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Adhering to behaviour change in pre-dialysis populations - What do patients think? A qualitative study

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ABSTRACT

Background: Chronic Kidney Disease (CKD) is associated with the development of serious co-morbidities. Patients with CKD are encouraged to adhere to regimens to lower this risk. This study aimed to explore the experiences of patients attempting to integrate lifestyle changes into their lives.

Method: Face-to-face recorded interviews were conducted with nine consenting patients with CKD Stage 4 under the care of a consultant nephrologist. Each recording was analysed by two independent investigators using thematic analysis.

Results: Five themes emerged: Self in relation to others, Control, Adherence, Beliefs about treatment and illness and Uncertainty. Participants highlighted the importance of personal support and recounted their sense of being a burden on close family. They described how they approached disclosure about their condition, their beliefs regarding treatment and their decision making processes and how these factors impacted on adherence to behaviour change.

Conclusion: Practical support from family and healthcare professionals, a willingness to disclose their condition and help to make good decisions in difficult circumstances were identified as important factors in supporting success with behaviour

change.

STATEMENT OF PROBLEM:

Non-adherence to lifestyle changes is common in people with Chronic Kidney Disease (CKD) and may increase the risk of these people developing co-morbidities. Little research exploring the impact of how specific behaviours and changed life style, which are recommended in pre-dialysis, impact on a person's life and what supports success with changing behaviour over the long term

INTRODUCTION

CKD is a debilitating condition that is associated with the development of serious co-morbidities. Consequently, patients are encouraged to adopt a number of lifestyle changes to limit this risk. It is well documented that non-adherence to recommended lifestyle changes is common (Denhaerynck *et al.* 2007) and is linked with poorer outcomes in renal patients (Leggart *et al.* 1998).

Self-management offers a tool to support behaviour change. It has been described as an individual's ability to manage his/her symptoms, treatment regimen and life style changes inherent in living with a chronic condition (Barlow *et al.* 2002). Interventions to promote self-management have been found to improve adherence to recommended behaviours in patients with CKD. Tsay and colleagues found a decrease in fluid weight gains three months post-adaptation training which involved helping patients to appraise stressors appropriately and restructure negative thoughts (Tsay *et al.* 2005). Su *et al.* (2009) reported improvements in treatment efficacy and self-efficacy (a measure of an individual's confidence to manage his/her condition) in peritoneal dialysis patients. Self-efficacy was enhanced by supporting patients to re-interpret symptoms and by using verbal encouragement to persuade patients that they do have the skills to succeed. Similarly, a nutrition intervention, utilising self-management, has been shown to improve outcomes in CKD patients (Campbell *et al.* 2008).

Patients entering CKD Stage 4 often have their care moved from a consultant nephrologist and primary care to the multidisciplinary team which means having to attend more hospital appointments. It is often at Stage 4 that patients' blood results indicate a need to alter diet and take more medication to manage symptoms, delay end-stage disease and decrease the risk of co-morbidities. So how do these patients successfully incorporate these changes into their lives?

In a qualitative exploration of patients' perceptions of kidney disease and the support required for CKD self-management, Costantini *et al.* (2008) found that patients engage in an iterative process of re-negotiating life. They found that as patients gained knowledge about their kidney disease and its implications they developed strategies to integrate the illness and its treatment into their lives. In addition, Velez and Ramasco (2006) examined the views of end-stage renal disease patients in regard to their illness and found that living with a chronic disease, a fear of death and pain and of being labelled by Health Care Professionals (HCP) were thoughts that shaped adherence to treatment. Patients described coping strategies that helped them adapt to living with the disease such as normalisation, family support and beliefs about control. Similarly, Rifkin *et al.* (2010) found that participants created coping systems to allow them to adhere to complex medication regimens.

Patients confronted with the immediacy of a diagnosis of CKD Stage 4 often experience feelings of helplessness and hopelessness (Sijpkens *et al.* 2008), however, many patients do successfully adapt to self-manage their illness. Exploring the patient experience qualitatively will help HCPs understand what support is required to encourage adherence to behaviour change.

METHODS:

Setting

The study (approved by the Cambridgeshire 1 Research Ethics Committee) was conducted in a large NHS teaching hospital renal unit, which provides care for more than 1100 CKD stage 4 patients of multi-ethnic origin and social background.

