BMJ Open Cultural influences on physical activity and exercise beliefs in patients with chronic kidney disease: 'The Culture-CKD Study'—a qualitative study

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ABSTRACT

Objectives This study used a mixed-method approach to explore cultural and ethnic influences on the perception of, and decision to engage with or not to engage with, physical activity and exercise therapy in patients with chronic kidney disease (CKD).

Design Qualitative research was conducted through the use of semistructured interviews and focus groups. Selfreported physical activity levels were measured using the General Practice Physical Activity Questionnaire (GPPAQ), and self-efficacy for exercise with Bandura's Self-Efficacy for Exercise Scale.

Setting This study was conducted in a non-clinical setting of a single National Health Service Hospital Trust between April 2018 and July 2019.

Participants Participants >18 years of age with a diagnosis of CKD, from black African, black Caribbean, South Asian or white ethnicity were eligible for the study. 84 patients with a diagnosis of CKD (stages 2-5), aged 25-79 (mean age 57) were recruited. Semistructured interviews (n=20) and six single-sex, ethnic-specific focus group discussions were undertaken (n=36).

Outcomes Primary outcome was to explore the perceptions, attitudes and values about exercise and physical activity in different ethnic groups through qualitative interviews, analysed using an inductive thematic analysis approach. Questionnaires were analysed using Pearson correlation to determine if there was a significant relationship between the self-efficacy and GPPAQ levels.

Results Qualitative analysis provided four primary themes: I am who I am, Change of identity, Influences to physical activity and exercise and Support and education. Quantitative analysis using Pearson correlation revealed a significant correlation between GPPAQ levels of activity and self-efficacy to regulate exercise behaviour (r=-0.40, p=0.001).

Conclusion Understanding the cultural, attitudes and beliefs of individuals with CKD from a variety of ethnic backgrounds is complex. Understanding of patients' experiences, thoughts and beliefs may be of relevance to clinicians when designing CKD

Trial registration number NCT03709212: Pre-results.

BACKGROUND

Chronic kidney disease (CKD) affects 1 in 10 people worldwide. CKD is associated

Strengths and limitations of this study

- ► The exploration of how culture shapes beliefs about exercise and physical activity for individuals with a diagnosis of chronic kidney disease (CKD) from a variety of ethnic backgrounds may aid clinicians to create culturally sensitive, individualised exercise prescriptions.
- The methodological strength of this study was utilising a mixed-method approach, including both semistructured interviews, focus group data and quantitative measures.
- This study was conducted in a single centre in an area which has a diverse ethnic population, and therefore cultural and ethnic views may not be be generalisable to the wider CKD population.

with increased risk of cardiovascular disease (CVD), reduced quality of life (QOL), 2 decreased physical function and muscle wasting. CVD remains the leading cause of death for individuals with CKD.³

Certain ethnic minorities have been found to be at higher risk of developing CKD. 45 In the UK, people from ethnic minority groups are more likely to suffer from obesity, type-2 diabetes and hypertension, which are all risk factors for developing CKD.⁶ As kidney disease progresses, individuals from ethnic minorities are three to five times more likely to start dialysis than Caucasians. In the UK, over a third of people waiting for a kidney transplant are from ethnic minority communities, while donors from these groups only make up 7.2% of the National Health Service (NHS) Organ Donor Register.7

There is a broad body of evidence to highlight the benefits of physical activity (PA) and exercise within the general CKD population, including positive outcomes on cardiovascular health, physical function and QOL.8 The American College of Sports Medicine



Canada

guidelines recommend that all patients with CKD (patients with CKD not on dialysis, as well as those on haemodialysis and peritoneal dialysis (PD)) perform aerobic exercise training at mild-to-moderate strength (40%–60% of VO₉ _{neak}) for 20-60 min/day for 3-5 days/week. These guidelines also recommend resistance exercise training for these patients, at 70%-75% of one-repetition maximum for a minimum one set of 10–15 repetitions on 2–3 days/ week. The National Kidney Foundation Kidney Disease Outcome Quality Initiative guidelines recommend that individuals diagnosed with CKD should engage in a PA programme for 30 min, 5 days per week. ¹⁰ Typically, people with CKD report high levels of physical inactivity, 11 and a number of barriers have been identified that may influence engagement with exercise training including poor health, fear of injury, lack of guidance from healthcare professionals and a lack of facilities. 12

A recent study undertaken by our research team, evaluating an exercise intervention with kidney transplant recipients, revealed that 11 of the 18 individuals who did not complete the intervention were from ethnic minorities. ¹³ Participant feedback identified that potential challenges involved undertaking exercise in a mixed gender group, where culturally appropriate clothing was essential. ¹³ Given overall low levels of PA in the CKD population, ¹⁴ ¹⁵ it is imperative that ways are established to engage all individuals with CKD with lifestyle changes that can facilitate an adherence with current guidelines.

A number of studies have evaluated the influence of cultural beliefs on engagement with PA in the general population. Others have evaluated the cultural influence on PA in cardiac rehabilitation programmes in the USA. To our knowledge no studies have evaluated the influence of culture and ethnicity on engagement with PA in people living with CKD.

Reducing health inequalities, particularly preventing the development and progression of kidney disease may help alleviate the burden of care to the NHS. ¹⁸ ¹⁹ One of the research strategies highlighted by the UK Kidney Research Consortium is to address health inequalities by increasing our understanding of the barriers for people in different ethnic groups to accessing high-quality care for CKD, and its risk factors. ¹⁹ ²⁰

Understanding the beliefs and cultural influences towards PA and exercise in ethnic minorities with a diagnosis of CKD is essential to ensure that interventions are designed to be culturally sensitive, and are appropriate and accessible for all people living with CKD in the UK. The aim of this study was to explore cultural and ethnic influences on the perception of, and decision to engage with or not to engage with, PA and exercise therapy in patients with CKD.

METHODS Objectives

To explore cultural and ethnic influences on the perception of, and decision to engage with or not to engage

| | Occupation | | | |
|---|------------------------|------------------------|----------------------|--------------|
| Physical exercise and / or cycling (hr/wk) | Sedentary | Standing | Physical | Heavy Manual |
| 0 | Inactive | Moderately Inactive | Moderately Active | Active |
| Some but < 1 | Moderately Inactive | Moderately Active | Active | Active |
| 1-2.9 | Moderately Active | Active | Active | Active |
| ≥ 3 | Active | Active | Active | Active |

Figure 1 Summary of the General Practitioner PA Questionnaire Physical Activity Index Scoring.²¹

with, PA and exercise therapy in patients with CKD. This included individuals of Black African (BA), Black-Caribbean (BC), South Asian (SA) and White (W) ethnicity. Individuals from these ethnic groups were selected, as the most widely represented ethnicities at this NHS Hospital Trust.

Study design

Qualitative data were collected utilising individual semistructured interviews (SSIs) and focus groups. SSIs were conducted in the first instance. Gender and ethnically specific focus groups were included to further probe how culture shapes beliefs about exercise and PA in order to create a deeper understanding of the perceptions surrounding this. Study protocol can be viewed through online supplemental material S1.

All participants independently completed the General Practitioner Physical Activity Questionnaire (GPPAQ), and Self-Efficacy for Exercise Behaviours (SEE) Scale, prior to attending the SSI or focus groups. This was to establish participants prior engagement in PA, as well as to facilitate purposive sampling, with different levels of PA and exercise represented in the data.

GPPAQ was utilised as a self-reporting measure to evaluate levels of PA and occupation, reported over the past week. It involves three questions, and provides a simple, 4-level PA Index (PAI) categorising patients as active, moderately active, moderately inactive and inactive. Figure 1 describes the scoring algorithm. The GPPAQ is a validated screening tool utilised in primary care settings, as well as being validated within the CKD population in comparison to accelerometery. The GPPAQ can accurately identify those not sufficiently active, identifying individuals most at need of a PA intervention. As a self-reporting measure to evaluate the provides a sufficiently active, identifying individuals most at need of a PA intervention.

The SEE scale, provided information on each participant's readiness to commence exercise. Self-efficacy scales for eating and exercise behaviours show evidence of being reliable and valid in the literature. The questionnaire consisted of 18 questions utilising a Likert scale between 0 and 100, with 0 being low confidence and 100 high confidence. Score was calculated by adding the total score in order to gain a cumulative total. Scores were categorised into low (0–600), medium (601–1200) and high (1201–1800).



Sample and setting

Recruitment occurred between and July 2019. Individuals aged 18 years of age and over, with a diagnosis of CKD, representative of one of following ethnic groups; BA, BC, SA, and W were considered eligible for inclusion. CKD was defined as abnormalities of kidney function or structure present for more than 3 months. ²⁶ The definition of CKD includes all individuals with markers of kidney damage, or those with an Estimated Glomerular Filtration Rate (eGFR) of <60 mL/min/1.73 m² on at least two occasions 90 days apart (with or without markers of kidney damage). ²⁶ Individuals with an uncontrolled medical or psychiatric condition were excluded.

Participants

Participants were identified using purposive sampling, to ensure that the sample included participants from a range of ethnic backgrounds, age, gender, renal modality and stage of CKD. Individuals were screened and approached during routine nephrology outpatient clinical appointments at a single NHS hospital trust. Ethnicity and gender were established from medical records, and confirmed on initial discussion with participants. Each individual was given 24 hours to review the participant information sheet and following this, provided written consent. Figure 2 displays the Consolidated Standards of Reporting Trials diagram of participant flow. Questionnaire data were translated for non-English speakers, and SSI and focus group interviews were conducted with multilingual facilitators, to ensure that all data collected were diverse and representative of the different ethnic groups of participants within this study. All qualitative interviews were held in a non-clinical setting of a UK NHS hospital.

Data collection

Topic guides were based on a review of the literature and in collaboration with the trial committee (SG, JM, JG, EC, PDH, PO), including the patient advisory group. Focus group topic guide questions were informed by the early individual interview data (online supplemental materials S2 and S3).

SSIs were undertaken in the first instance with 20 participants, and lasted on average 42 min. The primary researcher conducted all SSIs and focus group interviews (JM). Please see online supplemental material S4 for further descriptive details. Focus groups were undertaken with six groups, which were single-gender and specific to ethnicity. These were conducted by a facilitator and a moderator (JM, LH). Each group session consisted of 4–8 participants and lasted on average 58 min. SSI and focus group interviews were undertaken until data saturation was reached.

