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## Executive Summary

# Identifying chronic kidney disease patients' priorities and preferences for information topics

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# Executive Summary

## Title

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## Background

An integral part of quality health care provision is that patients are given information that addresses their needs (DoH 2000). In a long-term condition such as chronic kidney disease (CKD) patients are encouraged to self manage their illness to a large extent and maintain their independence, whilst receiving appropriate education, information and support. Innovative studies to identify and measure the information needs of patients (cancer and asthma patients) highlight that patients have priorities and preferences with regard to what information they need and when (Degner *et al* 1998; Luker *et al* 1996; Caress *et al* 2002). The premise of this study was that CKD patients with end stage renal failure (ESRF) will share similar traits and have preferred key information topics, which are of a priority to them, at different times during progression of their disease, and when considering or undergoing different modalities of treatment.

## Methods

The study aim is to describe the information needs of CKD patients and gain an understanding of the relationship between variables (such as age, gender, ethnicity, modality and duration on treatment). Patients were identified from a managed clinical renal network in the North of England, which encompasses in-centre haemodialysis patients, home/satellite haemodialysis (HD) patients, peritoneal dialysis (PD) patients and a pre-dialysis (PRE) patient population. A stratified sampling frame was used, grouping patients first by modality then time on/ waiting for dialysis, age and gender.

The study used a cross-sectional survey design replicating the method and approach adopted by Caress *et al* (2002). Phase One involved a comprehensive review of current CKD literature to identify information needs topic areas. Simultaneously, semi-structured interviews of CKD patients (n=20) were conducted to elicit core information themes that were then compared with the literature to identify key information items. The core information needs items were confirmed and verified by the patient group then developed into a CKD specific Information Needs Questionnaire (INQ) (Degner *et al* 1998; Caress *et al* 2005) adopting a Thurstonian

paired comparisons approach (Sloan *et al* 1994). The purpose of phase two was to confirm the findings from phase one with a larger sample (n=89), and to test the validity of a CKD specific INQ. Comparisons made between the sample and the target population found it to be representative of the wider population. Data was collected using face-to-face structured interviews then entered onto SPSS to undertake the Thurstone paired comparison analysis. Statistical analysis included using Kendall's coefficient (levels of agreement), descriptive statistics (rank ordering), and Independent-samples t-tests and one-way ANOVA were used to compare the mean Thurstone scale scores.

## Key Findings

### *Information needs of CKD patients*

- Nine core information needs were identified that were important to CKD patients.
  1. Information about what is chronic (long-term) kidney disease, what is the cause, how will it progress, what is the future
  2. Information about how the kidney disease may affect me, physically or in other ways, how to recognise symptoms and what to expect
  3. Information about the different treatment options, the advantages and disadvantages of each treatment, what the different treatments look like (such as machines etc) (Haemodialysis, Peritoneal dialysis, Transplant, Automated Peritoneal dialysis)
  4. Information about the practical issues of starting or changing treatment, what will happen to me and what can I expect (such as having a fistula, or peritoneal catheter, the frequency and length of time of treatment sessions or exchanges, fluid restrictions, base weight, ordering stock, using different strength bags, to up to date information on treatment changes)
  5. Information about what complications or side effects may occur as a result of the treatment or medication I'm taking
  6. Information about ways in which I can manage and influence my own condition such as food restrictions, medication, how to keep my blood tests/results stable or improve them
  7. Information about the ways in which the kidney disease and the treatment may affect my daily life, social activities, work opportunities and financial situation (benefits and allowances available)
  8. Information from other patients about what it can be like living with chronic kidney disease and receiving regular treatment (such as practical tips on what I can do)
  9. Information about how to cope with and adjust to chronic kidney disease and who can provide support if I need it
  
- The items ranked highest priority comprised of information needs which enhanced the understanding of what was happening to the physical self, recognising symptoms (item 2, scale value 0.13) and complications (item 5, scale value 0.19) and most importantly what they themselves can do about it (item 6, scale value 0.35). The lower priority items were

concerned with exploring the experiences of other patients and information about adapting and coping with a chronic illness psychological rather than physical support.

- There were no significant differences identified between the distance of the ranked items for demographic variables such as gender, time on renal replacement treatment, education level and co-morbidity. However differences existed between participants across modality/treatment groups, different ages and social circumstances, such as employed or unable to work due to ill health.
- Younger participants (<50yrs) placed a higher priority on information about managing their condition and the impact upon their lifestyle with lower priority for information about the cause of CKD and the future. Information about the experiences of other patients was considerably less important to older participants (>60yrs), compared with participants in lower age groups.
- Pre-dialysis participants expressed a higher priority for information about the practicalities of RRT (item 4, scale value 0.30). They also assigned lower priority to item 1 (information about the cause of CKD and the future) than HD and PD participants.
- The top-ranked priority information needs for participants in full or part-time employment were managing their own condition (item 6, scale value 0.40), complications and side effects (item 5, scale value 0.29) then the impact upon their lifestyle (item 7, scale value 0.09). The top-ranked item for those participants unable to work due to ill health was information about the physical affects and symptoms (item 2, scale value 0.22).
- Participants indicated a distinct difference in what information they perceive to be important for new patients compared with their own current needs, indicating that information needs change over time. The majority of participants (43.82%) identified that information about the cause and progression of CKD alongside understanding the future expectations (item 1) was the most important. Followed by information to explain the different treatment options (item 3) (17.98%). Over 50% of participants felt that they themselves did not receive enough information about the item they selected for new patients.
- The majority of participants (94.4%) reported knowing at least enough or more about their condition compared with 5.6%, still only knowing a little. There was no significant difference found between demographic variables with the exception of the time they had been receiving RRT (ANOVA,  $p=0.036$ ) which indicated an increase in knowledge levels over time and experience of treatment.