Method

A purposive sampling strategy was adopted to recruit potential participants. The aim was to sample a similar number of male and female participants with a range of ages and ethnicity.

Inclusion criteria:

1. Adult participants must have attended low clearance clinic for at least 6 months.
2. Be able to speak English.
3. Have an estimated Glomerular Filtration Rate (eGFR) ≥ 25 ml/min (MDRD formula).

Exclusion criteria:

1. Those who were judged by the consultant nephrologist as too ill to take part in the study.

Having recruited nine participants the investigators agreed that saturation of themes had occurred, i.e. transcripts had been analysed in full and no new themes or sub-themes were generated and therefore recruitment stopped.

All interviews were conducted in the renal outpatient department by a single investigator, using a semi-structured interview schedule. Interviews lasted 30–70 minutes. Questions were developed by discussing major lifestyle changes the patients faced when entering CKD Stage 4. Adherence to medications, dietary advice and attendance at hospital appointments were explored in depth. Participants were encouraged to speak freely. Prompts and probing questions were used when appropriate to explore areas of interest in more detail. The interview was digitally recorded with the participants' permission and transcribed verbatim. All identifiers were removed from the transcripts and original recordings were destroyed in line with good clinical practice.

Analysis

Transcripts were analysed using thematic analysis; a recognized method of identifying, analyzing and reporting patterns within qualitative data. First, the verbatim transcripts were read in full several times to allow familiarization with content. Initial codes were then generated using detailed quotes from the transcripts to provide evidence for subsequent interpretation. These codes were then grouped into themes. These steps were conducted independently by two investigators (RW, HJ) from different healthcare disciplines to ensure validity. These investigators then discussed similarities and differences between the initial codes and themes, the majority of which were concordant. The definition and naming of these themes and

codes was decided. Classification of themes, sub-themes and codes was independent of the frequency with which they were identified in the transcripts. Once agreement had been reached within individual transcripts, consistency across participants was reviewed by both investigators in an iterative fashion (Braun & Clarke 2006).

The analysis was supported by the interviewer's reflective diary, a written record of her initial thoughts and feelings about each dialogue immediately following each interview. The diary proved helpful during the analytical process to clarify meaning within the transcripts and in some cases resolve differences between the investigators.

The final stage of the analysis involved creating a summary story using thematic maps for each participant in relation to these themes and codes to highlight how the themes and codes were inter-related (Braun & Clarke 2006).

RESULTS

Nine participants took part in the study. Clinical and demographic characteristics of the participants are outlined in Table 1. Five themes emerged from the nine transcripts: Self in relation to others, Control, Adherence, Beliefs about treatment and illness and Uncertainty, which were common to all transcripts. In addition, several sub-themes and codes (see Table 2) were identified which were only present in some scripts.

Some themes and their sub-themes appeared to emerge clearly such as 'Burden/impact on others'. However, other subthemes moved between themes on closer reading of individual transcripts. For example, 'Establishing routines' moved from the theme 'Control' to 'Managing Adherence' as what was described was using routine to aid adherence rather than gain control.

Self in relation to others

All participants spoke about their relationships with others and the impact their disease and its treatment was having, particularly on those close to them.

Burden on others

Some participants felt strongly that they did not want to burden those close to them with their illness and particularly the lifestyle changes required. However, most recognized that despite this their illness inevitably impacted on them, which led to feeling guilty and uncomfortable.

"As you can imagine that when my wife does cooking. She doesn't use tomatoes at all..... and I feel guilty about that, I do tell them" (Participant 1)

In some instances the need to avoid burdening people led to concealment of the illness and treatment effects or avoidance tactics such as not thinking about or discussing the disease.

“At the moment I’m serving all my friends and asking them who are you going to vote for in the next election. (laughs). That sort of thing we talk about I mean I go to music I go to art galleries and theatre. And er er so and films that’s one reason why I live in London. And so all of this is really important not talking unceasingly about my health.” (Participant 2)

Receiving help

All participants accepted that they received help, whether it was emotional support or practical help from close friends, family and HCPs. This help was often directed towards supporting the lifestyle changes required to manage their illness.

Examples included providing advice, ordering medications, taking participants to appointments or encouraging them to engage in self-care.

