

Experiences of the Dietary Management of Serum Potassium in Chronic Kidney Disease: Interviews With UK Adults on Maintenance Hemodialysis

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**Experiences of the Dietary Management of Serum Potassium in Chronic Kidney
Disease: Interviews with UK Adults on Maintenance Hemodialysis**

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Abstract

Objective

Dietary potassium restrictions in kidney disease are complex to follow, and may reduce quality of life. However details on this impact are sparse. We therefore sought to explore patients' perspectives on the experienced impact of following low potassium diets, to inform clinical practice and research.

Design and Methods

Qualitative semi-structured interviews were undertaken in a UK teaching hospital with adults undergoing maintenance haemodialysis. Audio-recorded, transcribed interviews underwent thematic analysis.

Results

34 adults (19 female, 15 males, and mean age 66.7 ± 10.9 years) with end-stage renal failure (ESRF) participated. Our analysis identified three themes with subthemes: "*What is left for me to eat now?*"; "*I'm obviously different*"; "*Food can be socially awkward*", and one outlying theme: "*Money doesn't grow on trees.*" Practical difficulties experienced when coming to terms with dietary restrictions meant testing out advice and experimenting with low and high potassium foods, to find a reasonable compromise, despite worries they could die from eating too much potassium. Interactions with food providers were dependent on pre-existing relationships, and maintaining these, at the expense of their dietary needs. Obtaining dietary requirements in restaurants often resulted in conflict with less concern for maintaining a relationship with those in the restaurant. Some individuals experienced financial difficulties and decisions were made to prioritise family needs over their own dietary requirements.

Conclusion

Low potassium diets bring practical and psychosocial consequences which significantly impacts people living with end stage renal failure. Renal health professionals should offer more support to people on a low potassium diet. Public education on dietary potassium

requirements in chronic kidney disease, particularly in the food service industry to increase awareness, may be a worthwhile intervention.

Keywords

Diet, quality of life, renal, qualitative, patient and public involvement

Introduction

Although restricting potassium may help reduce associated mortality risk (1) in end stage renal failure (ESRF), qualitative evidence suggests people find the advice difficult to follow, due in part; to dietary recommendations that change with serum potassium levels (2). Daily living activities, such as cooking for family and friends, and eating out in social settings are particularly stressful to negotiate on a low potassium diet (3). Although taking potassium binding medications may allow a more liberalised diet and thus help reduce these issues (4) the accompanying gastrointestinal side effects often result in poor compliance (5). Therefore, adjusting dietary potassium remains an important intervention in ESRF.

As such, people with ESRF expressed opinions that research into dietary potassium restrictions are prioritised to help improve quality of life (6). It is important to understand patient perspectives on following dietary potassium restrictions as adherence may reduce mortality as increasing numbers of people are being diagnosed with ESRF worldwide (7) and need to self-manage serum potassium levels. We therefore conducted this study to explore how patients experience dietary potassium restrictions and what challenges and barriers they face to adherence. Themes identified in this study will inform future research on the development of patient reported outcome measures and help clinicians support people who need to restrict dietary potassium.

Methods

Patient and public involvement

Adults attending for haemodialysis were consulted as part of a pre-planned patient and public involvement exercise (PPI) to inform the study design (8). Views on participant recruitment, interview topics and data collection methods were sought. This PPI consultation group recommended interviewing patients whilst attending for haemodialysis, as one-to-one interviews, as opposed to focus groups after dialysis sessions due to increased fatigue post-dialysis.

Study Design, Setting, and Participants

A qualitative approach was chosen as recommended by the US Food and Drugs Administration for outcome development (9) and followed Consolidated Criteria for Reporting Qualitative Research (10) and dietetic qualitative research guidelines (11).

Participants had to adhere to their prescribed haemodialysis three times a week for four hours, have received dietetic advice to follow a low potassium diet (this was verified by one researcher reviewing dietetic records to confirm low potassium dietary advice had been given), and be over 18 years of age.

Purposive sampling was undertaken. A recruitment poster was displayed in the renal outpatient department that invited people on low potassium diet to participate and discuss their experiences of dietary potassium management. Written information about the study was given out and all participants gave informed written consent. Participants who were unable to converse and write in English were excluded unless an interpreter was present. University Hospital Coventry and Warwick NHS Trust gave ethical approval for this study.

