**Title**

Innovative education for people with chronic kidney disease: an evaluation study

**Abstract**

**Background**An innovative Community Kidney Service has been running since 2016 in four health regions in East London, UK. This paper focuses on the patient education (self-management) programme within the service.

**Objective**To understand the experiences of people with stage 1 – 3b chronic kidney disease invited to individual or group education sessions. To assess the usefulness of the programme’s educational resources to primary care nurses.

**Design**A mixed-method project. A steering group involving patients shaped both survey and interview questions.

**Participants**Paper surveys (n=266) were sent to patients 7-19 months after they had attended. Semi-structured interviews were undertaken with patients who returned the survey and indicated they were willing to be interviewed (n=9). Survey links were sent electronically to primary care nurses.

**Results**54 surveys were returned from patients. The education session increased self-reported knowledge about kidney disease and two thirds of patients reported making lifestyle changes. Analysis of interview data identified recognition of kidney disease, motivation to change and reliance on ‘experts’ as key themes. Surveys were returned from 21 nurses. Most were aware of the community kidney service but only one third had used the education resources with their patients.

**Conclusions**

Secondary care nursing involvement in primary care-based education for people with kidney disease is rare in the UK and internationally. This educational intervention, developed with patients, supports people to make changes that have the potential to reduce progression of kidney disease and our findings have significance for other teams working in chronic kidney disease management.

**Key words**  
Chronic Kidney Disease; Education; Evaluation; Self-management

**INTRODUCTION**

Improving the identification and management of chronic kidney disease (CKD) is an important objective for primary care and hospitals. A systematic review on global prevalence of CKD (Hill et al, 2016) suggested that future research should evaluate intervention strategies deliverable at scale to delay the progression of CKD and improve cardio-vascular outcomes. The UK National Health Service (NHS) has highlighted the need for new models of care to manage long term conditions with integration between primary and secondary care recognised as key. The NHS Long Term Plan (NHS England, 2019) has ambitions to encourage further collaboration between GPs, hospital teams and community services, as well as offering people more control over their own health and the care they receive.

*Community Kidney Service*

The East London Community Kidney Service was commenced in 2016 with the aim to improve care, understanding and experience for patients with CKD in East London. This innovative service comprises a virtual clinic; tools to help identify people with CKD (Hull et al, 2019) and those with rapidly progressive disease (Thomas et al, 2019); support and education for primary care; and patient education (Thomas and Rainey, 2018). The virtual clinic allows nephrologists to give advice to primary care clinicians by accessing the patient’s primary care electronic health record (with patient consent) without patients needing to attend a hospital outpatient appointment. This has led to a threefold increase in referrals to secondary care, although less than 20% of those have required a face to face hospital nephrology appointment (Hull et al, 2020).

The Community Kidney Service covers a geographical area that includes four boroughs in East London. The population is ethnically diverse with high levels of social deprivation and although younger than the England average there are high rates of diabetes (Goodyear, 2016). These populations risk higher than average progression to end-stage kidney disease, and higher rates of mortality and morbidity due to associated cardiovascular disease (Caskey and Dreyer, 2019). East London has a higher than expected prevalence of people receiving renal replacement therapy, and people start treatment at a younger age than the national average (UK Renal Registry, 2019).

A kidney nurse-led education service “*How to look after your kidneys*” was commenced in 2016 that aimed to provide education about CKD for those with CKD stage 1 – 3b who were referred to the virtual CKD clinic but were not offered a nephrology outpatient appointment. Suitable patients were invited to a group or individual session with a kidney nurse(s) covering cause of CKD, severity, risk of progression, acute kidney injury and behaviour modification to delay worsening and promote long term health. Face-to-face single sessions were for individuals assessed as being at higher risk of kidney disease progression or who needed an interpreter and lasted for 30 minutes. Group sessions were for those with non-progressive disease and their families and lasted for 1.5 – 2 hours.

Thomas and Rainey (2018) described the development and early evaluation of this programme. The programme development was based on previous studies that aimed to improve patients’ knowledge and self-management of CKD and used motivational interviewing as the behavioural change theory (Rollnick and Miller, 1995). A variety of educational tools were developed with patients, including a simple booklet with mostly images not text, a more comprehensive booklet, a conversation map and film.

