Conservative Care for ESRD in the United Kingdom: A National Survey

Ikumi Okamoto,* Sarah Tonkin-Crine,* Hugh Rayner,‡ Fliss E.M. Murtagh,§ Ken Farrington,¶ Fergus Caskey,** Charles Tomson,§ Fiona Loud,§ Roger Greenwood,§ Donal J. O’Donoghue,** and Paul Roderick*

Abstract

Background and objectives Conservative kidney management (CKM) has been developed in the United Kingdom (UK) as an alternative to dialysis for older patients with stage 5 CKD (CKD5) and multiple comorbidities. This national survey sought to describe the current scale and pattern of delivery of conservative care in UK renal units and identify their priorities for its future development.

Design, setting, participants, & measurements A survey on practice patterns of CKM for patients age 75 and older with CKD5 was sent to clinical directors of all 71 adult renal units in the UK in March 2013.

Results Sixty-seven units (94%) responded. All but one unit reported providing CKM for some patients. Terminology varied, although "conservative management" was the most frequently used term (46%). Lack of an agreed-upon definition of when a patient is receiving CKM made it difficult to obtain meaningful data on the numbers of such patients. Fifty-two percent provided the number of CKM patients age ≥75 years in 2012; the median was 45 per unit (interquartile range [IQR], 20–83). The median number of asymptomatic CKM patients who would otherwise have started dialysis was eight (IQR, 4.5–22). CKM practice patterns varied: 35% had a written guideline, 23% had dedicated CKM clinics, 45% had dedicated staff, and 50% provided staff training on CKM. Most units (88%) provided primary care clinicians with information/advice regarding CKM. Eighty percent identified a need for better evidence comparing outcomes on CKM versus dialysis, and 65% considered it appropriate to enter patients into a randomized trial.

Conclusions CKM is provided in almost all UK renal units, but scale and organization vary widely. Lack of common terminology and definitions hinders the development and assessment of CKM. Many survey respondents expressed support for further research comparing outcomes with conservative care versus dialysis.

Introduction

The increase in the rate of RRT in recent decades has been greatest among elderly people, many of whom are frail and have multiple comorbid conditions (1,2). Starting dialysis was associated with a substantial and sustained decline in functional status among nursing home residents (3), and RRT may not be beneficial in the context of increasing frailty and loss of independence (4–6). A conservative care pathway is increasingly recognized as an alternative treatment to dialysis and has been introduced in the United Kingdom (UK) (1,6–10), Australia (11,12), other European countries (10–18), and Asia (16–18).

Conservative care for ESRD is evolving in the UK (19), and information on how it is practiced is limited to individual units. In 2005, Gunda et al. (20) reported significant variation in the provision of palliative care for ESRD across the UK. Lack of resources was identified as a major problem, and some units gave palliative care a low priority because of workload (20).

We present the results of a national survey of practice patterns for treating patients aged 75 years and older with CKD stage 5 (CKD5) receiving conservative care, termed conservative kidney management (CKM) for the purposes of this study.

Materials and Methods

The content of the survey was based on existing literature, a qualitative study of 60 staff interviews from a representative sample of nine renal units, and feedback from content experts on the project steering group. A draft survey was piloted using cognitive interviews with three nephrologists and one renal nurse specialist. Two forms of the survey were developed: web-based and paper-based. Contact details of clinical directors from all 71 adult renal units were obtained from the UK Renal Registry, and both forms of the survey were sent to them in March 2013 (see Supplemental Appendix 1 for the survey).

Data were analyzed using basic statistics. Cross-tabulation was conducted to explore the relationship between variation in practice patterns and potentially related factors: the number of patients receiving CKM, the availability of staff responsible for CKM, and the allocation of staff time to CKM. Units were categorized
into two approximately equal groups according to their responses to the questions regarding the number of CKM patients age 75 and older in 2012 and the number of patients age 75 and older who stayed on CKM after they became symptomatic and would otherwise have started dialysis in the same year. Units that had >25 CKM patients or ≥20 symptomatic CKM patients were categorized as "larger" units. We related CKM size to the prevalent pool of patients age 75 and older who were receiving RRT (all were undergoing dialysis) in 2012 to examine whether this factor was associated with the development of the CKM program. The number of patients aged 75 and older who were receiving RRT was derived from UK Renal Registry data using the prevalent number of patients receiving RRT and the percentage of those aged 75 and older (21).

We tested for associations with these categorical variables using a chi-square test; given the potential for multiple testing and false-positive results we report only associations that were significant at *P* < 0.01. To measure how much renal staff were involved in CKM, the survey asked about full-time equivalent (FTE) time. An FTE of 1.0 indicates that a person is equivalent to a full-time worker, or two persons working half-time.