Data collection

Data were collected through semi-structured interviews in order to understand participants' experiences. These interviews were conducted face-to-face at a date and time convenient to the participants during their outpatient appointment, by (XX), who had over 10 years

qualitative interviewing experience. All interviews were audio recorded. Demographic and medical history data were collected at the interview stage.

A topic guide with open questions, informed by current literature and the PPI exercise, ensured all relevant material was covered. XX transcribed the recordings verbatim. No participants withdrew from the study.

Data Analysis

A thematic analysis was selected (12). This is a systematic method of analysing and interpreting qualitative data with a clear audit trail, which allows the five distinct stages of the analysis to be reviewed, increasing rigour. The stages include the following: familiarisation, semantic coding, indexing, charting and synthesising. Transcribed interview data were uploaded to NVivo 10 qualitative data analysis software for data management of this process (13). Data were reviewed until saturation and no new themes emerged from the data. This ensured that all relevant experiences have been captured. Reflexivity was undertaken in order to ensure transparency concerning researcher assumptions brought to this study (14). XX had preconceptions, informed by patient consultations in his role as a renal dietitian, that a low potassium diet was impractical; care was taken that this did not unduly influence the interpretation of participant transcripts. Member checking was undertaken by asking all participants to comment on the themes. Seven participants did not to comment due to reported time commitments (n=2), being on holiday (n=2) and hospital admission (n=3).

Results

Participant Characteristics

Thirty nine adults expressed an interest in participation. Five did not proceed to interview due to other time commitments (n=3) and inpatient admission (n=2). Thirty four adults (19 women, 15 men) with ESRF and self-managing a low potassium diet participated. Potassium

binding medication had been prescribed for three participants over the past year. Six participants had been prescribed this medication in the previous consecutive year.

The mean (SD) age of participants was 63.8 (± 10.9) years, and duration of ESRF was a mean (SD) 6.4 (2.4) years (range 1 – 8 years) after diagnosis. Twenty nine participants were of White European background. Five were of Asian background. All interviews lasted between 22 to 68 minutes.

The experiences of successful self-management strategies, in these individuals, to help restrict dietary potassium have been reported elsewhere (14).

Thematic analysis

There were three themes, made up of several subthemes, and one outlying theme (that was not common but important nonetheless), which captured the experiences and challenges of living on a low potassium diet, these are discussed below.

‘What is left for me to eat now?’

This theme shows the difficulties of coming to terms with following a low potassium diet, both from an emotional and practical point of view. One sub-theme is ‘*recalibration*’, participants described their initial reaction to following the low potassium diet as ‘life changing’ (P10) as ‘suddenly you’re restricted in everything’ (P12). Concurrent dietary management of diabetes was challenging, for example, people described perceived conflict between potassium restrictions and healthy eating with comments such as ‘what is left for me to eat now I have a potassium restriction?’ (P13). There was a sense of disbelief that the dietary restriction was necessary and this led to a reluctant compliance with a sub-theme of ‘*getting away with it*’. This involved experimentation to find meals that were ‘good to eat’ (P1); and that had the ‘estimated amount of potassium that I could get away with’ in them (P17). These actions imply that dietary potassium restriction were deemed unnecessary, or too difficult to incorporate into lifestyles, for example, eating portions of ‘high potassium

vegetables with cheese would not kill you' (P4) and consuming 'chocolate won't send your potassium through the roof' (P17).

There was a sense that the current dietetic service was 'lacking in support' (P13) to help manage dietary restrictions with a subtheme of '*support needs*'. Participants believed that low potassium diets needed to fit better into current lifestyles as the current advice was incongruent to many, needing to be 'placed into context' (P2) as 'most of my favourite foods were excluded' (P8). It was emphasised that negotiating the biomedical approach to education did not always help understanding of why potassium needed to be restricted.

'People come up to you and say 'this is bad, your bloods are bad' and you don't notice it so you think you can get away with it. There is no link to what you are eating and your potassium levels. You know it's 'I'm getting away with it so why are you telling me this?' Patients need to understand the link between food and their own potassium levels. We don't need your numbers (serum potassium) but we do need something to tell us in a less medical way' (P18)

Participants voiced distinct recommendations to help manage a dietary restriction. The need for supermarket tours to identify and discuss potassium content of 'real foods' (P9), cooking classes, and hand held self-monitoring devices, potassium-binding medication, and potassium-counting education are required for a more liberalised diet.