This paper reports an evaluation that aimed to understand the experiences of people with stage 1 – 3b CKD who had attended an education session during the second year of the service (January to December 2017). A secondary aim was to assess the usefulness of the education resources to primary care nurses.

***Literature review***

Prompt identification of CKD provides an opportunity to offer education about self-management and risk reduction to patients at an early stage of disease. However, there is a continuing debate about what this education should look like, particularly for those with multiple medical conditions, and whether primary care or kidney specialists should be responsible. A number of reviews aimed to evaluate the effectiveness of self-management interventions for people with CKD (Bonner et al, 2014; Welch et al, 2015; Lopez-Vargas et al, 2016). They found that the format, intensity and follow up period of self-management interventions varies widely, and that due to the variety of outcome measures, small sample sizes and relatively short follow up it is difficult to show efficacy. However, all concluded that it is desirable that individuals with CKD are supported to effectively self-manage day-to-day aspects of their health. Welch et al (2015) highlighted the heterogeneity of educational content and that no studies included all topics associated with CKD self-management (for example advice to stop smoking). More recently Peng (2019), in a meta-analysis including 19 studies, found that self-management interventions were associated with lower proteinuria and blood pressure, and better exercise tolerance, but were not associated with mortality or change in kidney function.

A complication is that CKD has a number of causes and varies in severity. People managed in primary care are different to those in nephrology clinics (Taal, 2013) and interventions should be tailored appropriately. Zimbudzi et al (2018) highlighted that interventions are often designed for single conditions rather than patients with complex multi-morbidity and included 8 studies in a meta-analysis of self-management support interventions for people with both diabetes and CKD. They concluded that such interventions may improve self-care activities, systolic blood pressure and diabetes control, but were unable to determine which elements were most effective.

One further criticism of self-management interventions is a mismatch between the views of patients and health care professionals with health care professionals viewing interventions as simply information-giving to promote compliance with advice whilst patients recognise the complexity of self-managing in everyday practice (Sadler et al, 2014). In an integrative review Havas et al (2016) identified 10 self-management topics that were important for people with CKD including disease-specific knowledge, lifestyle modification and the need for intervention early in the disease. Donald et al (2018) found that lifestyle topics were not included in many of the interventions studied and less than a third included information about comorbid conditions. They concluded that interventions should be co-developed with patients and informed by behavioural change theory.

The *“How to look after your kidneys”* programme attempts to address these concerns, providing education to patients who would not otherwise come into contact with a renal specialist, and goes some way to address “the need to involve patients to co-developed and evaluate a self-management intervention based on sound theories and clinical evidence.” (Donald et al, 2018).

**MATERIALS AND METHODS**The local Trust approved the project as a service evaluation (*name of hospital anonymised* Clinical Effectiveness Unit, ref number 9092).

The development of the evaluation framework for the patient education programme involved patients. A steering group was convened via existing Kidney Patients Association and Patient Forum groups. A patient member of the steering group was employed as a research assistant on the evaluation project and was involved in dissemination of the surveys, organisation of and conducting interviews and data analysis.

*Surveys*  
The patient survey was based on the pilot survey that was developed for the initial evaluation of the educational programme (Thomas and Rainey, 2018). During one face-to-face meeting and further email discussions, the steering group further shaped both survey and interview questions for patients. The final survey was circulated to the steering group for comment and no further changes made. The patient survey questions can be found in Appendix 1.

The primary care nurse survey questions were developed by the study team and can be found in Appendix 2. The survey was hosted electronically using Survey Monkey™. It was anticipated that the survey would take 10 minutes to complete. The survey link was emailed via Practice Nurse Forum chairs. It potentially reached primary care nurses from 167 GP practices.

