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Abstract

Background: When patients' kidney function deteriorates to Chronic Kidney Disease Stage 5, services offer patients a choice for the next phase of their care – conservative management (diet/fluid/medication) or renal replacement therapy (dialysis/transplant). Dialysis may not have survival benefits, and conservative management may have less treatment burden, for older patient groups with associated co-morbidities or frailty. Kidney professionals recognise the need for training and resources to support patients making treatment decisions that fit best into their lifestyle, consistently across UK services.

Aim: To develop an evidence-based patient decision aid for services to use with patients when making informed decisions between conservative management and dialysis care pathways.

Methods: Surveys a) identifying service need using an environmental scan of written resources, and interviews with staff and patients about current practice, b) assess the Yorkshire Dialysis and conservative management decision aid (YoDCA) acceptability in practice to staff and patients using observational and questionnaire methods.

Keywords

Patient decision aid, conservative management, dialysis, shared decision making.

Key points

- When patients transition from chronic kidney disease to kidney failure, services begin conversations with patients to plan for the next treatment phase offering either a conservative management or a renal replacement pathway (dialysis and/or transplant).
- There may be no survival benefit of dialysis versus conservative management for certain elderly patient groups, and the burden of dialysis treatment means conservative management may be a better option for some patients.
- Building on our previous highly successful work in this field, we will develop the Yorkshire Dialysis vs Conservative-management decision aid (YoDCA) to promote

informed decision making between conservative management and dialysis for patients with chronic kidney disease during consultations with health care professionals.

- Patient decision aids are resources to support patients making decisions by drawing on evidence of how to help people deliberate about treatment information in accordance with their personal circumstances.
- A supporting training package will be developed which focusses on providing health professionals with resources to enable the conversation about conservative management and facilitate decision making.

Reflective questions

1. How do patients think about changes in their disease state when clinical markers indicate a progression from kidney disease to kidney failure?
2. When should staff begin discussions about the conservative management/dialysis treatment decision with their patients?
3. What do patients need to know about their illness and treatment options for the next phase of their illness to make informed decisions about their short and longer term care plans?
4. What are the training needs of staff to successfully support patients at this transition point?
5. How do we effectively integrate a patient decision aid for the conservative management /dialysis decision into clinical practice?

Background

A transition point for the management of patients with worsening kidney disease occurs when kidney function deteriorates to Chronic Kidney Disease (CKD) Stage 5. Services begin conversations with patients to plan for the next treatment phase offering either a conservative management (CM) pathway (changing diet/fluid and medication regimens to control increasing

symptoms) or a renal replacement pathway (RRT; adding dialysis and/or transplant options to maintain some functions normally undertaken by the kidneys). When renal transplant is not medically appropriate, dialysis treatment (DT) has been offered as the most clinically effective treatment option. The age of patients receiving RRT has increased significantly over the last 25 years with the take-on rate of those >65 over twice the take on rate of those younger (Renal Registry, 1998, 2016), meaning patients starting DT are more likely to have co-morbidities, increased symptom burden and likelihood of being frail (Combs & Davison, 2015). Data from our Leeds unit suggests there may be no survival benefit of DT versus CM for certain elderly patient groups (Hussain, Mooney & Russon, 2013), and the burden of DT means CM may be a better option for some patients (Farrington et al 2017; Foote et al, 2014).

Pre-dialysis education is central to empowering patients to make treatment choices effectively (Hainsworth, 2004; NICE, 2008). There is variation in how services deliver pre-dialysis education in the UK, and how CM is offered within pre-dialysis services (Gunda, Thomas & Smith 2005). Some frame CM as a 'non-dialysis' option (passive) and/or as part of a palliative care pathway (Murtagh, 2016; Roderick et al, 2015). Further, 'advanced care planning' – the discussion of future plans for patients preferences about issues such as symptom management, quality of life and treatment preferences towards the end of life (Davison & Torgunrud 2007) - is typically only discussed with patients who opt for CM (Holley & Davison, 2015; Janssen et al 2013). Palliative care and end of life planning are options that should be made available to all patients with End Stage Kidney Disease (ESKD), alongside their DT and CM regimens. Hussain and colleagues (2015) reported that 19.7% of patients died before commencing dialysis over their 4 year study period, highlighting the importance of advanced care planning in this group.