**Results**

Of the 71 UK adult renal units, 67 (94%) responded (50 of 52 units in England, five of five in Wales, eight of nine in Scotland, and four of five in Northern Ireland). The survey respondents' roles varied; respondents described themselves as clinical leads (20), consultant nephrologists (17), nurses (15), and clinical directors (9). Thirty-two units indicated that the survey respondent consulted other staff member(s) when completing it. Thirty-seven of these 16 completed the web version and 30 the postal version. Of the 67 units, two did not fully complete the survey, and one had no patients with CKD5 who had actively decided not to undergo dialysis; this unit was automatically directed to skip all questions related to CKM. Therefore, for many questions the total number of responses was <67.

All but one unit (66 of 67) had a CKM pathway. There was no agreed-upon terminology to describe this pathway, although "conservative management" was most frequently used (30 of 65 [46%]), followed by "conservative care management" (eight of 65 [12%]).

**Size of Program**

When asked how many patients with CKD5 age 75 and older were receiving CKM and followed up in their unit during 2012, 35 units (52%) provided data: The median was 45 (interquartile range [IQR], 20–83; range, 4–152) patients per unit. When asked how many patients aged 75 and older in their unit chose to have CKM, became symptomatic of advanced CKD, and were not undergoing dialysis, 33 (49%) units provided data; the median number of patients was eight (IQR, 4.5–22; range, 1–50). In total, 47 units provided data on the number of CKM patients age 75 and older or the number of CKM patients who were symptomatic. Twenty-four and 23 units were categorized as "larger" and "smaller," respectively; 20 were unclassifiable because of missing data.

**Program Organization and Resourcing**

Two thirds (43 of 65 [66%]) of units had a single person or a small team primarily responsible for CKM; all were consultant nephrologists and/or renal nurses. Twenty-eight (45%) units had staff whose time was specifically allocated for patients with CKD5 who were on a CKM pathway; "larger" units were more likely to have such staff (15 of 24 versus eight of 23). Sixteen units had renal nurses whose time was specifically allocated for such patients; a median FTE of these 16 units was 0.9 (IQR, 0.5–1.0). Twelve units responded that consultant nephrologists had allocated time for CKM patients with a median FTE of 0.2 (IQR, 0.1–0.2). Nine units had predialysis education providers or dietitians whose time was allocated for CKM patients. These units had median FTEs of 0.4 (IQR, 0.18–1.0) and 0.2 (IQR, 0.1–0.35), respectively.

Twenty-three units (35%) had a written guideline on how to manage CKM patients. Fifteen units (23%) reported having clinics exclusively for these patients; in the other units, 22 most commonly saw them in predialysis clinics, 11 in general nephrology clinics, seven in the patient's home (three by renal staff and four by a general practitioner/community team), and nine in mixed settings. The availability of dedicated CKM clinics was closely related to whether units had staff primarily responsible for CKM (*P*=0.001); however, 64% of the units that had staff responsible for CKM practiced CKM without dedicated clinics.

Half of the units (33 of 66) provided renal staff with formal training or education regarding CKM. In the 21 units without such training, 11 unit respondents reported lack of time and eight lack of funding as reasons for not doing so. Five reported that staff did not need formal training because CKM was an ingrained culture in the unit.

CKM programs offered a variety of services to patients. All units assessed and managed symptoms and provided erythropoietin and iron therapy. Almost all units provided dietary advice (64 of 65 [99%]) and prescribed medication for uremic symptoms (63 of 65 [97%]) (Figure 1). Most but not all units reported providing advance care planning, which in the UK refers to a formal process for considering end-of-life care.

Only a minority of units (10 of 65 [15%]) had funding dedicated to providing CKM; in seven units this was from the National Health Service (NHS), in one unit it was from non-NHS sources, and two had funding from both sources. Only five units reported the amount; the median was £40,000 (IQR, £15,203–£85,629.50) in the 2011–2012 financial year. Funding was associated with the CKM population size (larger versus smaller) (*P*<0.01) and with dedicated staff time for CKM (*P* = 0.002); however, 68% of units with dedicated staff had no dedicated CKM funding.

The larger CKM units had more prevalent dialysis patients age 75 and older (median, 161; IQR, 118–201) than the smaller ones (median, 54; IQR, 43–122), and those with missing CKM data were intermediate in size (median, 95; IQR, 60–173). Intercountry comparisons were difficult because of the smaller number of respondents in countries outside of England.