The primary researcher kept a reflexive diary, to maintain accountability and transparency of the thoughts, feelings and experiences of the interview data. Field notes were made to capture impressions and any contextual

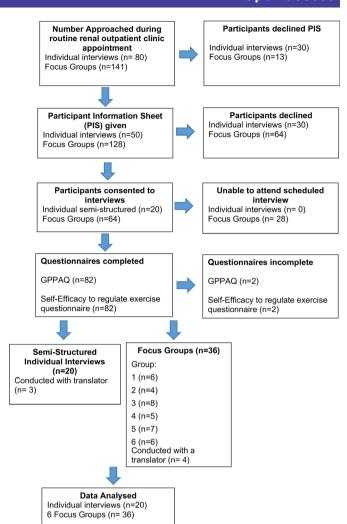


Figure 2 Consolidated Standards of Reporting Trials diagram for participant flow. GPPAQ, General Practitioner Physical Activity Questionnaire.

information from the SSI and focus group interviews. This was used to inform data analysis.

Analytical approach

All qualitative interviews were digitally recorded, transcribed and translated verbatim, and analysed using an inductive thematic analysis approach, and strategically followed guidance as demonstrated in online supplemental material S5.²⁷ SSIs were conducted and analysed in the first instance, to inform the focus group topic guide. Analysis was achieved through qualitative method triangulation. NVivo V.11 software (QSR International Ltd, V.11, 2016) was used to facilitate data management.

JM conducted the primary analysis of data. Transcripts were read a number of times and initial codes generated. Initial codes were then collated into similar groupings in order to create potential themes and thematic maps. Codes and themes were refined to enhance validity and clarity until consensus was achieved across the trial committee (JM, SG, JG, EC). This allowed refinement of codes into primary descriptive themes.

GPPAQ and SEE scale scores were entered into a secure database and analysed using Pearson product–moment correlation coefficient within SPSS V.25.0.

Qualitative and quantitative data were analysed separately. Qualitative and quantitative results were merged using triangulation to provide joint summaries in order to detect areas of convergence/divergence to the research question. See online supplemental material S6 for Consolidated criteria for Reporting Qualitative research checklist.

Patient and public involvement

The involvement of patients has been integral to this research. This involved patients of different ages, stages of CKD and representative of the different ethnic groups involved in this study. Initial meetings revealed several important points which required consideration and informed the study proposal. The need to host the focus groups in a non-NHS environment, and the use of a single-ethnicity, and single-sex focus group structure were identified as important factors to consider in this particular study. The patient advisory group participated in face-to-face meetings to review the protocol and advise on the lay summary, data collection methods, interview topic guides, study documentation and results.

RESULTS Quantitative

Pearson correlation revealed a significant correlation between GPPAQ levels of activity and Self-efficacy to regulate exercise behaviour (r=-0.40, p=0.001). This demonstrates that increased self-efficacy was associated with higher levels of PA. Correlation is negative because of direction of comparison between the two surveys.

Integrated mixed-methods analyses

The integrated qualitative and quantitative findings suggest that individuals who reported motivations to exercise had higher self-efficacy to regulate exercise behaviours and PAI scores in comparison to individuals presenting with challenges to PA and exercise. Those who identified the need for external support identified a lower self-efficacy, although this was not reflected in a low PAI score. Please refer to online supplemental material S7 for a joint display summarising findings from the integration of qualitative and quantitative results.

Qualitative

A total of 20 participants were recruited for SSI and 64 participants recruited for six single-sex, ethnicity-specific focus groups. Please see table 1 for detailed participant characteristics, and online supplemental material S8 for characteristics for each ethnic group. Individuals (n=141) were approached to participate in the study, of which 64 declined to consent. For the individual interviews, there were no refusals to participate. Of the 64 participants who consented to participate in the focus group discussions,

| Table 1 Participant characteristics | | | | |
|-------------------------------------|-----------------------------------|--------------------------|--|--|
| | Individual interviews n (%) | Focus groups n (%) | | |
| Number consented | 20 | 64 | | |
| Number attended | 20 (100) | 36 (56) | | |
| Gender | | | | |
| Male:female | 9:11 | 33:31 | | |
| Age (years) | 57 (31–73) | 59 (25–79) | | |
| Ethnicity | | | | |
| White Caucasian | 7 (35) | 20 (31) | | |
| Black African | 5 (25) | 12 (18) | | |
| Black Caribbean | 3 (15) | 12 (19) | | |
| South Asian | 5 (25) | 20 (32) | | |
| Modality | | | | |
| General nephrology | 4 (20) | 14 (22) | | |
| Low clearance | 4 (20) | 13 (21) | | |
| Renal transplant | 6 (30) | 17 (26) | | |
| Peritoneal dialysis | 3 (15) | 7 (11) | | |
| Haemodialysis | 3 (15) | 13 (20) | | |
| Stage of CKD | | | | |
| 1 (eGFR >90 mL/min) | 0 (0) | 0 (0) | | |
| 2 (eGFR=60-89 mL/min) | 3 (15) | 1 (2) | | |
| 3 (eGFR=30-59 mL/min) | 2 (10) | 7 (11) | | |
| 4 (eGFR=15-29 mL/min) | 1 (5) | 10 (15) | | |
| 5 (eGFR <15 mL/min) | 14 (70) | 46 (72) | | |
| Physical activity index | | | | |
| Active | 3 (15) | 9 (13) | | |
| Moderately active | 0 (0) | 13 (21) | | |
| Moderately inactive | 3 (15) | 12 (19) | | |
| Inactive | 14 (70) | 30 (47) | | |
| Self-efficacy to regulate exercise | | | | |
| Low (0-600) | 4 (21) | 21 (33) | | |
| Medium (601–1200) | 13 (63) | 31 (48) | | |
| High (1201–1800) | 3 (16) | 12 (19) | | |

CKD, chronic kidney disease; eGFR, Estimated Glomerular Filtration Rate.

28 were unable to attend the dates organised for discussions. Please refer to online supplemental material S9.

Major themes and sub-themes

Thematic analysis revealed four major themes; 'I am who I am', 'Change of identity', 'Influences to PA and exercise and 'Support and Education'. Please see figure 3 for a thematic map.

Theme 1: 'I am who I am'

Theme 1 encompassed individual identity, with varied responses voiced from the participants. Overall,

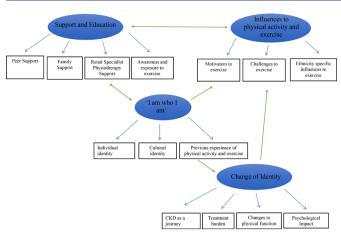


Figure 3 Thematic map.

individuals associated their identity with the environment and location they were raised in, with their family, their education and their work. Examples of quotations can be found table 2.

Perception of cultural identity was voiced by many of the individuals who participated in the research. The importance of family and intergenerational support was particularly evident in SA participants. This frequently arose in data expressed by SA women, associating their role with the home environment, as primary care givers. 'In the Asian culture, the woman is the home maker, so she's expected to be at home doing the work' (F, SA). This contrasted with the BA and BC participant discussions, which focused around associations with activity linking to environment, food preparation and family events. 'Coming from the Caribbean, I can only speak for myself but I had to do a lot of walking as we have a farm with lots of work and all of that...' (F, BC)

Previous exposure and experience of PA and exercise varied between participants, as illustrated by table 2. Overall, previous exercise exposure linked into exercise engagement as an adult 'I don't come from an exercising, sporty type background...But exercise was never really my thing' (M, W)

| Major themes | Subthemes | Examplar quotations |
|---|-----------|--|
| Individual identity | | 'Yeah [laughs] 'cos you know there is a lot of emphasis on errm culture you know I was thinking, well I'm happy, I was born in St Lucia, it is a very beautiful Island. I mean growing up education wise it was the colonial system, so we all followed it all, the books and things in the literature. I have lived here in Britain for a long time now so I have British citizenship, you know.' (M, SA) 'My dad was working out there in Malaysia as an accountant so we were born out there and I went to school out there as well. Up until age 17. My experience of my younger days there were that it was multicultural. Multicultural. Errm multithat's the main thing. (M, SA) |
| Cultural identity | SA Female | 'But I think, I mean and I'm not speaking for everyone but in the Asian culture the woman is the home maker, so she's expected to be at home doing the work.' (F, SA) 'Asian women areThey're busy with their children, the housework. You know like you said everything comes first, they come last.' (F, SA) |
| | BA and BC | 'Well no I think errm we encouraged my mum to do it. As we were growing up, it's something with West Indian families they don't really exercise and stuff like that.' (M, BA and BC) 'Coming from the Caribbean, I can only speak for myself but I had to do a lot of walking as we have a farm with lots of work and all of that, you know, so I always did it.' (F, BC) 'I was brought up here but my mum would drag me into the kitchen, 'don't think you're lying down, you could spend all day, you getting up.' Everything she done you would have to be there, even if it was just to pass an onion from here to there, you had to do it so you were moving.' (F, BA) |
| Previous experience of physical activity and exercise | | 'I mean I haven't been an active person for many years before I even went on dialysis but I remember when I was at school I used to do cross country running. Right, I used to be in the netball team and stuff like that and I think as I got older and I had to go to work and stuff like that I didn't do it and then things are not Things are different to how they are now to how they were when I was growing up and when I started to work and things like that. They wasn't pushing people to do exercises, it's only recently in the last ten years they've started to get everybody out there.' (F, BA and BC) 'Yeah, we, we, we, with that time in their age I can move back with a little bit of history, I grew in the BritishI was born in the British Empire. And in the British empire in the school they, they encouraged a lot of activities so by, by those times, our parents were encouraged to dancing. Communal dancing.' (M, BA and BC) |

BA, Black African; F, Female; M, male; P, Participant; SA, South Asian; W, White.