*Patient interviews*The interviews aimed to evaluate the usefulness of the kidney sessions and to understand the facilitators and barriers to self-management of kidney disease and behaviour change. The primary interviewer was a female kidney nurse and researcher with expertise in qualitative interviewing techniques. She had been involved in the development and early evaluation of the educational programme and delivery of the group education sessions. The co-interviewer was a female with lived experience of kidney disease and also a post-graduate student, studying public health at the time of this study. The interviewers explained that they were no longer directly involved in delivering the education sessions nor in patients’ ongoing care. It was hoped that this would encourage interviewees to speak openly about their experiences. The interview questions are shown in Appendix 3.

*Sample*All patients who attended group or individual education during 2017 were included: 44 patients attended group education and 241 patients attended individual sessions. 19 patients were excluded (10 had died, 1 had started dialysis and 8 patients were receiving treatment for a terminal or otherwise significant non-renal condition). Patients who were invited to an education session but did not attend were not surveyed. Paper surveys were mailed in hard copy to 266 patients in July 2018 (with a stamped return envelope). This ensured a delay of between 7 and 19 months between attendance at the education session and being surveyed. Participants were asked at the end of the survey if they were willing to be interviewed.

Patients who sent their contact details on the completed survey were telephoned by a kidney nurse to see if they still agreed to be interviewed. If so, a participant information sheet was posted prior to the interview taking place. The study was explained again before starting the interview with an opportunity to ask questions and verbal consent taken.

Interviews were audio-recorded and transcribed verbatim with consent. Three patients did not wish to be recorded but interview notes were taken by the interviewers.

***Data analysis***

*Survey data*  
Survey responses were summarised. Categorical variables were expressed as absolute numbers and percentages and difference in self-reported knowledge before and after attending the kidney session was tested using chi-squared test. Differences between those attending a group or individual session could not be tested due to the small number of surveys returned from those attending a group session.

*Interview data*  
A six-step thematic data analysis (Braun and Clarke 2006) was carried out by the research assistant. The six steps were: transcribing data; coding data; searching for themes; reviewing themes; defining and naming the themes; reporting the findings. Defining and naming the themes were discussed amongst all the authors.

**RESULTS**

**Patient surveys**  
54/266 surveys were returned (20%). Of these 11 had attended group education and 43 had attended an individual session (table 1). Data are presented for all patients combined. Some patients did not answer all questions, but their responses are included for the questions that were answered.

Knowledge  
Survey responses showed that there was variability in the explanation that patients had received about their kidney problem prior to attending the kidney session with 20/53 (38%) saying that it had not been explained at all, 17/53 (32%) it had been explained quite well and 16/53 (30%) explained very well.

Responses show that the session did improve patients’ knowledge about their kidney problem (Figure 1) with 87% (46/53) replying that they did not know anything or knew a little about their kidney problem before the session but 62% (32/52) replying that they knew a lot after the session.

34/52 (65%) responded that during the kidney session they always understood the explanation from the nurse, whilst 15/52 (29%) sometimes understood and 3/52 (6%) never understood the explanations.

Most responses to the question ‘*What is the most important thing you learnt during the session?* ’highlighted the importance of knowing the factors that help to maintain kidney function. Individual responses in free text on the survey were *“How much it can affect the body and it’s an issue that progressively worsens if not looked after”* and *“I learnt that there were things that I could do to try to help my kidneys from getting any worse.”*

Making changes

Two thirds of respondents reported that they had made changes to try to improve their health following the kidney session. 13/50 (26%) reported making one change and 21/50 (42%) reported making two or more changes. The changes reported were mapped to the factors covered in the kidney education session and are shown in figure 2. The most common changes reported were to change diet and increase fluid intake. One respondent wrote *“I limit salt, starchy food and increase vegetable fruits consumption. I also do some exercise”.* Another wrote *“I am drinking more. I am monitoring my blood pressure and diabetic control.”*

All the changes reported were factors covered in the kidney education session apart from one respondent who reported seeking a herbal remedy that she knew of from the Philippines.

Ongoing support

Almost half of respondents (21/47; 45%) reported that since the kidney session they felt much more or a bit more confident when talking to their GP or primary care nurse about their kidney problem. A similar number (20/47; 43%) reported that they had not discussed their kidney problem with their GP or nurse since the session.

Many respondents had not looked for more information about kidney disease after the session (24/54; 44%) but others had looked for information, most commonly by asking other people (12/54; 22%) or looking on the internet (11/54; 20%) (Figure 3).

