaded to NVivo software (QSR International, Melbourne, Australia) for analysis.

Body worn devices

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

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

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

Statistical analysis

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

Results

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

[Figure 1 near here]

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

[Table 1 near here]

Self-Report Measure of Health Status

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

Self-report Measures of Activity

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

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

Self-report Measure of Acceptability of Worn Devices

Mean daily accelerometer wear time amounted to 8.15 hours and ranged from 3-7 days. Twenty participants completed the device acceptability questionnaires and 18 found device wear acceptable overall. However, concerns included forgetting to wear the devices (8/20), discomfort (2/20) and reactions of others towards the camera (17/20).

Semi Structured Interviews on Motivators and Barriers to PA

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

1) Perceived benefits of increased PA

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

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

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

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

2) Perceived barriers to increased PA

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

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

> '*'...you can't do much especially when you are in a dialysis centre.....dialysis comes in and dominates your life a bit…''* (Participant 10, male, aged 80)

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

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

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

3) Cues to Action on PA

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

(i) PA designed specifically for patients on dialysis:

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

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

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

(ii) PA supervised by experienced trainer:

Ten participants (50%) (5 female aged 53 to 74, 5 male aged 39 to 82) said that they would like to be offered more physiotherapy, stretching or rehabilitation exercises as these would be suitable to their physical needs. Some had experienced rehabilitation support from previous hospital inpatient admission and felt they would have benefitted from more. They also pointed to the need for supervision, for example by a physiotherapist in a healthcare setting, their own home or another designated area that was not a public space, and suggested that demonstrating the exercises in a group or on a one-to-one basis would also be helpful. Only two participants (10%) (1 female aged 46 and 1 male aged 39) mentioned that they would prefer to attend a gym.

(iii) PA in the company of friends:

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

Discussion

This study has brought together data from self-report questionnaires, semi-structured interviews and quantitative activity data, to provide greater insight into current activity levels and perceptions of PA among HD patients. We found, as previous studies [37-38] have, that despite being active prior to starting dialysis, this population currently has low overall activity levels with high sedentary behaviour. Non-specific symptoms such as pain and fear of falling and no reason to leave the house were perceived to limit PA, as well as CKD specific barriers such as and muscle wasting. These barriers were identified by both male and female participants across the age range. Some participants did not want to exercise or engage in PA due to perceived poor health, a lack of time due to dialysis commitments or the view that PA would not benefit their wellbeing. Participants also reported that there was limited provision of, or access to, appropriate PA classes or groups suggesting a need for information of suitable PA opportunities or adjustments to existing exercise environments. Five participants were concerned about their fistula if they exercised during dialysis and some also reported a reluctance to engage in public classes as they were worried about changes in their blood pressure would lead to dizziness. Our findings add to previous studies where time constraints associated with dialysis and worries about fistulas[39] were identified as reducing motivation to engage in PA [17].

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

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

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

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

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

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

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

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

Limitations

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

Conclusion

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

Acknowledgments

To all the patients at the Oxford Kidney Unit who participated in this study. Dr Khzir Nawab-Oxford University Hospitals NHS Foundation Trust, Dr Patrick Esser-Oxford Brookes University, Dan Jackson- Newcastle University, Dr Clare MacEwen and Sven Hollowell-Nuffield Department of Population Health.

Declaration of interest

The authors report no declarations of interest.

SS acknowledges the support and funding of the NIHR RCF Grant number A13/052. SS and RP acknowledge the support and funding of Oxfordshire Health Services Research Committee Grant. The analysis was supported by the British Heart Foundation Centre of Research Excellence at Oxford (http://www.cardioscience.ox.ac.uk/bhf-centre-of-research-excellence) [Grant Number RE/13/1/30181 to AD]. HD is supported by Elizabeth Casson Trust, Health Education Thames Valley and the Oxford Medical Research Centre. The research was also supported by the National Institute for Health Research (NIHR)

Oxford Biomedical Research Centre (BRC). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Contributorship Statement

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

Data Sharing Statement

Will individual participant data be available (including data dictionaries)?
No

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

What other documents will be available?
Study protocol

When will data be available (start and end dates)?

Beginning immediately after publication, and ending 3 years after article publication

With whom?

Researchers who provide a methodologically sound proposal.

For what types of analyses?

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

By what mechanism will data be made available?

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

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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)
Ethnicity		
Caucasian	63	20
Black	9	0
South Asian	6	0
Other	0	0
Primary Diagnosis		
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

RRT= Renal Replacement Therapy, HD = Haemodialysis, IQR = Interquartile Range
FSGN = Focal Segmental Glomuleronephritis

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