“Well, for instance, when I see the doctor here every six months there is usually a dietitian sitting with her or him, which is great because then I ask their advice if I don’t under....for instance I like baked potato.” (Participant 2)

“But actually it is not a big problem for me because when I tell to my children I am running out (of medicines) then they will do it or they will collect it on time.” (Participant 7)

Relationships with health care professionals (HCP)

Contrasting relationships with HCPs emerged from the transcripts. Many patients felt they could trust their HCPs to provide the best care. They felt they were well monitored and looked after. However, others expressed frustration at what they felt to be a lack of respect, particularly in relation to the perceived lack of value placed on the patient’s time by the HCP or realising that they had previously been given what they felt was conflicting advice.

Control

This theme highlights ways in which participants gained a sense of control over their illness and treatment.

Self-monitoring

Some participants actively sought to monitor details of their illness. This enabled them to feel more informed and allowed them to feel in control of their condition by checking blood pressure readings or keeping copies of blood test. They reported that

they felt nothing unexpected would happen if they kept an eye on the disease process.

“Because that gave me what was the condition of the kidney going on because every time I come here take the blood tests and they give me the report, how the kidney is functioning, what is happening, sometimes take the printed report, put it in the file and check it” (Participant 5)

Disclosure or concealment

The ability of participants to disclose or conceal their illness and the consequent changes in lifestyle was a significant finding. Participants who concealed their illness did so to avoid ‘pity’ and ‘boring’ their friends and relatives. Those who were able to disclose their condition reported being better able to adhere to the lifestyle recommendations, in particular, the diet. Participants revealed that family and friends would alter what they ate or how they prepared food to support dietary change.

“...everybody knows, my friends of course know that that I have got kidney failure and I make everybody aware that I am a kidney patient.The advantage is that when you are just limiting your diet, people accept it. More you are open with everybody, where I go and stay with my nephew there, the wife knows, so she will boil the vegetable for me, throw away the water and cook separately for me.” (Participant 5)

Decision making

Patients recounted two distinct approaches to decision making with HCPs. On one hand some described collaborative interactions where they would discuss medication with their consultants, nurses and G.P.s, while others clearly allowed the HCP to take control and make decisions on their behalf.

Adherence

By and large, participants felt they were successfully adhering to the changes required to maintain health as recommended by renal healthcare staff. However, all described particular situations where they found adherence more difficult.

Dietary decisions

The burden of constant decision making in relation to food was obvious in most transcripts. Participants reported particular difficulty when eating outside of the home; often choosing food that was not necessarily ideal but ‘the next best option’.

Some described a coping mechanism where they allowed themselves treats or gave into temptation which they then used to reinforce determination to be more careful with their diet in subsequent meals or days. Some also described ‘tricks’ (such as using herbs instead of salt) they had discovered that allowed them to continue to enjoy food.

“Well it could be difficult in a restaurant if the menu is such that it has a lot of high potassium foods in it. I will try and avoid those as best as I can and if not entirely,

then I will take that as one my little treats and then go more carefully the next few days.”
(Participant 3)

“let me tell you to give you an example, erm if they are making a pizza...And they want to have tomatoes and mushrooms on it they can have it in three quarters. They bake one quarter without the mushroom and the tomatoes.”(Participant 1)

Establishing a routine

Establishing a routine was a common tool that participants used to manage adherence to treatment. Many used their daily routine, such as mealtimes, to remember to take medication. They also described using tally charts, diaries and wall calendars as memory aids.

“I have, as I said, a table system when my tablets are running out to re-order because there are so many of them it’s not just as easy as saying once a month, but they all run out different times and take different levels and what have you. So, I have to keep track of what we’ve got and when we have got it,” (Participant 8)

Beliefs about illness and treatment

All participants spoke of their understanding and beliefs about their kidney disease and lifestyle changes.

Cause of side-effects

Participants emphasised their belief that the medication resulted in side effects such as a lack of strength and energy or lack of sexual drive. Whilst many patients altered their dose or timing regimen in an effort to manage these side effects, only one individual reported not taking the medication in question at all.

“Yeah, I think it is lack of energy and strength mainly. Some of that might be due to the medication I am taking because I am taking a hell of a lot....” (Participant 3)

Medication harm

Media reports of adverse events and perceived disagreements between physicians (Family doctor vs. consultant) caused particular concern to participants and some questioned whether the combination of so many drugs produced harmful compounds.

“Only because there is so much of it, whether it works sometimes putting three things together might make a fourth, I sometimes wonder about that.” (Participant 8)

Value

The importance of taking medication and attending hospital appointments as a way of ensuring good health and prolonging life was clearly evident in the interviews. Participants reported that the medication had value because it kept them stable, off dialysis and ensured the kidneys continued to work in some capacity.