| Major themes | Subthemes | Quotations |
|------------------------------|---|---|
| CKD as a journey | Changing identity | 'Psychologically that was quite hard to come to terms with, and again I mean they explained the procedures for me so I supposed that helped a bit, but it's just really because I knew my life wouldn't be the same.' (F, BA) 'Because I used to enjoy the academic side of things because I used to read a lot on things. Err we need to, we, I used to do I mean as a core team you take on different subjects and we used to teach different things as well, sort of rolling programmesIt came to dialysis isn't it sort of thing and then I decided that I couldn't carry onSo those were difficult times. Err so that's that part of it. So illnesses can drag you down. Illnesses, it's the handicap.' (M, SA) |
| Treatment burden | HD | 'It's just fatigue and nothing else. They said you must do something, you can do it, not that, you know. So it's just fatigue and time. I dialyse in the mornings so I wake up at 7 o'clock and the night before I can't sleep because I'm scared that I ain't going to wake up and the thingSo the next day it's a workout because I'm just too tired. I sleep for 12 hours like you said' (F, BC) 'Oh when they said to me like you're going on, we think we're going to put you on dialysis right, let's say it was Tuesday that day and like Monday next week we're thinking of calling you in to star dialysis. I think I disappeared for a week, I just couldn't get my head round it that I had to do this thing 3 days a week' (F, BC) 'But right now my experience is err if there's a dialysis patient right now that's like me. You know the dialysis is sometimes isYou are well and sometimes you are not well. Sometimes for, for example in my experience, 60%–70% is unwell.' (M, SA) |
| | Transplant as a cure | 'You just look forward to the transplant so you can hopefully stop it. That's one of the reason that you try to exercise to be as fit as you can, so that you can have the transplant.' (M, W) 'That's why I hope some day that there is a kidney donor for me, and I have that transplant. And I pray to God that from tomorrow that Guy's Hospital call for me and say (P) come here and have a donor from the kidney and that is important. That's all, that is my experience.' (M, SA) |
| | Peritoneal dialysis | 'So sometimes with the machine in the night time, and when it's draining I wake up because I've got drain pain. So I might wake up for 20 min with drain pain and then maybe if I've turned to one side it's 'bleep, bleep, bleep.' I find my sleep is very disrupted with the drain pain and also the bleeps.' (F, BA) |
| | Low clearance clinic (typically eGFR <20) | 'So what they're saying is that my appetite will get better, and to be honest it hasn't got better, so I'm just eating for the sake of eating.' (F, BA) |
| | Transplant | 'I think with my friends as well I've been more anxious post transplant than pre, but everyone is that little bit more sympathetic before when they can see that you're ill/The minute I had my transplant and I was more you know, I suppose reasonably normal and then that's it you're one of us now. Sometimes I've had to stop and say hold on a sec, don't include me in that, don't ask me to do that.' (M, W) |
| Changes to physical function | | 'Well, you know I started physio after the operation, but before the operation it was bad. I could hardly walk a few distance, you know a few metres and that's it. And then I get very tired. You know no matter what you do, I had the strength but my legs they kept getting very tired and sometimes it there was a slight inclination or to go up the stairs. You just think of it and then sit down and that's it. So when you do that you feel pain and you don't want to go through that again.' (M, SA) 'But now I'm feeling tired, most of the day I need to be laying down err even for cooking, daily activities like cooking myeither my sister or my daughter help out.' (F, SA) |
| Psychological impact | | 'Psychologically illness as itself will put you back because it becomes a handicap, illness becomes a handicap at times although you, you know especially if you are working and things because you know that you need to take time off during your working life.' (M, SA) 'I don't know it was a bit strange because I went to my diabetes appointment and I met a doctor and I didn't think about, I wasn't thinking about kidney disease or anything like that and I just met a doctor at a diabetes appointment and just out of the blue she said I had kidney disease so I was thinking like I've been coming here for months and no one has mentioned that to me until this particular day.' (F, BC) |

Theme 2: change of identity

Individuals articulate a shift in identity to being an individual with CKD. Living with CKD was often described as a journey, from the initial diagnosis, which was frequently unexpected, and the variability of medical management and symptoms experienced as renal disease progresses. 'Psychologically it was quite hard to come to terms with...' (F, BA and BC).

Comorbid conditions and treatment burden were described as a challenge to continuing with day to day activities, resulting in an adaptation to individual lifestyle. This was primarily evident in those participants with CKD stages 4–5, where symptoms were perceived to be functionally limiting. These barriers were present by a variety of participants, irrespective of ethic or cultural heritage. Further examples are presented in table 3.

For individuals under the 'Low Clearance Clinic', most frequently who are preparing for commencement of renal replacement therapy, a number of challenges were raised. This included; disturbance to appetite, fatigue and the psychological impact of preparing for future treatment modalities. 'Yeah, with kidney [clears throat] failure, you, it comes as a shock when your doctor tells you you've got a kidney failure and then ah they say, 'Okay, you will be on dialysis' is something which will always be very, very, very new to yourself, your family and you feel phobia for the first time when the announcement comes to you' (M, BC). Experiences of those individuals undergoing haemodialysis treatment were focused on fatigue and loss of freedom, with attendance at hospital three times per week for treatment. For individuals undergoing PD, complications with infection, particularly peritonitis, were voiced as a challenge. Alongside this, sleep disturbance for those receiving automated PD overnight impacted their ability to continue with regular PA and caused disruption to day to day activities. 'So I might wake up for twenty minutes with drain pain, and then maybe if I've turned to one side it's 'bleep, bleep'. I find my sleep is very disrupted because with the drain pain and also the bleeps' (F, BA).

There were contrasting views of transplantation expressed from those pretransplant, and those who had received a kidney transplant. Of those with earlier stages of CKD, renal transplantation was often perceived as a solution to symptom burden. 'You just look forward to the transplant so you can hopefully stop it' (M, W). However, those with a renal transplant continued to report challenges, primarily with medication burden, time with medical appointments and the lack of understanding of this modality with friends and family. 'I think with my friends as well I've been more anxious post transplant, everyone is a little bit more sympathetic before when they can see that you're ill' (M, W).

A common concern of participants was the impact of CKD on lifestyle choices and the adaptations that individuals felt were required. 'The time comes when you're feeling depressed with your kidney condition and your ill health... I used to teach and work in a school for 18 years. Now I'm not doing anything but staying at home' (F,SA).

Theme 3: influences to PA and exercise

A number of participants voiced the perceived benefits to PA and exercise. Primary codes emerging from the data highlighted motivators and challenges to partaking in PA or exercise training across the participants. Please see table 4 for further information. The majority of individuals identified the role of exercise in maintaining muscle strength and preserving functional independence. A small number of those participants taking part in focus group discussions reported an improvement in health outcomes associated with a change in lifestyle, including reduction in blood pressure and decreased dependence on diabetic medication use. 'My GP is very pleased with the results of that daily walking... My blood pressure medication. I'll probably be able to get off this very soon' (F, SA).

There were a number of challenges to PA and exercise engagement. A lack of time due to numerous medical appointments, childcare and work commitments were the most commonly reported challenges. Access to community exercise services was voiced as a barrier, alongside the cost implications often associated with accessing local gym and community centres. Fear avoidance behaviours were evident, particularly concerns about injury or aggravating their kidney condition through exercise. 'It's very easy to get things wrong if you don't know what you're doing' (M, W).

Ethnic-specific influences to PA and exercise provided insightful information. Those of BA and BC ethnicity reported a primary motivator to exercise being weight management. 'Exercise and diet go really well together, it would be good for both teams to combine to help' (F, BA and BC). The importance of diet, including providing food for family, social gatherings and events was evident. Consensus within focus group discussions highlighted the conflict between cultural dietary choices, and a limitation of dietary choices that were associated with a reduction in renal function and weight management. 'What causes the problem for us African's is our food. Because all the food we are eating in Africa is carbohydrates...' (M, BA).

Those of SA background showed a preference for PA and exercise outside of the home environment, including within community centres. Providing exercise classes at flexible times of day was voiced as important to allow individuals to access services around other working or childcare commitments. Participants identified a strong cultural value to provide care for those unwell. Analysis also revealed a cultural view to avoid exercise or PA if someone is unwell. 'So in India if you are ill, they will say sit. Don't do anything' (M, SA).

Overall PA was described as incidental activity, for example cleaning or gardening. 'So physically active would be, say you know using the stairs instead of the lifts, it would be running around the house...' (F, W). Exercise was perceived as more intensive activity, often through a formal sporting activity such as running or football. 'Exericse can be anything as I say from swimming, running, that sort of thing' (M, W).

Individuals of BA and BC ethnicity reported greater incidental activity, linked to the environment and access to the community. Individual interviewees who immigrated to the UK, identified a change in activity behaviour and an increase in sedentarism due to a greater convenience of amenities. 'When you come from different countries, as he said, when you are from Africa, you walk, yeah you know you walk, because there is no two ways about it, when you come into a comfortable environment I think we all get lazy, and you just start falling off' (M, BA).

Males from a W ethnicity described past experiences and associations with exercise linked to social events and formal sporting activities for example, football and rugby. This formed an important aspect of exercise and over half the participants voiced a preference to exercise within a group environment. 'For me it's definitely the camaraderie.

| Major themes | Subthemes | Examplar quotations |
|---------------------------------|----------------------------------|--|
| Motivators to | Health maintenance | 'Well for me it's important thatFor me it would help me to live longer and make me feel better about mysel |
| exercise | | as well. And hopefully it could improve my condition and help me deal with it better.' (F, BC) |
| | Taking ownership of health | 'I remember one of the most important things is to be joyful, enjoy life. It's not the end of it. This is an organ that is very vital and how we treat it is how our emotions are going to get affected. So I try to make sure that on my non- kidney days, even on my kidney days I go for a walk or go to the gym. I just do what I can.' (F, SA) |
| | Psychological benefit | 'Well I suffer from depression and the exercise definitely improves your mood, so to me that's not a fringe benefit at all, it's a huge benefit to me. Until you jump in and start doing it, it's easy to tell people to exercise and you will feel better, and exercise is this, but funny that nature got me exercising. You don't get fresh idea sitting in a room with other people's thoughts.' (M, W) |
| | Maintaining independence | 'She's saying that although friends and family should support the person who is trying to do the exercise I think that self-motivation and supporting yourself as much as possible is key. Errrm in that she was diagnosed in 1984 and she has had her sister's help in the beginning but she feels that she doesn't want to be dependent on other people. She wants to stay independent and she wants to do things for herself and I think that that's really important for her.' (F, SA) |
| | Improvements in health outcomes | 'So because I've started walking, my GP is actually very pleased with the results of that daily walking. Errm my blood pressure medication, I'll probably be able to get off this very soon.' (F, SA) |
| Challenges to | Reduced confidence | 'It's very easy to get things wrong if you don't know what you're doing.' (M, W) |
| exercise | Time | 'Time is probably the most difficult thing because in between four sessions there are other things you've got to do, you know, see my mates, pick up the grandkids. There are all sorts of things going on, so to actually find the time to do a gym or anything like that. So for me it is certainly difficult. I wouldn't say it's impossible but difficult.' (M, W) |
| | Childcare | $^{\circ}$ I was always active as a small child, but I think when I went to fulltime and had children that just took over my life and I didn't then do exercise. $^{\circ}$ (F, W) |
| | Gym stereotypes | 'No, you know err yeah. I don't think I'd go to the gym. Although I'd love to do the treadmill and things. I wis I could do it without feeling shy.' (M, SA) |
| | Location | 'Errm I think what it is, if they had more local classes like in a community hall. 'Cause of where I am the nearest one to me is errm, the nearest one to me is X. So I think there's a dialysis unit closer? And that's only twenty minutes, so I think if there, they had like on a Friday or one day during the week I know there's a specific class there for people who have got kidney problems. I'd go to that.' (F, BC) |
| Ethnicity-specific BA and BC | Weight management | 'No matter what I did, my weight would fluctuate so for me that's an issue. So I am very conscious of my weight and I do try to make sure that I am doing, you know, the right things to try get it off as quickly as possible.' (F, BC) |
| | Diet | 'But it was about 3 and a half years ago I started the dialysis, so since then, I'm here, I'm um downstairs for the dialysis unit, so you see this condition, I was thinking, what causes the problem to us African's is our food. Because all the food we are eating in Africa is carbohydrates, it's fresh food but it is carbohydrates' (M, BA) |
| | Change of location | 'Can I say something, when you come from different countries, as he said, when you are from Africa you walk, you walk because there is no two ways about it. When you come into a comfortable environment we a get lazy, and you start falling off.' (M, BA) |
| Ethnicity-specific male W | Exercise as a social event | 'For me it's definitely the camaraderie. You know, football with your mates, then your pub cricket teams and stuff. Now I want a bowls club, but again a big part of the is hard work but a lot of it is social.' (M, W) |
| Ethnicity-specific SA female | Exercise away from home | 'P was just saying finally that she feels that exercise that is done out of the house, where you are out of the house setting. Where you are not surrounded by any other kind of distractions or stress. She finds that's the best kind of exercise.' (F, SA) |
| | Flexible timings | 'Ideally if you could have a place which is like a gym setting and it could be open at a certain sort of flexible timing, so that those who don't want the group setting they just come in work out when they want to work out at a time that is suitable for them. Because I know with Asian women, it's a little bit harder taking the tim out. So just flexible timings.' (F, SA) |
| Ethnicity-specific SA | Illness and exercise perceptions | 'So in India if you are ill, they will say sit. Don't do anything. So food and diet wise they will tell you something. But exercise wise it's like no, you mustn't get up from bed or anything.' (M, SA) |