**Decision-Making**

Most units (56 of 65 [86%]) reported that they discussed the option of CKM with all patients with CKD5 who were
75 years of age and older. Similar criteria were used to assess suitability for CKM for a patient, the foremost being patients’ preference for CKM (100%) (Figure 2). The option of CKM was most commonly first raised with patients when they were referred to the predialysis clinic (37 of 65 [57%]). In 15 units (23%) the option was raised when a patient’s eGFR reached a certain level (median, 20 ml/min per 1.73 m²; IQR, 19.0–20.0 ml/min per 1.73 m²) and in six (9%) at a specific time before the anticipated start of dialysis (median, 9 months; IQR, 5.3–12.0 months). Most units (54 of 65 [83%]) used decision aids when discussing the option of CKM with a patient. Booklets and handouts from national organizations (44 of 54) and those written by local renal unit staff (33 of 54) were commonly used. About half of the units (22 of 54) used DVDs from national organizations. Sixteen units used the NHS Right Care Patient Decision Aid (22). Once patients decided to have CKM, all units reported that they subsequently reviewed their decision, mostly at clinic visits.

Family and carers were actively involved in decision-making about CKM. Most units (62 of 65 [95%]) encouraged family and carers to attend clinics with patients, and they were also involved when the CKM decision was revisited with patients (50 of 65 [77%]). All responding units had patients who had changed their mind after deciding not to have dialysis, although this could not be quantified.

Liaison with Primary and Palliative Care

All units reported that they worked collaboratively with primary and palliative care teams. Most units (57 of 65 [88%]) provided general practitioners and their practice team with information and advice on the treatment of patients with CKD5 receiving CKM. All worked with palliative care services to provide care for CKM patients approaching the end of life: within the hospital (59 of 65 [91%]), at a local hospice (51 of 65 [79%]), in the community (55 of 65 [85%]), and from the primary care team (58 of 65 [89%]). Almost all units (62 of 65 [95%]) used more than one service; 38 of 65 units (58%) worked with all the above. More than half of units (36 of 65 [55%]) had a written guideline for renal end-of-life care, and 11 (17%) had one in preparation.

More than half of the units (42 of 65 [65%]) provided palliative care specialists with training or advice regarding the management of renal patients. Most units (57 of 64 [89%]) had trained their own staff in palliative/end-of-life care for renal patients, although in 39 of those 57 units it was only a small proportion of such staff.

Future Development

The factors reported to be most important to improve the provision of CKM in future were providing renal staff and general practitioners with more CKM training, and increasing communication and involvement with general practitioners, community, and palliative care teams (Figure 3). Eighty percent of unit respondents agreed that having better evidence of the comparative outcomes between CKM and dialysis would help improve the provision of conservative care.

The most common areas for planned development were providing renal staff members with more CKM training, and providing better end-of-life care by implementing advance care planning (Figure 4). Increasing the number of staff dedicated to CKM, setting up dedicated CKM clinics, and obtaining funding were not commonly cited.

CKM Research

Sixty unit respondents (92%) would consider entering a patient age 75 years and older with CKD5 into a prospective observational study of CKM versus dialysis; 28 of
Forty-two unit respondents (65%) considered it appropriate to enter patients into a randomized trial comparing CKM versus dialysis; 18 of those reported being definitely willing to participate in such a trial.

Discussion
To our knowledge, this is the first national survey to explore the practice patterns of renal units regarding the care of older adults who choose not to have dialysis. The study has demonstrated the widespread acceptance of a conservative pathway by UK nephrology services. CKM practice patterns varied markedly across units; some showed considerable investment in staff time and consequent processes, such as dedicated clinics, guidelines, and staff training programs. However, the CKM decision-making process was similar across units: most reported that they undertook shared informed decision-making with patients with CKD5 age 75 years and older by presenting treatment options, including CKM, and decision aids were widely used.

Many units did not report the numbers of patients receiving CKM, indicating that these data were not captured...
prospectively. In units that did report the number of patients designated as receiving CKM, the wide variation indicates lack of clarity regarding CKM patients, reinforcing the need for a more precise definition of CKM. It may be that two designations are needed to capture key points on the pathway: (1) a decision to opt for conservative care and not to prepare for dialysis and (2) a decision to have conservative care and not to start dialysis despite uremic symptoms.

The number of patients receiving CKM was related to the number of patients age 75 and older receiving RRT and was relatively small in comparison. The units that did not report CKM numbers were intermediate in terms of the number of RRT patients age 75 and older, suggesting no major bias in response regarding the size of unit.

Many renal units first raised the option of CKM with patients when they were referred to the predialysis clinics or when their GFR was about 20 ml/min per 1.73 m². This compares with a study conducted by Morton et al. (23), in which 84% of Australian patients received information about treatment options when their eGFR was <15 ml/min per 1.73 m². Only a minority of units used predicted time to dialysis rather than eGFR to decide when to discuss the CKM option with a patient. Many patients with CKD have a non-linear eGFR trajectory or a prolonged period of nonprogression in contrast to the traditional notion of steady GFR progression over time (24). This suggests that careful assessment of kidney disease progression is needed to decide when to discuss CKM with patients.