“Well if it keeps me alive, I am quite happy, if it helps my health, I always I feel for my age I feel very well actually. So um no, there is no problem, I will take medication if I think it is necessary.” (Participant 4)

UNCERTAINTY

Most participants expressed feelings of uncertainty in relation to their illness and treatment, not understanding the rationale behind their management plans. In particular, they questioned why they were taking certain medications or following an altered diet and what the future held in terms of symptom burden and outcome. Some expressed ambiguity about whether their current symptom burden was due to their chronic illness or to the inevitable process of aging.

“It’s hard to say whether my condition affects my life or my age affects my life but two are sort of really together aren’t they” (Participant 2).

DISCUSSION

In this qualitative study we identified five themes, which captured the experience of CKD patients attempting to incorporate lifestyle changes; ‘The self in relation to others’, ‘control’, ‘adherence’, ‘beliefs about treatment and illness’ and feelings of ‘uncertainty’. A number of participants described how their condition and illness impacted on friends and family. This sense of burden often led to concealment of their condition that then led to difficulties adhering to a desired regime. Despite finding it particularly hard to adhere to dietary alterations when eating out or travelling, some were still unable to disclose their medical need for a specific diet. This anxiety about being a burden was identified as a significant theme by Harwood *et al.* (2005) when exploring pre-dialysis CKD patients’ feelings and is a common finding in other chronic diseases (Martensson *et al.* 1998; Beverly *et al.* 2007). Participants who were able to talk about their illness identified that this disclosure enabled friends and family, particularly in terms of diet, to assist them in adherence.

A number of studies in chronic illness highlight the importance of support from family and friends (Patel *et al.* 2005; Molzahn *et al.* 2008). In this as in other studies, practical as opposed to emotional support in particular encouraged adherence. (DiMatteo 2004; Velez & Ramasco 2006; Mitchell *et al.* 2009; Browne & Merighi 2010). Our participants valued help with transport, sorting out medication and alterations in eating and cooking to support adherence to dietary advice.

Self-management was previously described as the ability to manage treatment regimens and lifestyle change. This study highlighted behavioural management techniques that were developed by these participants to limit the impact these changes had on their lives. Tong *et al.* (2009) found that CKD patients described situations in which they compensated for eating something they should not, by being extra vigilant on subsequent days. Similarly, Krespi *et al.* (2004) in a study of haemodialysis (HD) patients report how they describe ‘getting around’ dietary ‘rules’ by consuming alternative food or eating minimal amounts of ‘forbidden’ food. This study mirrored these findings.

In other chronic conditions, patients have been shown to hold strong beliefs about their illness. According to the 'selfregulatory model of illness cognitions' (Leventhal *et al.* 2003), these beliefs provide a framework for how a person copes with and understands their illness. There has been some research looking at the role of illness beliefs in CKD suggesting considerable impact on quality of life. In particular how disruptive the illness and treatment is and how much control the patients feel they have over their disease (Griva *et al.* 2009). Importantly, mortality rates have been found to be higher among CKD patients who believed that their treatment is less effective in controlling their disease. (Tsay *et al.* 2005).

This study revealed that participants held strong beliefs about treatment and were often anxious about the possible side effects and harm of their medication. Interestingly, these beliefs rarely resulted in complete nonadherence but did impact upon the frequency and dosage of medications. This may have been because the assumed beneficial effects of the medications, keeping well and not requiring dialysis, counterbalanced these concerns. Studies by Tong *et al.* (2009; 2011) found that although transplant kidney patients tried to negotiate a change in medication to limit side effects, they continued to take medication to avoid dialysis as this was believed to be worse than the possible side effects. Tong also found that patients experiencing side effects from multiple medications continued to adhere to the treatment regimen both out of a sense of duty to their HCP and because they believed the medications would help them to survive (Tong *et al.* 2009). In this study, participants described trusting relationships with HCPs. They believed that healthcare staff were making the best decisions for patients whether the patients were collaborating in the decision-making process or not.

In contrast, participants also expressed uncertainty about aspects of their illness and treatment. For some, uncertainty was combated by maintaining a sense of control over their condition and using routines as memory aids. Similar coping strategies have been reported in studies of renal patients by Iles-Smith (2005) and Hollingdale *et al.* (2008). Many of the uncertainties particularly around whether their symptoms were kidney-related or age-related probably reflecting the older age of these participants.