You know, football with your mates, then your pub cricket teams and stuff" (M,W).

Theme 4: support and education

Multifaceted support was identified as a key influence to engagement in PA and exercise. Examples of this theme are highlighted in table 5. Education and awareness of the role of exercise within the management of CKD was highlighted as a need across the participants. This

included both raising the profile of specialist renal physiotherapy services, as well as increasing the presence of physiotherapists within the clinical setting to form part of routine care for individuals with CKD. 'When I used to have every 3 months a check up, I wasn't given any guidance to do exercise. Or how exercise could make a difference in renal failure.' (F, SA). Individuals identified the requirement for education and guidance early within their treatment



| Table 5 Theme 4: 'support and education' | | |
|---|---|---|
| Major theme | Subtheme | Quotation |
| Peer support | Online support platforms | 'As I mentioned before we started this, that my biggest support is the facebook kidney care group where I can reach out to other patients, even though I don't know them, I can put a question out there on the page and just say 'has anyone experienced this, or what do you think about that? Sometimes I will get a hundred comments of different tips and tricks and I think that's my best support, year Kidney Care UK on Facebook.' (F, W) |
| | Peer support platforms | 'So yeah I definitely think you're touching on a point there, that on the medical side of it you have to go for the days learning, don't you before you go on dialysis or before you have your transplant and that, I just think both need counselling. There should be people in a room like this discussing it with other people who say they've been through it (exercise), it's brilliant, it's free, go for it. You're only finding out about yourself, it is nothing to worry about and again, you may have picked up three new people here today, so if they are arranging informal meetings for patients then I think it would be a blessing for a lot of people don't you?' (M, W) |
| | Peer support | 'I think that is another thing, you're doing something that is beneficial to you and you can see that you're helping other people without realising it. It makes you feel better about yourself and you are more than happy to do it. Like my partner, he has changed his diet to match my diet. He doesn't need to because he is perfectly fine but that helps me because it is extra support. Like if I have someone, or you guys said we are going to do this exercise today, it is going to make me keep going because I think I don't want to let the team down. I don't want to let my little family down — it definitely makes a difference.' (F, BA) |
| | Group exercise | 'Coming to classes it just encourages you to do more. I think. And errm, I'm lacking that, I'm lacking the motivation. I'm lacking the motivation of that football team, if you like. Because you create the programme. I'm lacking that.' (M, SA) |
| | Inclusivity | 'Personally, I think it's good with a mixture of ethnicities and age, and men and women because I think we are all in it together sort of thing. The commonality is we've got an illness and I think that there's a kind of empathy that goes with that. Personally I'm not in favour of any segregation.' (M, W) |
| Family support | Family providing motivation | 'Errm, very much so, because like my sister we used to go, when I was able to so we used to go to the gym. Sometimes when I didn't want to, 'cause when she was going she would kind of like pick me up and say, 'oh I'm going today, are you coming?' (F, BC) |
| | Ethnicity-specific SA | 'I mean, well according to our cultural values we are very family based. We live in a family group, so I think if I lived on my own then I would have to face all those situations and I think that would have been difficult for me.' (F, SA) |
| Renal specialist Physiotherapy support | Specialist physiotherapy as part of routine care | 'When I used to have every 3 months a check up, I wasn't given any guidance to do exercise. Or how exercise could make a difference with renal failure.' (F, SA) |
| | 'Prehabilitation' | 'I think before that I had the operation I wanted to be as fit as possible because the fitter I was going in the quicker I recover coming out, which I think is probably quite true because I was walking quite well within a couple of days after the operation up and down the hospital aisles and things.' (F, W) |
| Awareness and exposure to specialist physiotherapy services | | 'I think you you promote, promote as this male said promote more in the hospital in the environment in the renal centres, in the clinics get people interested involve there are so many people good people here that will spread the word as well to say yeah look exercise is really good, you know.' (M, BC) |
| Patient education around the benefits of exercise in CKD | | 'Errm I think education is key. I think I've learnt from my experience that I need to be healthy, it's not just you know one sided. I can't just rely on doctors to treat me I have to help myself so I think education is important.' (F, SA) |

CKD, chronic kidney disease.

pathway, to improve physical function and to aid with self-management. 'But I think it is something that should be introduced early so that you're prepared for it when the time comes and you need it properly' (F, BC).

Participants voiced the importance of peer support, involving access to online digital support platforms, as well as peer support groups within their local community. Overall consensus revealed that individuals felt a group exercise environment to be beneficial, to aid motivation, increase social interaction and enjoyment. Access to renal-specific exercise services were also highlighted, to

increase confidence with exercise, and for access to peer support. 'It is therapeutic because you talk to people with the same problems. Discuss your feelings and talk and it's nice to share. Always helps you' (F, SA)

SA participants emphasised the importance of involving family within their care, and the value of this support to encourage and facilitate exercise behaviour. 'Mind you I find that family makes a lot of difference... Everyday ringing me to find out how I am doing. That's a big support for me' (F, SA). One participant raised a concern of exercising within a mixed gender exercise group, due to concerns

| Table 6 Practical applications to engagement in PA and exercise interventions | | | |
|---|--|--|--|
| Ethnicity | Practical applications | | |
| White | Include a peer and social support element to exercise programmes. Consider providing a variety of exercise options, for example, the opportunity to engage in structured team sports as well as individually. | | |
| Black African and black Caribbean | Consider location, access and the environment when setting up renal exercise services. Consider a multidisciplinary approach to clinical services, for example, involving dietitians and physiotherapists within the same setting to provide diet and exercise counselling. | | |
| South Asian | Involve family members within consultations and care plans. Flexible timing of clinical appointments to allow family members of more elderly patients to be able to attend appointments together. Consider the exercise environment, particularly the choice for individuals to be able to exercise away from their home environment in order to dedicate protected time to exercise. Provide education to clinicians to increase understanding around cultural perceptions of illness and exercise within the SA population. | | |
| Non-English speakers | Ensure that interpreters are utilised to increase understanding of exercise interventions, both during assessment, as well as during exercise sessions. Translate exercise resources for individuals to their primary language. | | |
| Overall | Include patient education around the benefits of exercise in CKD in patient consultations. Increase the presence and use of specialist renal physiotherapists within routine clinical care. Clinical appointments should be undertaken initially 1:1 to ensure that individual patient needs are understood and exercise interventions are tailored. | | |

CKD, chronic kidney disease; SA, South Asian.

with appropriate clothing however, this was not felt to be a challenge for the majority of participants. Overall cross-sectional analysis revealed the preference for inclusivity with exercise interventions. Individuals with different cultural backgrounds and genders exercising together was seen as a benefit to engagement in exercise.

DISCUSSION

In this qualitative study, we found the influences to PA and exercise in individuals with CKD from different ethnic backgrounds to be complex. In accordance with other research, participants within this study felt that the main motivators to engage in PA and exercise were taking ownership of health, health maintenance and professional support and education. ¹² Challenges varied depending on renal modality but some common barriers included symptoms associated with CKD and treatment undertaken, comorbidities, time, lack of confidence and fear avoidance behaviours associated with lack of specialist education and support. These themes, have been emphasised in other recent qualitative research. 12 31 32 Similar barriers have also been demonstrated across a number of other long-term conditions, including chronic obstructive pulmonary disease and heart failure. 33 34

This study suggests that individuals from across the representative ethnic groups were more likely to report motivators to exercise if they had higher levels of self-reported self-efficacy and PA levels, in comparison with individuals who reported a number of barriers to exercise. This finding resonates with previous research into self-efficacy behaviours in relation to exercise in CKD, which demonstrate that higher cardiorespiratory fitness

and self-efficacy levels were associated with an increased odds of being active. ³⁵ The identification of the requirement for support was indicated by more individuals with low self-efficacy to regulate exercise behaviour. The role of exercise and PA interventions and support for people living with CKD may be warranted in order to facilitate exercise behaviours. This was demonstrated in a recent study, which indicated that although a structured exercise intervention did not improve self-reported PA levels, it increased patients' self-efficacy for PA. ³⁶

There was variation between ethnic groups regarding the reason they engaged in, or do not participate in PA and exercise. Data from individuals of BA and BC ethnicity indicated cooking and diet to form a large part of their cultural identity. Consensus in focus group discussions identified the need for specialist and culturally sensitive dietary advice, and the need for combined education on both diet and exercise. Weight management was a key driver expressed in this group for engagement in exercise interventions.