Staff recognise a need for more training and resources to help them discuss CM as an active option with patients (Bristowe et al 2014, Fortnum et al 2015). They report a need for balanced information on the benefits and risks of both CM and dialysis, impact on patients' quality of life, carer burden, and end of life care planning (Noble et al 2009). Patients with ESKD report

wanting more guidance in making treatment decisions (Hussain et al, 2015), and at earlier phases in their care pathway (Wright Nunes et al, 2016), yet doctors feel unprepared for discussing end of life issues with patients (Schell & Cohen, 2014; Schell et al, 2012). To support patients to make reasoned decisions between options, staff need to present balanced and equitable information about options and their consequences. This enables patients to evaluate these details with their beliefs, and help patients trade-offs the preference that fits best in their lives (Bekker et al, 1999; Winterbottom et al, 2016).

Patient Decision Aids (PtDAs) are resources that support people to make more informed decisions between treatment options than those receiving usual care (Bekker et al, 1999, 2015; Bekker, 2010, Winterbottom et al, 2016). PtDAs are evidence-based, drawing on decision science studies to identify components that boost, or bias, people's thinking (Bekker, 2013; 2010; Volk et al, 2013). We established that patients represent the 'dialysis decision' as a hierarchy of nested choices, i.e. first the dialysis versus 'no dialysis' decision, and second the 'between dialysis modalities' decision (see Figure 1; Winterbottom et al, 2014). We developed The Dialysis Decision Aid Booklet (Bekker et al, 2015) to support people with worsening kidney disease make informed decisions between the second of these choices - the choice between dialysis modalities (Winterbottom et al, 2016). It was not designed to help people think about whether or not to have dialysis, although this decision was signposted. The reasons people give in retrospect for deciding between CM and dialysis are varied and include patient lifestyle, treatment preferences, healthcare and end of life perceptions; communication and service delivery (Morton et al, 2012). People identify attributes important to them for their decision, and they trade-off what is important to them. However it is unclear how to present this information neutrally and in a way that supports people to reason proactively between the 'dialysis treatment' and 'CM' options, before making a choice. Several patient resources present CM as an option for comparison alongside three renal replacement options (haemodialysis, peritoneal dialysis and transplant; e.g. Pritchard & Thomas, 2013; Rightcare, 2012). It is likely this presentation weights the content of the resource towards preparing for RRT, rather than as

a way of helping people consider which option best suits them when adapting their lifestyle to advancing kidney disease and worsening health state (Shafir et al, 1994).

<Figure 1 about here>

This Kidney Research Yorkshire (ref: KRY 16-118) funded project will carry out the research needed to a) develop a PtDA for kidney services to use with patients making informed decisions between CM and dialysis care pathways, and b) assess its acceptability in renal services.

Methods

All aspects of the research are discussed with the steering group. A patient representative will attend steering group meetings and provide input/feedback throughout the project as appropriate e.g. reviewing patient information sheets/protocol submission/interview schedules. The study is awaiting Health Research Authority, ~~under review by the Yorkshire and Humber~~ National Research Ethics Committee (re: IRAS231121, Dec 2017) and National Institute for Health Research (NIHR) Clinical Research Network approval.

Aims and objectives

This research will develop a theoretically driven, evidence based resource to support patients with CKD choosing between conservative management and dialysis treatment options in consultation with health professionals. The objectives are to:

- Ensure the PtDA content is accurate, complete and relevant to patients by conducting a needs assessment examining the sufficiency of patient resources (Phase 1).
- Establish the clinical context and challenges to developing the PtDA using interviews and observational methods (Phase 2).
- Develop the PtDA using guidelines to inform the content, frameworks for their development and our experience of investigating patient decision making about dialysis (Phase 3).

- Develop a staff training package to support health professionals use of the PtDA and assess its acceptability in clinical practice using interviews, focus groups and observational methods (Phase 4).