The education session did not increase anxiety for more than half of respondents with 19/51 (37%) not anxious and 12/51 (24%) less anxious about their kidney condition after the session. However, 10/51 (20%) reported feeling a bit more anxious and 10/51 (20%) a lot more anxious since the session. 9 of the 20 patients who reported feeling more anxious had not discussed their kidney problem with their GP or nurse since the session.

**Primary care nurse surveys**The number of nurses who received the survey link is not known. 21 completed online surveys were received. Some respondents did not answer all questions. 17/21 (81%) of respondents were aware of the Community Kidney Service with 13/21 (62%) aware of the virtual clinic but only 8/21 (38%) were aware of patient education sessions.

10/20 (50%) had attended an education session run by the kidney team and had changed their practice following this. One nurse wrote *“Yes, I now include self-management of chronic kidney disease in part of diabetes and hypertension reviews”* whilst another wrote *“Yes!. More aware of impairment and GFR measurements and drugs used and BP targets”*

9/18 (50%) of primary care nurses had seen the patient education materials developed by the kidney team, but only 6/18 (33%) had used the materials with patients to explain CKD and self-management. Reasons for not using the materials included a lack of awareness of the materials; not having them easily to hand; and being overwhelmed in general practice with chronic disease management.

Suggestions about how the kidney team could facilitate self-management of kidney disease in primary care included more education for nurses and targeting identified patients, with one respondent suggesting holding group sessions in patients’ own GP practices.

**Patient interviews**Nine patients agreed to be interviewed. 3 had attended group and 6 had attended an individual session. One person undertook a face-to-face interview whilst the remainder were undertaken by telephone. Interviews lasted from between 10-19 minutes.

Three main themes were identified from the interviews. These were recognition of CKD, motivation to change and reliance on ‘experts’.

Recognition of CKD

Finding out that they had a kidney problem was unexpected for many people as they felt well with no symptoms attributable to CKD. One patient said

*“It was a bit of a shock, yes, because I had no noticeable symptoms at all”* (Participant 4).

Some had known that they were at risk of CKD because of diabetes or hypertension with Participant 6 saying

*“It came back from a blood test. I’m Type 2 diabetic and they do yearly checks, so it’s been monitored for a little while”*.

But others had not been aware of the risk despite having regular screening. Participant 1 said

*“When you’re a diabetic it can affect your kidneys, I didn’t know that. I never had a conversation about my kidneys with a doctor or the nurse.”*

Motivation to change

Although being told that they had a kidney problem could be shocking, for many this was a motivation to make lifestyle changes. Participant 6 said

*“I knew it was something to be worried about, but I knew that if it wasn’t that drastic then there were measures we could take to turn things around”.*

People expressed relief that there was something they could do to reduce their risk of worsening CKD with Participant 1 saying

*“I’m happy that it’s under control and if I can keep it that way”*.

Many reported improvements in their blood pressure or diabetes having implemented changes following the education session such as

*“The specialist had said that my blood pressure should always be controlled which I know that my blood pressure is really under control now”* (Participant 5).

Reliance on ‘experts’

The lack of symptoms made it hard for people to track the progress of their CKD. They knew that changes would show up in blood tests but were reliant on health care professionals to request tests and interpret results. Participant 2 said

*“When I go for the blood test and I go for the result she would only say there’s a bit of a problem with the kidney and that’s it”*.

Most people were confident that their CKD was being monitored but were not always informed about their progress. Participant 3 said

*“I go and have these blood tests ……. I’m assuming I’ve not heard from them because there’s nothing to hear”*.