Data gathered from the SA focus groups highlighted the strong family bond that exists in this culture. Involvement of family members in healthcare was evident, and the importance of intergenerational support that these members provide for individuals with long-term health conditions was well cited. Females within this group also identified themselves as having a role within the home as the main care provider, which placed challenges on time and access to exercise services in the community. However, exercising away from the home in the local community, at flexible times was deemed as important to allow the individual to dedicate protected time to



exercise. Jepson et al. 37 emphasised the centrality of crossgenerational family relationships and how this played an important role as to how individuals of SA background socialised.³⁷ These relationships may need to be taken into consideration when developing exercise services or PA interventions for this population.

White males generally associated exercise as something that happened as a social event. Preference for choice of exercise was largely within a group setting, and the importance of peer support was also highlighted to aid motivation. Clarke et al^{12} expressed the need for practitioners to consider renal-specific exercise programmes as a potential benefit to aid engagement in PA and exercise for individuals with CKD.¹²

All interviews and focus groups identified a need for further specialist support and education to provide information with regards to exercise. Challenges with the lack of specialist knowledge of PA and exercise for people with CKD in the community were identified as a barrier, alongside a need for renal physiotherapists as part of the multidisciplinary care delivered during routine outpatient appointments. Table 6 summarises practical applications to engagement in PA and exercise interventions.

Overall, participants felt that exercise within a group setting with other individuals with CKD would provide an environment for peer support, facilitate an increase in confidence and provide accountability with exercise. Participants felt that exercise should foster inclusivity and should be diverse across ethnicity, age and renal modality. This relates to the quantitative data analysis, revealing a significance between self-efficacy to regulate exercise behaviours and self-reported PA levels. This affords a link to a number of psychological theories, including the Social Cognitive Theory (SCT) and the Self-Determinism Theory. 38 39 SCT demonstrates that the reproduction of an observed behaviour is influenced by environmental and behavioural factors. This highlights the process through which efficacy beliefs, outcome expectations and goals influence behaviour.³⁶

Limitations

Some potential limitations should be considered. This study was conducted in a single centre in South-East London. This area has a diverse ethnic population, and therefore cultural and ethnic views may not be be generalisable to the wider CKD population. Only a small number of ethnicities were included in this study. Findings are therefore specific to those individuals and ethnicities included in focus groups and interviews that are relevant to our centre population. The focus groups included individuals from a BC background, and individuals from BA background together within the discussions. This is acknowledged as a limitation.

It is important to acknowledge that the quantitative data are cross-sectional; findings may not be similar if looked longitudinally. This has been explored in previous research which demonstrated a change in self-efficacy but no change in PA levels.³⁸ Future research would benefit

from including additional analysis to look at modifiers of relationship between Self-efficacy and PAI scores.

At this NHS Hospital Trust, there is an existing culture within the renal department to promote exercise behaviours. While attempts were made to maintain reflexivity and rigour during the research, prior understanding of rehabilitation held by the researchers may have shaped the research process. To mitigate this, participants were recruited using purposive sampling. Participants with prior engagement in exercise services were limited to minimise sample bias. The main interviewer also used a reflective journal to insure themes were data driven. Themes were agreed with discussions with an external qualitative researcher.

Lastly, there were a number of participants who were unable to attend the focus group discussions. Attempts were made to create a suitable time and date which would be inclusive for the participants. Due to the challenges on time that patients with CKD face, as well as variability in symptoms day to day it was difficult to accommodate all participants at a single date and time.

CONCLUSION

Thematic analyses suggest the understanding, attitudes and beliefs to PA and exercise among different ethnic groups are complex. CKD-specific group exercise interventions may facilitate peer support, improve self-efficacy and health maintenance in individuals with CKD. It is imperative that exercise interventions foster a supportive and inclusive environment, and are designed alongside service users. Raising the profile of specialist renal physiotherapists within the outpatient clinical setting, to provide individualised education and exercise prescription for individuals across the spectrum of CKD may allow for personalised and culturally sensitive exercise and PA education and support. Future research is needed to design exercise interventions that are sensitive to different ethnic groups needs and to evaluate its impact on patient outcomes.

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PROTOCOL

FULL TITLE: Cultural influences on physical activity and exercise beliefs in patients with Chronic Kidney Disease

Short Title: CULTURE CKD

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This trial will be conducted in compliance with the protocol, GCP and the applicable regulatory requirements.

Sponsor Representative: Liba Stones, R&D Manager, King's College Hospital

Funder: The Kidney Patient Research Partnership, Kidney Care UK & BRS Joint Grants Programme 2017

Study Site: King's College Hospital, London, SE5 9RS

CULTURE CKD Protocol version 1.0 – 12.12.17 **IRAS project ID**: **241792**

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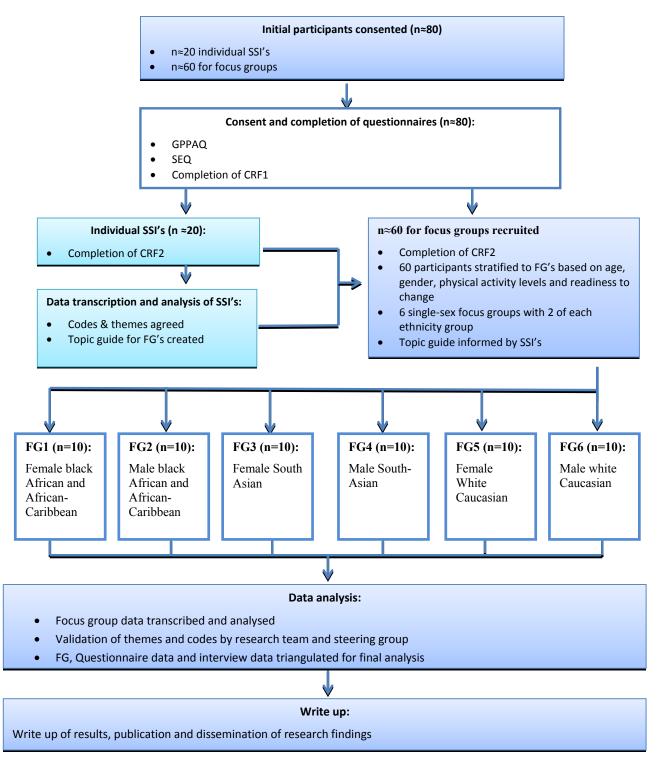
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1 INTRODUCTION

Cardiovascular disease (CVD) remains the leading cause of death in patients with Chronic Kidney Disease (CKD). Patients who spend a lot of time being inactive have an increased chance of developing CVD. Thus, interventions that can help to increase the levels of physical activity in patients with CKD are needed. A recent study we completed with kidney transplant participants showed a benefit from our supervised exercise programme. However, our results showed that 11 of the 18 patients who dropped out from the 12-month study were from black and minority ethnic groups. Some patient feedback from these participants suggested that cultural beliefs; including women not being comfortable to exercise in front of men in an exercise class environment, and difficulties around appropriate dress for exercise classes, contributed to some of these participants' decisions to withdraw from the study. This has prompted us to investigate, and seek to understand, the cultural influences that may contribute to patient decisions about partaking in physical activity and exercise training. The aim of this study is therefore to invite patients with CKD from the three most widely represented ethnic groups found in our South-East London Hospital Trust (Black African and African-Caribbean; South Asian, and White Caucasian patients) to discuss their beliefs and the cultural influences that may affect their decision on whether to engage with exercise and physical activity. Participants will complete a questionnaire on physical activity levels, and a questionnaire that looks at a patient's readiness to be involved in physical activity), prior to attending interviews or group discussions. The questionnaires will be translated for use with non-English speaking participants and will be used to ensure we get views on physical activity from those participants who are active and not, and ready to be involved in physical activity, and not. A combination of individual interviews and group discussions will then be used to explore the understanding of the terms 'physical activity' and 'exercise', and cultural barriers to participation. We will have interpreters present for all discussions, which will take place in the community. The work from this pilot study will be used to inform and design a larger multi-centre study. We will learn about appropriate ways to recruit and engage with patients from different cultures, and whether the pilot study design is appropriate for a larger study. The ultimate aim is to design physical interventions that are culturally sensitive, and are appropriate for all patients with CKD in the UK.

1.1 STUDY FLOW DIAGRAM CULTURE CKD (n=80)



NB. FG= Focus group, GPPAQ=General Practice Physical Activity Questionnaire, SEQ=self-efficacy for exercise Questionnaire, SSI= semi structured interviews,n=sample., CRF=clinical record form.

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2 BACKGROUND AND RATIONALE

Low exercise capacity and physical inactivity have been identified as prognostically important for cardiovascular disease (CVD) and all-cause mortality in patients across the CKD trajectory (1-3). At King's College Hospital (KCH), a large teaching hospital in South-East London, we have a diverse ethnic population that attends our renal rehabilitation programme. A recent study completed by our research team (4) had a good retention of research participants (42/60) who were willing to complete a 12-month study (5). However, on further analysis of those participants who did not complete the study (18 participants), it became apparent that 11 of them were from a non-white ethnicity. Some patient feedback from these participants suggested that cultural beliefs; including women not being comfortable to exercise in front of men in an exercise class environment, and difficulties around appropriate dress for exercise classes, contributed to some of these participants' decisions to withdraw from the study. This has prompted us to investigate, and seek to understand, the cultural influences that may contribute to patient decisions about partaking in physical activity and exercise training. We know that physical inactivity and sedentarism is common in patients with CKD (1), and it is therefore imperative that we find a way to engage all of our patients with CKD with lifestyle changes. By understanding the differing ethnic and cultural views on exercise therapy and physical activity engagement, we can improve the way we promote and engage patients with these interventions. Although a number of studies have evaluated cultural beliefs and physical activity in the general population with particular regard to encouraging sporting activity in younger people (6), and some work has been done looking at cultural influence and physical activity in cardiac rehabilitation programmes in the USA (7), no studies have evaluated the influence of culture and ethnicity on physical activity in patients with CKD.

This present study will utilise Stokol's Social Ecological Theory of Health Behaviour as the main theoretical framework (8). This multi-level Ecological theory suggests that an individual's behaviour results from a complex interaction between the individual, the environment, and community in which they live (9). Multi-level theories are thought to be more robust and explanatory, in comparison to single-level approaches as they are representative of the public health approach to population change (10). Ecological approaches such as Stokol's Social Ecological Theory form a robust base to evaluate complex multifactorial behaviours such as physical activity. This theory has been used, and is promoted for use, in designing community-level health programmes, such as physical activity interventions for different ethnic communities. David Howe, a sports anthropologist, will advise the research team with the interpretation of the data using this framework.