One limitation of this study was that participants recruited had an average age of 76. Only 50% of the local renal population are over 60 so this represents the older cohort only. It is well reported that older patients are likely to be more adherent (Horne & Weinman 1999; Karamanidou *et al.* 2008) and it is possible that those who felt they were generally adherent were more likely to accept an invitation to be involved in this study. Younger patients may have aspects to their lives they consider more important than their health and feel themselves to be at lower risk of developing co-morbidities than an older cohort. Future qualitative studies should focus on recruiting younger patients to determine their experience of incorporating behaviour change into their lives. Only English-speaking participants were invited to take part in the study as it was deemed too expensive to have interpreters present at the recorded interviews and have the transcripts translated. Non-English speaking

CKD patients may well have a very different experience of attempting to incorporate lifestyle changes into their lives. However, the participants recruited represented the ethnic mix that is the local renal population. It is inevitable that questions asked and responses given will be biased towards the health care disciplines of the researchers. Results had a strong emphasis on diet but this has been balanced by the analysis given by a health psychologist who highlighted attitudes to medications and participants relationships and how these impacted on adherence.

CONCLUSION

To our knowledge this study is unique in that it focuses on the experience of older pre-dialysis patients attempting to implement the recommended lifestyle changes. It clearly identifies the difficulties faced by this patient group. However, many participants managed these changes successfully and a number of potentially transferable coping strategies were identified. Disclosing their illness and the lifestyle changes needed and drawing on support offered by friends and family enabled successful engagement. Conversely, those concealing their condition felt less able to follow the recommended life changes. Negative beliefs and anxieties concerning medications or treatment were frequent but did not impact significantly on adherence. Thus, we posit that future beneficial strategies should be focussed around helping patients to disclose the nature and impact of their illness, support to make good decisions in difficult circumstances and finally accessing practical support from family, friends and HCPs.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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AUTHOR CONTRIBUTIONS

RW wrote protocol, collected data, analysed data and wrote up results. HJ wrote protocol, analysed data, and helped write up the results. AB helped write up the results.

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Table 1 – Participant characteristics

Participant	eGFR mls/min	Age in years	Gender	Ethnicity	Family Status	Employment status	Number of months in low clearance clinic (pre-dialysis)
1	<15	66	Male	Indian	Married with children	Employed	108
2	19	80	Female	Other	Widow, lives alone, supportive children	Retired	24
3	22	83	Male	Jewish British	Lives alone, no family	Retired	22
4	25	76	Female	White British	Married	Housewife	72
5	<15	75	Male	Other	Widower, lives alone, supportive children	Retired	30
6	20	93	Female	Jewish British	Widow	Retired	24
7	<15	71	Female	White British	Married	Not working	11
8	<15	63	Male	Asian	Lives with children	Not working	20
9	<15	76	Female	White British	Lives alone	Retired	28

Appendix 1 Interview Schedule

(1) DIET

- ☐ How might the food that you eat effect your kidney disease?
Probe: Has anyone spoken to you about what foods are recommended/not recommended?
- ☐ Can you tell me about any changes you have made to your diet since you found out about your kidney disease?
- ☐ What makes it difficult/easy to stick to these changes?
Probe: personal taste, social events, going out, other people, cooking, memory, work, strategies,
- ☐ How do the changes in your diet effect your every day life?
Prompts: work, social life, personal relationships, emotionally, medically

(3) MEDICATION

- ☐ Why might the medications you have been prescribed be important for your kidney disease?
- ☐ How do go about taking your medication on a day to day basis?
- ☐ What makes it difficult/easy to take your medication?
Probe: Is there anything that might stop you from taking your medication/alter the way you take it?
Probe: social, memory, work, other people
- ☐ Do you have any concerns or worries about your prescribed medication?
Probe: side effects
- ☐ How does taking your medication affect your everyday life?
Probe: work, social life, personal relationships, emotionally, medically

(3) OUTPATIENT APPOINTMENTS

- ☐ I understand that having kidney disease means attending the hospital for appointments on a regular basis. How do you feel about this?
- ☐ Have there been times when you have not wanted to attend an appointment?
- ☐ What made you attend/not attend?
- ☐ Do you have strategies or thoughts that help you attend?