Design

This is a prospective observational study employing survey methods. There are distinct phases to developing, evaluating and implementing complex interventions (Medical Research Council (MRC), 2008; Coulter et al, 2013). The plan of investigation for this PtDA falls within the first phase: developing and modelling prior to formal evaluation.

Phase 1: Needs Assessment (September 2017 – February 2018)

To ensure that the PtDA content is accurate, complete and relevant to patients we will conduct an environmental scan to examine the sufficiency of patient resources to support this decision. Environmental scans are tools for retrieving and organizing data from a wide variety of sources. They are broader than systematic reviews in that they are capable of identifying work that may not have been subject to a published evaluation (Graham et al, 2008).

Audit of written patient information

Sample – A survey of all UK renal units and national UK kidney charities.

Materials - A questionnaire designed for purpose asking about provision of patient information for DT/CM choice. A coding frame will be developed with reference to renal policy guidelines and checklists of content, style and formatting known to be associated with written information quality and decision-making facilitation. These materials will be adapted from our work surveying dialysis information (Winterbottom et al, 2007).

Data collection – Renal units will receive a copy of the questionnaire by post. Completed surveys will be returned in a SAE along with any relevant copies of written patient information. Requests for patient information will be sent via email to UK kidney charities.

Data analysis – Questionnaire and coding frame data will be summarised using descriptive statistical analysis. For each item in the coding frame, a leaflet could score ‘0’ or ‘1’, ‘1’ if the item appeared in the leaflet. The overall leaflet quality score will be calculated by adding up all items. Statistical analysis will be conducted using SPSS version 22 (IBM Corporation, Armonk, NY).

a) *Quality assessment of PtDAs that include CM as a treatment choice*

We will critically evaluate the strengths and weaknesses of decision support interventions designed for this decision context.

Sample - PtDAs published internationally comparing treatment options for patients with CKD/ESKD.

Materials – Data extraction form developed for purpose and informed by our past work in dialysis decision making and PtDA research (Bekker et al, 1999, 2013; Winterbottom et al., 2007; Sepucha et al., 2017), including IPDASv4 checklist for assessing PtDA quality (Volk et al, 2013).

Data collection – PtDAs will be selected from literature searches and contact with leading researchers in the field. For each PtDA key characteristics (e.g. treatment options described, description of health issue) will be identified and extracted systematically using the data extraction form. Two judgments-of-resource-quality grids will be applied: IPDAS criteria grid describing 12 criteria identified as minimum standards for inclusion within patient decision aids (Joseph-Williams, 2014); informed decision making (IDM) grid describing 10 components known to boost active, and minimise biases in reasoning (Bekker et al, 1999; Bekker et al 2003; 2010). Each item scored either 0 (not present) or 1 (present); total scores calculated by adding all items, ranging from 0-12 (IPDAS grid) and 0-10 (IDM grid).

Data analysis - The lead researcher (AW) will perform the quality assessment and data will be discussed with team members (HB & AM) to ensure its validity.

Data will be analysed using SPSS (version 22) and summarised using descriptive statistical analysis.

b) *Review of evidence:* to include renal guidelines to identify risks, benefits and

effectiveness of CM/DT (NICE, 2008), service frameworks; existing patient information; patient/professional surveys of CM/DT choices (e.g. Morton et al, 2010; van Biesen et al, 2014; Caskey 2016); behavioural decision support guidance and frameworks for PtDA development (Joseph-Williams et al, 2014); our experience of investigating patient decision making about dialysis (Winterbottom et al, 2007, 2012, 2014, 2016).

Phase 2: Establishing the clinical context (March 2018 – August 2018)

Sample and recruitment – A purposive sample of adult patients with kidney disease to include those at any stage of decision making about CM or DT, including those who change their mind and/or late referrals; new and established patients receiving DT/CM treatments including those who have switched treatments; and staff who oversee and manage the care of these patients will be invited to take part. Exclusion criteria: adults unable to speak English and/or those lacking cognitive capacity to take part in an interview. Participants will be recruited and consented at outpatient clinics at the Adult Renal Unit, St James University Hospital, Leeds by research nurses/project manager.