The recently published UK Kidney Research Strategy (11) highlights the increased need "to increase and promote equitable access for research to minority groups with kidney disease – recommendation 2" and to "embed commitment to robust and appropriate patient focused and patient-led qualitative research to allow improvements in quality of care, healthy, quality of life and patient empowerment – recommendation 7". This current application addresses both of these recommendations.

2.1 Purpose of proposed investigation

The purpose of this present study is to utilise a mixed-methods design to explore the understanding of physical activity and exercise, and factors that contribute to a decision to be physically active or sedentary, in patients with CKD from different ethnic backgrounds. We

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intend to measure self-reported physical activity levels with the General Practice Physical Activity Questionnaire (12) and self-efficacy for exercise (readiness to start doing exercise) with Bandura's self-efficacy for exercise scale (13, 14). We then aim to explore perceptions, attitudes and values about physical activity and exercise therapy in different ethnic groups. We will ensure that we capture views from patients stratified by activity, readiness to be active, age and gender. To accomplish these goals, the present study will explore: (i) the understanding of the terms 'physical activity' and 'exercise'; (ii) the interpretation of the socio-cultural contexts in which they choose (or not) to be physically active, and; (iii) their understanding of physical activity and exercise opportunities and barriers in their local environment. All questionnaires will be translated for non-English speaking participants, and individual and focus group discussions will be facilitated with translators.

2.2 Primary objective

To explore the perceptions, attitudes and values about exercise and physical activity in different ethnic groups.

2.3 Secondary Objectives

- 1. To explore the understanding of the terms 'physical activity' and exercise
- 2. To explore the interpretation of the socio-cultural contexts in which they choose (or not) to be physically active
- 3. To explore the participants understanding of physical activity and exercise opportunities and barriers in their local environment
- 4. To measure self-reported levels of physical activity (GPPAQ) and self-efficacy for exercise

3 STUDY DESIGN

This study is a prospective mixed methods pilot study recruiting participants from three ethnic groups (Black African and African-Caribbean; South Asian, and White Caucasian patients) at King's College Hospital NHS Trust. These three groups are representative of the ethnicity of our local population.

Objectives and hypothesis:

The aim of this pilot study is to use a mixed method approach to explore cultural and ethnic influences on the perception of, and decision to engage with or not to engage with, physical activity and exercise therapy in patients with CKD.

We aim to recruit participants from three ethnic groups (Black African and African-Caribbean; South Asian, and White Caucasian patients) and will then use stratified sampling to ensure equal numbers of participants according to age (18-49; 50-80 years), gender, physical activity level and readiness to be active (utilising the GPPAQ physical activity questionnaire and Bandura's self-efficacy for exercise questionnaire) to explore the following themes in both individual and focus group discussions:

- The understanding of the terms 'physical activity' and 'exercise'
- The interpretation of the socio-cultural contexts in which they choose (or not) to be physically active

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• Their understanding of physical activity and exercise opportunities and barriers in their local environment.

Outcome measures:

- 1. Physical activity (self-reported) by the General Physical Activity (GPPAQ) (12)
- 2. Self-efficacy for exercise behaviours questionnaire (15) a measure of confidence in changing behaviour
- 3. Qualitative interviews and focus groups

Safety and tolerability objectives:

- All-cause hospitalisation
- Hospitalisation for infection
- Infection episodes
- Serious adverse events, ADRs, and SUSARs

4 STUDY SCHEDULE

All Participants (n= 80) will have the two questionnaires completed at the time of written consent. 20 participants will complete individual semi-structured interviews and our research team estimates 60 participants will take part in 6 focus groups, consisting of approximately 10 participants per focus group.

| Procedure | Visit 1 | Visit 2 |
|---|---------|---------|
| Informed consent | Х | |
| Medical history and demographics | Х | |
| QUESTIONNAIRES: | Х | |
| GPPAQ questionnaire (measure of physical activity) | | |
| Self-efficacy questionnaire (measure of confidence in changing physical activity) | х | |
| QUALITATIVE DATA: | | Х |
| Individual qualitative interviews (n=20) | | |
| Focus groups (n=60), 6 single-sex focus groups approx. 10 participants per group | | Х |

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5 CONSENT

Patients will be screened and identified by clinicians working in the renal outpatient department and delegated members of the research team. Potential participants will initially be provided with patient information sheet (the current Research Ethics Committee (REC) and Health Research Authority (HRA) approved version) and a covering letter explaining the trial to them and inviting them to participate in the trial. This will occur in the renal outpatient clinic during the clinic service. They will have time to consider the trial and decide whether or not they wish to take part, and to discuss the trial with their family and friends if they would like to. If they are non-english speakers, they will be offered the opportunity to discuss the study in detail and ask any questions via the language line phone translation service.

At their next clinic appointment, potential participants will have plenty of time to discuss the trial further and to have any questions that they may have about the trial answered. The nature and requirements of the trial will be carefully explained. The investigator, or designated medically qualified personnel, will explain that there is no obligation for a potential participant to enter the trial, that trial entry is entirely voluntary, and that it is up to the potential participant to decide whether or not they would like to join. It will also be explained that they can withdraw at any time during the trial, without having to give a reason and that their decision will not affect the standard of care they receive. Any reasons for non-participation will be recorded if the information is volunteered.

Participants if willing to participate will be consented as per the GCP guidelines. Only adults above the age of 18, with capacity to consent will be accepted into the study. Non-english speakers will be consented via language-line phone translation service. The participant and responsible clinician will sign the informed consent form and the responsible clinician will perform a final confirmation of eligibility. Informed consent will be obtained before any trial-related procedures are undertaken. A copy of the signed informed consent form will be given to the participant. The original signed form will be retained at the study site in the Investigator Site File and a copy placed in the medical notes. A copy will also be sent to the Chief Investigator of the study. With the participant's prior consent, their General Practitioner (GP) will also be informed. If new safety information results in significant changes in the risk/benefit assessment, the consent form and PIS will be reviewed and updated as necessary. Participants will be re-consented if appropriate.

6 ELIGIBILITY CRITERIA

Full Ethics Committee approval and R&D approval will be sought for the study. Each participant must meet all the inclusion criteria, and none of the exclusion criteria, at entry to the study. Those who are ineligible, or decline to participate will be captured on the secure and encrypted recruitment and screening log.

6.1 Inclusion criteria:

- Participants with a diagnosis of CKD that are representative of one of the 3 ethnic groups that will be studied (Black African and African-Caribbean; South Asian, and White Caucasian patients)
- Age > 18 years of age
- Informed consent

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6.2 Exclusion criteria:

- Uncontrolled medical condition (e.g. uncontrolled angina)
- Unstable psychiatric condition

7 RECRUITMENT

7.1 Selection of Participants

Patients who meet the entry criteria may be recruited and consented by the investigator, or any GCP qualified member of the local trial team who has delegated responsibility for trial recruitment. Participants will be recruited from the KCH renal unit. Currently, patients with CKD under the care of a nephrologist are reviewed at least every 6 months in a hospital outpatient clinic. Potential trial participants will be identified when presenting for their routine hospital clinic visits. Members of the site staff will screen for potential eligible study participants using the inclusion/exclusion criteria. Screening logs will be kept on the secure "renal physio" drive and will be encrypted for confidentiality. All eligible and ineligible patients, plus those declining to participate will be logged on the secure screening log. Patients who fulfil the inclusion criteria will have their eligibility confirmed by the research team. After confirming eligibility, eligible patients will be approached by an appropriately trained member of the clinic team to ascertain interest in entering the study. This individual will give a comprehensive verbal explanation of the trial. Time for questions throughout the discussion will be given and questions adequately addressed. Potential participants will have a minimum of 24 hours to reflect on the patient information sheet (PIS), which will be provided during the initial discussion with the patient.

Participants that agree to enter the study will then be asked to consent to undergo study assessments. If the participant is willing to take part then they will be asked to sign the consent form with a member of the research team countersigning. A copy of the consent form will be given to the participant, and copy will be filed securely with the participant's trial records. As potential trial participants will be identified when presenting for their routine hospital clinic visits, this reflects the secondary care basis of the proposed research. Due to the broad inclusion criteria and low time burden of the study, it is estimated that we will be able to recruit the 85 patients within 6 months. Patients will receive a small inconvenience payment for their participation in addition to travel expenses, should their visit be outside of their routine hospital appointments.

8 STATISTICAL METHODS

8.1 Sample Size

We aim to recruit up to 20 patients (for the individual interviews) and 60 patients (for the 6 single-sex focus groups), aged over 18 years or over with CKD from the 3 identified ethnic groups, will be recruited to the study. Each patient must have met the inclusion and exclusion criteria at entry level to the study. For focus groups we will aim for between six to twelve participants per group, so that the group is small enough for all participants to speak freely,

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yet large enough to create a diverse sample (16). Appropriate topic guides will be developed and discussed with the patient advisory group, and the steering group. We will continue with individual interviews and focus groups until we reach data saturation, there is no new data, no new themes, no new coding and we are able to replicate the study (17, 18).

8.2 Statistical Analysis

Baseline demographics of the patients will be described using summary statistics. Continuous variables will be summarised using the mean and standard deviation (SD) if approximately normally distributed. Continuous variables that are not normally distributed will be summarised using the median and IQR.

Qualitative analysis: Individual interviews will be transcribed and translated verbatim, and analysed using an inductive thematic analysis approach (19, 20), informed by techniques from grounded theory, including line-by-line open coding grounded in the data and constant comparison of all instances of codes (19). This will be linked to the main concepts of Stockols ecological theory (8). Deviant case analysis will be employed to ensure that perspectives that diverge from dominant trends are not overlooked. Focus group discussions will be transcribed and translated verbatim and the identified themes and subthemes from the individual interviews will be analysed by group to provide the collective voice that is associated with focus group research confirming data saturation. We will also aim to link the quantitative measures and domains with the topic guides and analysis framework to tie up the whole study with respect to patient experience, which is also linked to physical activity behaviour and self-efficacy. The 2 questionnaires will not only aid purposive sampling and therefore ensure equal representation of different physical activity levels, and different levels of readiness to be physically active within both the individual interviews and the focus groups, it will also allow us to link these outcome measures with patient experience to develop theories regarding physical activity and exercise behaviour and cultural barriers to physical activity, which can be transferrable wider than the local CKD patient population. Data triangulation (multiple sources of data) will enhance the reliability of results (21) and the attainment of data saturation in this study.