'I'm obviously different'

This theme focuses on the detrimental impact that a low potassium diet had on participants' perceptions of self, with an awareness that 'I'm obviously different' from others. The overriding feeling of being 'offbeat' (P26) was due, in part, to the burden of having to deal with 'powerful, and often negative emotions' (P16) associated with this 'unwelcome diet' (P11).

‘You’re sat there with your friends, and you know all the stuff, but I still fancy a little something. It’s a real drag... I just feel resigned to the fact that I can’t eat certain things that they can’ (P24).

There was an awareness of being a ‘nuisance’ (P2) and ‘troublesome’ (P6) when comparing themselves to family and friends in social situations. The sub-theme of *‘avoiding unwanted attention’* represents how the avoidance of unfamiliar places, and where ‘menus were perceived as high potassium’ (P1), helped reduce perceptions of feeling dissimilar. This avoidance behaviour, which participants undertook as a means of ‘not going to let this intrusive diet into my life’, helped reduce ‘the worry experienced on a daily basis’ (P10). However avoiding extra attention from hosts, family and friends, as a result of discussing low potassium food options, often meant dietary needs went unmet. Perceptions of resentment and resignation to the fact that favourite foods could not be eaten were common, as this avoidance strategy did not help minimise the negative feelings of being ‘obviously different’.

A sub-theme of *‘scared of dying’* highlights the negative impact on quality of life and the challenges that people had around dietary non-compliance and the connotations of death. This negative perspective intensified the sense of feeling different to others as ‘they’re not going to die if they eat a banana’ (P5). People were unsure as to the exact effect dietary potassium would have on blood results, which resulted in rumination on thoughts of ‘dropping down dead’ (P23) as ‘there are no warning signs of high potassiums’ (P1).

‘I went obsessive with it; constantly worrying and I stopped eating, so scared I was going to die’ (P23).

‘Food can be socially awkward’

This theme is around dissonance experienced in relationships with food providers ranging from family and friends to restaurant staff. The subtheme of *'Oh it looks lovely!'* captured behaviour aimed to maintain established relationships with family and friends.

'I find it difficult. Social situations are hard. Eating out or having friends out, or going to friends where you are not in control of what is put on the table and what you eat. Alternatively, you are at their house, it is very rude to sit there, and say, "I can't eat that...I'm not supposed to eat that much potassium," you sound like a right idiot.'

(P4)

'Food can be socially awkward. You don't want to look to cause offense by not eating stuff, especially at Christmas time, so you say "oh it looks lovely" and look like you're eating a bit of everything.'

(P19)

The subtheme *'Why are you asking?'* related to relationships with food providers when eating out. There is a sense that the caterers lack knowledge of renal dietary requirements, and the important implications that this causes for people. Participants felt they were 'not believed by staff' (P5) which often resulted in confrontation with restaurant staff when asking for a low potassium diet. Such assertiveness in these situations was easier than with family and friends as it did not jeopardise an important friendship, for example, 'You know you can be more confident asking for something, when you don't know them, you don't need to pussy foot around, whereas with friends it's trickier to ask' (P13).

'I went up and asked if he would boil the veg for me and the chef argued and said 'we steam' and 'other kidney patients have eaten this', so basically, 'why are you asking?' I also got the feeling that they thought it was someone being picky...not a real diet...just someone got an intolerance ...' (P9)

'Money doesn't grow on trees'

This outlying theme (uncommon across the group but important nonetheless) focuses on the financial difficulties experienced in adhering to a low potassium diet. Participants had to make decisions or compromises with the subtheme of an ‘acceptable quality of life’ living with ESRF, as ‘money doesn’t grow on trees to pick off when you fancy a night out’ (P30).

‘I’m not working cause of this [kidney failure]. There isn’t £25 to eat out. We do go out occasionally, to treat the kids. We turn supermarket vouchers into restaurant vouchers so we can all go out for a meal, but even then we compromise on portion sizes. I’ll have a kids menu’ (P3)

A decision was made, with the subtheme ‘*alternatives*’, in which the foods with lower potassium contents were ‘balanced up against the cost’ (P8) against consuming reduced quantities of higher potassium foods. People considered, but dismissed dairy milk-substitutes such as oat and soy, as ‘they cost too much’ (P2), ‘can’t get them at my local shop’ (P24) and ‘taste like wall paper paste’ (P7). There was a sense that participants needed to be resourceful on limited money and ‘think outside the box’ (p4), for example, people visited food banks who provided support for a low potassium diet as the ‘tinned fruits and veg are fantastic for low potassium diets’ (P5).