People accepted that pressures in primary care limited their involvement, with Participant 4 saying

*“I have not discussed it with my GP …… they are absolutely overwhelmed”*.

although this contrasts with the positive impact of ongoing support described by Participant 6

“*The kidney function, it was one of the best levels that they’d ever been, so obviously I’ve taken heed from that, I took notice and my doctor was really pleased”.*

**DISCUSSION**This paper describes the evaluation of a CKD education service co-designed with patients and delivered by kidney specialist nurses to people with CKD stages 1 – 3b who were being managed in primary care. The Community Kidney Service promotes recognition of CKD in primary care and the virtual clinic gives clinicians easy access to nephrology advice, but the survey results suggest that patients are not always fully informed about their condition. Prior to the education session people had limited knowledge about CKD with many reporting that their kidney problem had not been explained even though they had been referred to nephrology services for advice. This may be a reflection of concern amongst primary care clinicians about potential harm from over-diagnosis of a ‘disease’ which does not cause symptoms (Moynihan et al, 2019) despite evidence that this may lead to shock, anger or upset when patients subsequently find out (Stevens et al, 2018). Variation in disclosure of diagnosis of CKD in primary care has been reported by both health care professionals (Crinson et al, 2010) and patients (Daker-White et al, 2015) potentially restricting involvement in self-care and limiting opportunities for promotion of self-management. The patient interviews suggest that the lack of symptoms experienced by people with early CKD is an important consideration as has been reported elsewhere (Costantini et al, 2008). We found that people did not anticipate a CKD diagnosis because they did not feel unwell, highlighting the need to inform people about screening.

Our nurse education service for patients who would not otherwise see a kidney specialist ensures that information about diagnosis and nephrology advice is communicated to patients. The session includes an explanation about cause of CKD, likely progression and discussion of lifestyle factors that can reduce the risk of worsening CKD. Explaining CKD in this way seemed to be meaningful with two thirds of survey respondents reporting that they made lifestyle changes after the session and interviews suggesting that being informed about CKD diagnosis has potential to be a ‘teachable moment’ – an event that can promote health behaviour change (Lawson, 2009). A small number of patients did not understand the session underlining variation in health literacy (Taylor et al, 2017) and the need to individualise information.

Ongoing support is essential for successful self-management (Dwarswaard et al, 2015; Donald et al, 2019) and in our programme this is provided in primary care. Despite some feeling more anxious after the education session many patients had not discussed their kidney problem further. They could not monitor the progression of early CKD due to lack of symptoms, but some were able to self-monitor blood pressure and diabetes. Interviews showed that patients were aware of the importance of blood results but were dependent on clinicians to order and report test results – electronic health records have the potential to improve access to results, but patients may need help to interpret these. Vandenberg et al (2018) found that contextualizing blood test results helps patients understand the purpose of monitoring and can motivate engagement with self-management.

Primary care nurses are ideally placed to provide support as part of long-term conditions monitoring but Armstrong et al (2016) have suggested that condition-focused interventions may be challenging to implement in primary care due to competing demands. Our programme highlights the links between diabetes, hypertension and kidney disease and how lifestyle advice is broadly similar. We received very few responses to our primary care nurse survey but those received suggest that renal services need to support primary care if potential benefits of self-management are to be realised. Education sessions are part of this, but innovative solutions are also needed to ensure that resources are available at the point of contact (Galbraith et al, 2018).

**Limitations of the study**

This was a small study based on self-reported behaviour. Patients and nurses who completed the survey may not be representative of those who did not respond. In particular those who attended an education session are likely to be more engaged with their healthcare than those who did not attend, whilst those who did not remember the session or who found it unhelpful may be less likely to have responded to the survey. Despite this we feel that the results suggest that the “How to look after your kidneys” programme has potential. Our next steps include further work with primary care clinicians to support the earlier disclosure of CKD diagnosis as part of routine long-term conditions monitoring and to enhance ongoing support for patients with CKD to reduce anxiety. We feel that this is key to ensure that all patients with CKD are able to access appropriate information and support and reduce anxiety.

We were not able to compare group to individual education sessions due to the small number of responses but plan to work with primary care nurses to develop group consultations based on our programme.

**Implications for practice**

Primary care has a key role in management of long-term conditions, but specialist services need to develop resources to support this. New models of care based on integration between primary and secondary care need to consider how patients will receive education (and from whom) to promote self-management.

Including patients at an early stage of development can ensure that services are designed around their needs and that resources are appropriate.