GPPAQ data will be coded into physical activity levels, and Self-efficacy for exercise questionnaire will be scored and transferred to SPSS for analysis. Pearson Chisquare (X2) test will be performed to determine whether there is a significant relationship between the Self-efficacy for exercise scores and GPPAQ levels. Alpha (α) will be set at 0.05 for 95% confidence.

8.3 Randomisation procedures

There is no randomisation in this study.

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9 PATIENT AND PUBLIC INVOLVEMENT (PPI)

The involvement of patients and participants has been integral to shaping this proposal. We have 3 patient representatives that represent each of the ethnic groups we are including in the proposed study. These 3 patients are named co-applicants in this study and will receive training and support to be an active member of the research team and contribute to interpretation of findings and dissemination of results. They have had several face to face meetings with the rest of the team to review the protocol, and advise on the lay summary. We have also had several face to face meetings with our CKD patient advisory group at KCH, and those meetings revealed several important points which required consideration. The need to host the focus groups in a non-NHS environment, and the use of a single-ethnicity, and single-sex, focus group structure were identified as important factors to consider in this particular study. The patient representatives will be involved in the identification of different strategies to engage and recruit patients from the different ethnic groups, if approaching potential participants in routine clinic visits proves not to be a feasible option.

10 FUNDING

The research team has been awarded £30,966.70 by the British Renal Society. This grant covers staff time and resources needed to conduct this study.

11 DATA HANDLING AND MANAGEMENT

All paper data recording sheets will be stored in lockable filing cabinets at the renal rehab team office for 5 years. Documents will also be archived using iron mountain software. Electronic data spreadsheets will be kept on the private renal rehab team drive and will be password protected. All patient indefinable details (name, address, hospital number) will be removed in place of trial ID numbers.

All staff involved in this research project will ensure data is handled with strict confidentiality in line with local trust policies. Data will be reviewed regularly by the research team.

12 PEER AND REGULATORY REVIEW

This study has been peer reviewed within KCH, by an independent and relevant peer reviewer/committee, the renal research governance board on the 3rd of April 2018. This project has also been peer reviewed by the Sponsor (Britsh Renal Society) and they have accepted these reviews as adequate evidence of peer review.

The study was deemed to require regulatory approval from the following bodies (list). Each approval will be obtained before the study commences.

HRA

•REC

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13 MONITORING AND AUDITING

The Chief Investigator will ensure there are adequate quality and number of monitoring activities conducted by the study team. This will include adherence to the protocol, procedures for consenting and ensure adequate data quality.

The Chief Investigator will inform the sponsor should he/she have concerns which have arisen from monitoring activities, and/or if there are problems with oversight/monitoring procedures.

14 INDEMNITY ARRANGEMENTS

KCH will provide NHS indemnity cover for negligent harm, as appropriate and is not in the position to indemnify for non-negligent harm. NHS indemnity arrangements do not extend to non-negligent harm and NHS bodies cannot purchase commercial insurance for this purpose; it cannot give advance undertaking to pay compensation when there is no negligence attributable to their vicarious liability. The Trust will only extend NHS indemnity cover for negligent harm to its employees, both substantive and honorary, conducting research studies that have been approved by the R&I Department. The Trust cannot accept liability for any activity that has not been properly registered and Trust approved. Potential claims should be reported immediately to the R&I Office.

15 ARCHIVING

During the study, all data will be kept securely and confidentially at the Renal Physio office. After the study has ended, paper data recording sheets, the Trial Master file and patient consent forms will be archived at a long term storage facility (Iron Mountain) for 5 years. Data spreadsheets will be encrypted, name and contact details removed, and stored on a private Renal physio team folder with limited access.

16 PUBLICATION AND DISSEMINATION POLICY

The research team plans to disseminate the study research findings in the following settings:

- Conference presentation of study process and results at the British Renal Society Conference and either the American Society of Nephrology Conference or the European Renal Association conference
- Publication of results in a renal specific recognised impact journal.

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Appendix 1: PROTOCOL VERSIONS

| Version No | Version Date | Detail the reason(s) for the protocol update |
|------------|--------------|--|
| 1.0 | 12.12.17 | N/A Current version |
| | | |
| | | |
| | | |

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Culture CKD Study Outline Topic Guide

1. Introduction:

- Introduce self and why we are asking this participant for interview discussion 1:1.
- Inform that discussion will be focussed around experiences of living with CKD, understanding
 of exercise and physical activity alongside cultural background and how that may influence
 decisions to be physically active or take part in exercise.
- Explain about recording device and transcription, emphasise that all information is anonymous and will be stored securely.
- Inform how long the interview will go on for (up to one hour)
- Ethical considerations for example right to withdraw, what will happen to the recording and confidentiality of data.
- Ask if the participant has any questions and reassurances that this discussion is to explore their perceptions and experiences.

2. Experiences and perceptions of living with CKD

2.1- I am interested to understand about your experience of living with CKD, can you talk to me about your journey of living with a kidney condition?

Prompts:

- Could you give me an example?
- How does CKD affect your day to day life?
 - O What are the challenges?
- What treatments have you been through in the kidney clinic?
- What are your thoughts and feelings about living with a long term condition?
 - o Why?
 - o How does that make you feel?

3. Understanding of exercise and physical activity

3.1- What do you understand by the term 'exercise'?

Prompts:

- What are the benefits of exercise to you?
 - o Could you give me an example?
- What types of exercise do you enjoy?
- What are the barriers to exercise for you?
- What are the benefits to exercise for you?
- Have you always been involved in exercise?



3.2- What do you understand by the term 'physical activity'?

Prompts:

- Can you give me an example being physically active?
- How does this differ from exercise?
- What are the benefits of being physically active?
- What are the barriers to being physically active?
- 4. Exercise options and services in the local community
- 4.1- What exercise options of services are you aware of in your local community?

Prompts:

- Can you give some examples?
- How do you find out about services available?
- How easy or difficult are these to be able to attend?
- What services would be helpful to assist kidney patients to exercise?
- What services are you aware of to help kidney patients be active?
- 5. Cultural influences
- 5.1- How do you feel that your cultural background affects your day to day life?

Prompts:

- Could you give me an example?
- Could you explain more about that topic?
- 6. Cultural influences on exercise and activity
- 6.1- Would you be able to talk to me about your childhood and any exercise you were involved in?

Prompts:

- Could you talk to me about your parent's views on physical activity and exercise?
- What has influenced you with regards to your exercise or physical activity choices?
- Could you provide some examples of this?
- 6.2- How does your cultural background influence your decision to be involved in activity and exercise?

Prompts:

- What about your family or friends?
- What about your local community or environment?
- What about social support?



- What do your family recommend or feel about your condition and exercise?
- 7. Perceptions of other cultures and influences on activity
- 7.1- How do you think other people from different backgrounds view physical activity and exercise?

Prompts:

- What factors may influence decisions to exercise?
- What do we as clinicians need to take into consideration with providing exercise advice for different cultures?



Culture CKD Study Outline Topic Guide – Focus Groups

Introduction and ground rules:

- Introduce self (and colleague) and role within the research study
- Inform that discussion will be focussed around experiences of living with CKD, understanding of exercise and physical activity alongside cultural background and how that may influence decisions to be physically active or take part in exercise.
- Explain about the need for audio-recording in order to provide a full account of everything, and participants are asked not to talk over each other for this reason.
- Inform how long the interview will go on for (up to one hour)
- Ethical considerations for example right to withdraw, what will happen to the recording and confidentiality of data.
- Inform that the focus group will be in the form of a discussion and that participants should not wait to be invited before stepping in.
- Re-assurances that there are no right or wrong answers, everyone's views are of interest and that the aim of the discussion is to hear as many different thoughts as possible.
- Add that there are likely to be different views or experiences among the group, and everyone should feel able to speak freely, and if they agree or disagree with other participants' views, to say so.
- Ask the group to treat what other people say as confidential and not to be repeated outside of this session.
- Clarify that all members are happy with this introduction and invite any questions about anything that has been raised so far.
- Participants in group to give an individual introduction prior to start of discussion.

1. Experiences and understanding of activity and undertaking exercise

We are keen to explore more about your general activity and more formal exercise.

1.1- What are your thoughts and experiences of physical activity and exercise?

Prompts:

- What do you understand by the term 'exercise' and 'physical activity'?
- Can you give me an example of this?
- What types of exercise do you enjoy?
- What are the benefits?



1.2- Before diagnosis were you regularly physically active?

Prompts:

- If so what did this involve? / Could you give me an example?
- If not could what influenced this?
- What influenced your decisions to exercise or to be physically active?

2. Disease Impact

We are interested to understand about your experience of living with CKD.

2.1- What is it like living with CKD?

Prompts:

- How do you feel you are supported?
 - By whom?
- What is the impact of living with CKD?
 - -Physical
 - Psychological
- How does that make you feel?
- What are your thoughts and feelings of living with a long term condition?

Other:

How would you describe your cultural background?

Prompts:

- What important factors link to your culture?
- What do you feel that this influences?



3. Activity

3.2- What gets in the way of exercise?

Prompts:

- What are the challenges to exercise?
- Can you give me an example of what influences these beliefs?
- Can you explain more about this?

3.3-What do you think influences these choices to exercise?

Prompts:

- Does your cultural background affect these choices?
- Do you think gender plays a role?
- Can you give me a specific example?
- How does your cultural background influence your decisions to be active?
- How does your gender influence your choice of exercise and activity?

3.4- What is important for us to consider when providing support for kidney patients from a range of cultural backgrounds to be active?

Prompts:

- What type of activities and exercise?
- Accessibility- how easy is it to find or access these services?
- Who provides services?
- Could you give me an example of what would be helpful?
- What about for those who are non-English speaking?



3.5- Do you think your kidney condition influences your choice of exercise or decisions to be active?

Prompts:

- If so why?
- How does CKD have an effect on function?
- What are the benefits of exercise with a kidney condition?
- What are the challenges?
- Could you give me an example of this?

3.6- Can anyone tell me if they have been through a structured exercise programme such as Renal Rehabilitation? If so how did that make you feel?

Prompts:

- How did this influence exercise beliefs?
- What were the benefits?
- What were the challenges?
- How does this influence your decisions to be active?
- What do we need to consider to make this accessible for people from a variety of cultural backgrounds?

- 3.7- How does support influence you with regards to maintaining exercise or being physically active? **Prompts:**
 - What about support from family and friends?
 - What about support from other patients?
 - Education from healthcare professionals?
 - Previous exercise exposure?
 - Other factors that may influence decisions to be active?



3.8 – What types of exercise would you chose to engage with/ would be your preference?

Prompts:

- What influences your choices with exercise?
- Why do you feel drawn more to that type of exercise?
- How does your cultural background link to the type of activity or exercise you prefer?