Study materials - Study information sheets, consent forms to inform and recruit participants and an interview guide for staff and patients are developed.

Data collection – from two sources:

- a) *Semi-structured interviews with staff, patient and carers* will elicit views about how to make sense of CKD and changes to management over time using current PtDAs as prompts. Staff will be interviewed about how they support patient's decisions with transitions in CKD between different treatment pathways (CM/DT/withdrawal) and discuss training needs. Interviews will be conducted by project manager (AW), last no longer than 60 minutes and take place at a location suitable to the participant (home/hospital).

- b) *Audio-recorded consultations between health professionals and patients* will explore current practice in terms of how options are introduced and discussed and further identify training needs. Consultations last approximately 20-30 minutes.

Data analysis - Interviews and observations will be tape recorded, transcribed and analysed using a thematic analysis (Braun & Clarke, 2006). Data collection will be continued until it is judged no new themes are emerging from data (saturation). Interviewing about 30 patients and staff and observing approximately 10 consultations should be sufficient (Richie & Lewis, 2005).

Phase 3: Development of the PtDA (September 2018 – November 2018)

The information included in the PtDA will be structured so that it encourages people to evaluate all decision options and their consequences in accordance with their values, to help patients make trade-offs about treatments in discussion with kidney professionals (Bekker et al, 1999; Winterbottom et al, 2016). The PtDA will be developed in paper format only; content will be informed by phase 1&2 and also include:

- Guidelines on the development of complex interventions to ensure that text is readable (Coulter et al 1998), language used is accurate and value-free (Bekker et al, 2009), risks are presented in numeric and pictorial form to aid understanding (Lipkus, 2007). Value clarification tasks (Stigglebout, 2000) will help patients unpack the choices in this decision. Technical details will be packaged within phrases that help patients make sense of the treatments within their representation of kidney disease (Timmers, 2008).
- Regular meetings with study steering group to decide the content and design of the PtDA.

Phase 4: Staff training and implementation package development (December 2018 – June 2018)

We will develop and pilot a staff training package for use in conjunction with the PtDA. The training package will ensure that the PtDA is practicable within the clinic setting and helps staff

implement decisions made in consultation with patients across hospital systems and in inter-professional communication. We will draw on current training guidelines/existing training packages (Diouf et al, 2016) and evidence from interviews with staff (phase 2) about training needs and assess its acceptability for use in clinical practice.

Sample and recruitment – Staff, patients and carers will be recruited from the Adult Renal Unit, St James Hospital, Leeds and consented to the study by research nurses/project manager (AW).

Materials – Study information sheets and consent forms to inform Staff, patients and carers of the studies and to recruit them to take part have been developed. The PtDA and training package will be included for use.

Data collection – Data will be collected from two sources:

- a) *Focus groups with staff* to provide feedback on resource development and identify changes in system factors to ensure the resource can be integrated into existing operating procedures to allow inter-professional communication across services.
- b) *Audio-recorded consultations between health professionals and their patients* and carers will explore how the PtDA is used in practice and identify barriers and facilitators to use as well as identify further training needs. Each consultation will last approximately 20-30 minutes.

Data analysis - Focus groups and observations will be tape recorded, transcribed and analysed using a thematic analysis. Approximately 30 staff will be invited to take part and approximately 10 clinic observations/recordings should be sufficient.

Discussion

Staff and patients require more support with the CM/DT decision in terms of how and when it is discussed as patient's transition from CKD to ESKD. The PtDA will provide health professionals with a resource and implementation package to facilitate this discussion during the consultation. This should improve patients' experience and participation in their care by providing a tailored approach through the development a theory driven, evidence-based resource. It should also

increase patient uptake of the most appropriate treatment option allowing efficient resource allocation and lead to patients receiving appropriate management for their ESKD by enabling patient preferences to be integrated into care planning. Whilst this research will not provide evidence of the PtDAs effectiveness on healthcare outcomes our findings will provide evidence to inform the study design for evaluating the effectiveness of this complex intervention and this will form the basis of future grant applications.

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