The survey has identified the need for more education and training of renal professionals in delivering a CKM pathway. Because of the very specific challenges entailed, renal-specific training may be useful, such as the training in advanced communication skills tailored to advanced kidney disease developed by Bristowe et al. (25).

Most units reported having no dedicated funding for CKM, and although many units thought that more funding could help develop CKM, only a minority were planning to apply for funding. In England, preparation for RRT (or "renal assessment") and RRT per se are commissioned as specialist services, and there are specific "payment by results" tariffs. However, while CKM is mentioned within the renal assessment pathway, it is commissioned locally on the basis of the rationale that CKM does not require specialist RRT infrastructure. The lack of a tariff for CKM care was seen as a barrier to developing these services, especially considering that CKM care can last up to a few years because it is not only end-of-life care.

All units reported working collaboratively with primary care. Many units felt that increasing communication and involvement with general practitioners, community, and palliative care teams was very important to improve CKM. Such teams, including social care professionals, have a central coordinating role in the end-of-life phase and need renal-specific training.

In the UK, specialist palliative care was previously restricted to patients with malignant disease (20). However, recent data (26) demonstrate that specialist palliative care services accepted more referrals of patients with ESRD. Our survey has shown that all units now work with specialist palliative care service for CKM patients approaching the end of life, and 79% of units worked with palliative care services from local hospices. Similarly, over half have a written renal end-of-life care guideline compared with 20% 10 years ago (20). Almost all units have staff who have been trained in palliative end-of-life care for renal patients. The variation in the proportion of such staff may relate to a lack of resources or a higher priority being given to involving palliative care specialists rather than developing the skills of renal staff.

Figure 4. Distribution across renal units of responses to the question: “What, if any, of the following changes are planned in your unit regarding the provision of conservative care? Please tick all that apply.” Values are expressed as percentage of units (n=63). ACP, advance care planning; CKM, conservative kidney management; GP, general practitioner.
Although we achieved an excellent response rate across all parts of the UK and used a detailed structured questionnaire, some limitations need to be addressed. The survey responses were self-reported by renal staff, and we could not check their validity. Some of these data were necessarily estimates and so should be regarded with caution, such as the number of CKM patients age 75 years and older and the number who were symptomatic. This survey focused on CKM patients age 75 years and older, but patients younger than 75 years may benefit from CKM (11). While we examined whether some selected factors were associated with the use of certain practices regarding CKM, we could not determine causal relationships from the cross-sectional design. Our categorization of units into larger and smaller categories was somewhat arbitrary. Furthermore, most questions in the survey were multiple-choice questions that asked respondents to select the best possible answer out of the choices from a list. This may have limited their responses, although a selection of "other" was provided.

On the basis of this survey we conclude that the following would facilitate the development and assessment of CKM services: (1) an agreed-upon terminology and definition of CKM; (2) identification and provision of funding for CKM; (3) education and training of renal staff in advanced communication skills and in how to discuss and address palliative and supportive care needs, including end-of-life care; and (4) better communication and information-sharing with primary and palliative care teams and their training in the renal-specific elements of CKM care.

We have identified support from renal clinicians for further research into the benefits and costs of CKM compared with dialysis to inform decision-making by staff, patients, and their families. While widely supported, an observational study would be hampered by confounding caused by nonrandom treatment allocation and by the imprecision of the timing of the start of the CKM pathway. A clinical trial in which patients are allocated to CKM or dialysis by random allocation would overcome many of these problems but would pose substantial ethical issues. Nonetheless, many respondents in this UK survey expressed support for such a trial. Further study of the feasibility of such a randomized clinical trial is warranted.

Acknowledgments
We would like to thank all clinical directors of the renal units and the additional staff members who responded to the survey. The results presented here are part of a larger study, CKMAAPS (Conservative Kidney Management Assessment of Practice Patterns Study). CKMAAPS was funded by the NIHR Health Services Research (HSR) Programme (project number 09/2000/36) and will be published in full in the Health Services and Delivery Research Journal. Further information available at: http://www.nets.nihr.ac.uk/projects/hsdr/09200036.

Disclosures
None.

References


**Received:** May 21, 2014 **Accepted:** September 26, 2014

Published online ahead of print. Publication date available at www.cjasn.org.

This article contains supplemental material online at http://cjasn.asnjournals.org/lookup/suppl/doi:10.2215/CJN.05000514/-/DCSupplemental.