3.9- What environment would you choose to undertake exercise or to be active?

Prompts:

- Why would you choose that location or environment?
- How easy is it to find places to undertake exercise?
- What are your thoughts on exercising with other people?
- What would put you off a choice of activity or exercise?

Final close:

Is there anything we've left out of our discussion today, or that people feel that they haven't had a chance to say?

Thank you all for taking the time to participate in an interesting discussion today. We would just like to again emphasise understanding other people's views within the group and maintain this information as confidential outside of this meeting today. As you are aware today was to have an open discussion around experiences of living with chronic kidney disease as well as understanding and influences to participating in exercise and physical activity. This information is valuable to help our team to understand our patient's needs and will be used to shape the services we provide for our CKD patients in the future.

| Personal Characteristics | Details |
|--|--|
| Primary Researcher Credentials | BSc in Physiotherapy |
| Occupation | Specialist Renal Physiotherapist at an NHS Hospital Trust. |
| | Expertise in behaviour change interventions, working with individuals across the spectrum of CKD. |
| Gender | Female |
| Experience and training | Previous experience working within qualitative and quantitative research in the area of exercise and CKD. |
| | Training in qualitative research methods and analysis. Supported by a highly experience trial committee. |
| Relationship with participants | |
| Relationship Established | No prior relationship established prior to the interview. |
| Participant knowledge of the interviewer | Informed of background of primary researcher, working as a clinical and research Physiotherapist. Interest in understanding and facilitating behaviour change interventions within CKD population. |
| Interviewer characteristics | Information provided to participants regarding researcher, and trial team reasons for conducting research study, as well as interests in research topic. |

Supplementary Material 3.0- Descriptive details of research team and reflexivity

| Phase | Description of the process |
|---------------------------------------|--|
| 1. Familiarise yourself with the data | Transcribing the data, reading and rereading the data, noting down initial ideas. |
| 2.Generating initial codes | Coding data across the data set, collating data relevant to each code. |
| 3. Searching for themes | Collating codes into potential themes |
| 4. Reviewing themes | Checking if themes work in relation to the coded extract. Checking if themes work in relation to the entire data set. Reviewing data to search for additional themes. |
| 5. Defining and naming themes | Generating clear definitions and names for each theme. Ongoing analysis to define the specifics of each theme. |
| 6. Producing the report | Selection of vivid, compelling extract examples. Final analysis of selected extracts Relating analysis back to the research question, objectives and previous literature review. |

S4- Phases of Thematic Analysis [27]

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

| Domain 1: Research team and reflexivity Personal characteristics Interviewer/facilitator Credentials 2 What were the researcher's credentials? E.g. PhD, MI Occupation 3 What was their occupation at the time of the study? Gender 4 Was the researcher male or female? Experience and training 5 What experience or training did the researcher have? Relationship with participants Relationship established 6 Was a relationship established prior to study comment Participant knowledge of 7 What did the participants know about the researcher later interviewer Interviewer characteristics 8 What characteristics were reported about the interviewer. Interviewer characteristics 8 What characteristics were reported about the interviewer. Domain 2: Study design Theoretical framework Methodological orientation 9 What methodological orientation was stated to unde grounded theory, discourse analysis, ethnography, phy content analysis Participant selection Sampling 10 How were participants selected? e.g. purposive, convenient analysis Participant selection 11 How were participants were in the study? Non-participation 13 How many participants were in the study? Non-participation 14 Where was the data collected? e.g. home, clinic, worl presence of non-participants 15 Was anyone else present besides the participants and participants Description of sample 16 What are the important characteristics of the sample data, date Data collection Interview guide 17 Were questions, prompts, guides provided by the aut tested? Repeat interviews 18 Were repeat interviews carried out? If yes, how man Audio/visual recording 19 Did the research use audio or visual recording to colle Field notes 20 Were field notes made during and/or after the interview Suda as asturation discussed? Transcripts returned 21 What was the duration of the interviews or focus grounds asturation 22 Was data saturation discussed? | | Reported on | |
|--|-----------------------|-------------|-----|
| Interviewer/facilitator Interviewer/facilitat | | Page No. | |
| Personal characteristics Interviewer/facilitator | | | |
| Interviewer/facilitator Credentials Cupation Credentials Cupation Credentials Cupation Credentials Cupation Credentials Cupation Coupation Credentials Coupation C | | S3 | |
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| were transcripts returned to participants for commen | ziit aliu/Ui | P6, 37 | |
| | | P6, 38 | |
| | | P7, 21 | -30 |

| Topic | Item No. | Guide Questions/Description | Reported on |
|------------------------------|----------|--|---------------------|
| | | | Page No. |
| | | correction? | |
| Domain 3: analysis and | | | P7, 4-9 |
| findings | | | F 7, 4-9 |
| Data analysis | | | Figure |
| Number of data coders | 24 | How many data coders coded the data? | 1 19310 |
| Description of the coding | 25 | Did authors provide a description of the coding tree? | P6, 48 |
| tree | | | P7, 1-2 |
| Derivation of themes | 26 | Were themes identified in advance or derived from the data? | P7, 21 (|
| Software | 27 | What software, if applicable, was used to manage the data? | |
| Participant checking | 28 | Did participants provide feedback on the findings? | |
| Reporting | | | Tables |
| Quotations presented | 29 | Were participant quotations presented to illustrate the themes/findings? | |
| | | Was each quotation identified? e.g. participant number | Results |
| Data and findings consistent | 30 | Was there consistency between the data presented and the findings? | Results |
| Clarity of major themes | 31 | Were major themes clearly presented in the findings? | Results |
| Clarity of minor themes | 32 | Is there a description of diverse cases or discussion of minor themes? | L |

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Supplementary Material 5 (S5)- Joint Display summarising findings from the integration of qualitative and quantitative results

| Main | Qualitative Results | GPPAQ | Self- | Mixed-Methods |
|------------|---|--|--------------------------------|---------------|
| Themes | examples | Physical Activity | Efficacy | Inferences |
| | | Index Score (PAI) (%) | Score (%) | |
| Motivators | Health maintenance. Psychological benefit. Maintaining functional independence. | Active- 25 Mod Active- 12 Mod Inactive- 22 Inactive- 41 | Low- 21 Med- 46 High- 33 | Complementary |
| Barriers | - Time - Fear Avoidance - Household commitments - Location | Active- 4 Mod Active- 9 Mod Inactive- 30 Inactive- 57 | Low-44 Med- 43 High-13 | Complementary |
| Support | Peer supportFamily supportSpecialist support | Active- 31 Mod Active-23 Mod Inactive-15 Inactive- 31 | Low- 39 Med- 46 High- 15 | Complementary |

Supplementary Material (S6)- Participant Characteristics for individual ethnic groups

| Variable | | White | White Caucasian Black | | Black African | | Black Caribbean | | South Asian | |
|-----------------------|----------------------|---------|-----------------------|---------|---------------|---------|-----------------|---------|-------------|--|
| | | | | | | | | | | |
| | | SSI | FG | SSI | FG | SSI | FG | SSI | FG | |
| Participant Numbers | | 7 | 20 | 5 | 12 | 3 | 11 | 5 | 21 | |
| Age (years) Mean (SD) | | 60 (13) | 57 (14) | 49 (15) | 57 (6) | 53 (15) | 60 (14) | 63 (18) | 55 (12) | |
| Gender, (Male:Female) | | 3:4 | 9:11 | 3:2 | 9:3 | 2:1 | 2:9 | 2:3 | 12:9 | |
| Modality, n (%) | General Nephrology | 1 (14) | 3 (15) | 2 (40) | 2 (17) | 1 (33) | 3 (27) | 0 (0) | 6 (29) | |
| | Low Clearance Clinic | 1 (14) | 5 (25) | 1 (20) | 3 (25) | 1 (34) | 3 (27) | 2 (40) | 1 (5) | |
| | HD | 2 (29) | 6 (30) | 1 (20) | 2 (17) | 0 (0) | 1 (10) | 1 (20) | 5 (24) | |
| | PD | 2 (29) | 2 (10) | 1 (20) | 4 (33) | 0 (0) | 2 (18) | 0 (0) | 2 (10) | |
| | | | | | | | | | | |

| 2 (29) 4 (57) 1 (14) 1 (14) | 3 (15) 11 (55) 5 (25) 6 (30) | 0 (0) 3 (60) 2 (40) | 4 (33) 6 (50) 2 (17) | 1 (33) 2 (67) 0 (0) | 2 (18) 6 (55) 3 (27) | 1 (20) 4 (80) 0 (0) | 7 (33) |
|--------------------------------------|---------------------------------------|---------------------|----------------------------|---------------------------|----------------------------|---------------------|---------|
| 1 (14) | 5 (25) | | | | | | |
| | | 2 (40) | 2 (17) | 0 (0) | 3 (27) | 0 (0) | 2 (10) |
| 1 (14) | 6 (30) | | | | | 1 | |
| ` ' | 0 (30) | 1 (20) | 0 (0) | 1 (33) | 0 (0) | 0 (0) | 2 (10) |
| 0 (0) | 4 (20) | 1 (20) | 4 (33) | 0 (0) | 1 (9) | 0 (0) | 0 (0) |
| 0 (0) | 2 (10) | 0 (0) | 4 (34) | 0 (0) | 3 (27) | 2 (40) | 7 (33) |
| 6 (86) | 7 (35) | 3 (60) | 4 (33) | 2 (67) | 7 (64) | 3 (60) | 12 (57) |
| | | | | | | | |

Supplementary Material 7.0- reasons for non-attendance and declining participation

Reasons for participants declining participation in focus group discussions

| Number | Reason for decline to consent to focus | | | |
|-----------|---|--|--|--|
| | group | | | |
| 17 | CKD not perceived a problem | | | |
| 32 | Unable to contact | | | |
| 2 | Distance too far to travel | | | |
| 5 | Too many hospital appointments | | | |
| 1 | Away travelling abroad for significant time | | | |
| 5 | Not enough time | | | |
| 2 | Not wanting to participate in a focus | | | |
| | group | | | |
| Total= 64 | | | | |

Reasons for non-attendance to focus group sessions

| Number | Reason for non-attendance in focus | | | |
|-----------|---|--|--|--|
| | group | | | |
| 7 | Work commitments | | | |
| 2 | Childcare commitments | | | |
| 11 | Unavailability on date/ time of focus group | | | |
| 4 | Feeling unwell | | | |
| 4 | Unable to contact | | | |
| 3 | Did not attend on the day | | | |
| Total= 28 | - | | | |