Discussion

We investigated how adults with ESRF experience low potassium dietary advice using qualitative methodology. Our study highlights the impact that dietary potassium restrictions have on the lives of people with ESRF. We contribute a more in-depth understanding of quality of life issues around renal dietary restrictions to current literature. For example, a thematic systematic synthesis of renal dietary experiences identified that the renal diet is challenging to incorporate into lifestyles (16), which supports our study findings. Indeed we have provided evidence that dietary potassium restrictions may limit social interactions, make

people feel they are a burden to others, and also have to self-manage 'fighting temptation' (16). Our study offers evidence that it is the low potassium diet that may bring these experiences, as reported in Palmer et al.'s (2015) meta-synthesis, for example, it is the part of the renal diet that has the most negative consequences of 'the fear of dropping down dead' (P23). Indeed subsequent meta-analysis report evidence that sodium and phosphate are less troublesome. We do, however, acknowledge that there is no direct evidence from this study to support this theory, and therefore it is still unknown if it is the entire renal dietary restrictions together or dietary potassium restrictions in particular that have a negative influence on people's lives.

There are several findings to note from our study for practicing dietitians who support people on a low potassium diet: people with ESRF experiment with given recipes involving high potassium foods. This is consistent with reports in other dietetic qualitative studies, where individuals experiment to help make sense, and cope with a renal diet (16). Eating high potassium foods and meals containing high potassium foods was reported by many in our study, as was non-disclosure of low potassium dietary needs when eating out. Our study adds to the evidence that adherence to therapeutic diets often results in disclosure avoidance (17). For example; efforts were made to de-identify themselves with dietary potassium restriction to avoid further questioning on food choices, and attention from others, when out in social settings.

There was lack of reported consideration for the consequences of eating high potassium foods, even when people expressed they may 'collapse dead' (P2). Indeed this issue around eating high potassium food and associated increased risk of a myocardial infarction has been identified in previous studies (18). Perhaps the lack of any symptoms or immediate effect means the threat is perceived as less real. This is in contrast to other conditions where consumption of certain foods can have an immediate and drastic effect, for example, such as

the risk of an anaphylactic shock in peanut allergy (19). In these cases individuals know, from experiencing frightening symptoms, the effect that the food would have on them. Food choice pragmatism is clearly demonstrated in this study, as suggested by non-compliance to advice in the '*getting away with it*' subtheme. Therefore it is important for dietitians to recognise that people with ESRF may deem restrictions as unnecessary, even when the myocardial infarction consequences are explained.

Whilst there is evidence for the majority of experiences in this study, less is reported on the financial and relational impact of dietary potassium restrictions. Both are relevant to people undergoing maintenance haemodialysis as they may have lower incomes (20), and if adherence is complicated by finances, then it is important to provide access to support needed.

Education for caterers should include information on what constitutes a low potassium diet; the rationale for providing such meals in ESRF; and practical advice on how to adapt the potassium content of menus. Help with advertising that the establishment will cater for dietary potassium restrictions may allow a wider clientele with ESRF to eat out by providing some reassurance that caterers have an understanding of dietary needs in ESRF.

In this study, data underwent triangulation from peer review and member checking to increase rigour. One limitation to our study is our findings are not transferable to people with ESRF worldwide who may follow a low potassium diet.

Other limitations included potential bias from a clinician undertaking research on people that they may have supported with dietary changes. We were therefore careful to exclude people who had received advice from the primary researcher. Future research comparing peoples' comments about dietary potassium restriction experiences to results from quality of life surveys would provide quantitative evidence to supplement this qualitative data.

Practical Application

People who need to restrict dietary potassium may not understand the relationship between their serum potassium results and diet. Support with managing circumstances around food choice, such as eating out, should be an important role of the dietitian, for example, demonstrating how to choose lower potassium foods from online restaurant menus or facilitating practical sessions on potassium portion counting/estimation. If people disclose that communication of dietary needs is an issue which prevents them enjoying their meal out, then discussing ways to ask for their dietary needs in a social setting, for example, using assertive communication skills, may be an option to consider during consultation.

Article information section

Authorship

AM and DL designed the study. All authors contributed to the analysis and interpretation of the data. All authors contributed to the writing of the manuscript. All authors critically reviewed the manuscript and approved the final version submitted for publication.

Conflict of interest

No conflicts of interest are declared

Statement of funding

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