### ***Information sources and provision***

- The hospital consultant was the most used resource for information about CKD, with 82.1% (n=73) of participants rated the information provided as '*okay*' (n=15), '*good*' (n=20) or '*very useful*' (n=38). Similarly, the dietician, renal community nurse and renal unit nurse were found to be useful sources for information.
- The majority of participants seldom used sources such as the General Practitioner (68.5%); self-help groups/patient associations (70.8%), pharmacists (74.2%), family and friends (76.4%), practice nurses (84.3%) and NHS direct (96.6%) to locate information about CKD.
- It was noted that 87.5% of older participants (over 60 years) did not use the Internet as a source of information about CKD.
- Receiving information verbally face to face to the patient alone was in the top three ranked preferences for 85.4% of participants, verbal face to face with the family present 70.8% and written information 62.9%. Comments suggested that a combination of the three top ranked methods is the best overall approach for the majority of participants. A high proportion of participants felt strongly that they '*would never like*' information provided using an audiotape (61.8%); face to face within a group (47.2%); using a DVD (32.6%); or a video (32.6%).
- Of the 47.2% who '*would never like*' information to be provided face to face within a group, the majority (59.52%) were from the older age group (>60 years). Participants with a higher education level (>first degree/professional qualifications) showed greater preference towards written information compared with participants with no formal/lower qualifications.
- Participants were asked whom they preferred to receive information from. The majority of participants (53.9%) preferred to receive information from the doctor, 23.6% the nurse and a further 5.6% either the doctor or the nurse. It was interesting to note that although the majority preferred to receive information from a doctor a third actually had it provided by the nurse. Despite this 86.5% of participants expressed that they were either '*okay*,' '*happy*' or '*very happy*' with the information provided.

### ***Need for information and information seeking behaviour***

- CKD patients are desirous of information. The study found that the majority of participants (67.4%) would like to know as much as possible, 22.5% needed to have basic level of information to make decisions, 7.9% only wanted information about what was going to happen next, and 2.2% participants did not want to know anything.

- A higher proportion of HD participants (45%) needed to know as much information as possible, compared with PD (30%) and Pre-dialysis (25%). Furthermore, a higher percentage of males (60%) needed to know as much information as possible compared to females (40%), as did those with higher qualifications (66.5%) compared with those with lower/no formal qualifications (53.6%).
- Just under 5% more females (55.5%) tended to seek out additional information '*always*' compared to males (50.9%). A higher proportion of Pre-dialysis participants (63.6%) seek information more often than patients receiving RRT (PD, 51.7%; HD, 48.6%). Employed patients (77.3%) were more likely to always seek out additional information compared with those unable to work (51.9%) and those retired (40%). However, retired participants and participants unable to work were more likely to seek out additional information if they don't understand something. Those participants with a higher education level seek out information more often (61.1%) than those with lower or no formal qualifications (32.1%).

### ***Methodological findings***

- In this study of 89 participants, the chi-square=52.21 ( $p<0.05$ ), produced a significant result, signifying that the expected scale values were not a good fit with the Thurstone Case V model. However, there was congruence between the list of ranked items from the Thurstone paired analysis and the list of items generated when participants placed them in simple priority order. The lack of fit could indicate the need to test with a larger sample and to provide greater clarity when describing items to overcome inconsistencies and ensure accurate interpretation and understanding, or use a different model. Further testing is required to observe the fit between the Thurstone Case III model and the Averaged Preferred Proportions (APP) model (Sloan *et al* 1994).

### **Conclusion**

The findings of this study suggest that CKD patients have identifiable priorities and preferences with respect to information needs that change over time, as the disease progresses. The study identifies core information topic areas that could be targeted by professionals to focus discussion and education in order to satisfy the information needs of CKD patients. The CKD INQ was tested and found to be useful but additional statistical modelling is required to establish coherence between the data and the underlying model assumptions. Nationally the findings would help to inform the development of the web-based care plan, 'RenalPatientView', to support people with all stages of CKD, including those who are receiving end of life care and

in turn the development of the NHS 'HealthSpace' portal (DoH 2005). Patient organisations such as the National Kidney Federation could use the findings to generate patient resources materials. The study has yielded a large body of valuable data which adds to and extends the current knowledge CKD patients information needs raising at the same time a number of questions for further research.

### **Recommendations for Practice**

- Healthcare professionals may use the nine core information need items as a tool to facilitate and focus information provision in clinical practice or to develop educational programmes grounded on the needs of CKD patients.
- When providing information to CKD patients health care professionals need to consider the influences of age, social circumstances and stage of disease alongside individual characteristics to facilitate effective information provision.
- Strategies should be introduced to measure and monitor a patients knowledge level to identify how often or when information should be provided or repeated to address the needs of CKD patients.
- A multi-method approach to information provision is recommended using, for the majority of patients, face to face verbal information giving with the patient alone or with their family, supported where appropriate by written information.

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