**CONCLUSION**Secondary care nursing involvement in primary care-based education for people with CKD is rare in the UK and internationally. This educational intervention, developed with patients, supports people to make changes that have the potential to reduce progression of kidney disease and our findings have significance for other teams working in chronic kidney disease management.

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APPENDIX 1: Patient survey

1. Before you came to the kidney session, how well had a doctor or nurse explained your kidney problem to you?

* It had been explained very well
* It had been explained quite well
* It had not been explained at all

2. Before you came to the kidney session how much did you know about your kidney problem?

* I knew a lot
* I knew a little
* I did not know anything about kidney disease

3. During the kidney session, how often did the nurse explain things in a way you could understand?

* Never
* Sometimes
* Usually
* Always

4. After the kidney session, how much did you know about your kidney problem?

* I knew a lot
* I knew a little
* I still did not know anything about kidney disease

5. During the kidney session, what was the most important thing you learnt about kidney disease?

6. After the kidney session, did you still have questions about your kidney problem that had not been answered?

* No
* Yes

If yes, what questions did you still have?

7. Since the kidney session, have you changed anything to try to improve your health?

* I have not changed anything
* I have made one change
* I have made two or more changes

If you have made any changes, then please explain what you have done

8. If you have tried to change anything since the kidney session, how difficult has it been to change what you do?

* I have not changed anything
* It has not been difficult
* It has been a bit difficult
* It has been very difficult

If it has been a bit or very difficult, please explain why

9. Since the kidney session, how confident have you felt when talking to your GP or Practice Nurse about your kidney health?

* I have not discussed my kidney problem with my GP or nurse since the kidney session
* I have felt much more confident when discussing my kidney problem with my GP or nurse
* I have felt a bit more confident when discussing my kidney problem with my GP or nurse
* There has been no change in the way I have discussed my kidney problem with my GP or nurse

10. Since the kidney session have you looked for more information about kidney disease? (Tick all the answers that apply)

* No
* Yes, I have looked on the internet
* Yes, I have used social media (Facebook, Twitter etc)
* Yes, I have rung a charity helpline (Kidney Care UK, National Kidney Federation)
* Yes, I have asked other people
* Yes, I have looked for more information elsewhere

If you have looked for more information please tell us where you looked

11. Since the kidney session do you feel more or less anxious about your kidney condition?

* I am a lot more anxious
* I am a bit more anxious
* I am less anxious
* I am not anxious at all

12. Please add any other comments you have about the kidney session here

APPENDIX 2: Practice nurse survey

**Q1. Are you aware of the East London Community Kidney Service?**

Yes

No

**Q2. If yes, which parts of the Service are you aware of? (tick all that apply)**

e-clinics

Patient education: 1-1 / Group education

Staff education

Trigger tools

Other

**Q3. Have you attended any of the education sessions run by the Kidney Team?**

Yes

No

**Q4. If yes, please explain whether the content of the education session changed your practice?**

**Q5. Have you seen the 'How to look after your kidneys' patient education materials?**

Yes

No

**Q6. Have you used these materials with patients?**

Yes

No

**Q7. If yes, what did you use them for - if no, please explain why not?**

**Q8. Is there anything that the Kidney Service can do differently to facilitate self-management and behaviour change for kidney disease?**

**Q9. Have the education components of the Kidney Service had an impact on your confidence in managing CKD?**

1 I feel less confident

2 There's been no change in my confidence

3 I feel more confident

**Q10. Do you have any other feedback about the Community Kidney Service?**

APPENDIX 3: Interview questions for patient interviews

|  |  |
| --- | --- |
| **Topic** | **Questions** |
| **Background / warm up** | **Question**: Did you understand the purpose of the kidney session? |
| **Concept of good health, feelings, meanings and understanding** | **Question:** Can you describe when you first became aware of kidney disease?  **Question:** Could youunderstand what the nurse was explaining about your kidney health?  **Question:** Hasthe kidney session has helped you to ask more questions? |
| **Experience and gaining further information** | **Question:** Have you tried to improve your health since the kidney session?  **Question:** Have you tried to understand more about your kidney health?  **Question:** How would you find out more about your kidney health? |
| **Future developments** | **Question:** Is there anything you think could improve the way the kidney session is run? |